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<sup>&</sup>lt;sup>1</sup> Only a part of this publication relates to carers

<sup>&</sup>lt;sup>2</sup> Only a part of this publication refers to carers

<sup>&</sup>lt;sup>3</sup> Only a part of this publication relates to carers

## **Summary and Overview**

This Section constitutes the second part of my PhD submission. It is made up of five chapters including this summary and overview. The four main chapters contain original published work made up of six papers, one book chapter and four reports. These are organised under key headings for ease of presentation and reading.

This Section is underpinned by a number of key themes which are identified in Chapter 11 by the 'Caring in Later Life' report (R5) and two papers drawing on this (A14 and A15). Firstly, the number of older carers is growing both in absolute terms and as a proportion of the total number of family carers in the UK. The profile of older carers is also ageing with the number of very elderly carers i.e. aged 80 yrs and over, increasing steadily. That late life caregiving is long term, is embedded in a lifelong relationship and operates within a dyadic context distinguishes it from caring earlier in the life course. The growth in the number of people with dementia, an issue explored in depth in Section 1, is a particularly powerful dimension of late life caring. Being a sole carer and having their own health problems are also key characteristics. That the older carer population is increasingly diverse is a notable recent trend; one marked by different types of caregiving relationship, multiculturalism and emerging 'new' sub populations.

Chapter 12 highlights the profile and needs of a number of these sub populations: carers of people with dementia from black and minority ethnic communities (A16); carers of people in care homes (A17); carers of people with a learning disability (A18 and C6); women carers in mid life (R6); and older husband carers (A19). Whilst each group faces its own set of unique care related challenges they share a number of common experiences. These include a reluctance to use formal services, 'invisibility' from the gaze of welfare agencies and a powerful long term commitment to caregiving. The fundamental issue of whether they are perceived as carers either by themselves or the 'outside world' is also significant.

For carers of people with dementia from the American African community, and to a lesser extent the British black community, caring is shared between relatives and other community members, there is minimal stigma attached to dementia and carers tend to feel more positive about their role (A16). These are all elements that distinguish this population from the mainstream. The fact that 'dementia' is conceptualised as a response to lifelong stressors and disadvantage may, in part, explain these differences alongside religiosity and a greater cultural emphasis on emotional, rather than verbal, communication.

Relatives of people in care homes are only now emerging as a group of carers who need, and benefit from, specific support (A17). It has long been assumed that once a person is admitted to a care home their carer no longer provides care. Certainly health and social care agencies are no longer obliged to support them or assess their needs. In fact most people continue to be involved with caring for their relative, often providing some of the most intimate types of care such as bathing, and may even 'help out' with other residents or visitors to the home. Many carers attend and benefit from carers support groups. Sometimes these are based in the home itself, others are organised by a community organisation like the Alzheimer's Society.

The growing number of older carers of people with learning disabilities is an important dimension of a paper and book chapter exploring the needs of the cared for person (A18 and C6). Ageing parents in particular tend to be ill prepared for the future and most have no plans in place for the care of their son or daughter after their death. That services for adults with a

learning disability tend to withdraw when the user reaches 50 years of age and that they often develop complex age related health problems (e.g. all those with Downs Syndrome will suffer from Alzheimer' disease by their mid/late 40's) is a primary challenge for both carers and services. Most carers of people with a learning disability are mothers, reflecting the overarching gendered bias of the caring population. Mid life women carry a particularly heavy burden as is made clear in my report 'Women at the Crossroads' (R6). They tend to be employed and have to combine working with looking after their disabled relative; they may also have dependent children to support as well. It is often at this stage of their lives that women wish to devote time to building up an adequate pension for old age. Some will have reduced their working hours to look after young children in the past and may have plans to return to full time work. Being obliged to care for an ill or disabled parent or parent in law can undermine women's economic future and also damage their mental and physical health.

Spouse care has, and continues to, dominate the older carer terrain. Once an older person becomes chronically ill, it is their spouse who is the most likely person to become their carer. Notably, and conversely to every other group of carers, as many men provide spouse care as do women. That spouse carers provide the most intensive care over many years to partners with long term and complex health problems is widely evidenced in research. Their prominence in dementia care is particularly notable. Whilst older husbands do very similar care tasks to older wives and care over a similar time period, there is emerging evidence that they experience caring differently than their female counterparts (A19). They are viewed by others as heroic, enjoy an unproblematic relationship with asking friends, family and services for support, and tend to employ a work related template to their role as caregiver. For some it is even treated as a replacement for paid work. They also retain power within the marriage whether they are the carer or the cared for; this is an issue hitherto unrecognised in care related research which tends to adopt a survey methodology to assessing the roles and needs of carers. This may result in a rather superficial appreciation of the more complex nuanced and gendered reality of spousal care.

The needs of another invisible group of carers are highlighted in one of the papers in Appendix 1 which focuses on older people living in rural England (Milne et al, 2007). Carers living in rural areas tend to be isolated and marginalised, particularly if they live in a remote situation or are caring for someone with a long term condition such as dementia on a co resident basis. This combination of factors is more often experienced by older and/or spouse carers. Rural carers, and those they look after, also tend to be allocated smaller care packages than their urban counterparts due to the additional unit costs of providing services in rural areas. Whilst rural communities are supportive to a carer when the cared for person has a moderate level of need, when needs become more severe, support falls away. This often exposes the carer to a set of challenges they are unprepared for. Needs are also amplified by the loss of general services e.g. post offices or transport, and health services in villages and small towns and the fact that the carer's own children have usually moved away. The fact that the 'default perspective' of policy makers is an urban environment and, in this context, the needs of urban elders and carers, suggests that little will be done to alleviate the disadvantages experienced by rural carers. A coherent effort to locate rurality at the heart of policy development is required if rural communities and their carers are to have their particular needs recognised and addressed.

A local perspective on caring is provided by the 2008 report 'Caring in Kent, Profiles and Patterns' (R7); this constitutes chapter 13. It offers a detailed review of Kent carers drawing primarily on data collected from a wide ranging 2005 survey entitled 'The Kent Health and

Lifestyle Survey'. The survey, which is conducted in Kent every four years, contained a specific module on carers in its 2005 version<sup>4</sup>. The module was very similar to that included in the General Household Survey. My research contribution involved helping with design and data analysis (SPSS), data interpretation, writing up the report and providing background and context materials. Although much can be learned from national surveys, local studies provide the opportunity to explore in depth who cares for whom, what support carers receive, the health and well being of carers and the type and extent of caring tasks. Whilst the survey did not focus on one group of carers in particular, it does provide evidence about the number of, and nature of, late life caring in Kent, working carers and the role and efficacy of local policy and services for carers and those they support. The report helpfully complements national data; the authors are currently writing a paper based on the report's findings.

Chapter 14 is the final draft of a report entitled 'Employment Support for Carers' (R8, to be published late summer 09), which was funded by the Department for Work and Pensions in 2008/09. The report is timely in that one of the key foci of recent policies for carers (most prominently the 2008, New Deal for Carers, and Carers Strategy) is working carers. The research employed a qualitative methodology to explore how working carers balance work and care; what they find helpful in enabling them to remain in, or return to, work; and what more could be done by agencies to facilitate paid work amongst carers. The study identified a number of cross cutting issues that could make a difference to carers capacity to work: more and better designed care packages for the cared for person that take account of the need for the carer to work; a joined up approach by health and social care agencies to supporting carers; a 'one stop shop' for carers to get advice on money, services, and support; and a more focused, sensitive and appropriate approach to aiding carers in seeking work by the Department for Work and Pensions. Whilst a number of these issues are being taken up by the recent policy drive to improve quality of life and inclusion for carers (e.g. see above and Shaping the Future of Care Together 2009) specific case study evidence of the sort highlighted in the report adds depth and a 'real life' perspective that is often missing for policy makers and commissioners. My role in this project included: linking with a number of carers agencies to help recruit respondents, designing the questionnaire, conducting a number of interviews with carers, and writing up a substantial portion of the report. Overall, a third of the final report was written by me.

Although this Section of my submission is shorter than Section 1, taken together the contributions provide evidence of a range of published work in the field of mid and late life caring. The papers and reports constitute a body of work that has made a significant contribution to understanding the roles and needs of older carers in particular, but also mid life carers. Additionally, I have explored and foregrounded the needs of marginalised and hidden groups of carers. As noted in the 'Introduction, Rationale and Methods' since the publication of my 2001 report (R5), older carers have been much more widely acknowledged in research, policy and service development than hitherto. The work on women as carers, working carers, carers from black and minority ethnic communities, and rural carers has also raised awareness of these groups and made a contribution to research knowledge. One of the key areas that links the two bodies of work, Section 1 and 2, is dementia caring, an issue which is prominent in policy and practice in the field of age related mental ill health and family caring. This is reviewed in more depth in Section 3.

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<sup>&</sup>lt;sup>4</sup> The survey does not usually contain a whole module on caring; this was a particular feature of the 2005 survey

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# Caring in Later Life:

Reviewing the Role of Older Carers







Hisa Milie



# Caring in Later Life

Reviewing the Role of Older Carers

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Help the Aged

With support from Carers UK.





# Caring in Later Life

# Reviewing the Role of Older Carers

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# **Executive Summary**

Considerable research has been undertaken to identify the needs and experiences of carers. However, much of it either regards carers as a homogeneous group or focuses on those in the 45–59 age group. Little specific attention has focused on older carers, despite the fact that they have unique needs which may have been hidden in previous research.

This review, commissioned by Help the Aged, with support from Carers UK, brings together existing evidence and supplements it with fresh analysis of the General Household Survey 1995, to draw out the particular needs of carers over the age of 60. The picture of older carers that emerges from this study is significantly different from that of carers overall.

This review suggests that more should and can be done to improve the health and quality of life of older carers and to develop a deeper understanding of the nature and consequences of caring in later life. The National Service Framework for Older People provides a unique opportunity for health and social services agencies to review the support they offer to older carers.

## **Review findings**

 Nearly 2 million carers (out of an estimated 5.7 million carers in the UK) are aged over 60. Four-fifths of them are aged 65–74 and one-fifth are aged 75 and over. The proportion of male to female carers is about 50/50.

- The number of older carers is increasing, and they form an increasing percentage of all carers, presumably as a reflection of policies designed to enable older ill or disabled people to remain in their own homes for as long as possible. This pattern is expected to continue.
- Older carers predominantly look after older people. One-third of older carers support spouses, one-fifth care for parents or parents-in-law, one-fifth for friends and/or neighbours and under one-fifth care for 'other relatives'. Just under one-tenth are parents caring for an adult child with a disability.
- Over 40% of older carers live in the same household as the person they care for. The vast majority of these are spouses. This care is often interdependent in nature and the carer/cared-for roles are sometimes indistinguishable from each other.
- Those caring outside the home offer care to a number of different groups: parents, friends/neighbours and 'other relatives'. They tend to care for fewer hours per week, to offer more practical support and to be involved on a more limited basis.
- Older carers are likely to offer higher levels of personal and physical care than other carers. A third of older carers are

- providing personal care such as washing and dressing to the person they care for.
- Over two-thirds of those being cared for by older carers have physical disabilities, Just over one-tenth have 'physical and mental impairments', just under onetenth have 'mental impairments only'.
- Nearly 40% of older carers are providing support for over 20 hours a week.
   Half of those are providing care for over 50 hours a week.
- The older a carer is, the more likely they are to be spending long hours providing care. Whilst about one-fifth of carers aged 60–74 provide 50+ hours per week, one-third of carers aged 75 and over provide this amount of care. This suggests that significant numbers of fourth age older carers are providing very high levels of personal care.
- Many older carers are not only caring intensively for many hours per week, but they have been caring over a long period of time. Well over one-quarter of older carers have been caring for 10 years or more. There is a particular concern about carers aged 75+ who are likely to be in poor health themselves.
- The consequences of caring in older age are far reaching and long-term:
  - Older carers are one of the poorest groups in the UK. In particular, if caring begins before retirement age it impacts upon the carer's earning capacity and in turn pensionable status. There are also additional costs related to caring.
  - The benefits system does not recognise the effects of long-term caring and longterm poverty amongst older people.
     Older carers may have little access to welfare rights advice.
  - Many older people are caring for others while suffering from a serious health condition themselves. Over half of older carers report a long standing illness or disability.
  - Older carers experience increased stress and depression. Between one-third and one-half of all spousal carers of people with dementia suffer from depression.

- One-third of intensively involved older carers who have been caring for between 5-14 years have not had a break of two days or more since they started caring.
  - Services associated with improved well-being among carers are respite care, day care, community nursing and sitting services.
  - Carers also benefit from contact with other carers. Carer support groups may be particularly valued by carers of people with dementia.
  - Satisfaction with the help received from family and friends is one of the most significant ways in which carers manage. Networks seem to act as 'stress buffers' for carers and protect them against social isolation.
- Many older carers are physically and socially restricted by their caring commitments. They become detached from their interests and social networks.
- Older carers welcome support from health and social care services, but the policies which target help towards those who live alone overlook their needs. Threequarters of older carers living with the cared-for person receive no regular visits from health or social services.
- Older carers from minority ethnic communities. There are many gaps in the present understanding of the structure and dynamics of informal care within ethnic communities. In particular little is known about the nature and the experience of informal care amongst black communities.
  - Evidence suggests that the need for support among older carers from minority ethnic communities is as great
     or greater – than it is for white carers, particularly for respite care.
  - Linguistic, economic and cultural factors can adversely affect the take-up of health and social care services by older people and older carers.
  - Older carers from minority ethnic communities looking after a relative with dementia seem to have particular difficulties accessing appropriate services.

- Rural carers. Current research identifies rural carers as 'hard to reach'. Evidence suggests that rural carers receive fewer services because they are often dispersed across a wide area. Myths about the selfhelp nature of rural communities also limit investment in services.
- Former carers, who have looked after someone before that person died or was admitted to a care home, require special consideration.
  - Most people want to remain involved after their relative is admitted to a care home. Many remain 'a carer' in an emotional and psychological sense. In spite of this, care staff frequently fail to involve carers in the care of their relative.
  - The impact on the carer following the death of the cared-for person has received very limited research attention, although it is evident that the transition from caring intensively to not caring at all is very emotionally unsettling and difficult.

#### **Recommendations**

It is evident that more overall support is needed for older carers. The cumulative impact of the physical, financial, social and emotional consequences of caring in older age is insufficiently understood and requires further work. Policies and services need to work preventively to alleviate the impact of these consequences on carers.

Based on the evidence of this study, we recommend the following action to enhance the status and quality of life of older carers.

## **Policy**

#### Tackling poverty among older carers

- Older carers need access to sufficient financial support. Age barriers associated with financial benefits are discriminatory in their effect and should be removed.
- Outreach work and points of access for benefits advice are needed.

- At present older carers do not receive Invalid Care Allowance. The age barrier should be removed (in line with government plans) so any carer of any age can apply for ICA.
- The benefits system does not recognise that caring takes place over different periods of time or that different levels of care may be needed. Two levels of ICA could be created; a lower level paid to carers for the first three months of caring and thereafter to carers giving fewer hours of care; and one at the level of the basic retirement pension available after three months to all carers giving greater levels of care.
- The level of Invalid Care Allowance should be raised in line with long-term benefits such as Invalidity Benefit and Retirement Pension.
- There is a strong view that carers should be compensated for the actual costs of caring. This could take the form of a carer's allowance which could be nonmeans tested and paid to all carers in all circumstances.
- As credits for contributions to the basic state pension are related to the qualifying criteria for ICA, measures to increase access to ICA would also improve pension rights for carers including older carers.
- Proposals aimed at improving pensions for women, recognising that they make up the majority of those whose pensions are affected by broken employment and reduced contributions, could be extended to all carers. These measures include improving basic pensions; scrapping contributions for pensions and linking increases in state pensions to earnings not prices.

#### **Improving housing**

Poor housing is strongly related to long-term poverty and is more prevalent among those aged 75 and over.
 Improving housing is a key aim of the Government's initiatives to support carers. Good accommodation can make a considerable difference to the lives of disabled people and their carers, as do adaptations such a stair lift.

## Injury prevention and health promotion

 Many of the physical injuries suffered by carers could be prevented by the provision of training in lifting and moving the person they care for.
 Sometimes carers will need special equipment installed in their home to help them do this.

## **Services**

- Local authorities need to be proactive in seeking out and working with older carers to support them throughout their caring role. Preventive early intervention services for older carers should be developed.
- Agencies should take account of the changing pattern of caring and review the support they offer to older carers and to older couples. They should ensure:
  - that older people living at home as part of a couple are not discriminated against in the provision of home care, community nursing and GP services;
  - that older carers automatically receive a Carer's Assessment in their own right (in line with the Carers and Disabled Children Act 2000). Assessments should address changing needs quickly and flexibly;
  - that older people and their carers have equal access to respite and sitting services and other forms of support;
  - that older carers are enabled to retain their own networks of friendship and interests, to relieve stress and ensure they still 'have a life'.
- Local authorites should be proactive in developing the option of offering older carers direct payments as a substitute for direct services (as allowed under The Carers and Disabled Children Act (2000)) so that it is a realistic and positive alternative option to receiving services commissioned by the local authority.
- Partnerships between care homes and carers and services for former carers should be developed.

- New approaches to meeting the needs of rural carers should be developed – for example, developing outreach work, providing transport, and publicising services effectively.
- Services for older carers from minority ethnic communities should be developed which are culturally and socially acceptable.

#### Areas for further research

The review highlights a number of research deficits. In particular, attention needs to be given to:

- The needs and experiences of carers about whom little is known:
  - older couples
  - older carers from minority ethnic groups
  - older gay and lesbian carers
  - former carers
- The finding that older people provide a lot of care to 'other relatives'. Changing family patterns may be creating new bonds and obligations between individuals (between ex- or step-relatives for example) which need to be acknowledged and supported
- The finding that older people provide significant amounts of help to others outside their own families. The significance of friendship and neighbourliness in the lives of older people has not been widely explored. The role of older people in providing the glue that holds communities together has significant implications for policies of urban regeneration and neighbourhood renewal
- Understanding the experience of 'being an older carer'
- Qualitative data about the process and meaning of spousal care.

To receive the full report send a cheque for £8.00 (includes p&p) payable to 'Help the Aged' to Policy Unit, Help the Aged, 207-221 Pentonville Road, London N1 9UZ.

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# Executive Summary

#### 1. Introduction

There has been a growing recognition of the important role that carers play in enabling vulnerable adults to remain in the community. Recent legislation has recognised the role of family carers and encouraged the development of support services. Considerable research has been undertaken to identify the needs and experiences of carers in general but little specific attention has focused on older carers. This is despite the fact that they have their own unique needs which may have been hidden in previous research. This review commissioned by Help the Aged brings together existing evidence and supplements it with fresh analysis of the General Household Survey 1995 [GHS 1995] to draw out the particular needs of carers over the age of 60.

## 2. Numbers of older carers

There are an estimated 5.7 million carers in Great Britain. Older people constitute an increasingly large proportion, with one-third aged over 60. This represents nearly two million older carers in total, with four-fifths aged 65-74 and one-fifth aged 75 and over. Equal proportions of older carers are male and female.

#### 3. Care provided by older carers

One-third of older carers support spouses, one-fifth care for parents, one-fifth for friends and/or neighbours and under one-fifth care for 'other relatives'. Just under one-tenth are parents caring for an adult son/daughter with a disability.

#### 4. Older carers caring for spouses

Estimates suggest that between a third and a half of all unpaid care for older people is provided by older carers living in the same household. The vast majority of these are spouses. On average, older carers supporting a spouse provide 65 hours of care per week; this is higher than any other group of carers. These older carers also

offer higher levels of personal and physical care than other carers. This care is often interdependent in nature and the carer/cared for roles are often indistinguishable from each other.

## 5. Older carers caring for parents/ parents-in-law

Nearly half of all carers who look after parents/parents-in-law are aged over 60 and the majority of these are women. This group of carers has reduced since 1985 when half of carers of parents were aged over 60, due to changes in household composition and social mobility.

## 6. Older carers caring for their adult sons/daughters

There are also a small number of older parents caring for an adult son/daughter. Although it is not known how many older people care for younger adults with mental health problems, research suggests that many such carers are older parents. This group is particularly at risk of becoming isolated; as the care they provide tends not to be practically based, their needs are less likely to be recognised by support services.

## 7. Older carers providing care to other relatives

Of particular interest is the number and level of involvement of older carers supporting 'other relatives', but further research is needed to identify who these relatives are.

## 8. Co-resident and extra-resident older carers

Two-fifths of older carers live with the person being cared for and three-fifths live outside the home. The vast majority of those living in the home are spouses. They often care intensively, over very considerable periods of time with little support from services. A significant number of older spouses have been caring for 10 years or more.

#### Friends, neighbours and other relatives

Those living outside the home offer care to a number of different groups: Parents, friends/neighbours and 'other relatives'. They tend to care for fewer hours per week, to offer more practical support and to be involved on a more limited basis.

## 10. Tasks undertaken by older carers

Over two-thirds of those being cared for by older carers have physical disabilities, about a sixth receive care because they are 'old', just over one-tenth have 'physical and mental impairments' and just under one-tenth have 'mental impairments only'. Of the significant number who have physical and mental impairments, many will have dementia.

The key caring tasks of older carers are: Personal care, 'other practical help', help with paperwork/finances and physical help. A smaller number of older carers are only involved in 'keeping the cared for person company', 'keeping an eye on the person they care for', or 'taking them out'.

## Intensity of care provided by older carers

Two-fifths of older carers offer between 0-9 hours each week, one-fifth provide between 10-19 hours and two-fifths provide over 20 hours. Of these, over half provide more than 50 hours. Carers living in the home of the cared for person provide considerably more hours of care than those living outside.

Whilst about one-fifth of carers aged 60-74 provide 50+ hours per week, one-third of carers aged 75 and over provide this amount of care. This suggests that significant numbers of fourth age – and possibly frail – older carers are providing high levels of care

The evidence suggests that older spousal carers carry the heaviest caring responsibility. Older carers tend to provide more intensive care than middle aged carers (those aged 45–59). Middle aged carers offer more support with paperwork and financial matters than older carers, with a smaller proportion offering personal care and physical help.

## 12. Time spent caring by older carers

Many older carers are not only caring intensively for many hours per week but have been caring over a long period of time. Well over one-quarter of older carers have been caring for 10 years or more. There is a particular concern about carers aged 75+ who are likely to be increasingly frail themselves.

## 13. Consequences of caring

The consequences of caring in older age are far reaching and long term. In particular, evidence shows that there are financial, health, emotional and social consequences.

Older carers have been identified as one of the poorest groups in Great Britain. Research indicates that older carers providing substantial amounts of care face much financial hardship. In particular, if caring begins pre-retirement it impacts upon earning capacity and in turn pensionable status. There are also additional costs related to caring.

Although the relationship between health and caring is complex, older carers appear at increased risk of health problems. Over half of older carers report a long-standing illness or disability and of these, two-thirds say that their illness/disability limits their activities.

Evidence about the link between caring and emotional health is much stronger. Older carers in particular experience increased stress and depression, with between one-third and one-half of all spousal carers of people with dementia suffering from depression.

There are a number of social costs related to caring. Being physically and socially restricted by caring is particularly challenging to living an independent life. Many carers become detached from their interests and social networks.

Carers of people with dementia face a particular set of challenges; these include managing and coping with behavioural problems and memory problems. Secondary difficulties include reduced social contacts, strained family relations and health problems.

It is important to note that caring can also be a source of considerable satisfaction for many carers.

## 14. Support received by older carers

Carers of all ages have identified that time off from caring; reliable support from services; satisfactory help from other carers/friends; information and advice and recognition of their role and contribution all assist them in their caring capacity.

Those services that are associated with improved well-being among carers are respite care, day care, community nursing and sitting services. Carers also benefit from contact with other carers. Carer support groups may be particularly valued by carers of people with dementia.

Satisfaction with the help received from family and friends is one of the most significant ways in which carers manage. Networks seem to act as 'stress buffers' for family carers and protects them against social isolation.

Most older carers looking after people with dementia are spouses, although a few are older adult children. A number of services are of particular value here, including specialist day care, overnight respite care and sitting services specifically tailored to the needs of people with dementia. Additionally, carer support groups and a number of other specialist services have been developed to help carers of people with dementia cope more effectively.

But three-quarters of older co-resident carers and two-fifths of extra resident carers receive no regular visits from services at all. One-third of older carers had not had a break since they started caring.

## 15. Older carers from minority ethnic communities

Research shows that there are many gaps in the present understanding of the structure and dynamics of informal care within ethnic communities. In particular little is known about the nature as well as the experience of informal care amongst black communities. Evidence suggests that the need for support among many ethnic minority carers is as great - or greater - than it is for white carers, particularly for respite care.

Linguistic, economic and cultural factors can adversely affect the take-up of health and social care services by older people and older carers. Ethnic minority carers looking after a relative with dementia seem to have particular difficulties accessing appropriate services.

#### 16. Rural carers

Current research identifies rural carers as 'hard to reach'. They are likely to be older as many people retire to the country, and to be more isolated. Evidence suggests that rural carers receive fewer services because they are often dispersed across a wide area. Myths about the self help nature of rural communities also limit investment in services.

Meeting the needs of rural carers may be more a matter of approach rather than providing additional services – for example, developing outreach work, providing transport, and publicising services effectively.

#### 17. Former carers

Former carers, those who have previously looked after someone before that person died or was admitted to a care home, require special consideration. Contrary to popular perceptions, most people want to remain involved after their relative is admitted to a care home. Many remain 'a carer' in an emotional and psychological sense. In spite of this, care staff frequently fail to involve carers in the care of their relative.

The impact on the carer following the death of the cared for person has received very limited research attention, although it is evident that the transition from caring intensively to not caring at all is very emotionally unsettling and difficult.

## Introduction: Caring in later life

## Aims and remit of the review

Recent years have seen a growing recognition of the important role that carers play in maintaining vulnerable adults in the community. The NHS and Community Care Act 1990 and the Carers (Recognition and Services) Act 1995 have been particularly influential in recognising the role of family carers and encouraging the development of support services.

Considerable research has taken place to identify the needs and experiences of carers, but much of it either sees carers as a homogeneous group or focuses on carers in the 45-59 age bracket. It is suggested that older carers may have their own unique needs relating to caring which may have been hidden within previous research. As the population continues to age and expectations placed on older carers increase, it is crucial to understand the circumstances of older carers and explore ways to meet their needs. This review commissioned by Help the Aged attempts to draw together existing evidence and supplement it with a new analysis of the GHS 1995 to draw out the particular needs of carers over the age of 60.

#### This review aims to:

- Identify the prevalence of older carers in the population and to map their key characteristics. These include: gender, age, race, type of relationship, needs of the cared for person, health, living circumstances, finances, and amount and type of caring input
- Explore the roles, needs and difficulties of older carers; the impact of caring on their health; financial situation and quality of life. This includes exploring those issues specific to spousal carers, carers of parents, carers of a son/daughter and carers of people with dementia
- Explore the type, extent and effectiveness of support from informal sources – family, friends, neighbours – as well as formal services
- Identify the gaps in knowledge, research and policy in relationship to older carers

## Contributors to the study

The review was conducted by Alisoun Milne, Lecturer in Social Gerontology at Tizard Centre, University of Kent with assistance from two university colleagues Eleni Hatzidimitriadou and Christina Chryssanthopoulou and Tom Owen from Help the Aged. The study was supported by Gail Elkington and Tessa Harding at Help the Aged and Emily Holzhausen at Carers UK.

## Parameters of the study

Every effort has been made to review as wide a range of literature as possible. Sources have included existing and recent research on older carers; relevant work which may not have adopted a specific focus on older carers; reports and other papers from carers' organisations; policy documents and associated commentaries. The study also incorporates information gleaned from detailed secondary analysis of the GHS 1995.

As some carers do not define themselves as such, they tend to be difficult for researchers to reach. Any research on caring therefore tends to be biased towards those who 'perceive themselves' as carers and make themselves accessible to social inquiry.

Most of the literature reviewed dates from 1990 to the present day (2001), although relevant or seminal texts published prior to 1990 are included. The vast majority of literature focuses on the UK, although some studies from the USA are also referenced; when evidence refers to a non-UK population this is stated in the text.

The majority of the literature on caring either focuses on the experiences of carers of a specific cared for group, ie carers of people with dementia, or it adopts a general brief. Given that older carers care for nearly every group of vulnerable adult, from older people with physical disabilities to younger adults with mental illness, the task of exploring the needs of older carers has been particularly challenging. Where it has been possible to explore issues specific to older carers this has been done; where a study or a review has adopted a general focus, only those points of clear relevance to older carers are discussed.

Most policy and research attention has been paid to those carers who are more heavily involved in practical and physical caring activities and for whom caring absorbs a considerable amount of time. This review reflects this interest although every effort has been made to incorporate older carers who provide less tangible forms of care such as emotional support or supervision.

A key part of the study has involved secondary analysis of relevant data from the GHS 1995 (OPCS, 1998). It is therefore able to offer original information about older carers in Great Britain as well as a comparison with carers in the 45-59 year age group which was the focus of the Office of National Statistics report following the GHS 1995 (Rowlands, 1998).

Older carers of people with a learning disability In 1998 Carol and Alan Walker were commissioned by the Joseph Rowntree Foundation to conduct a study entitled 'Uncertain Futures: People with learning difficulties and their ageing family carers' (Walker & Walker, 1998). The report provides a comprehensive and current review on the topic. As a consequence, this group of older carers has been excluded from this study.

## Terminology

In the context of this report, the term 'older' is taken to apply to all those aged over 60. The term 'carer' is used to denote informal, unpaid or family carers. 'Person being cared for' or 'cared for person' denotes the individual receiving care. 'Informal care' refers to care usually provided by a relative and which is unpaid. 'Formal care' refers to care provided by a service or agency where the person delivering the care is paid. The term 'care' refers to the performance of tasks which go beyond the normal reciprocities between adults. A 'co-resident carer' is a carer who shares the same household as the cared for person; 'extra resident' refers to a carer who lives in a separate household. A glossary of other terms is provided in Appendix One.

## Structure of the report

The review is presented in eight sections.

- Section One explores the context of caring in Great Britain.
- Section Two summarises the findings of new analysis of the GHS 1995.
- Section Three draws together previous research evidence relating to the dominant groups of older carers in Britain.
- Section Four describes the consequences and impact of caring.
- Section Five explores formal and informal support for older carers.
- Section Six discusses those issues relating specifically to older carers of people with dementia.
- Section Seven summarises the evidence relating to the needs and circumstances of older carers from ethnic minority groups, rural older carers and former carers.
- Finally, Section Eight discusses the implications of the study for research, policy and practice.

# Section One

## The Context of Caring

Section One will outline the context of caring. Specifically, it will offer a definition of caring; a brief review of the policy context of caring; and a summary of the demography of caring across all age-groups in Britain.

## What does "caring" mean?

Twigg & Atkin (1994) suggest that the concept of caring is a mixed one, drawing on five key elements:

- 1. The performance of tasks of a supportive character where these go beyond the normal reciprocities common between adults. Caring means doing things for the person that they are unable to do for themselves; personal care tasks such as bathing or washing are clear examples. Sometimes it is difficult to distinguish clearly between caring, and the support and tending which are an intrinsic part of gender and family relations. The tasks that women routinely perform for their husbands and children would be classified as caring (Allen, 1994). While caring may involve arduous labour, the emphasis on such activities reflects early attitudes which focused on carers of physically disabled older people. To a significant extent the performance of physical tasks remains central to our concept of caring.
- 2. The second element of caring is related to kinship obligation. Caring has always taken place within a context of kinship (Finch, 1989; Qureshi and Walker, 1989). The most intensive care is normally provided by spouses and adult sons/daughters (Arber & Ginn, 1990) and it is these 'heavily involved carers' who tend to be the focus of social policy and public concern. The support provided by neighbours and other members of a local community is typically more limited, involving errands like shopping or collecting prescriptions rather than intimate or personal care (Wenger, 1990; Sinclair,

1990). This role is normally described as 'informal helping'.

- 3. Thirdly, caring is associated with emotion and feelings. Caring relations are often defined by love and this underwrites many of the duties and obligations associated with the provision of care. Twigg (1992) and others also argue that emotion is significant to caring because it constitutes a key feature of caring activity; caring represents a form of emotional labour in itself. However, an important distinction should be made between 'caring about' (the emotional tie) and 'caring for' (practical assistance), (Morris, 1994).
- 4. Co-residency has become established as a defining feature of intensive caring. Sharing a household radically affects the experience of caring, and co-residence alerts us to the important ways in which caring is not just about the performance of tasks, but the consequences of a relationship. Carers' lives are inevitably sculpted by their caring role. The limitations experienced by the person being cared for are shared by the carer; behavioural challenges associated with dementia for example are significant determinants of the experience of being a carer (Ashkam, 1995).
- 5. Caring involves a feeling of responsibility for the person being cared for. This can mean monitoring behaviour, negotiating with services, offering care on a flexible basis, and 'carrying the can' when things go wrong. In fact 'being responsible' may be the primary care task, particularly where the person being cared for has no physical care needs.

For most older carers, caring is both a role and a relationship where all five elements co-exist as an intrinsic part of the caring paradigm. The needs of the person being cared for and the nature of the relationship between carer and cared for are powerful defining features of the caring role.

## The range of caring tasks

The ambiguous terminology often used to describe the tasks involved in caring reflect the complex nature of a caring relationship. For the purpose of this study, four broad categories have been developed as follows:

**Personal care** – this includes bathing, dressing, getting in and out of bed/bath, lifting, help with the toilet, walking, taking medication, assistance with meals and feeding, managing continence and associated household duties. Many of these tasks are physically demanding which creates particular problems if the carer is elderly and infirm. Incontinence is one of the most stressful aspects of caring for a disabled relative and one that is stigmatising for both carer and cared for. Apart from the embarrassment it causes, it also poses a range of practical difficulties ranging from soiled bed linen to managing catheters. It can also alienate friends and family.

Two features of personal care govern the difficulties experienced by carers. The first is its intimate nature. Personal care involves touching, nakedness and contact with bodily fluids. What may be acceptable for a mother to do for an adult son/daughter may not be appropriate for an adult son/daughter to do for a parent and assumptions should not be made about the extension of marital intimacy to other forms of physical intimacy. Gender is also an important dimension, with women being 'allowed' to perform intimate tasks for men that are not felt to be appropriate in reverse.

Nursing tasks - the boundary between personal care and nursing tasks is not a clear one. The nurse's perspective on what constitutes a nursing task - a medical need - may be in conflict with the carer's view that an activity such as changing dressings or giving injections requires nursing skill. Older carers are often expected to perform complex tasks without training or understanding of their significance.

Household and practical tasks - older carers often have particular difficulties with household tasks. This may be due to their arduous nature or the fact that it is 'just another activity' to add to their list of tasks.

Older women may be less prepared to accept help with household chores than older men, regarding them as a measure of their ability to maintain a clean home. Frail older carers with health care problems are particularly at risk of injuring themselves by carrying out domestic tasks beyond their capacity (Social Services Inspectorate (SSI)/Department of Health, 1995). Paperwork and financial affairs are also included in this category. For older carers, their duties may have previously been undertaken by the cared for person. particularly if this is a spouse who had the role of cooking, cleaning or managing financial affairs.

Emotional and social support - caring also requires emotional input. This is particularly true when caring for an older person with dementia or an adult with challenging behaviour. These needs often mean taking responsibility and dealing with difficult or embarrassing behaviour. Furthermore, these carers are often more isolated and provide care alone.

## The policy context of caring

Recent years have seen a growing recognition of the key role that carers play. While families have always been the main providers of support and care to relatives with dependency needs, it was not until the 1980s that a series of studies, reports and discussion papers highlighted their role and prompted a debate on care.

A number of issues underpin this enhanced focus on carers. Concerns over demographic change have highlighted the rising numbers of older people, and provoked anxiety over the consequent dependency ratio between the frail and able bodied in society (Martin et al, 1988). Between 1995 and 2025 the number of people over the age of 80 is set to increase by almost half and the number of those aged over 90 will double.

The significance of an ageing population, particularly increased longevity, is the rising incidence of disability in successively older age groups. There is a rapid increase in severe incapacity over 70 years of age. The fastest growing cohort is among the over

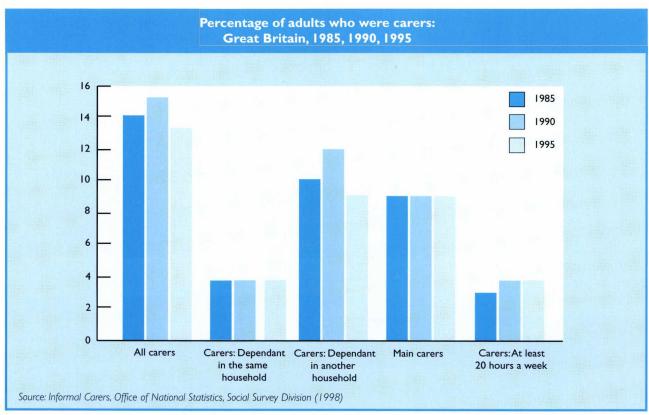


Table 1: Caring in Great Britain

80s. Approximately 1.5 million of those aged 85+ have dementia and 3.5 million have a limiting long standing illness (Audit Commission, 2000). If the prevalence of disability amongst older people continues at present levels, by the year 2031 there will be two million more people in Great Britain with degrees of disability sufficient to require daily personal help (Department of Health, 2001).

The NHS and Community Care Act 1990 (Department of Health, 1990) was the first piece of legislation to acknowledge the need to support carers. The White Paper, 'Caring for People' - which preceded the Act - underlined the importance of carers' contribution to community care for vulnerable adults. One of its key objectives was to ensure that service providers made practical support for carers a high priority. The practice guide to assist local authorities in implementing the Act described community care as a partnership with users and carers and stated that a separate assessment of carers' needs could be offered where appropriate. Balancing the needs of users and carers was viewed as a key task of the care management process (Carers National Association, 1997a & b).

Despite the intentions behind community care, concerns about provision for carers continued, leading to the Carers (Recognition and Services) Act 1995 (Department of Health, 1995). The Act is primarily concerned with informal carers who are providing 'regular or substantial care'. It offers an assessment of their own ability to care and gives local authorities a duty to take into account carers' capacity when looking at service provision for the person being cared for.

Publication of the National Carers Strategy in February 1999 represented the culmination of years of campaigning by pressure groups to secure more support, increased rights and improved recognition for carers. It offers a comprehensive review of the policy changes which impact upon carers and examples of good practice, and sets out an integrated strategy for future action by the Government. The key recommendations of the strategy include: A grant of £140 million to local authorities in England to help carers take a break; a future power to allow local authorities to provide services directly to carers; more flexibility for carers in organising their own support; and a number of measures to assist working carers and carers wishing to return to work (Department of Health, 1999).

The Carers and Disabled Children Act (2000) has responded to some of these recommendations: Carers can now receive services and an assessment of their own needs even if the person cared for has refused an assessment for, or the provision of, community care services. The Act also empowers local authorities to make direct payments to carers to meet their own needs and to provide short-term break voucher schemes to allow carers the flexibility to manage their own care support.

Whilst the legislation is welcome, it remains unclear how in practice these powers will be executed particularly given current budgetary constraints.

## A summary of caring in general across Great Britain

The 1985 General Household Survey (OPCS, 1989) was the first national survey to give accurate estimates of the number of people involved in caring for, or helping, older and disabled people in the community (Green, 1988). This revealed a much higher number of carers than previously suggested and approximately six million people were identified as having 'extra responsibilities for or providing some regular service to a sick, handicapped or elderly relative, friend or neighbour'.

By the time of the 1990 GHS this estimate had risen to around 6.8 million carers (OPCS, 1993). Latest figures published in a report 'Informal Carers' in 1998 as part of the GHS 1995 indicates that there are about 5.7 million carers in Britain; about one in eight households contains a carer; 3.3 million are women and 2.4 million are men. Nearly half of all carers are employed and one-quarter are retired; the remaining quarter is economically inactive or unemployed (Rowlands, 1998).

## Who are carers caring for?

Nine out of 10 carers care for a relative, with two out of 10 caring for a spouse or partner and four out of 10 caring for parent(s). Just under two million are coresident and nearly four million are extra resident (Rowlands, 1998). Of those carers sharing a household, over half care for a spouse and one-fifth care for parents or parents-in-law.

Between 1985 and 1995, the number of carers caring for an older spouse or cohabitee increased from 40 per cent to 56 per cent whilst the number of those cared for by their children/children-in-law decreased. By 1995, spousal carers constituted the largest group of co-resident carers (Rowlands, 1998).

Changes in patterns of caring are consistent with both the growth in the older population, the policy shift away from the large-scale use of institutional care, and a decline in the proportion of older people living alone and not with their adult son/daughter as may have previously been the case.

## Age and needs of the cared for person

Evidence from successive GHS surveys point to the fact that the vast majority of those receiving care are older. Of the approximately 1.7 million carers from the GHS 1985 estimated to be providing heavily involved care, 1.2 million were caring for older people (Parker, 1992). When asked to describe the reasons for providing care, two-thirds of carers said they were looking after someone with a physical disability, under a tenth looked after someone with a mental disability, one-fifth said they were looking after someone because of 'old age' and about one-twelfth were looking after someone with both a mental and physical disability.

Evidence also indicates that, compared to the later 1980s, people being cared for tend to be significantly older and are also more likely to have mental impairments such as dementia.

#### What carers do

The 1998 'Informal Carers' study revealed that one-third of carers are involved in providing personal care such as washing, nearly one-third administer medicines and nearly three-quarters give other practical help (Rowlands, 1998). Comparing figures from the 1995 GHS with those from the 1990 GHS, it is clear that carers have, over a decade, become more involved in providing personal care (31 per cent in 1992 compared to 22 per cent in 1990) and administering medicines (27 per cent compared to 16 per cent) whereas proportionately fewer carers are providing practical help (73 per cent compared to 79 per cent).

## Nature of caring

While there appears to have been a slight reduction in the overall number of carers between 1990 and 1995, research suggests that there has been an increase in the number of carers providing intensive support, from 1.5 million in the early 90s, to nearly two million in the mid 1990s. Of this group, over half care for more than 50 hours per week (Parker, 1998).

Intensively involved carers constitute about three in 10 of the total number of carers. As might be expected, co-resident carers tend to provide more intensive levels of care than extra resident carers; spouses in particular provide higher levels of personal care. They are often older people and most likely to be caring with little or no help from others. They are more likely to be women, and in particular wives (Arber and Ginn, 1991).

Those carers defined by Parker (1992) as 'helpers' constitute about seven out of 10 carers. They provide practical help for friends, neighbours and less close relatives who usually do not live in the same household. They may do this for relatively few hours per week but may have been involved for some years. They tend to be sharing care with others.

# Section Two

## Caring in Later Life: New Analysis of the 1995 General Household Survey

Section Two draws together original secondary analysis of the 1995 General Household Survey (GHS) carried out by authors and offers a comprehensive picture of 'who cares in later life'.

#### Introduction

The data set used for this secondary analysis is a combination of data on 'informal carers' collected as a part of the 1995 General Household Survey (Rowlands, 1998) plus additional data from the wider survey itself (OPCS, 1998). In particular it explores the demographic characteristics of older carers and those they care for, service usage and health, and compares this group with those carers who are middle aged - many of whom will become older carers in the future. Data has been analysed from an older carer's perspective and in this regard is unlike any previous work. The analysis differs from that previously carried out by Rowlands (1998) where middle aged carers were the main focus. Definitions of 'caring' and 'cared for' used in the 1995 General Household Survey are offered in Appendix Two.

## Older carers in Great Britain: the basic facts

As can be seen from Figure A, 31 per cent of the total number of carers are aged 60 or over, this represents approximately two million older people in Britain. This compares to 37 per cent of carers who are aged 45-59, 23 per cent who are 30-44 and nine per cent who are aged 16-29.

"There are an estimated two million older carers in Britain..."

Eighty per cent of older carers are aged 65-74 while 20 per cent are aged 75 and over. About half of older carers are female (53 per cent) and half male (47 per cent). Most older carers are economically inactive as many are retired. 99 per cent of all GHS respondents are white.

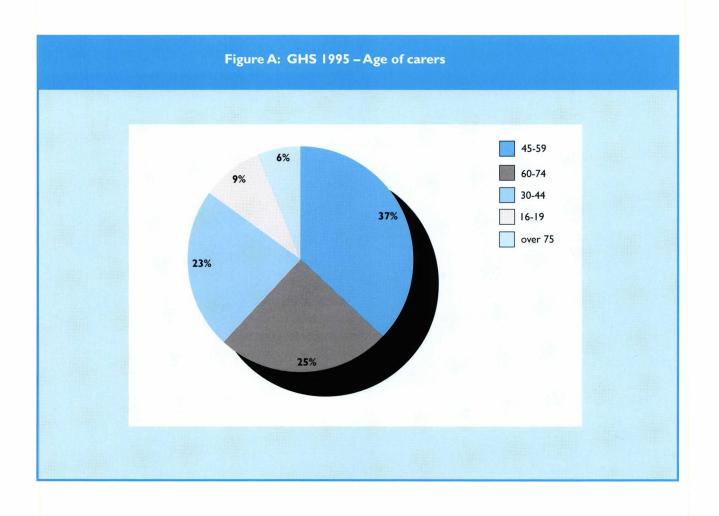
The majority of older carers (80 per cent) are married or cohabiting, 16 per cent are widowed, separated or divorced. A very small proportion (four per cent) are single. More women are widowed compared to men. Given the social profile of the current older population this pattern is to be expected. 90 per cent of older carers look after one person. Those looking after more than one person are likely to be carers supporting both their elderly parents.

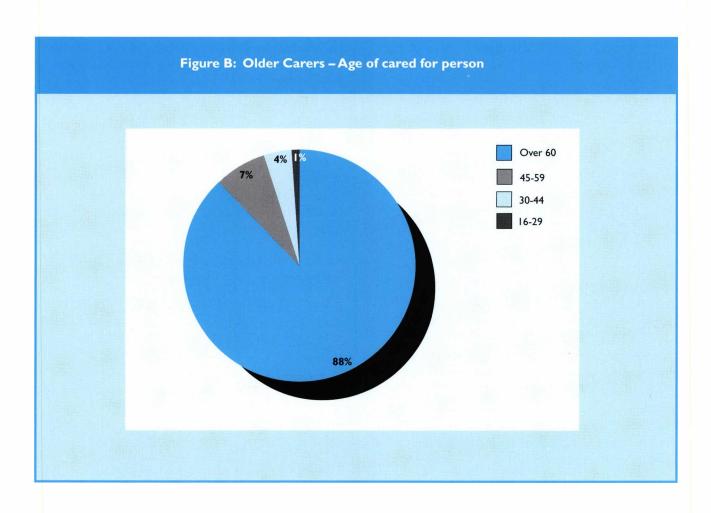
## Who do older carers look after?

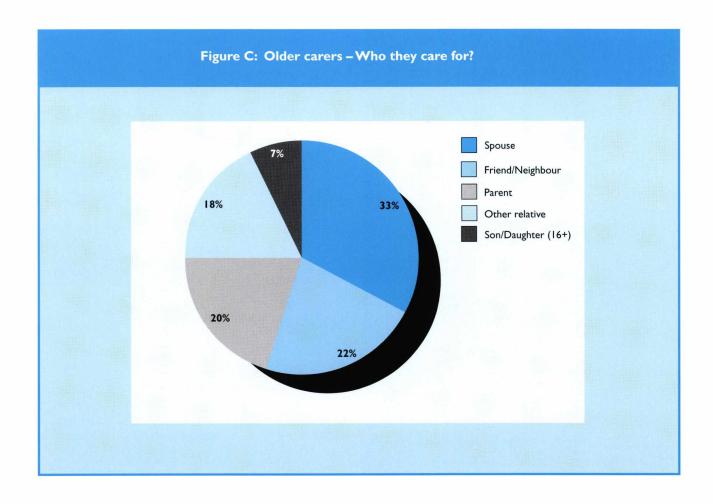
The overwhelming majority (88 per cent) of those people receiving care from older people are older themselves (Figure B). This finding echoes previous research (Arber and Ginn, 1995; Parker, 1992). Analysis by Arber and Ginn, in 1990 indicated that one-third of care provided for older people was provided by older people and suggested a continuing trend towards an ever greater number of older people being cared for by same generation carers.

## "Older carers predominantly look after other older people..."

As is illustrated in Figure C, one-third (33 per cent) of older carers care for spouses, 20 per cent of older carers look after elderly parents, 22 per cent care for friends/neighbours and 18 per cent care for 'other relatives'. Seven per cent of older carers look after a son or daughter with physical and/or learning disabilities. In discussing these findings it is helpful to







make a distinction between close kin and extended kin. This in turn reflects the distinction between co-resident and extra resident carers.

## Spouses, children and parent carers: close kin

As might be expected, the majority of older carers care for spouses, of whom half are female and half are male (Figure C). This finding is consistent with earlier research which identified spousal carers as the largest group of co-residential older carers (Rowlands, 1998).

Whilst a significant number of adult children over 60 offer care to a parent, this is a clear reduction from 10 years ago when nearly half of carers of parents were identified as older (Parker, 1990). This decline is considered to reflect changing patterns of household composition, in particular a reduction in the proportion of older people living with their children. Further it reflects increased social mobility and increased levels of independence amongst older people. It could be argued

that as a consequence of extended community based living for greater numbers of fourth age elders, extra resident care by an adult son/daughter may expand in the near future.

The number of adult sons/daughters receiving care is small at under 10 per cent, although the likelihood of this group having permanent complex and multiple needs is high. Most of the cared for individuals are people with learning disabilities and some may also have physical disabilities.

## Other relatives and friends/neighbours as carers: extended kin

An interesting and surprising finding is the number of 'other relative' carers identified in this analysis. We do not know who these relatives are but can make some assumptions that they include siblings, nieces, nephews and cousins, as well as half and step relatives such as step-parents and ex-spouses /partners, ex-parents-in-law and other 'ex' relatives. These 'other relative' carers are more likely to be extra resident.

This suggests two things. One is that further work is needed to explore and define 'other relative' carers. Secondly, it may be that the reconstructed family continues to care for its members, albeit along different lines of reciprocity to the 'traditional family' (Allen & Perkins, 1995). This lends weight to the argument that people offer care on the basis of affection and attachment as well as out of a sense of duty and obligation (Bornat et al, 1997; Finch & Groves, 1983; Graham, 1991).

One thing is clear though: the 1995 GHS failed to capture an accurate picture of who 'other relatives' are and needs to offer a more flexible and broader list of options. The pattern of 'who cares in later life' is changing and surveys aimed at gathering such data need to change with it.

Another interesting finding is the number of friends and neighbours offering care, with over one-fifth of older carers in this group. Previous research has identified a helping role for older friends and neighbours (Wenger, 1989 & 1995); this analysis suggests that they may constitute a larger group than has previously been thought and that they are adopting more intensive caring roles (Phillipson, 2001).

## Older carers and household type

"Two-thirds of all co-resident care of older people is by older people."

It is clear from the previous discussion that older carers are much more likely to be living with the person they care for compared to younger carers. Findings suggest that about two-thirds of all coresident care of older people is by older people. Most carers of this kind are spouses with men and women contributing equally. Overall 41 per cent of older carers are coresident and 59 per cent are extra resident.

## Characteristics of those being cared for

The GHS offers four categories for describing the characteristics of the person needing care. Analysis suggests that 65 per cent of those being looked after by older carers have 'physical disabilities' and 15 per cent receive care because they are 'old'. Eleven per cent are described as having 'physical and mental impairments' and eight per cent have 'mental impairments only'. The vast majority of those with only a physical disability will be older and have an age related chronic disability such as arthritis.

A higher proportion of older people receiving care are described as suffering from either a mental impairment only or a physical and mental impairment. The majority of older people with a mental impairment are likely to have dementia.

Slightly more women care for people with both physical and mental impairments and those needing care due to 'old age'. These findings are consistent with earlier evidence that slightly more wives offer care to husbands with dual disabilities and also that more women provide support to friends and 'other relatives', many of whom need low levels of support due to advancing age.

## The roles and commitments of older carers

## Tasks carried out by older carers

Table Two illustrates that the main caring tasks carried out by older carers are: 'personal care' (32 per cent ) and 'other practical help' (26 per cent ). This is followed by 'help with paperwork/finances' (17 per cent ) and 'physical help, for example with mobility problems' (13 per cent ). Very few older carers simply define their role as 'keeping the cared for person company', 'keeping an eye on the person they care for', or 'taking them out'.

Given the nature of the questions asked by the GHS it is likely that there is a significant under-reporting of caring tasks of a non-practical nature such as supervising someone with a mental health problem.

The range of caring tasks carried out is not significantly different between men and women. However, slightly more men offer help with paperwork/financial matters and physical help, and slightly more women offer personal care.

	Total	Gender of carer		
		Older Men	Older Women	
Personal care (eg washing)	32%	28%	34%	
Other practical help (eg shopping)	26%	26%	26%	
Paperwork or financial matters	17%	19%	16%	
Physical help (eg walking)	13%	16%	11%	
Keeping company	4%	3%	5%	
Taking out	3%	4%	2%	
Giving medicines	1%	0.3%	1%	
Keeping an eye on dependant	3%	3%	4%	
Other help	1%	0.7%	1%	
TOTAL	n=652	n=300	n=352	
	(100%)	(100%)	(100%)	

The vast majority (85 per cent) of personal care provided by male carers is for their wives. Whilst women carers do provide personal care for their husbands (55 per cent) they also provide this type of support to parents (22 per cent), other relatives (nine per cent) and children (eight per cent). They may have to travel some distance in order to provide such care.

"This evidence suggests that there is a growing group of intensively involved carers supporting increasingly frail older people in the community."

As older carers are more likely to be caring for an older person with a range of health care needs, they are also more likely to be performing health care support tasks such as changing dressings, administering medication and sorting out problems with incontinence. This is, in part, a consequence of the shift of care for adults with dependency needs from institutional

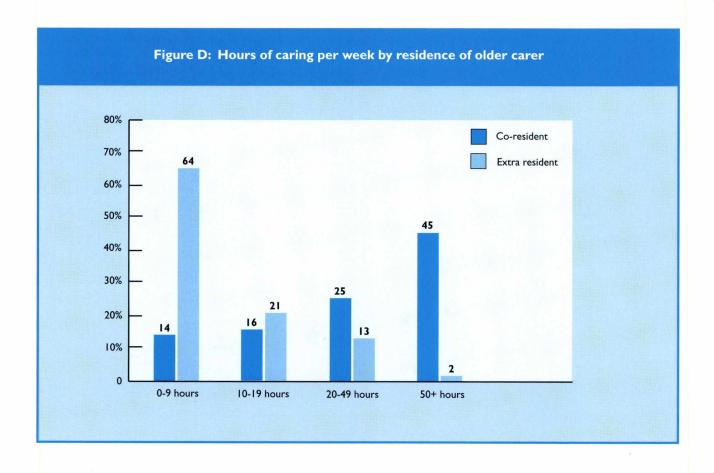
care to community based care, and in part, a result of the attendant shift from care provided by formal service to care provided by family carers (Goldstein & Rivers, 1996).

## Time spent caring

In terms of the number of hours of care provided per week, older carers tend to be split roughly into two groups: those providing intensive care (over 20 hours of care per week) and those who could be described as helpers who are providing low levels of support (between 0-9 hours of care per week). Helpers make up 42 per cent of total older carers. A similar proportion are 'intensive carers' (38.5 per cent) of whom half provide more than 50 hours.

There are also older carers who provide a mid-range of care (10-19 hours). These constitute about one-fifth of all carers. Similar proportions of men and women provide care at all levels.

As might be expected, co-resident older carers provide considerably more hours of care than extra-resident carers. Figure D shows that 45 per cent of co-resident carers



provide 50+ hours of care per week, while 64 per cent of extra resident carers provide between 0-4 hours of care per week.

Between 1985 and 1995 the distinction between those older carers providing intensive care and those who are 'helpers' seems to have widened. Those providing intensive care tend to provide it mostly to older people who are either parents, parents-in-law, or spouses and live in the same household with little or no help from others (Arber & Ginn, 1990). This pattern is in contrast to older 'helpers' who are often part of a caring network where other informal supporters or formal services share the care. While these helpers play an important part in supporting older and disabled people in the community, they are unlikely to have the same needs for substantial support as those who are more heavily involved.

## Time spent caring: carers 60-74 and 75+

While one-third (34 per cent) of carers aged 60-74 provide 20+ hours per week, half (50 per cent) of carers aged 75+ provide this level of care. Further, about one-fifth (18 per cent) of carers aged 60-74 provide 50+ hours

per week and more than one-third (31 per cent) of carers aged 75+ provide this level of care.

"Carers aged 75+ are more likely to be intensive carers than those aged 65-74"

Forty-five per cent of carers in the 60-74 age bracket provide care for less than 10 hours per week. Thirty-four per cent of carers aged 75+ provide care for less than 10 hours per week.

This suggests that significant numbers of the oldest carers are providing care for substantial periods of time. As they are likely to have health problems themselves and their caring activities are likely to be onerous and stressful, caring may well be placing many of these elderly carers at considerable physical and psychological risk. This risk is often compounded by social isolation, which intensive carers frequently experience (Becker, 2000; Milne et al, 1999).

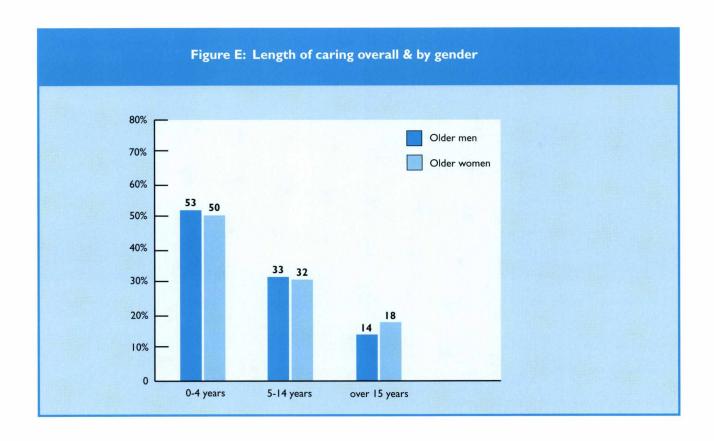


Table 3: Length of caring by age of older carer						
	Age of older carer					
Length of caring	60-74	75+				
0-4 years	51%	52%				
5-10 years	25%	21%				
Over 10 years	24%	27%				
n	515	130				

## The care group requiring the most intensive care

It is clear that spouses need the most intensive support. Nearly three-quarters (70 per cent ) of spousal care is intensive, ie more than 20 hours per week. This is consistent with previous evidence which suggests that older spouses spend on average 65 hours per week on caring tasks (Arber and Ginn, 1991).

Conversely, over half the friends/neighbours in the sample receive less than five hours of care per week. Parents fall in the middle with about a half requiring less than 10 hours per week and one-quarter requiring between 10-19 hours per week.

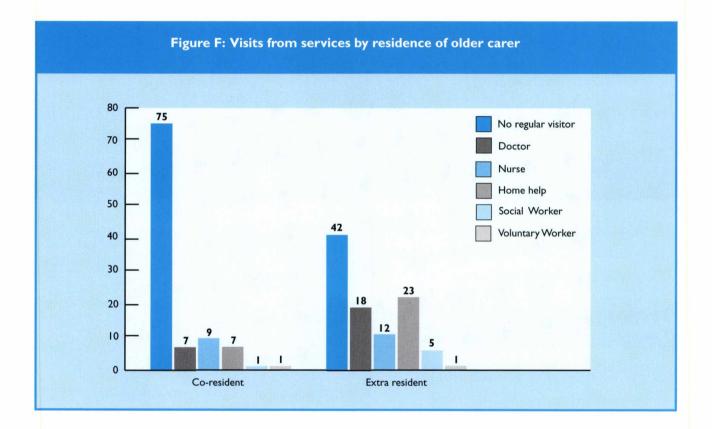
## Number of years spent in caring role

Around half of older carers have been caring for between 0-4 years; about one-third for 5-14 years and about one-sixth for 15 years or more (Figure E). A similar proportion of men and women care for short to medium periods of time with slightly more women caring for periods of 15 years or more. These women are likely to be spouses looking after frail older husbands.

## Length of caring by age of older carer

Table Three shows that one-quarter (24 per cent) of carers aged 60-74 and well over one-quarter (27 per cent) of carers aged 75+ have been caring for 10 or more

Table 4: Long-standing illness/Disability of Older Carer by Age							
	Age of old	ler carer 75+					
Long-standing illness	54%	56%					
No long-standing illness	46%	44%					
n	574	146					
	37.1						



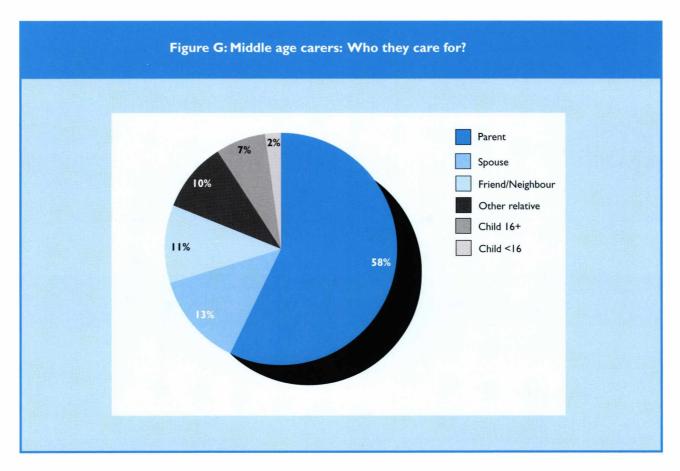
years. Additionally, one-quarter (25 per cent) of carers aged 60-74 and just under a quarter (21 per cent) of carers aged 75+ have been caring for between 5-10 years.

"Many of the oldest carers are not only caring intensively for many hours per week but have been caring over a long period of time."

This finding suggests that many of the oldest carers are not only caring intensively for many hours per week but have been caring over a long period of time. This is a particular concern given that carers aged 75+ are likely to be frail themselves.

#### Health of older carers

Over half of older carers report a longstanding illness or disability (See Table Four). Even more strikingly, two-thirds of those with a long-standing illness or disability say their illness limits their activities. This suggests that many older people are caring for others whilst suffering from a serious health condition themselves and that they continue to care despite their illness and despite the limitations it places on their activities. As many older carers care for sustained periods of time, it also suggests the real possibility of carers' health being adversely affected.



"Many older people are caring for others whilst suffering from a serious health condition themselves."

#### **Older Carers and services**

#### Residence type and service receipt

Co-resident carers receive far lower levels of support from services than extra resident carers (Figure F). Three-quarters (75 per cent) of older co-resident carers and two-fifths (42 per cent) of extra resident carers receive no regular visits from a health or social care worker.

"Three-quarters of older co-resident carers receive no regular visits from a health or social care service."

Similarly whilst nearly one-fifth of extra resident carers (18 per cent) receive support from the doctor and nearly one-quarter (23 per cent) from the home help service, only one-tenth of co-resident carers receive any such service. These findings

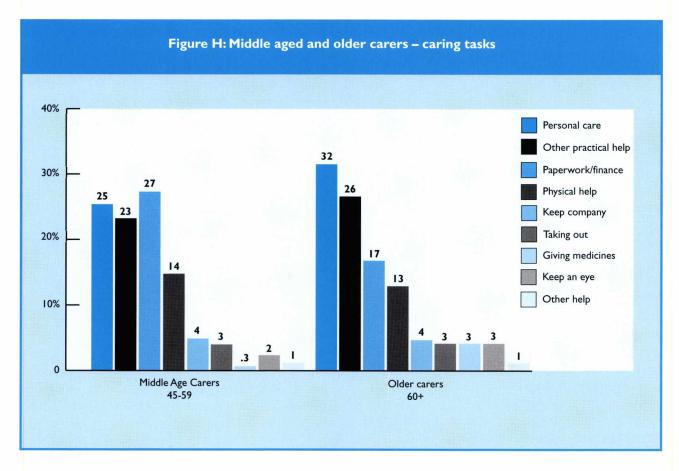
support existing evidence that services are targeted at older people living alone (Pickard, 1999; Sinclair et al, 1990).

An additional concern is that those older carers caring for 20+ hours per week – most of whom would be co-resident – receive lower levels of services than older carers providing under 20 hours per week. Whereas 14 per cent of older carers providing under 20 hours of care receive visits from a doctor and 19 per cent from a home help. The corresponding figures for carers providing 20+ hours per week are 10 per cent and 12 per cent.

Welfare agencies need to be more responsive to the needs and health risks associated with older co-resident carers as a higher – or at least equal – priority to those risks associated with dependent elders living alone.

## Taking a break from caring

Thirty-three per cent of intensively involved older carers who had been caring for between 5-14 years had not had a break of 'two days or more' since they started caring. This was also true for 54 per cent of carers who had been caring for 15 years or more. In total 61 per cent of intensively involved



carers reported 'needing help to have a break' and only 36.5 per cent had a reliable 'other carer' they could trust were they to take a break.

"One-third of older carers who have cared for between 5-14 years have not had a break of 'two days or more' since they started caring."

Thirty per cent of intensively involved carers had not access to temporary care whilst 22 per cent did. Of this group most identified a nursing/residential care home as the 'temporary care' available.

## Comparing older carers with middle aged carers (aged 45-59)

Although the focus of this study is older carers, it is important to acknowledge the contribution of middle aged carers. Many of this group care for older people - mainly parents - and many will continue to be carers into their retirement.

Over one-third of carers are aged 45-59. 60 per cent are women and 72 per cent are extra resident. The vast majority of both

male and female carers in this age group are married (86 per cent). Compared with older carers, more middle aged carers are extra resident and fewer are male.

## Who do middle aged carers care for?

Over half care (58 per cent) for their parents, 13 per cent for spouses, 11 per cent for friends/neighbours and 10 per cent for 'other relatives'. A small number care for adult sons/daughters (7 per cent) and children under 16 of age (two per cent). This contrasts sharply with older carers who predominantly care for spouses (Figure G).

## Time spent caring

Fewer middle aged than older carers care intensively, with far fewer caring very intensively: 30 per cent of middle aged carers spend 20+ hours caring per week including 12.5 per cent who care for 50+ hours. This compares with 39 per cent of older carers who care for 20+ hours per week, with half this group caring for 50+ hours.

## "Fewer middle aged carers provide intensive care than older carers."

This reflects a number of issues. The dependency needs of the main group being cared for by middle aged carers – elderly parents – will be generally less severe than the needs of older spouses. It also reinforces the fact that many middle aged carers live in a separate household, that many will be working and unable to commit as many hours as a retired carer to caring activities.

## Caring tasks

Middle aged carers primarily offer support with paperwork/financial matters (27 per cent), personal care (25 per cent), 'other practical matters' (23 per cent) and physical help (14 per cent). While these are also the primary care tasks of older carers, a larger proportion of personal care support is provided by older carers and less support is provided with paperwork (Figure H).

About double the number of women carers in the 45-59 age group provide personal care and a slightly higher number offer other practical help eg shopping. More men help with paperwork/financial matters (Stoller, 1992).

## Comparing older and middle aged carers:

The largest group being cared for by middle aged carers is parents, while the largest group being cared for by older carers is spouses. In addition, older carers also provide care to other groups whereas middle aged carers predominantly care for parents only.

Overall, compared to older carers, the 45-59 age group make up a slightly larger proportion of the total group of carers, more are female, significantly more are extra resident and fewer are involved in intensive care.

## Summary

This analysis makes it clear that older carers offer a great deal of care to relatives and friends with dependency needs. In particular older carers support spouses and parents and a small but significant number care for an adult son/daughter with a disability.

The findings echo earlier work in highlighting a fundamental distinction between caring for someone on a coresident and extra resident basis. These two settings vary in terms of the time devoted to care, the intensity of the caring tasks and the relationship of the carer to the person being cared for. The vast majority of coresident carers are spouses, reflecting expectations of mutual care within marriage. Typically, spousal carers adopt the role of carer gradually over time; men and women accept care responsibilities on an almost equal basis. A significant number of older sons/daughters are caring for their very elderly parents.

Older carers can be distinguished from other groups of carers in a number of unique ways. They are more likely to have health problems of their own and their care-giving is likely to take place within the context of a long term relationship. Dementia is also more likely to be present in the care-giving experience of later life and older carers are also much more involved in intimate and personal care.

This analysis shows a high level of devotion to caring amongst older carers. Many provide intensive care over a long period of time in very demanding circumstances with little or no support from services. Despite the circumstances of many co-resident older carers, services continue to be targeted at older people who live alone (Bauld et al, 2000). This tendency ignores the considerable risks associated with providing long term care in later life.

# Section Three

## Groups of Older Carers

This section reviews the evidence as it relates to the dominant groups of older carers. In particular it explores the relationships which characterise caring in later life.

## Older people as care givers as well as care receivers

One of the more damaging consequences of regarding older people as dependent recipients of services is that their contribution to the life of the family and community is often overlooked. It has repeatedly been shown that the majority of those aged 75+ remain active and not in need of care and attention. Moreover, many of those in need are not simply passive recipients of care but are providing help and support to others.

The dominant concern in literature on the care of older people to date has been the burden faced by women caring for frail relatives (Arber and Ginn, 1991; Dalley, 1993 & 1996). This presents a one sided account of older people as a 'social problem' to be 'cared for', and generates panic about the increased proportion of older people in the population. Furthermore, it inhibits work about caring between older people particularly spouses - and the role of older male carers.

Many older people who provide care do not describe themselves as a 'carer' and there may thus be a much higher number of older carers than is formally recorded. This is likely to be particularly true in familial relationships where care is accepted as part of a close personal relationship or an understanding of 'duty', as is the case in long term marriages (Finch, 1995; Church and Summerfield, 1995). The fact that only one-third of those aged 80 and over require formal care (Walker and Warren, 1996), suggests there is a great deal of mutual caring in the family.

## Spousal care

Caring in later life is most likely to take place in the context of a lifelong relationship, predominantly marriage (Lewis et al. 1998). This tends to be regarded by both carer and person cared for as an extension of the companionship and mutual assistance that has been given and received over many years. Caring for someone is inextricably intertwined with caring about the person (Ungerson, 1997). It is clear that the willingness of spousal carers to continue caring in highly stressful circumstances goes beyond that of other groups of carers. In part this can be understood as an expression of the expectations that underpin marriage, particularly the assumption that a couple will remain together until death (Atkin and Rollings, 1992; Manthorpe, 1994).

Spousal care tends to involve intimate care and to be interdependent in nature, with the carer/cared for roles often indistinguishable from each other (Lewis et al, 1998). Spousal carers tend to adopt the caring role gradually over time as disability increases and often drift, without realising it, into offering increasing levels of support and help (Ashkam et al, 1992).

Although there is a strong commitment amongst most spouses to provide continuing care for a disabled husband or wife, it should not be assumed that adopting the carer role is unproblematic. People do not enter marriage expecting to provide intimate physical care and this can challenge the basis of marriage (Parker, 1990, 1992). Impairments associated with changed behaviour or personality are particularly stressful for spouse carers (Briggs & Ashkam, 1999).

Another notable feature is that spousal carers often face a limited social life as a result of the inability of their husband or wife to share in it (Parker, 1992; Twigg and

Atkin, 1994). This creates a series of dilemmas. Spouse carers often want a break from caring but the person they most want to go away with is the relative they care for, and they often feel guilty about enjoying themselves when the person they love cannot. It can be difficult for the carer to articulate a need for an independent social life and wanting respite may seem disloyal (Parker 1992). Building up a separate social life may seem to undermine the relationship, yet, at the same time, constantly being in each other's company may create an enormous strain.

On a related note, Parker's study of preretirement spousal carers identifies the issue of isolation which has considerable resonance for older carers (Parker, 1983). She found that the marital bond made caring a more isolating experience; carers found it difficult to distance themselves from the caring role and had no one to share experiences or stresses with.

## Older carers of parents/ parents-in-law

Analysis of the 1990 GHS suggests that nearly half of carers of parents/parents-in-law are aged over 60 (Parker, 1993). With the future expectation of increased longevity among older people, more carers of parents will be over retirement age. The majority of this group are women and those caring for a parent in the same household are more likely to be heavily involved.

The nature of the relationship between child and parent sets up different expectations than in other kin relationships. Tasks involving physical intimacy, for example, are less likely to be seen as an accepted part of an adult daughter or son's relationship with the parent than that of a parent caring for a child. Another key factor is that an adult son/daughter will have developed a separate and independent life prior to the need for caring, which is not the case for spouse carers (Parker, 1992).

Carers of parents fall into two broad groups: those who are co-resident and those who are extra resident. Among those who share a household, there is a distinction between those who have never left home or who have moved back in the wake of marital separation, and those who have set up a joint household specifically in order to care for their elderly parent. Among coresident carers, there is rarely a conscious decision to care, and these individuals tend to drift into the role. This pattern is particularly the case with sons. Particular problems for this group include isolation, being physically and emotionally trapped in a caring role, and feeling anxious about the future (Levin et al, 1989).

Some shared households are formed specifically in order to offer care, with the carer moving in with his/her parent, or the parent(s) coming to share the home of an adult son/daughter. The period directly following the move represents a significant transitional stage in the relationships and requires considerable adjustment. This group of carers report that balancing the conflicting demands of family and parents with the demands of work is very challenging and can cause great stress (Drewett et al, 1994).

There are also a small number of older carers caring for siblings or another same generation relative. Some of this care will be intensive and will share some of the associated characteristics of spousal care.

## Older carers of adult sons/daughters

Under 10 per cent of older carers provide care to an adult son or daughter, however care provided may be complex and long term. There is evidence that older people also retain long term caring responsibilities for adult children with physical disabilities and with learning difficulties (Walker & Walker, 1998). As stated in the introduction to the report, caring for adults with learning difficulties will not be examined in detail within this report.

## Older carers of younger adults with mental health problems

Although it is not known how many older people care for younger adults with mental health problems, research suggests that many such carers are parents and are thus likely to be older (Perring et al, 1990).

Issues relating specifically to carers of younger adults with mental health problems are rarely explored. Traditional views of caring have a strong task orientation and this means that caring for someone with a mental health problem is not regarded as 'caring' (Perring et al, 1990). These carers, although rarely performing physical tending, do have to assume responsibility for the cared person person, as well as deal with the consequences of sharing their life with them. This can mean providing a home, coping with money or public authorities, managing periodic crises or hospitalisation, and trying to prevent the cared for person falling into lethargy and self-neglect. Mental health problems can disrupt family life and impose long term social isolation. Carers often feel that they are dealing with a world that no one else understands or wants to be part of, and as a consequence feel isolated and trapped (Twigg & Atkin, 1994).

The onset of a mental health problem is a particularly stressful time for a parent; they may have to come to terms with a fundamental change in their child, their level of functioning and their own lives. Carers often feel an acute sense of loss. They may also feel that they are living with a stranger and do not know how to cope with either their relative or their own feelings of anger, bewilderment and frustration. Carers identify support and reassurance, as well as information and advice about how to cope with onset and with possible future crises, as particularly important types of support (Perring et al, 1990).

The differences in the experiences and management of caring for someone with a mental health problem depend very much on the relationship between the carer and the cared-for person. As schizophrenia most often manifests itself in the late teens

and early 20s, the person is more likely to be cared for by parents who are often older. As with ageing parents of adults with a learning disability, concerns about the future care of the adult with a mental health problem is a persistent concern for many older parents (Walker & Walker, 1998).

In addition, the experiences and needs of older carers looking after someone with a mental health problem are less likely to be recognised by support services. Carers usually have contact with services which have a strong medical focus, whose concern is to encourage the independence of the user rather than offer support – or even acknowledge the role of – the carer. Carers, however, report wanting service input. They want to be able to talk to someone about their role, receive advice and information about how and where to get help and meet other carers in similar circumstances. Carers however report that they rarely have long term contact with professionals and they often have difficulty contacting a worker at a point of crisis (Twigg, 1989; Twigg et al, 1990).

# Section Four

### The Consequences and Impact of Caring

Most of the evidence in this section relates to carers providing intensive support and has been gathered from smaller scale research projects.

### The effects of caring on older carers

There is considerable literature on the effects of caring on carers' lives. It suggests that the consequences of caring are far reaching and long term and relate particularly to:

- Financial consequences of caring
- Physical health related consequences of caring
- Psychological and emotional consequences of caring
- Social consequences of caring

The range and magnitude of these effects is largely related to the nature of the disability and the amount and type of care required.

# The financial consequences of caring in later life

#### Carers and poverty

Older carers have been identified as one of the poorest groups in Britain (Milne & Williams, 2000). Research indicates that carers providing substantial amounts of care – many of whom are older - face much financial hardship (CNA, 1992). Half these carers' incomes are within the lowest two-fifths of income distribution (CNA, 1998) and one in five older carers have difficulty paying for essentials such as fuel bills (CNA, 2000). Housing is strongly correlated with income. Parker's research suggests that those who care intensively are less likely than their counterparts to be in

owner occupied accommodation. Some of this undoubtedly reflects the prolonged lowered income status of both the disabled person and their carer, many of whom will be older (Glendinning, 1992).

### Caring and employment

The relationship between employment and care is not straightforward (Glendinning, 1992; Parker and Lawson, 1994; Caring Costs Alliance, 1996). Caring responsibilities can impact on employment in a variety of ways with reduced levels of participation through fewer hours of work, movement from full-time to part-time employment or withdrawal from the labour market altogether (Department of Social Security, 1999). This is true for both men and women.

Many carers currently lose the opportunity to make proper provision for their retirement because their working lives are interrupted by a period of caring. In the case of women this may be a second interruption, following one they have already taken to bring up children. Many of today's older carers began caring whilst they were still of working age. This has compromised their earning capacity for the remainder of their working lives, as well as for retirement because they will have paid reduced pension contributions. As Evandrou points out, 'Lower pension rights may extend the employment impact of caring well beyond statutory retirement age' (Evandrou, 1995). To compound these financial disadvantages, carers over 65 are not entitled to claim Invalid Care Allowance (ICA), a welfare benefit designed to support carers. However, carers who applied for ICA before pensionable age and continue caring into later life may retain an entitlement to a carer premium and other means tested benefits.

Hancock and Jarvis (1994) investigated the long term effects of being a carer using data from the OPCS 1988 Retirement Survey. They concluded that 'caring has long term financial consequences which affects carers after caring has ceased'. This appears particularly true for carers who have devoted many years to caring; those who had been caring for more than 10 years were financially disadvantaged in almost all respects compared with both non-carers and those who had been caring for shorter periods. This was true for both retired and non-retired people and both men and women.

Recent research by the CNA produced similar findings and concluded that there is a consistent and marked depreciation in carers' financial circumstances once they have been caring for between five and 10 years (CNA, 2000).

### Costs related to caring

Caring can also involve extra costs. Glendinning explored this in her study of 30 working age, non-spouse, co-resident carers who were intensively involved with their relatives (1992). While the group studied were younger carers, many of the issues apply, and some are amplified for older carers. The study found that carers often incurred substantial extra costs including specialist housing, adaptations, extra heating, additional laundry, clothing, bedding and toiletries. Costs arising from care giving included the costs of substitute care; adaptations to the carer's home; extra travel costs associated with visits/health care appointments etc; extra clothes due to damage or wear and tear and telephone costs to keep in touch with the cared-for person (Glendinning, 1992).

To meet these extra costs, carers in the study drew on their savings and those of the person they cared for; used credit and delayed the payment of bills; cut back on regular saving and cashed insurance policies; borrowed money and curtailed spending on both non-essential, and at times essential, items. This results in carers entering later life with reduced financial resources.

Another issue which causes financial stress is local authority charges for services such as home care, day care and meals on wheels, which have greatly increased recently. Poorer households are increasingly being asked to contribute to their care costs despite the consequent financial hardship this causes. In their survey of the financial status of carers, the CNA revealed that three-quarters of carers aged over 70 are paying for services out of their savings (CNA, 2000).

As might be expected, costs associated with caring are directly related to the intensity of the care provided. The number of carers who find the 'costs of care' a drain on income rises from one-third of those providing less than five hours care a day, to nearly three-quarters of those caring 24 hours per day (CNA, 2000).

# Physical health related consequences of caring

Older carers are at increased risk of experiencing health problems or disabilities themselves, especially if they are aged over 75 (Arber & Ginn, 1991). The analysis of the 1995 GHS conducted as part of this review found that over half of older carers have a long standing illness or disability.

Despite this, many older carers cannot afford to either be ill or be admitted to hospital due to the intensity of their caring role - particularly if they are not properly supported by services. Early discharge from hospital is of no value to a carer who is told to 'rest' but who must care for her disabled husband. This is particularly the case for those carers without any regular support from family (Hirst, 1998).

While evidence about the impact of caring on a carer's physical health is mixed, a number of features are known to have a negative effect. Evandrou (1996) found that poorer health is associated with:

- carers living with the cared for person
- bearing the main responsibility of care with little or no support
- caring for someone with both mental and physical impairments and
- caring for over 50 hours per week.

In particular, being a spouse carer raised the likelihood of ill health. Specific health outcomes include physical strain and musculoskeletal problems; this finding is also echoed by more recent work (Henwood, 1998).

The relationship between health status and caring is complex and the evidence on whether carers suffer proportionately more health problems than other people of the same age is not conclusive. Physical injuries in particular become more common as people age; for many older carers their vulnerability to injury whilst performing arduous caring tasks will be compounded by their age (Henwood, 1998). But the 'stressors' associated with caring certainly increase the vulnerability of older carers to injury and impaired physical health.

# Psychological and emotional consequences of caring

Evidence about the link between caring and reduced emotional health is much stronger (Parker, 1990; Draper et al, 1996). Recent work using the British Household Panel Survey has suggested that caring has a significant negative impact on the emotional health of carers (Hirst, 1998; Henwood, 1998). This is especially true for those providing intensive co-resident care and many older spousal carers fall into this category (Evandrou, 1996; Hirst, 1998).

Stress among carers is widely reported and is particularly associated with depression. Around one-third of those caring for a disabled spouse experience clinical level depression (Levin et al, 1994; Ballard et al, 1995). In Liston et al's study, one-third of the 93 carers interviewed felt their health was affected by caring, with nearly two-thirds reporting stress and half reporting depression (1995).

The psychological consequences of caring are most prevalent among people caring for a person with a serious disability, dementia or with a chronic mental health condition like schizophrenia. The most convincing evidence relates to the impact of personality change or behavioural

difficulties associated with dementia or other chronic mental health problems (Parker, 1990).

### The social consequences of caring

There are a number of social costs related to caring. Leading a life constrained by caring is described by Twigg (1994) as 'restrictedness'. This refers to being unable to leave the person cared for, as well as broader constraints such as a limited social life, being kept at home, facing a timetable of caring tasks and worrying when leaving the cared-for person. Looking after a person with 24 hour needs, for example a spouse with dementia, can severely restrict the carer's ability to retain any independent life. As mentioned earlier, this is a particular challenge for spouse carers.

Intensive caring demands can restrict a carer from leaving the house for any length of time. This often results in intense social isolation as carers become detached from their social networks (Wenger, 1992) and lose touch with community supports. Isolation is a particular feature of caring for someone with behavioural problems or incontinence (Wenger, 1994). Many carers enjoy a chance to talk and this is particularly the case when the person being cared for is unable to sustain a conversation. Most carers prefer to talk to other family members although this is not always available (Moriarty & Webb, 2000).

It is important to note that caring can also be a source of considerable satisfaction for some carers and that it is associated with improved emotional well-being in contexts which enhance a carers sense of self worth or value (Nolan et al, 1996).

### Abuse and older carers – afterword

Although uncomfortable to acknowledge, it is important to recognise that older carers can be both perpetrators and victims of abuse (McCreadie, 1996). Current research evidence suggests that the 'risk factors' for being abused are; being over 75; suffering from a chronic physical and/or a mental illness; being socially isolated and living with - or being cared for intensively by - a spouse or adult son/daughter (Penhale &

Kingston, 1995). Carers of older people with dementia appear to be particularly likely to abuse the cared-for person. Much of the abuse in this context relates to coabuse where the carer abuses the cared-for person and the cared-for person abuses the carer. (Manthorpe, 1995).

Specific triggers for abuse appear to be aggression and violence, verbal abuse and high levels of physical and psychological demand. Caring for sustained periods of time and caring intensively, ie performing a number of intimate and personal care tasks at frequent intervals, are also cited as factors (Biggs et al, 1995). Research also indicates that abuse is more likely in contexts where the caring relationship was poor prior to caring and where older carers are thrown unwillingly into a caring relationship (Manthorpe, 1995).

Given that many older carers provide very intensive levels of care, over long periods of time with very little support, the consequences of care facing this group are often considerable. This fact needs to be recognised in policy and practice development.

# Section Five

### Formal and Informal Support for Older Carers

This section addresses the value and role of services and family based support for older carers.

### Service provision for older carers

There is little evidence about services specifically for older carers, much of the research evidence outlined below relates to studies on adult carers in general.

Services for carers take two main forms; specific carer services and carer "allocations". Specific carer services include carer support groups and respite care. Carer allocations are those services allocated to the cared-for person with the intention of offering support or relief to the carer. This may be explicit, such as a day care place to provide respite, or less explicit such as a cleaning service which also benefits the carer (Twigg, 1992).

In general, carers have difficulty accessing community social services as they tend to be targeted at older people living alone. This finding was borne out by a number of studies conducted in the 1980s. The services most affected are home care, meals on wheels and day care (Davies et al, 1990; Bowling et al, 1991; Bowling et al, 1993). The effect of this allocation system has meant that carers can look after a very disabled person but may receive little or no support from services. There is some evidence that as a consequence of the Carers (Recognition and Services) Act 1995- and to a lesser extent community care legislation – services may now be more oriented towards carers and that care managers are directing care towards supporting and relieving carers (Bauld et al, 2000). It is hoped that the Carers and Disabled Children Act (2000) may further encourage carer-centred assessment and services.

### Which services support older carers?

The GHS 1995 (OPCS, 1998) provides information about the number of carers whose relative receives regular visits from a health professional, social services (including private sector services) or voluntary sector service. Home help (30 per cent), community nursing (16 per cent) and contact with a doctor (15 per cent) are the most common service types. However, the 1995 GHS suggests that nearly three-quarters of older co-resident carers and two-fifths (42 per cent) of extra resident carers have no regular visits from any service providers.

Of those carers caring for more than 20 hours per week, under one-third (29 per cent ) are receiving some social services help, including that which they purchase privately. Those who are caring for over 50 hours per week – who are mostly older – receive slightly more help (31 per cent ).

Carers are regularly in touch with the NHS. A recent survey of carers' experience of the NHS showed that nearly nine-tenths (88 per cent) of carers had seen their GP in the previous 12 months (Henwood, 1998). Half of carers had seen a district nurse (51 per cent), and nearly a third a community nurse (28 per cent).

### What carers find helpful

There is no evidence specifically relating to what older carers want from services, although research on carers in general suggests the following priorities:

- Time off from caring
- Formal services for carers
- Support from family and social networks

- Support from other carers
- Information and advice
- Recognition of their role and contribution
- Financial support

### Time off from caring

Time off from caring means different sorts of breaks depending on the needs and circumstances of the carer and the person they are caring for. Crucially, the aim should be to allow the carer to maintain aspects of their own life, including employment. Carers value the freedom to have a life of their own – in particular the ability to spend time with family and friends or with the person for whom they are caring, free of the normal caring responsibilities. Such time is enormously valuable in helping carers retain or regain emotional and physical health.

Although the protective effect of 'taking time out' is now well demonstrated, the 1995 GHS shows that few carers are able to do so. Heavily involved carers and/or those looking after someone in the same household find it particularly difficult to arrange any sort of break. Furthermore, these carers are unlikely to have an activity such as paid employment, which takes them out of the home. As we have seen from the GHS analysis, over a half of intensively involved older carers have had no break since they began caring; for many this has been for more than 15 years.

### Formal services for carers

The right services for the person they care for is very important to carers; integrating this desire with their own needs is central to delivering the right type of response. Carers want to be assured of the quality of services – both at present, and in the future, particularly in the event of the carer becoming ill or dying. Being able to influence the ways in which services are provided and the right to be 'listened to' by professionals are both important (Bamford & Bruce, 2000; Pickard et al, 2000).

Maintaining health and well-being

There is evidence that a number of services improve the well-being of the carer. The

'Caring for Older People: An Assessment of Care in the 1990s' study conducted by the Personal Social Services Research Unit found that day care reduced stress amongst carers and could delay the need for institutional care (Bauld, 2000). However, one of the paradoxes of day facilities is that they are often unwilling to accept elders with 'challenging behaviour' or incontinence when it is precisely these issues which may increase the carers need for respite (Twigg, 1994). Carers may be reluctant to reuse a day care facility if their relative returns home more confused or disoriented than when they went (Parker, 1993, Levin et al, 1994).

Respite care has also been found to reduce carer stress, particularly amongst coresident carers (Henwood, 1998). Respite care appears to be in short supply and the problem may have been accentuated by community care changes. As private care homes replace local authority homes which provided the bulk of short term care, the service diminishes and carers have greater difficulties accessing it (Tinker et al, 1998).

Many carers value respite care (Homer & Gilleard, 1994) and more would take advantage of it if it was available to them. In their study Levin et al found that of those carers who had never had any respite from caring for a relative with dementia, five in six had not been offered respite care and two in five would have accepted breaks if offered (Levin et al, 1994).

Sitting services are popular with carers, especially co-resident carers as they offer flexibility, regularity and reliability (Twigg et al, 1990). The service also tends to be more acceptable to the cared-for person than day care. The availability of sitting services is limited; some restrict access and some operate a waiting list (Twigg et al, 1990). There appear to be particular benefits to the carers of older people with cognitive impairments.

The home care service is highly valued by carers who receive it. Home helps are often praised for their emotional support and company. This is particularly true for older carers who are looking after someone with dementia with whom they can no longer have a conversation (Twigg, 1992). As little as 40 per cent of dementia

sufferers in Levin's study received a home help; many more of the carers would have liked one (Levin et al, 1989). Levin and her colleagues found that a home help could improve the mental health of the carer (Levin et al, 1989).

Despite the fact that nurses can offer emotional and practical support to carers (Nolan & Grant, 1989), few actually receive this service. Community nursing services are allocated on the basis of a disability or levels of dependency and carers' needs are not significant (Davies et al, 1990). Over the last 10 years there has been a consistent reduction in their provision of support to carers (Parker, 1998). Carers who do receive support from community nurses value the practical hands-on advice and support they offer, particularly relating to incontinence (Twigg, 1992).

Despite their limitations, carers place a high value on services and almost universally want more to be available on a more intensive basis. There are some differences according to the nature of the caring relationship. Carers of dementia sufferers particularly value respite care and day care although these are less popular with spouse carers of older people with physical disabilities. Evidence suggests that flexible forms of home relief services, such as sitting services and care attendant schemes, can be more acceptable to both the carer and the older person, but these schemes tend to be of limited availability.

#### Care management and assessment

Care management is generally viewed as a useful and positive process by older carers. although recent research suggests that carers do not always know they have received an assessment of their needs and are not aware of their legal rights under the Carers (Recognition and Services) Act 1995 (Arskey et al. 2000). Carers value a face-toface discussion with a social worker or care manager and generally find the process of assessment beneficial. Recent work by the Personal Social Services Research Unit also suggests that care managers are shifting the focus of their work towards supporting carers and that carers' needs are a higher priority for care managers than they have been in the past (Bauld et al, 2000).

### Support from family and social networks

Social support and assistance from family and friends play an important role in maintaining the mental well-being of carers both in terms of practical and emotional support (Mittelman et al, 1995).

Although limited evidence exists, some studies have found that carer stress is reduced when they are satisfied with the amount of help they get from others, regardless of how much help that actually is (Parker, 1990).

Much work has been done in the field of gerontology and sociology to explore the support networks of older people, although the focus on older carers is more limited (Wenger, 1989; Phillipson et al, 2001). All research identifies the primacy of support networks in the lives of older people.

Support networks have been shown to act as a 'stress buffer' for family carers (Nolan et al, 1996) and to protect them against social isolation. Furthermore, these are often related to the demand for, and use of, formal services (Wenger, et al 1994). The role of networks in supporting older carers is thus of relevance to both their quality of life and in accessing support services.

Wenger's research identified that while most dependent older people rely predominantly on one relative, the caring relationship may only survive because of support provided by others in the social network (1984). Carer well-being is enhanced by brief visits, telephone calls or letters; expressive help such as listening to problems or merely acknowledging the carer's input was particularly valued. Carers may also be receiving practical help with transport, shopping or outings with the person being cared for. Without this support many carers said they would not be able to continue caring.

These findings are substantiated by Phillipson et al's recent study of the family and community life of older people in three urban areas (2001). This finds that 'family care' is increasingly provided by one close relative, usually a spouse, and that the extended family plays a relatively limited role in supporting carers. Friends are the dominant supporters of older carers; they are local and tend to offer both emotional

and practical support. These lower levels of family assistance reflect the fact that more older people are living alone and that families are smaller and more dispersed.

It is clear from these studies that social trends have altered the nature of the networks that support older carers. A key consequence of these changes may be greater pressure on spouses and other older carers; the reduced size of networks and the fact that relatives are no longer local may result in carers receiving less support. At the same time, friends are becoming much more significant and – as research suggests – are likely to become increasingly important providers of support to both older people with care needs and their older carers.

The reduced capacity to replace support when network members are lost through death, incapacity or geographical mobility can leave carers and cared-for people with limited options.

Although there is some evidence about what older carers consider to be supportive, we are at an early stage in understanding what aspects of support networks are conducive to providing reliable and effective support for both the cared-for and carer.

### Support from other carers

Research suggests that carers benefit from contact with other carers in similar situations. Such contact provides: information about services, advice about coping with stress, and mutual support and reassurance. In a study exploring the role of a carers' centre, carers revealed the specific benefits of being able to talk to someone who listens, links with other carers, and advice about welfare benefits (Tinker et al, 1998).

Carer support groups are one of the few forms of support that are provided specifically for carers. Some groups are offshoots of a facility like a day hospital or adult training centre; others are free standing. Some are open to all carers; others focus on a particular user group, or even a particular medical condition (Twigg, 1992).

A report by the SSI highlighted the importance of carers' centres and support groups (SSI/Department of Health, 1995). Volunteers - many of whom are former carers - provide information and advice, telephone support, a 'listening ear' and practical help like shopping, laundry and gardening.

Carers support groups play a particularly important role for older carers of people with dementia (Burns & Rabins, 2000). Research by Cummings (1996) suggests that offering carers a forum to meet reduces carers' stress and isolation, increases carers' understanding of dementia and improves knowledge of medical treatments and specialist services (Bourgeois et al, 1996). Links with a support group help carers continue to provide care (Mittelman, 1993).

Not all carers will want to join a support group, preferring to use any free time they have pursuing interests or socialising (Twigg, 1992).

#### Information and advice

Information and advice about the health or condition of the person they are caring for, how to cope with it and about the services and benefits available, are vital for carer welfare.

Research continues to show that carers have difficulty in obtaining information and advice and this has been identified as a particular deficit within mainstream services. Yet this kind of support is highly valued by carers (Tinker et al, 1998). While carers' groups can offer both information and advice to carers, there does not appear to be a routine way for carers to access this help.

The majority of carers of people with dementia are unaware of the range of services that are available and many provide care for a long period before receiving any help (Philp et al, 1995; Moriarty & Webb, 2000). Even where carers are offered respite services, very limited written information is provided (Levin et al, 1994). This lack of information about services, as well as limited communication and feedback, raises important concerns about the ability of carers to make informed choices about

the most appropriate care solutions for themselves and those they care for (Fisher, 1990; Bamford & Bruce, 2000).

## Recognition of the caring role and the contribution they make

It is important to carers that their contribution is recognised. They value an acknowledgement of their role in providing care and want to be treated as a partner in discussions about the help provided to them and the person they care for. Research emphasises that carers appreciate recognition that caring takes place within an existing relationship. Spousal carers in particular want themselves and their partner to be regarded as a 'couple', a long term relationship characterised by bonds of obligation, affection and reciprocity. Support for carers needs to acknowledge both the benefits and the challenges involved in caring (Nolan et al, 1996).

### Financial support to older carers

### Financial Provision for Carers

The most important financial provision for carers in the UK is the Invalid Care Allowance (ICA), a social security benefit for carers. ICA was designed to support carers of working age, to partially replace earnings lost as a consequence of providing at least 35 hours of care a week. Eligible carers must not earn more than £72 per week from paid employment. Carers are only eligible to claim ICA if the person they care for is in receipt of Attendance Allowance, Constant Attendance Allowance or the middle or highest rates of the Care Component of Disability Living Allowance.

ICA has a number of positive features: It is a benefit which recognises the rights of carers to an income that is independent of the person they are caring for, it is located within the social security system and is thus governed by universally applicable principles and entitlements, it is not viewed as a substitute for services and it is payable to both relatives and non-relatives (Glendinning & McLaughlin, 1993).

ICA has been widely criticised for being unsatisfactory in terms of scope, criteria and level (Baldwin, 1994): One of the main groups excluded from receipt of ICA are older carers. Since ICA is intended to replace earnings they are not eligible; it is also a consequence of 'overlapping benefit' rules which mean that ICA cannot be paid in addition to another income replacement benefit such as the Retirement Pension.

However, carers who were entitled to Carer Premium and Income Support before they reach their 65th birthday retain this entitlement to Carer Premium - a top-up payment to Income Support. This means that they may receive higher amounts of means tested benefits such as Council Tax Benefit and Housing Benefit.

The Government is currently planning to change the eligibility conditions to ICA to allow carers who start caring over the age of 65 to make a claim for the benefit. In practice, although carers with a higher Retirement Pension might not receive ICA due to the overlapping benefit rules, the new conditions would give carers on very low incomes underlying entitlement to ICA and access to additional income through to Care Premium and other means tested benefits.

# Section Six

### Older Carers of People with Dementia

Most research exploring carers of people with dementia does not distinguish between those carers who are older and those who are not. However the vast majority are older spouses caring for people with more severe dementia.

### Who cares for people with dementia?

In the UK, it is estimated that some five per cent of the population aged 65 and over and 20 per cent of the population aged 80 and over suffer from dementia (Audit Commission, 2000). It has also been estimated that at least half of those who care for a person with dementia are aged 65 or over (Melzer et al, 1994). In a study of social services users by Levin et al (1994) almost 64 per cent of carers of people with dementia were older. About three-quarters of people with dementia who are co-resident, live with their spouse or another close family member. Thus most older carers of this group are spouses although a few are adult sons/daughters. When the person with dementia has a spouse, he or she is most likely to become the primary carer (Aneshensel et al, 1995; Levin et al, 1994; Arber & Ginn, 1991; Barusch & Spaid, 1989).

Much like older carers generally, older spousal carers usually support adults with more severe dementia, provide more intensive care and care over longer periods of time than other carers (OPCS, 1999; Moriarty & Webb, 2000; Arber & Ginn, 1991).

# The impact and consequences of caring for a person with dementia

Although research has identified a range of challenges confronting carers of people with dementia, it is possible to distinguish two broad categories of difficulty (Pearlin et al, 1990). These are problems relating directly to the effect of dementia and those which are the consequences of being a carer.

### Difficulties associated directly with the effect of dementia

There are a number of difficulties which relate directly to providing care to a person with dementia. They are:

- Functional problems: Many people with moderate or severe dementia need help with self-care tasks and other daily living activities. These range from intimate care tasks such as bathing and dressing to shopping and cleaning. The extent and level of care provided can be great and can impose a considerable physical burden on carers. The stress may be particularly acute for older spousal carers who - apart from having health problems themselves - may also be less willing to seek and accept help from services (Twigg et al, 1990; Moriarty & Webb, 2000). The loss of reciprocity between the carer and the person they care for, commensurate with functional dependency, has been identified as particularly distressing by many carers
- Memory problems: Memory problems are a common feature of dementia and they can result in an inability to adapt to new circumstances and remain orientated. Apart from the practical difficulties that arise from memory loss, it can cause emotional stress and a sense of loss for carers; particularly in marital relationships, the loss of memories related to past events and shared experiences undermines the nature and basis of marriage and can reduce the carer's commitment to care (Murray et al, 1999; Fearon et al, 1998)

Behaviour problems: These constitute a painful reminder of the changed personality of the person with dementia and pose a considerable source of stress for the carer as constant surveillance may be required. Carers often feel trapped by this role. Wandering out of doors and behaving dangerously at home, for example leaving a gas fire unlit, are particularly difficult challenges for carers. Apathy, depression, the failure to act or react and limited recognition of family and friends threaten the sense of mutuality and intimacy which is crucial to maintain a marital relationship (Ballard et al, 1995; Lewis, 1998)

The impact of these problems may be exacerbated if the carer lacks accurate information about diagnosis and prognosis. This knowledge offers greater control, earlier planning and greater awareness of the implications of the illness (Gillies, 2000; Cummings, 1996). In the UK, diagnosis of dementia is not yet offered to carers consistently (Rice & Warner, 1994; Moriarty & Webb, 2000). In a recent Audit Commission Survey (2000), only half of the carers of people with dementia reported having been told about either the diagnosis or prognosis of dementia. Failure to offer an accurate and complete diagnosis may be due to several factors including difficulties in recognising dementia symptoms; lack of adequate training as well as the belief held by many GPs that 'nothing can be done' (Iliffe, 1997).

# Secondary difficulties associated with caring for a person with dementia

There are a number of secondary difficulties that arise from caring for a person with dementia:

• Social life: Social problems may be more pronounced for older carers looking after a person with dementia. Friends and relatives may feel uncomfortable around the person with dementia, particularly if they are disruptive (Wenger, 1994; Moriarty & Webb, 2000). Spouses themselves may also feel embarrassed about their partner's behaviour and as a result, withdraw from social activities (Gillies, 2000).

- Although sons or daughters often act as confidantes for older carers, carers often refrain from discussing their difficulties for fear of being perceived as disloyal
- Family life: Dementia brings about changes not only in the relationships between the carer and the person cared for but also in relationships with other family members. These depend to a large extent on the relationships that have been established prior to the onset of the disease (Aneshensel et al, 1995). Although research is limited, it has shown that family members may disagree about the degree of the patient's impairment, family care arrangements and ways of managing the needs of the person with dementia (Aneshensel et al, 1995). In particular, there may be conflicts about whether other members of the family provide adequate support to the carer (Ory et al, 2000; Speice et al, 1998; Pruchno et al, 1997)
- Finances: Financial problems for carers of people with dementia are particularly pronounced because expensive packages of care are often required and placement in residential care often has to be considered (Dellasega & Nolan, 1997)
- Psychological and physical health: Since Fengler and Goodrich (1979) described the spouse carer of someone with dementia as the 'hidden patient', there has been a growing concern about the negative health effects of care-giving (Clipp & George, 1993; Livingston et al, 1996)
- The psychological impact of caring for someone with dementia has been widely researched and it has been estimated that 33-52 per cent of carers suffer from mental ill health, primarily depression (Schulz et al, 1995). This is particularly the case for older spousal carers (Pollitt et al, 1991, Cummings, 1996; Livingston et al, 1996; Moriarty & Webb, 2000). A recent study by Kiecolt-Glaser et al (1991) found that 25 per cent of their sample of older spousal carers suffered from a depressive disorder.

The physical health consequences of caring for someone with dementia are not as firmly established as the psychological consequences. Spouse carers certainly perceive their health to be poorer than non-carers (Rose-Rego et al, 1998; Fuller-Jonap & Haley, 1995). They are also likely to report more sleeping problems and be less physically active than non-carers of a similar age and gender (Fuller-Jonap & Haley, 1995; Burton et al, 1997). Limited research suggests that spouse carers of people with dementia are at increased risk of hypertension and upper respiratory infections (Kiecolt-Glaser et al, 1991; Vedhara et al, 1999).

### Rewards and benefits of caring for a person with dementia

Research on the impact of caring for an adult with dementia has only recently focused on positive outcomes (Braithwaite, 1996; Nolan et al, 1996; Rapp & Chao, 2000) and has revealed a number of sources of satisfaction that are "diverse, pervasive and subtle" (Nolan et al, 1996, p 106). Becoming more patient, compassionate and strong and feeling more appreciated, needed and productive are some of the rewards older spousal carers report (Nolan & Grant, 1989).

# Services for older carers of people with dementia

A range of services is available for older carers of people with dementia. This section presents evidence in two parts; mainstream services and specialist services. Only those findings which relate specifically to carers of people with dementia are reported in this section; where findings mirror those for older carers more generally, they are reported in Section Five.

#### Mainstream services

#### Services which offer breaks or respite care

The majority of services provided to carers of people with dementia - and the ones that have received most research attention - aim to offer relief from caring by providing day or longer breaks (Gottlieb & Johnson, 2000). Such services include day care, sitting services and residential respite care.

The benefits of these services to carers include:

- Sense of normality: Respite care provides a sense of 'normality' for carers, allowing them to catch up on chores, see friends and resume a sense of their lives prior to caring. It has been argued that given the relentless nature of dementia caring, such seemingly mundane jobs take on a new meaning and are perceived as achievements (Ashworth & Baker, 2000)
- Flexibility (sitting and carers' support schemes): An additional benefit of sitting and carers' support schemes is that they address the varying needs of carers and care recipients. For example, they may offer a valuable contribution to people who have been recently diagnosed as suffering from dementia and act as a referral point for other community services. At the same time, they can be extremely helpful to older carers supporting more dependent people who may be unsuitable for day care. Sitting services are particularly valued by carers because of the flexibility they offer and the fact that they do not involve the cared-for person being taken out of the familiar home environment (Ashworth & Baker, 2000)
- Delay of placement to long term care:

  There is some debate as to whether respite services enhance carers' abilities to continue caring at home. Several studies have indicated that it may contribute to the continuation of care (Kosloski & Montgomery, 1995), although other research suggests that respite care does not impact on admission to residential care (Montgomery & Borgatta, 1989; Burns et al, 1990). In fact, it has been suggested that respite care may cause some carers to recognise the advantages

of ceasing to care and hence, may be a way of gradually preparing for placement in a care home (Levin et al, 1994). There is inconclusive evidence on the value of respite care in enhancing carers' well-being, particularly in the longer term. (Briggs & Ashkam, 1999; Flint, 1995; McNally et al, 1999)

One of the most frequently expressed needs by carers of people with dementia is for more day care (Mudge, 1995; Audit Commission, 2000). Continued contact with social services and assessment of needs appears to be restricted only to carers who experience severe difficulties and some carers who may be in need of social work support do not always receive it (Moriarty & Webb, 2000). Furthermore, there is overwhelming evidence that those carers receiving least help from traditional services are co-resident carers of people with the most severe dementia who are usually elderly and frail themselves and hence, in most need of support (O'Connor et al, 1989).

### Specialist services

People with dementia – and their carers – have access to a number of specialist services, both support services and therapeutic interventions.

#### Admiral nurse schemes

Admiral nurse schemes provide a specialist community psychiatric nursing service offering support and advice to carers of people with dementia. As this is a fairly recent development in dementia care, studies have not yet evaluated their impact (Briggs & Ashkam, 1999) and there are still concerns as to how their role dovetails with mainstream community services (Quinn, 1996).

#### **Memory clinics**

Memory clinics established for people with memory disorders offer outpatient assessment, early diagnosis, treatment and advice. Although such services focus mainly on the person with dementia, they may be of great benefit to the carer by reducing cognitive and behavioural problems. Research suggests that memory clinics provide an opportunity for users, carers and professionals to work together to plan treatment and care and may have the

capacity to prevent the development of some problems (Moniz-Cook & Woods, 1997). Attending the clinic and being involved in the process of assessment, education, counselling and planning provides carers with a sense of control over the situation and enhances their understanding of dementia (Logiudice et al, 1999).

#### **Telecommunication services**

The use of telecommunications as a way of disseminating advice, support and information, and even as a diagnostic and referral tool, has received some attention by researchers (Harvey et al, 1998). O'Donovan (1993) found that a telephone helpline assisted in identifying carers needs, disseminating information about services and advising carers about diagnosis. Evidence is however limited.

The emergence of the internet as a source of information has also led to the development of telecomputing-based projects. Smyth and Harris (1993) in the United States examined the applicability and usefulness of a computer-based information system which enables carers to communicate with each other. Such approaches could be beneficial for carers who have problems obtaining information from other sources or who are geographically isolated, for example rural carers. Although preliminary findings on the effectiveness of this computer network are encouraging, it should be noted that such services are not widely available in Great Britain and rely upon computer access which many older carers do not have.

### Therapeutic interventions

A number of specific therapeutic services have been developed for carers of people with dementia:

#### **Skills training**

Although inconclusive, evidence suggests that 'teaching' carers specific skills in order to cope with challenging behaviours and problems can reduce feelings of burden (Pinkston et al, 1988; Bourgeois et al, 1996).

### Counselling programmes and multicomponent interventions

Counselling strategies have the potential to enhance carers' well-being by helping them understand their feelings and by exploring new or different ways to manage difficulties. Evidence suggests that certain models of counselling can significantly reduce symptoms of psychological distress and depression in carers (Marriott et al, 2000). In addition, counselling can offer a supportive environment for carers to consider their own emotional responses such as anxiety, frustration, anger, loneliness and guilt (Charlesworth, 2000).

Multi-component interventions offer information about dementing illnesses, how they affect the person with dementia, carers and the wider family and are aimed at improving family communication and co-operation as well as strengthening carers' practical skills and self-confidence. Carers reported better coping skills, greater understanding of difficult behaviour and lower levels of depression (Ostwald and her colleagues, 1999).

The main drawback of all three of these approaches is that their availability is often very limited and they can be particularly inaccessible to older carers who are isolated from services.

# Section Seven

### Groups of Older Carers with Particular Needs

This section covers the needs and experiences of carers from minority ethnic communities, former carers and rural carers. Whilst every attempt has been made to review the evidence relating specifically to older carers from these groups much of the current research literature adopts a broader view which does not distinguish older carers from other carers. It was also intended that the review would explore the needs and situations of older gay and lesbian carers; as no evidence exists specifically about this group, this has not been possible.

Most of the research reviewed in this section - particularly that relating to ethnic minorities - is locally focused; little national data exists. As the 2001 Census contains a question about caring, more useful national data may be forthcoming.

### Black and minority ethnic older carers

### Demography and older carers from ethnic minorities

The proportion of older people from black and minority ethnic communities is small but growing. It was estimated that between 1981 and 1991, the percentage growth of people of pensionable age from black and ethnic groups increased 168 per cent (from 61,200 in 1981 to 164,306 in 1991). Figures from the 1991 Census estimate that the total black and ethnic population is just over three million which is about five per cent of the total population of the UK (Department of Health, 2001).

The African-Caribbean population has the largest number of people of pensionable age. At present black Caribbean, Chinese, Indians and 'other Asians' tend to have an older age profile than 'black others', the

Bangladeshi population and the Pakistani population. It is likely that older men will significantly outnumber older women in these populations for at least a decade despite greater female longevity (Blakemore and Boneham, 1994). This gender imbalance reflects original immigration patterns (Morris et al, 1991).

The age profile of a population is relevant to this review for two reasons. Although at present most minority ethnic populations contain few older carers, they contain increasing numbers of 'middle aged carers' who will become older over the next decade. Secondly, it is inevitable that these populations will age as the white population has and it is important to take account of patterns of family and community living to develop appropriate services to meet user and carer need (MacCalman, 1990).

### Family care in minority ethnic populations

There are many gaps in the present understanding of the structure and dynamics of informal care within different ethnic communities. Atkin and Rollings (1992) suggest in particular that there is very little information about the basis and nature of informal care among black communities or the experience of 'being a carer'. Hence what it means to be a carer – either older or younger - within an ethnic community in Britain is still a question to be explored.

To compound matters, misplaced myths and stereotypes about different ethnic groups prevail. Foremost amongst these is a common perception that black and ethnic minority groups live within a predominantly extended family system and that 'black people look after their own' (SSI/Department of Health, 1998).

Bhalla and Blakemore (1981), in their study of 400 European, African-Caribbean and Asian elderly people, found that while

far more Asian older people received support from relatives following hospital discharge, a minority had no close relatives living in Britain. This is supported by Atkin and Rollings (1992) who describe a significant proportion of Asian people as living alone with few relatives in this country. One-third of African-Caribbean older people live alone and the number who live in three generational households is of a similar proportion to that of white people.

Changes in family and household structure, as well as the geographical dispersal of families, make it increasingly difficult for family life to continue around the extended kinship network; this is particularly the case for Asian families (Ahmad, 1996). In any case living within a large family does not necessarily mean that services are not needed; one recent study for example found that an expressed need for respite services was twice as high for Asian families as for white families (Robinson and Stalker, 1992).

Continuing with the Asian community as an example, Gunaratnam (1993) criticises the simplistic categories based on ethnic identity. She points out that Asian people in Britain come from a variety of countries and cultures and represent different languages, dialects, religions, histories and customs. She identifies patterns of social and economic relations connected with the gender, age and country of origin of the carer which directly affect the experience of care. Her research underlines the particular importance of the carer's identity and perceptions in determining the distinction between the simple presence of family networks, the actual practical help available and how it is received.

Another misconception is that each ethnic group is homogeneous in terms of family organisation and culture. Frequently overlooked is the important question of migration and the associated patterns of settlement and adaptation. Families from different racial and ethnic backgrounds have been settling in Britain for many years with the result that cultural norms will be susceptible to change. The beliefs, values and experiences of first-generation immigrant families are likely to differ

significantly from those born here and the generations that follow. Yet we know next to nothing about the relationship between race, ethnicity and intergenerational differences in approaches to care.

Inequalities in health and socio-economic disadvantage experienced by many minority ethnic populations - Indian, Pakistani, Bangladeshi and African-Caribbean communities at least – affect patterns of caring (Nazroo, 1997; OPCS, 1996). For example, evidence suggests that amongst minority ethnic groups co-resident care giving is considerably more common than in white populations. The higher levels of co-resident care giving may reflect economic need as well as cultural norms. Evidence from the fourth national survey of ethnic minorities, conducted in 1994, shows that a very high proportion of Asian elders - around two-thirds - live with one or more of their adult children (Berthoud and Beisha, 1997). As we know that more intensive care is offered on a co-residential basis and that co-resident carers tend to receive lower levels of service input, this pattern suggests that many minority ethnic carers are caring intensively without support from services.

### The meaning of care among minority ethnic communities

Research has shown that minority ethnic carers - as do white carers - describe their relationship in terms of duty, love, affection and reciprocity (Katbamna et al, 1998; Netto, 1998). The expectation that family members will offer care, particularly to a frail spouse or parent, also emerges as a powerful assumption of caring relationships (Katbamna et al, 1998; Townsend & Godfrey, 2001). An interesting point, however, is that in many languages the term "carer" is nonexistent; it is viewed as a service-created category used by white carers rather than by Asian and black people (Eribo, 1991; Connell & Gibson, 1997). Townsend and Godfrey found that apart from problems in translating and describing the term, many of the South Asian carers in their study had difficulties relating to the concept and found they were unable to distinguish between their caring responsibilities and traditional kinship ties.

### The role of services

Research provides ample evidence that older people from black and minority groups under-use health and social services (Blakemore & Boneham, 1994); this applies to both older service users and their carers. Studies have repeatedly shown that linguistic, economic and cultural factors can adversely affect knowledge about and take-up of services (Bhalla & Blakemore, 1981; Guneratnam; 1993). This is seen less as a manifestation of the allegedly insular characteristics of these communities than a failure of policy and formal services to find appropriate, non-discriminatory ways to inform and support individuals (Yee, 1995).

Despite these difficulties, a range of effective strategic and service responses have been developed. These include the establishment of multi-ethnic panels, producing information in appropriate languages and taking account of particular issues in service design, for example, the mixed sex nature of day care which is not acceptable to many Asian carers. The recruitment and training of people from different ethnic communities into services is seen as one of the long-term ways of securing a meaningful dialogue with users and carers from the same communities (Carlisle, 1994; Anwar & Hill, 1994).

Service developments include support groups for minority ethnic carers; culturally sensitive respite care; undertaking local research studies to ascertain need and service development initiatives, to improve the cultural sensitivity of mainstream services.

Minority ethnic carers looking after relatives with dementia seem to have particular difficulty in accessing appropriate services (Moriarty & Webb, 2000; Townsend & Godfrey, 2001). In an investigation of carers of African Caribbean and South Asian descent, Adamson (1999) found that most were looking after relatives with advanced dementia without any formal support. One reason for this may be problems in communication and language. At present those who are developing dementia are in the main first generation minorities and hence, more likely to speak their language of origin, particularly when they develop more

advanced dementia. This has clear implications in terms of managing dementia and understanding its consequences (Adamson, 1999, Townsend & Godfrey, 2000). Lack of awareness of dementia in conjunction with language difficulties may impede the early identification of symptoms and delay referral and access to the appropriate health and social services.

The cultural appropriateness of the services offered seems to be a crucial determinant of service usage by carers of people with dementia. Awareness of cultural needs such as food preferences and religious orientations as well as the availability of staff who can speak the same language, are key elements in assuring carers of the quality of the support provided (Adamson, 1999; Townsend & Godfrey, 2001).

### Older carers living in rural areas

Current research identifies rural carers as 'hard to reach' and as having particular needs for support. There are few studies which have specifically focused on rural carers although they have been considered as a subset of more extensive research.

One in five people live in rural areas in the UK and the rural population tends to be older. Rural carers are thus more likely to be older and many will be people who moved to the country post retirement. Further, as there are fewer job opportunities in the country and younger people move away, older spouses are more likely to be caring alone without support from adult children (Wenger, 1995).

Evidence suggests that carers in rural areas receive fewer services than carers in towns despite there being no evidence that their need for support is any lower. Services may also be difficult to access, involving long journeys to day centres or hospitals. Geographical dispersal and limited mobility may mean that rural carers are particularly isolated and disadvantaged (National Federation of Women's Institutes [NFWI], 1993).

Rural carers present particular challenges to services (Osmond, 1992). According to the myth of rural life, rural communities are relatively wealthy and local problems are dealt with by self-help mechanisms. Although there is no evidence to support this, it is often used to justify the lack of service support in rural communities; carers living in rural communities are just as likely to need support as carers in urban areas. Organising support in rural areas is difficult because of the scattered nature of the population. The cost of service delivery is likely to be higher and rural dispersal also makes it difficult to bring together people with specific difficulties, for example for a carers' group.

Research suggests that meeting the needs of rural carers may be more a matter of approach rather than providing additional services. Developing outreach work, providing transport, and publicising services effectively can all play their part. Some innovative projects have been developed in rural areas. For example, the 'Home from Home' scheme, developed in West Oxfordshire, provides day care support to older people in a rural area. A host family provides day care to the person being cared for; they are provided with transport, lunch, social interaction and stimulation and the carer receives a break (Hawley & Hawley, 1998). Those services that provide local accessible transport or services that are delivered to the carer's home fit most effectively with the needs of rural carers.

Voluntary organisations are the main service providers in rural areas. The advantage of the voluntary sector is that it can work more flexibly and is able to devise models of working to address the specific challenges posed by rural living. However, relying on voluntary agencies is problematic as the temporary nature of much of their funding means many schemes are short term. When funding ends there may be no statutory net to offer back up. Church groups, local carers' groups, parish councils and residents' groups also provide a great deal of quasi-formal support for carers in rural areas (NFWI, 1993).

One of the only pieces of work which has explored rural carers is a survey conducted by the National Federation of Women's Institutes (NFWI). It gathered data from

nearly 8,000 rural carers (NFWI, 1993). Nearly three-quarters of respondents were aged 55 and over – one-third were aged between 55-64 and one-third were 65 or over. The survey concluded that living in a rural area particularly disadvantages carers. As the infrastructure diminishes - as shops, hospitals, and post offices are closed, and public transport services are eroded - rural communities and the carers within them become more isolated and marginalised.

The study found that rural carers' access to information and services such as respite care is severely limited. Often services do not exist in the local community; carers are thus obliged to rely on services which are further away and may be difficult to reach. Without adequate transport they may not be accessible at all. Many older carers, particularly older women, do not have access to a car; some will also be disabled or unable to drive (Milne et al, 1999). Even with transport available, the distances involved may mean a rural carer has to leave their relative in day-care or respite-care for longer periods than they may wish.

Following this survey the NFWI recommended that a number of issues be addressed to help rural carers:

- Carers' legal rights and the services that may be available to them should be advertised widely in rural areas
- Information about welfare benefits should be widely publicised
- One point in a county/unitary authority should act as a 'one stop shop' for carers; a telephone number and information about opening hours should be advertised

#### Former carers

The term 'former carers' is used here to refer to individuals who have ceased caring at home. Generally, older carers withdraw from caring because they develop health problems, or because the person they care for has been placed in a residential or nursing home or has died. In this section we will review the research relating to the latter two situations (Zarit & Whitlach, 1993).

### Carers of people in care homes

Over half a million older people currently live in long term residential or nursing home care in the UK (HM Government, 1999). About one in 10 are married; most have spouses still living in the community (OPCS, 1993).

Over the last few years there has been increasing recognition of the strain experienced by many relatives looking after an older person at home, but until very recently, an apparent blindness to the difficulties experienced by carers once the older person has entered residential or hospital care (Bowers, 1988). Research suggests that following the admission of their relative to a care home carers experience loss, grief, guilt, anger, sadness, loneliness and depression; they also report that these emotions continue in the long term (Lewis, 1998). Guilt feelings are strongly associated with anxiety and depression and may arise from long standing feelings of responsibility and obligation towards the cared-for person (Qureshi & Walker, 1989; Woods and Matthison, 1996). Placement, as Aneshensel and his colleagues (1995) argue, is often viewed as a failure on the part of the carer and as a betrayal of trust and of powerful emotional ties as well as a violation of potent social norms governing family obligations in times of need. This is particularly true for spouses.

Contrary to popular perceptions, most relatives wish for continued involvement following admission. Many remain 'a carer' in an emotional and psychological sense. In spite of this desire, and as well as evidence demonstrating the benefits of involving family members, care staff frequently fail to recognise and draw upon the expertise of family carers in planning and implementing care (Woods and Matthison, 1996).

A few studies have specifically explored what happens to carers when their relative is admitted to a care home. These suggest that carers perform four major roles: checking the quality of care; providing companionship; handling finances and helping with hands-on care (Wright, 1998).

The key roles adopted by carers are:

- Checking the quality of care: As might be expected, carers are very concerned to ensure that their spouse receives a high quality of care. Many carers feel intimidated by being expected to choose a care home without help or guidance and often in a hurry to clear a hospital bed. Important factors influencing choice are location and atmosphere. Once their relative is in the home, carers feel concerned about inadequate stimulation; inadequate cleanliness; inappropriate dress and lack or overuse of medication
- Companionship: Both British and American research findings demonstrate that, when long term care residents have relatives, ongoing contact is common. Spouses visit frequently, some as many as five times per week (Wright, 1998). This reflects the strong attachment and interdependency between long term married couples discussed in Section Three. Spouses tend to view the marital relationship as either the same or worse post admission. Maintaining companionship is a challenge as most care homes do not offer opportunities for couples to share private time. In most homes neither bedrooms nor communal lounges provide environments conducive to privacy and spouses rarely appear to be invited to attend meals (Wright, 1998)
- Finances: Handling finances is a source of confusion for most carers (Woods and Matthison, 1996). Most cared for people - particularly if they have dementia - do not manage their own finances and carers tend to take over this responsibility. For many the complexity of dealing with care home fees, pensions and allowances is stressful and little help or guidance is available. Most carers also pay for some 'extras' for the cared-for person, including essentials like underwear, clothing and shoes as well as luxuries such as sweets or special foods. 'Additional services' such as chiropody and hairdressing often have to be paid for and travel expenses are also a financial drain for many spouses. This

is particularly difficult for spouses on low incomes

• Hands-on care: Few spouses help the cared for person with personal care even though many want to have this continued involvement. Spouses are often actively discouraged by care staff despite the fact that both the resident and the relative are more likely to adjust well to the changed situation if they are given this role.

Most significantly, older spouse carers must adjust to a substantial change in their role. They move from having been in charge of the caring situation to having a secondary role (Almberg et al, 2000). Prior to placement, caring may have been a 24-hour occupation and a key part of their identity. Being deprived of this role can lead to feelings of resentment, frustration and exclusion especially when communication with the nursing home staff is problematic (Henwood, 1998). Adjusting to the regulations of the facility and trusting others to provide care to the person with dementia may be quite difficult for some spouses, especially when the carer has been very involved and/or they feel they are excluded from care decisions (Duncan & Morgan, 1994; Almberg et al, 2000).

Changes in the role and responsibilities of carers can lead to distress. Rosenthal and Dawson (1991) describe the transition to institutional care as 'quasi widowhood': a feeling of bereavement whilst not actually being bereaved. McKenzie and McLean (1992) argue that spouses are faced with two conflicting roles; that of a married person with commitments to the institutionalised spouse but without the companionship associated with marriage, and being alone in the community but unable to start a new life.

### Developing partnerships between care homes and carers

Research suggests that carers' continuing role in a resident's life is not adequately encouraged or protected by care homes (Wright, 1998). A more active policy of sustaining family relationships is needed. Being encouraged rather than discouraged from helping their partner in

a practical way, and being invited to stay for the occasional meal, might help carers to feel more involved and reduce guilt. Private space should also be made available to couples who wish to be alone together, particularly if bedrooms are shared or too small to accommodate armchairs. Introducing 'relative friendly' policies has cost and time implications for care homes, including the provision of extra space and/or training of care assistants.

The importance of maintaining family relationships following the move to a nursing home, both for the older person and their carer, has been demonstrated by research (Nolan et al, 2001). Several studies have highlighted the need for care home staff to be made more aware of a relative's needs both at the time of admission and subsequently. Woods and Matthison suggest that a range of responses are required: Individual and group support; closer working relationships; greater involvement of relatives in the management of the home, including selection and training of staff; more flexible boundaries between the home and the community and more involvement in care-planning. First, the need to involve carers must be recognised (Woods and Matthison, 1996).

A few studies have evaluated structured approaches to supporting and involving relatives in the 'care home' process. Nolan and Dellasega (1999) identify four potentially useful interventions which might enable residents to maintain relationships with close family and friends in a way that is mutually beneficial:

- Creating a welcoming environment which encourages and supports visiting, and working with carers to maximise their involvement and facilitate a sense of purpose
- Recognising and clarifying roles and responsibilities for both groups
- Valuing and accessing the carer's knowledge and expertise and utilising this as an important component of care planning
- Helping carers to create a positive perception of the admission,

acknowledging their need to both receive and provide help, and dealing with emotional reactions

In encouraging the involvement of relatives, it is important to recognise the different roles which carers may wish to adopt.

## Carers and the death of the person being cared for

The effects on older carers of the death of the cared-for person have received very limited research attention.

Schulz et al (1997) found that despite the negative effects of bereavement, many carers experienced a number of positive effects: Feelings of relief; improvements in quality of life; an increase in social and recreational activities and lower levels of burden and stress. Carers of people with dementia may have had some time to grieve prior to their death and may have prepared themselves - at least practically for the change of role and loss. The emotional and practical support that carers have called upon during their caring career may help carers cope with bereavement (Schulz et al, 1997).

Evidence about the specific experiences of older carers following the death of their partner is at present exploratory. Further research is required to explore the validity of the accounts reviewed here.

# Section Eight

### Implications for Services, Policy and Research

### This study has clear implications for services, policy and research:

#### Services

Older carers welcome support from services. Suggested changes include:

- Assessment of need and allocation of services should be around older 'couples'; a dual focus is needed
- The development of preventive early intervention services for older carers
- Services that can offer carers a 'break' but which can be delivered 'in the home'
- Assessments should address changing needs quickly and flexibly
- The development of partnerships between care homes and carers and services for former carers

### **Policy**

The status and quality of life of carers could be enhanced in a number of ways:

- Tackling poverty and social exclusion amongst older carers – a key policy issue
- Encouraging preventive policies and health promotion for carers
- Investing in the infrastructure of poor neighbourhoods, for example in transport and housing
- Recognition of the need to prioritise home/day/and respite care for older couples.
- Monitoring the implementation of the Carers and Disabled Children Act (2000) across local authorities to evaluate and encourage the delivery of carer-centered assessment, services and direct payments.

#### Research

The review highlights a number of research deficits. In particular:

- Understanding the experience of 'being an older carer'
- Qualitative data about the process and meaning of spousal care
- How patterns of extra resident care are changing, particularly in regard to 'other relatives'
- The needs and experiences of older carers from minority ethnic communities
- The needs and experiences of former carers
- The needs and experiences of gay and lesbian older carers

### Services and support for older carers

Older carers should be a priority for government attention. The fact that this group receive fewer services or none at all should be a prime concern for welfare agencies. The situation of many older carers remains intolerable; many have health problems of their own and suffer isolation and depression.

There are a number of ways in which services could be improved:

### Extending the range and nature of interventions

Carers value the input of a range of community services, particularly those that offer day care and respite care. Time off from caring is known to reduce the psychological and emotional stress faced by many carers. But in the last decade since community care has been implemented, community services have been targeted away from users who live with carers.

- An expansion of, and greater access to, these services would considerably improve the quality of life of older carers and extend their capacity to care. Carers of people with dementia would particularly benefit from additional specialist respite services
- More innovative and flexible approaches to providing respite care, for example night services and sitting and carers' support schemes, would be of great benefit to older carers. The needs of disabled people change considerably over time and ongoing assessment of need and flexible access to support services are essential features of good quality care. Access to up-to-date information about services is also important
- Older carers require more real choice about the extent of their involvement in care giving and more effective support in the ways in which they choose to give care. Services need to be designed with the needs and preferences of older carers in mind. Professionals working with older carers need to understand the context, motivations and situations of older carers. Services need to be offered in ways which are acceptable and helpful to older carers. The crisis oriented nature of service allocation and the location of many services outside the home is unhelpful to older carers who do not want the person they care for removed from their surroundings. For these changes to take place, there needs to be a focus on early intervention. Evidence suggests that much can be done to prevent a breakdown in caring if services are delivered in a way that is acceptable to carers and at a point when support is both effective and preventive
- Spousal carers have particular needs.
   That services are allocated to individuals rather than couples or caring situations fails to offer older spouses the support they need in a way which takes account of both parties. Adopting a dual focus for assessment and service allocation reflects the reality of spousal care

 It is also clear that much work needs to be done to ensure that the needs of former carers are met by care homes and that carers are not abandoned at the point of their relative's admission. Carers whose relatives die also need support

#### Developing community-wide services

The stresses associated with caring can be relieved by tackling infrastructure issues including public transport systems and reducing social isolation by promoting educational and social opportunities for carers.

### Proposals for Improving Support for Older Carers

There are also a number of specific proposals, which have the potential to improve support for carers:

- Whilst the Carers and Disabled Children Act (2000) removes the legislative barrier to providing support to carers in their own right, most services continue to be accessed via an assessment of the person being cared for. This clearly acts as a barrier to meeting carer need and undermines the development of partnerships. Further, older spouses may not see themselves as 'carers' and local authorities may be reluctant to seek them out when services are already rationed
- Increased support for the person being cared for can relieve the burden of care on the carer as well as being significant in its own right (Arksey et al, 2000). This is consistent with the perspective of the disability movement, which regards adequate support for disabled people as a means by which they can live more independently and be less reliant on their family. Such an entitlement can be put into effect via services or direct payments but both have considerable resource implications

- Whilst legislation now allows local authorities the option of offering money as a substitute for direct services for both the cared for person and the carer, there is little evidence as yet to whether direct payments are likely to be attractive or widely available to older carers
- Whilst the cash entitlement model may increase choice and enhance independence for the disabled person, it may have disadvantages for the carer (Ungerson, 1997). Cash based systems tend to accentuate the differences of interest between the carer and the person being cared for. As Twigg argues, 'the needs of the carer are more likely to be acknowledged in a service-based approach where discretionary assessment can reflect the duality of interests and balance the needs of the two parties' (1996). The fundamental challenge to a service entitlement model would be the significant resources required to underpin it

### Older carers and policy

Policy makers have a significant contribution to make to improving the situation of older carers:

### Social inequalities and older carers

Evidence suggests that both age related and lifelong social inequalities impact upon the lives and health of older people (Milne & Williams, 2000). As a consequence of caring, many older people are disadvantaged by a range of inequalities including chronic poverty, poor physical and mental health and limited access to mainstream resources. Those carers who provide care over a long period and on an intensive basis are particularly disadvantaged. We know that older carers are most likely to have been caring for many years.

### Financial support for carers

Poverty is a key indicator of vulnerability to social exclusion. The Government's report on poverty and social exclusion recognises that carers are particularly vulnerable to the problems of social exclusion, including isolation and poverty (Department of Social Security, 1999). There are two other ways in which poverty amongst older carers can be alleviated: improved welfare benefits and enhanced pensions.

### Improving welfare benefits

A number of key changes to welfare benefits are suggested:

- Financial support for older carers at present older carers do not receive either Invalid Carer Allowance, Carers Premium or Income Support (Baldwin & Parker, 1991). The age barrier should be removed so any carer of any age can apply for ICA (CNA, 1998)
- Different levels and periods of caring the benefits system does not recognise that caring takes place over different periods of time or that different levels of care may be needed. Two levels of ICA could be created; a lower level paid to carers for the first three months of caring and thereafter to carers giving fewer hours of care; and one at the level of the basic retirement pension available after three months to all carers giving greater levels of care (Baldwin & Parker, 1991)
- There is a strong view that carers should be compensated for the actual costs of caring. This could take the form of a carers' allowance which could be nonmeans tested and paid to all carers in all circumstances. (Glennerster, 1993)
- The level of ICA should be raised in line with long term benefits such as incapacity benefit and retirement pension (Carers National Association, 1998)

• Improve access to ICA without the necessity of the person being cared for receiving Attendance Allowance. All carers who provide at least 35 hours care per week should be eligible

### Enhanced pensions

Additionally there are a number of proposals to improve pensions for carers:

- Increased entitlement to the Basic State Pension – because credits for contributions to the Basic State Pension are related to the qualifying criteria for ICA, measures to increase access to ICA would also improve pension rights for carers including older carers
- There have been proposals aimed at improving pensions for women, recognising that they make up the majority of those whose pensions are affected by broken employment and reduced contributions. These include abolishing SERPS and improving basic pensions; scrapping contributions for pensions and linking increases in state pensions to earnings not prices (Joshi & Davies, 1994)

### Improving housing

Poor housing is strongly related to long term poverty and is more prevalent among those aged 75 and over. Improving housing is a key aim of the Government's initiatives to support carers. Living in the right sort of accommodation can make a considerable difference to the lives of disabled people and their carers, as do adaptations such a stair lift.

### Prevention and health promotion

Many common health problems suffered by carers are preventable. The Government's new National Priorities Guidance for the health and social services in England, issued in September 1998, asks GPs, members of primary care teams and social services staff to identify carers in order to direct them to support and to alert GPs to health problems related to caring (Department of Health, 1999/2002).

Many of the physical injuries suffered by carers could be prevented if training was provided in lifting and moving, particularly at points of transition such as hospital discharge. Sometimes carers will need special equipment installed in their home to help them do this. But even straightforward actions, such as helping someone to sit up in bed, can cause injury.

Carers also need to be encouraged to 'look after themselves' a message that can be delivered by a wide range of workers and agencies that have contact with them.

Offering effective support to carers is in itself a health promotion exercise.

### Research relating to older carers

It is clear from this review that there are significant gaps in current knowledge about the needs and roles of older carers.

• Little is known about spousal carers on a qualitative basis. If policy and services are to meet the needs of this growing group of carers, decisions need to be informed by evidence which takes account of the contexts, views and caring experiences of spousal carers. Future work needs to reflect two key characteristics of spousal caring: those of interdependent long term relationships and the care of wives and husbands with a range of physical and mental health problems. Current studies tend to focus on the illness of the person cared for and not the care context

- The needs and experiences of older spouse carers of people with dementia require further exploration
- The needs of a number of minority groups of older carers are unknown. The needs and experiences of older gay and lesbian carers for example, are completely unexplored in the UK context
- Former carers are beginning to attract academic attention but much work still needs to be done to explore the support needs of former carers, to ensure good practice and to build a service framework which does not abandon carers as soon as they stop being 'active'
- The needs of older carers mainly parents – of adults with mental health problems, remain largely unknown and this research is needed if appropriate services are to be developed
- 'Other relatives' appear to be a significant group who receive support from older carers, but national data does not reveal who they are or whether new patterns of care are emerging
- From a perspective which recognises that older people are as often providers of care as receivers of care, caring is best viewed as a social process rather than primarily as an individual experience (Nolan et al, 1996). This signals the need to develop dynamic models of caring as well as temporal perspectives of the caring experience. As many older carers have been caring long term a retrospective study exploring the development of their caring role within the marriage or other relationship would be invaluable
- There is also a need for good quality population data on carers from minority ethnic communities

### **Conclusion**

In concluding this review it is important to highlight those issues that require further exploration and draw out the themes that have dominated the discourse.

It is clear that there are increasing numbers of older carers and that they form an increasing percentage of all carers. The picture of older carers that emerges from this study is significantly different from that of carers overall - they have a distinctive profile. Older carers are more likely to live with the person they care for, they are often in poor health themselves, they are often providing very intensive care for many hours a week and they carry on doing so for many years.

- The General Household Survey 2000 will undoubtedly shed further light on a number of quantitative issues this analysis has highlighted; such surveys need to track the changing pattern of caring in our society and highlight changing trends so that policy can adapt to emerging needs
- There are also significant knowledge gaps regarding older carers which qualitative research would address. These include information about those who care for 'other relatives' and for friends, who they are caring for and why; the development of caring within a long term marriage relationship; the nature and extent of caring amongst older gay and lesbian couples; the nature of caring within many minority ethnic communities; and the needs of carers whose relative has moved into a care home or who has died
- The impact of caring on the lives and health of older carers is well documented, but the cumulative impact of the physical, financial, social and emotional consequences is insufficiently understood and requires further work. Policies and services need to work preventively to alleviate the impact of

these consequences on carers, including those who become carers later in their life. Priority should be given to meeting the needs of older carers across the board to ensure that caring itself does not result in long term disadvantage

- It is clear that older carers particularly carers of people with dementia welcome support from health and social care services, but the policies which target help towards those who live alone overlook their needs. It is very evident that more overall support is needed for older carers and that further exploration is warranted into what older carers want from services and what would be most effective. Evaluation of innovative carer support services has much to offer service development in this field
- Research also suggests that insufficient attention is paid to identifying and meeting the needs of older spousal carers. Services by and large fail to support couples in ways which acknowledge the 'dual focus' of caring and which take account of the individual circumstances of each caring situation
- Older carers have remained largely invisible both amongst the general body of research on caring and in the policy arena. This analysis demonstrates that their numbers are growing and their circumstances and their needs are significantly different. Research, policy and practice should recognise these differences and take far greater account of the voices of older carers if they are to be nurtured and supported in a coherent and effective way. There are signs that those voices are beginning to be heard and the vast contribution of older carers recognised. This review suggests that more should and can be done to improve the health and quality of life of older carers and to develop a more in depth understanding of the nature and consequences of caring in later life

### **Appendix One: Glossary of Terms**

Day care is usually offered at a day centre or in a day hospital. It offers care for a dependent adult during the day most usually to give carers a break. Day care is usually provided by the statutory sector.

Sitting and other types of home care relief services provide alternative care for a disabled person at home, enabling the carer to take a break. Such schemes overlap with the provision of the Crossroads Care Attendant Scheme which combine a care function with respite on a regular and more intensive basis. In some areas night sitting services are also available. Voluntary sector providers tend to provide sitting services.

Respite care usually refers to overnight care in an institutional setting; a care home or a hospital ward. It is designed to give carers a break from caring. Most carers receive about two weeks of respite per year with a minority receiving rotational respite where the cared for person is admitted regularly.

Home care is the social services department's most extensive service. Since community care, home care has increasingly provided personal care; whilst housework and other domestic tasks have become marginalised. It has also developed into a more intensive support service targeted at more dependent people at risk of admission to residential care.

Personal care is care which involves support with bathing, washing, dressing, going to the toilet, help with getting in and out of bed, walking and getting up and down stairs.

Care management is the process by which a local authority social worker/care manager assesses need, plans care and provides services to a user and/or a carer. It is the pivotal mechanism by which community care is arranged and delivered to those in need of support.

### **Appendix Two:**

# Excerpt from: The General Household Survey 1995: Section on informal caring.

'This section is intended to cover those informants who look after chronically sick, handicapped or elderly people - either

relatives or non-relatives, adults or children. Also included are those who provide some regular service eg shopping or doing odd jobs, for someone who is sick, handicapped or elderly.

We do not want to include those who are paid a wage for their services but foster parents of a disabled child or young adult should be included, as should carers who receive Invalid Care Allowance or informal carers who are paid by their dependants, as none of these is caring professionally.

We do not want to include those who provide purely financial support; who look after someone with a temporary illness or injury (eg acute sickness, broken leg); or those looking after other healthy members of the family.

We also wish to exclude people who look after handicapped infants who, in practice, receive no more care than normal children of the same age.

We are also not interested in people who look after someone as part of their work for a voluntary organisation or whose dependant lives permanently in an institution. Any such carers identified will be excluded automatically.

Include respondents who provide care relatively rarely, perhaps in response to an asthma attack or an epileptic fit. Providing support over the telephone does not count as caring'.

### The question asked of respondents is:

"I'd like to talk now about caring informally for others. Some people have extra responsibilities because they look after someone who is physically or mentally sick, handicapped or elderly. Is there anyone, either living with you or not living with you who is sick, handicapped or elderly whom you look after or give special help to, other than in a professional capacity (for example, a sick or handicapped (or elderly) relative/husband/wife/child/friend etc)?"

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Patron HRH The Prince of Wales

Price £7.50 ISBN: 0-905852-56-7 September 2001

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# The *Gaing in Leie Life* report

### A secondary analysis of the 1995 General Household Survey

Alisoun Milne and Eleni Hatzidimitriadou

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### **ABSTRACT**

Caring in Later Life is a review of the needs and roles of older carers (Milne et al, 2001). It brings together a wide-ranging review of academic and policy literature with an original meta-analysis of the 1995 General Household Survey (OPCS, 1995). This paper focuses on the findings of the GHS analysis. The picture of older carers that emerges is significantly different from that of carers overall.

It is clear that older carers constitute a large and growing number of the carers and represent an increasingly large proportion of the total number of UK carers. They can be distinguished from other groups of carers in a number of ways: older carers are more likely to live with the person they care for, caring is likely to take place within the context of a long term relationship, dementia is a dominant feature and carers are more likely to be involved in intimate and personal care. Many also have health problems of their own. The analysis confirms a distinction between older carers who offer support on a co-resident basis and those who are extra resident. There is clearly a high level of devotion to caring amongst many co-resident carers, with many providing intensive care over long periods of time with little or no support from services. Most of these carers are spouses. The authors suggest that more should and can be done by policy and services to improve the health and quality of life of older carers.

### INTRODUCTION

In October 2001, the Caring in Later Life report was published (Milne et al, 2001), bringing together a wide-ranging review of academic and policy literature with a meta-analysis of the 1995 General Household Survey (OPCS, 1998; Rowlands, 1998). This paper, by the two lead authors of the report, presents findings from the secondary analysis offering a detailed commentary on those

findings in the light of previous research. The paper covers all categories of older carers and does not examine specific groups. Older carers of people with dementia, who constitute a significant subgroup of older carers, is the subject of a second paper and carers with particular needs – minority ethnic carers, former carers and rural carers – will also be the subject of future publications. We begin by offering a context for this paper; an

introduction to the *Caring in Later Life* report and a brief review of caring in the UK.

# CARING IN LATER LIFE REPORT

Recent years have seen a growing recognition of the important role that carers play in enabling vulnerable adults to remain in the community. The NHS and Community Care Act 1990 and the Carers (Recognition and Services) Act 1995 have been particularly influential in recognising the role of family carers and encouraging the development of support services (Department of Health, 1990, 1995). While much research has been done on caring, its focus has substantially been upon all carers, or carers of particular groups of people (Parker, 1998). Although much relevant work exists none has, until now, reviewed the needs of older carers in any comprehensive way, or considered this group for attention by researchers, policy makers, or the caring

The aim of the *Caring in Later Life* report was to address this deficit. Specifically, it intended to:

- identify the prevalence of older carers in the population and to map their key characteristics
- explore the roles, needs and difficulties of older carers
- explore the extent of support offered to this group
- identify ways in which their needs could be addressed more effectively.

Older is defined as 60 years and over (Milne *et al*, 2001). The report employs a range of sources including: academic and research literature dating from 1990, policy reviews and related documents and literature from carers' organisations; and an original analysis of GHS data (Rowlands, 1998; OPCS, 1998).

## CARING IN THE UK

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The 1985 General Household Survey (GHS) was the first national survey to give accurate estimates of the number of people involved in caring for older and disabled people in the community (Green, 1988). Approximately six million carers were identified in the survey; a much larger number than had been expected (OPCS, 1989). By the time of the 1990 GHS, this estimate had risen to around 6.8 million carers (OPCS, 1993). Latest figures published in a report on *Informal Carers* in 1998 as part of the 1995 GHS indicates that there are about 5.7 million carers in Britain (Rowlands, 1998). Thus, about one in eight households contain a carer in the UK.

A helpful distinction has been made between those people offering intensive care support that involves the provision of intimate care such as bathing and toileting, and the commitment of many hours of time - and those people 'tending', providing lower levels of support for a few hours a week. According to the 1995 GHS, intensively involved carers constitute about three in ten of the total number of carers. As might be expected, coresident carers,2 particularly spouses, tend to provide more intensive levels of care than extra resident carers. Those carers defined by Parker (1992) as offering 'tending' constitute about seven in ten carers. They provide practical help such as shopping, to friends, neighbours and more distant relatives on an extra resident basis3 and are often part of a caring network (Wenger, 1994).

Whilst there has been a slight reduction in the overall number of carers between 1990 and 1995, research suggests that there has been an increase in the number of carers offering intensive support, from 1.5 million in the early 1990s to nearly 2 million in the mid 1990s. Of this group, over half care for more than 50 hours per week (Parker, 1998); most of this group are spouses and many are older. Evidence also indicates that compared to the late 1980s, the people receiving care tend to be significantly older and are more likely to have a mental impairment such as dementia (Drewett *et al*, 1994; Parker & Lawton, 1994).

It was against this backdrop that the *Caring* in *Later Life* study was conducted, including

<sup>&</sup>lt;sup>1</sup>The study was commissioned by Help the Aged and supported by Carers UK. The work was conducted by researchers from the Tizard Centre, University of Kent in partnership with Tom Owen from Help the Aged (Milne *et al*, 2001).

<sup>&</sup>lt;sup>2</sup>Co-resident carers live in the same household as the cared for person.

<sup>&</sup>lt;sup>3</sup>Extra resident carers live in a separate household.

the original analysis of the 1995 General Household Survey.

# The 1995 General Household Survey

The aim of the secondary analysis of the GHS data is to explore a large national data set adopting a focus specifically on older carers. This is new in that the focus of previous analyses has been all carers, and to interrogate the data from the perspective of the older carers is a challenge to the traditional perspective of the cared-for person or service provider. Thus, this analysis is both original and unique. The data set is a combination of data on 'informal carers' collected as a part of the 1995 General Household Survey (Rowlands, 1998) plus additional data from the wider survey itself (OPCS, 1998).

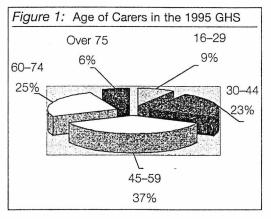
Before discussing the findings of the analysis, it is important to note some of the limitations and strengths of the General Household Survey. One important limitation is the likely underestimation of the number of carers, as the survey depends on individuals being prepared to identify themselves as carers. 4 This may be of particular relevance in relationship to older people, who tend to perceive care within familial relationships as 'normal reciprocity' or duty (Finch, 1995; Church & Summerfield, 1995). Another issue is that the nature of the questions asked in the GHS may result in a significant underreporting of caring tasks of a non-practical nature such as 'taking responsibility' for someone with a mental health problem. Another limitation relates to the nature of the sample. The GHS is designed to address a wide variety of issues, carers being a subsection of these. Carers of people living in institutional settings, isolated carers and 'hard to reach' groups of carers tend to be excluded from a survey. In addition, evidence relating to networks of care, or codependency is not gathered by this approach.

The main strength of the GHS is that it is a large national survey, which collects much descriptive data of relevance to older carers, including caring situations and demographic data. Furthermore, it is a robust and rich representative dataset which offers reliable material for research analysis.

Findings of the secondary analysis will be presented under a number of themed heads. Each section offers the main findings around that topic before discussing their nature, meaning and relationship to previous research. We begin by describing the social demography of older carers.

# Social demography of older carers

This section explores the number, ages and household types of older carers, as well as identifying the characteristics of those being cared for.



A third (31%) of the total number of carers identified in the 1995 General Household Survey are aged 60 or over (25% are 60–74 and 5% over 75 years). This compares with over a third (37%) being aged 45–59, a quarter (23%) being 30–44 and under a tenth being 16–29 (9%) (see *Figure 1*). Thus, approximately 2 million carers in the UK are older people.

Four fifths (80%) of older carers are aged 60–74, whilst one fifth (20%) are aged 75 and over. About half (53%) of older carers are women and half men (47%). The vast majority are economically inactive and most are retired (98%). Nine tenths of older carers look after one person, with one tenth looking after more than one person. Almost all (96%) of the respondents who identified themselves as older carers in the 1995 GHS are white.

The vast majority (80%) of older carers are married or cohabiting with about a fifth (16%)

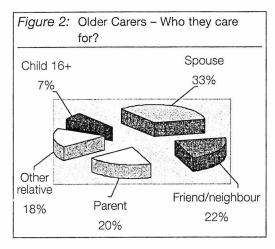
<sup>&#</sup>x27;The GHS adopted a particular definition of carer and of cared for. Specifically, according to the instructions given to interviewers, the specific part of the survey referring to informal carers 'is intended to cover those informants who look after chronically sick, handicapped or elderly people – either relatives or non-relatives, adults or children. Also included are those who provide some regular service eg shopping or doing odd jobs, for someone who is sick, handicapped or elderly'.

being widowed, separated or divorced. A very small proportion (4%) is single. Slightly fewer women than men carers are married with just under a quarter (24%) of women carers being widowed or divorced.

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As might be expected, the overwhelming majority (88%) of those people receiving care from older people are older themselves; only about 12% are under 60. In fact, over a third (36%) of the total number of older people in need of family care are cared for by same generation relatives or friends.

Two fifths (40%) of older carers are coresident, whilst three fifths (60%) are extra resident. Most co-resident carers are spouses; 33% of all older carers are in this situation. As is illustrated in *Figure 2*, a third (33%) of older carers care for spouses, a fifth (20%) are adult children caring for elderly parents, a fifth



(22%) care for friends/neighbours, just under a fifth (18%) care for 'other relatives' and just under a tenth (7%) are parents caring for a child with physical and/or learning disabilities.

The GHS offers a number of different categories for describing the characteristics of the person cared for. Analysis suggests that over two thirds (65%) of those being cared for have physical disabilities, about a sixth (15%) receive care because they are 'old', just over a tenth (11%) have physical and mental 'impairments' and just under a tenth (8%) have 'mental impairments' only (*Table 1*).

# The characteristics of older carers

This analysis confirms earlier work that a significant number of all carers are aged 60 or

Table 1:	The disabilities of	those	
	supported by olde	r carers	
Cared for	person's disability	N (%)	
Physical di Mental imp Old age Mental/phy Other TOTAL	sability pairment /sical and mental	439 (65.3%) 52 (7.7%) 103 (15.3%) 71 (10.6%) 7 (1%) 672	

over and that the majority of older carers look after other older people. This challenges the widely held assumption that older people are predominantly consumers of care and supports the contention that a great deal of mutual caring occurs between older relatives and friends (Phillipson *et al.*, 2001).

As has been noted by previous commentators, compared with previous GHS data, the number of older carers is greater (Parker, 1998). This is to be expected as the UK population is ageing and increasing numbers of older people with dependency needs remain in the community. Of particular note is that within the older carers' cohort, it is the group of carers aged over 75 that is increasing most rapidly; a trend which primarily relates to the reduced use of institutional care (Pickard, 1999; Carers National Association, 1998).

The socio-economic profile of older carers in the GHS sample echoes existing findings about their status; the majority of are retired and most are married with a higher number of older women carers being widowed. Although the GHS offered little data on income, it is known that older carers are one of the poorest groups in UK society. Research indicates that carers providing substantial amounts of care – many of whom are older – face much financial hardship. There are also additional costs related to caring (CNA, 2000; DSS, 1999; Glendinning, 1992).

## Caring relationships

The GHS analysis powerfully suggests that older carers fall into two broad groups: coresident and extra resident. As has been identified in previous research, there is a strong correlation between type of relationship, and type of household, and in turn this relates to the nature of care activities

with co-resident carers tending to be involved in more intensive care (Nolan *et al*, 1996; Pollitt *et al*, 1991; SSI, 1995).

## Co-resident carers

The dominant profile of co-resident older carers caring for other older people echoes existing research findings and suggests a continuing trend towards ever-greater number of older people being cared for by same generation carers (Parker, 1998). This trend has clear implications for policy and services and suggests a need for a much greater recognition of the contribution of older carers (Milne *et al*, 2001).

Findings also confirm that spousal carers are the largest group of co-resident carers (Pickard, 1999). A key aspect of spousal care is its mutuality and interdependence with the carer/cared for roles being indistinguishable from one another. Caring within marriage, unlike most other caring relationships, tends to be regarded by carer and cared for as an extension of the intimacy and companionship that characterises marriage (Parker, 1983; Lewis, 1998). Spousal care also poses a challenge to a service allocation system that focuses on individuals rather than contexts (Arskey *et al*, 2000).

Although the number of adult children receiving care from older parents is small, the likelihood of the cared for group having complex and multiple needs is high. The majority will have learning disabilities and/or physical disabilities (Walker & Walker, 1998), although some will be younger adults with mental health problems (Perring *et al*, 1990). Whilst the number of adult children over 60 caring for an elderly parent is relatively

modest at present, it is likely to increase as community living is extended for greater numbers of fourth age elders. Due to the fact that parents in this context will be very elderly, they are likely to be particularly frail.

In contrast to younger groups of carers, it is interesting to note that older carers are equally distributed between males and females (Dalley, 1993; Arber & Ginn, 1995). In part this reflects the fact that many older carers are spouses and may also reflect a different caring pattern amongst older people compared with younger cohorts (Rowlands, 1998).

## Extra resident carers

An interesting and surprising finding of the analysis was the relatively high percentage of 'other relatives' identified as extra resident carers. The survey data does not specify who these relatives are, but the group is likely to include siblings, nieces, nephews and cousins, as well as half and step relatives. It may also include ex-spouses, ex-parents-in-law and other 'ex-relatives' as they do not 'belong' under any of the other descriptive heads.

This finding suggests two things. One is that further work needs to be done to explore and define 'other relative' carers. Secondly, it may be that instead of abandoning caring, the reconstituted family continues to care for its members, albeit along different lines of reciprocity and in a different constellation than the 'traditional' family. Such conjecture requires exploration, but may lend weight to the argument that people offer care on the basis of affection and attachment as well as out of a sense of duty and obligation (Twigg & Atkin, 1994; Dalley, 1996). Another related finding, which challenges existing research, is

	Total	Gender of c	arer
		Men	Women
Personal care (eg washing) Other practical help (eg shopping) Paperwork or financial matters Physical help (eg walking) Keeping company Taking out Giving medicines Keeping an eye on dependant Other help TOTAL	205 (32%) 170 (26%) 111 (17%) 86 (13%) 25 (4%) 20 (3%) 4 (1%) 24 (3%) 7 (1%) 652	85 (28%) 77 (26%) 56 (19%) 47 (16%) 8 (3%) 13 (4%) 1 (.3%) 9 (3%) 4 (.7%) 300	120 (34%) 93 (26%) 55 (16%) 39 (11%) 17 (5%) 7 (2%) 3 (1%) 15 (4%) 3 (1%) 352

The GHS offers respondents carers the following categories: spouse/cohabitee, own/adopted child, foster child, parent, parent-in-law, other relative, friend/neighbour.

the significant number of friends and neighbours offering care (Twigg, 1992; Phillipson *et al*, 2001). Both groups are larger in number and may be more involved in caring than has previously been thought.

It is clear from the GHS that as the pattern of those 'who care in later life' is changing; surveys need to change with it. Future GHS and other national surveys needs to ensure that they capture an accurate picture of caring profiles and are not constrained by traditional assumptions about family care.

# Characteristics of the cared for population

As noted the majority of those being cared for are older themselves. In terms of the characteristics of those being cared for, it is likely that many of those with physical disability and those with a physical and mental impairment are frail elders, whereas those receiving help 'because they are old' will have more minor ailments. The vast majority of those with a physical disability will have an age-related chronic disability such as arthritis. Most of those elders with a mental impairment - either alone or in conjunction with a physical disability - are likely to have dementia; this is a deteriorating condition and is widely considered to be particularly stressful for carers to manage (Ashkam, 1995; Burns &

Rabins, 2000). Many of the carers in this situation are spouses (Briggs & Ashkam, 1999). This finding highlights the fact that many older people with demanding and difficult conditions are being looked after by similar-aged carers.

## The roles and commitment of older carers

This section discusses the tasks performed by older carers, time spent caring, length of caring commitment and which groups need the most intensive care.

The GHS data (*Table 2*) reveals that the key caring tasks of older carers are: personal care (32%), 'other practical help' (26%), help with paperwork/finances (17%) and physical help eg help with mobility problems (13%). Far fewer older carers keep the cared for person company, keep 'an eye on the person they care for', or take them out. A tiny minority give medicines (1%). There are few differences between men and women carers.

In terms of the number of hours of care provided per week, findings suggest that two fifths (42%) of older carers offer between 0–9 hours, a fifth (18%) provide between 10–19 hours and two fifths (38.5%) provide more than 20 hours; of these over half (53%) provide more than 50 hours. Co-resident carers provide considerably more hours of care than

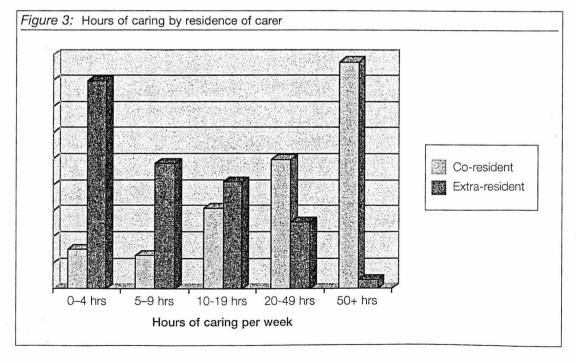


Table 3: Time spent caring and length of caring	by age of older carer		
	Age of older carer		
	60-74	Over 75	
Length of caring 0–4 years (n=332, 51%)	264 (51%)	68 (52%)	
5-10 years (n=152, 24%) Over 10 years (n=161, 25%) TOTAL	125 (25%) 126 (24%) 5.15	27 (21%) 35 (27%) 130	
Hours of caring 0-9 hrs 10-19 hrs 20-49 hrs 50+ hrs TOTAL	219 (45%) 94 (19%) 90 (18%) 88 (18%) 491	43 (34%) 21 (16%) 24 (19%) 39 (31%) 127	

extra-resident carers (*Figure 3*). To illustrate; whereas about two fifths of co-resident carers (45%) provide 50+ hours of care per week, nearly two thirds of extra resident carers (64%) provide between 0–4 hours of care per week. In terms of the length of time an older person has been a carer, it was found that about half (51%) of older carers have been caring for between 0–4 years, while equal numbers of older carers care for five to ten years (24%) or more than ten years (25%).

When time spent caring is further explored in relationship to carers aged 60–74 and over 75, an interesting difference emerges. As can be seen from *Table 3*, whereas a third of carers 60–74 (34%) provide 20 hours per week, a half of carers aged 75 or over (50%) provide 20+ hours per week. Additionally, whilst about a fifth (18%) of carers aged 60–74 provide over 50 hours per week, a third (31%) of carers aged over 75 are in the same position. Both age bands of older carers care for similar lengths of time, that is a quarter (24%) of carers aged 60–74 and well over a quarter (27%) of carers aged over 75 have been caring for 10 or more years.

Spouses and people with physical and mental impairments need the most support. 72% of spousal care is intensive, ie more than 20 hours per week. Almost a quarter of adult children (26%) also require very intensive levels of care (more than 50 hours per week). Conversely, the vast majority (75%) of friends/neighbours in the sample require between 0–9 hours of care per week. Parents fall in the middle with about a half (47%) requiring less than 10 hours per week and a quarter requiring between 10–19 hours per week. Those cared-for people with a mental and physical disability consume 70% of the

most intensive care (more than 20 hours per week).

# Caring activities and time spent caring

As discussed earlier, intensive caring is a combination of task and time and tends to reflect type of residency. Evidence suggests that there are many intensively involved coresident carers who provide both physical and personal care for many hours per week. The majority of co-resident carers are spouses, although some are adult children (Parker, 1990; Twigg et al, 1990). In the early 1990s, Arber & Ginn (1990) identified spouse carers as spending an average of 65 hours per week caring; these findings suggest that little has changed since then. As many carers in this situation will be looking after an older person with a range of health care needs, they are also more likely to be performing health care tasks such as changing dressings and dealing with incontinence (Goldstein & Rivers, 1996).

The trend towards older carers becoming more involved in providing intensive care is in part a consequence of the shift of care for adults with dependency needs from institutional care to community-based care and, in part, a result of the shift from care provided by formal service to care provided by family carers (Goldstein & Rivers, 1996). That the 'tab' for care is being increasingly picked up by older carers is a hitherto unrecognised consequence of these community care changes; the repercussions for their health and wellbeing is also largely unknown, although this paper identifies some areas for concern.

Many older carers are not only caring intensively for many hours per week, but have

been caring over a long period of time; many for more than ten years. Again, a higher proportion of carers aged 75 or over are in this position, further compounding the risks identified above. All those carers who have been caring for 10 years or more are coresident and the vast majority are spouses. This finding adds further weight to the profile of older spouse carers as shouldering a very heavy caring responsibility.

# Carers aged 60-74 versus carers aged 75 and over

Analysis makes it clear that carers aged 75 and over are more likely to be providing intensive levels of care for many hours per week than carers aged 60-74. This finding probably reflects the serious nature of the illness or disability of the cared-for person, who is also likely to be very elderly. As these fourth age older carers may have health problems themselves and the extent and nature of their caring activities is likely to be onerous and stressful, caring may well be placing them at considerable physical and psychological risk. This risk is likely to be further compounded by social isolation, which carers of people with dementia and other chronic conditions often experience (Wenger, 1994; Milne et al, 1999; Becker, 2000).

# Which groups need the most intensive care?

When one explores which cared-for group and which type of disability requires the most

intensive care, it is clear that spouses and those people with physical and mental impairment are in this situation. A small number of grown up children - many of whom will have a learning disability – also require intensive levels of care. At the other end of the caring continuum, it is clear that many friends and neighbours require very low levels of support; most of those needing help because they are 'old' only require 'tending' (Wenger, 1994). Parents appear to fall in the middle with some needing low levels of support, whilst others need more intensive care. This clearly reflects the nature of dependency need as well as the household type. Those parents who are frailer will need higher levels of care and will tend to be living with their adult son/daughter, whereas those who are less frail require lower levels of support and will be extra resident. It also reflects the changing nature of lifestyles amongst older people with more choosing to live alone.

# Health issues and support for older carers

This section explores health issues for older carers and the range and extent of support offered by services.

Although there is only limited evidence about the health of older carers from the GHS, a number of findings are clear. Over half of older carers (54%) report a long-standing illness or disability (*Table 4*). Even more strikingly, of those with a long-standing illness or disability, two-thirds (65%) say that their illness limits their activities; slightly more carers aged 75+ report this than carers aged

	Age of older	carer
	60–74 yrs	75 + yrs
Long standing illness/Disability of old	or carer	
Long-standing illness/Disability of old Long-standing illness	308 (54%)	81 (56%)
No long-standing illness	266 (46%)	65 (44%)
TOTAL	574	146
If long-standing illness or disability lim		
Yes	116 (64.4%)	42 (67.7%)
No	64 (35.6%)	20 (32.3%)
TOTAL	180	62 `
Health in the last 12 months by age of	older carer	
Good	244 (58.1%)	51 (50%)
Fairly good	115 (27.4%)	36 (35.3%)
Not good	61 (14.5%)	15 (14.7%)
TOTAL	420	102

60–74 yrs. Interestingly, over half the older carers (56%) report their health as 'good' and another third (29%) as 'fairly good' over the last 12 months.

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Despite these findings it is clear that only 43% of older carers receive support from services. As is illustrated by Figure 4, there are some interesting differences between the two types of residency. Namely, only a quarter (25%) of older carers who are co-resident and less than three fifths (58%) of older carers who are extra resident regularly receive support from a health or social care worker. This pattern is most evident in relationship to the doctor and the home help service. Whilst nearly a fifth of extra resident carers (18%) receive support from the doctor and nearly a quarter (23%) from the home help service, this applies to only under a tenth of co-resident carers

Additionally, those carers caring for more than 20 hours per week – most of whom would be co-resident – receive lower levels of most services than carers providing under 20 hours per week. To illustrate, of carers providing less than 20 hours per week of support, 14% are receiving visits from a doctor and 19% from a home help, but the corresponding figures for carers providing more than 20 hours per week are 10% and 12%.

A third (33%) of carers caring for between 5–14 years had not had a break of two days or more since they started caring; this was also true for about a fifth of carers who had been caring for 15 years or more. For those carers caring for 20 hours or more per week, nearly two thirds (63.5%) reported needing help to have a break and only one third (36.5%) had a reliable other carer they could trust to support the cared-for person were they to take a break. Of the fifth of older carers who considered temporary care to be available, most identified a nursing/residential care home (61.5%). A third (30%) considered no temporary care to be available.

## Health issues for older carers

The findings about carer health not only suggest that many older people are caring for others whilst suffering from a serious health condition themselves, but also that they continue to care *despite* their illness and

despite the limitations it places on their activities. Additionally, we know many older carers care intensively for sustained periods of time; this further suggests that they may be placing themselves at long-term risk of damaging their health on a permanent basis (Hancock & Jarvis, 1994; Hirst, 1998). Earlier in this paper we mentioned the 'caring tab' being picked up primarily by older carers. These findings powerfully suggest that there are direct health consequences for older carers - and particularly upon those aged 75+ and least able to bear it - of this shift in the balance of care. That most carers describe their health as 'good', may be more a reflection of the fact that they are obliged to continue to care, than of any objective assessment of health status.

## Services for older carers

The combined finding that co-resident older carers receive lower levels of services than extra resident older carers and that intensively involved carers receive lower levels of services than less involved carers, highlights a number of issues.

These findings support existing evidence that services are targeted on older people living alone, rather than on couples or coresident households (Pickard, 1999). Living alone has long been regarded as a 'risk factor' by welfare agencies and positively influences the rationing of both health and social services (Bauld et al, 2000). However, we know that co-resident carers tend to be more intensively involved than extra resident carers, that many are spousal carers and have health problems of their own and that they care for more dependent individuals (Warner, 1995). Living with a carer appears to be associated with 'reduced risk' by services however vulnerable a couple or carer may be and regardless of any assessment of 'actual' risk (Pickard, 1999). This situation leaves many carers without support and managing highly stressful and complex situations alone (Bamford & Bruce, 2000). It is a paradox that those carers who need the most support, appear to receive the least. As we go on to discuss, some services have the capacity to be very helpful to carers; it is identifying and targeting services more

effectively, as well as a re-working of the concept of risk that presents the challenge.

Previous research suggests that older carers appreciate input from most services (Bourgeois *et al*, 1996; Pickard, 1999). Specifically, carers identify the following as helpful:

- · time off from caring
- · reliable support from services
- · support from other carers/family members
- · information and advice
- · recognition of their caring role.

Those services that improve a carer's wellbeing are:

- · respite care
- · day care
- sitting services (Levin et al, 1994; McNally et al, 1999; Ashworth & Baker, 2000).
- overnight respite for carers of people with dementia (Flint, 1995; Gottlieb & Johnson, 2000).

Despite the importance of both day and longer breaks for carers' health and wellbeing, the GHS analysis suggests that many older carers fail to gain access to any service that offers them a break. This appears to be a reflection of the co-resident nature of much caring associated with later life, as well as a reluctance on the part of many older carers particularly spouses - to ask for help from services (HM Government, 1999). This is partly as a consequence of a normative expectation that spouses will care for their partner unaided, but also knowledge that services may offer a poorer quality of support than they can offer. The interdependent nature of many older couples who care for each other also makes it difficult to distinguish between user and carer and hence to 'allocate' a service to an individual (Pickard, 1999). Thus, even if a carer is identified as 'in need of help' there are a number of social, emotional and bureaucratic barriers to overcome. This is a challenge services must accept if co-resident carers, particularly married couples, are to receive the support they so evidently need.

## CONCLUSION

The GHS meta-analysis makes it clear that there are increasing numbers of older carers and that they form a rising percentage of the total number of carers. They are also ageing as a group in parallel with the population profile of the UK, and are caring for increasingly frail relatives. Older carers can be distinguished from other groups of carers in a number of unique ways: they are more likely to live with the person they care for, care-giving is likely to take place within the context of a long term relationship and there is a greater chance of carers having health problems of their own. Dementia is also more likely to be a feature of caring in later life.

The analysis clarifies the previously noted distinction between older carers who offer support on a co-resident basis and those who are extra-resident. It also confirms that there is a strong correlation between type of relationship, type of household, and nature of caring activities. There is clearly a high level of devotion to caring amongst many coresident older carers; they often provide intensive care over a long period of time in very demanding circumstances with little or no support from services. Most of these carers are spouses, although some are parents. It is also clear that there is a growing group of less involved extra resident carers who tend to offer tending to friends and more distant relatives. Of particular note is the increasing number of 'other relatives'.

Despite the fact that we know older carers welcome support from health and social care services, it is clear that many intensively involved carers are not receiving sufficient support. Services appear to be targeted upon those who live alone overlooking the needs of couples; this approach fail is to acknowledge the dual nature of spouse care and take account of the wider caring situation. This analysis also suggests that older carers are increasingly involved in providing intensive care as a result of the combined shift of care from institutions to the community and from formal services to family care. The consequences of picking up the 'tab' for caring are likely to be long term social and health problems for older carers.

Up until now older carers have been invisible to both researchers and policy makers. The National Service Framework for Older People (Department of Health, 2001) alongside the National Carers Strategy (HM Government, 1999) offers a key opportunity to

focus attention on older carers. This analysis highlights the particular needs and circumstances of older carers and suggests that more should be done to develop understanding of the nature and consequences of caring in later life, extend knowledge, and improve the health and quality of life of some of the most committed and intensively involved carers in the UK.

## Note

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## **Acknowledgements**

The authors would like to thank Help the Aged for their support.

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## Mental health issues for older people

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A one or two-day training course aimed at housing and social work staff, police and probation officers, staff from benefits agency, advice workers, nurses, accident and emergency staff, occupational therapists and non professionally affiliated staff in Adult Mental Health Services with a year or more experience of mental health.

## Learner outcomes:

- identify stereotypes which may influence attitudes towards mental health in old age, including the effect of ageism
- examine the process of assessment and diagnosis and understand key facts relating to dementia and depression
- · consider the issue of communication with people with dementia
- identify ways in which psychological needs might be met in a care setting
- · address political issues relating to the power of older people within services



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# Developing a Profile of Older Carers

## Alisoun Milne

## Introduction

Recent years have seen a growing recognition of the important role that carers play in enabling vulnerable adults to remain in the community (H.M Government, 1999). Whilst much research has been done on caring, none has-until now-reviewed the needs of older carers in any comprehensive way (Parker, 1998). In 2001, Help the Aged commissioned a report to address this deficiency; 'Caring in Later Life: a review of the needs and roles of older carers' was published in October 2001 (Milne et al, 2001). The review was conducted by researchers from the Tizard Centre, University of Kent and brought together a wide-ranging review of academic and policy literature with an original analysis1 of the 1995 General Household Survey (OPCS, 1998; Rowlands, 1998).

This paper will offer an overview of those findings that contribute to the development of a 'profile' of older carers: a demographic picture of prevalence and key characteristics. Where appropriate, commentary is supplemented by data from the GHS analysis (OPCS, 1998; Milne & Hatzidimitriadou, in press). The review extends and deepens our understanding of who cares in later life and offers a detailed 'profile' of older carers in the UK; the key features of this profile will now be discussed.

## Who Cares in Later Life?

It is clear that older carers constitute a large and growing number of carers; older carers also represent an increasingly large proportion of the total number of carers. A third of the total number of UK carers are aged 60 or above—this equates with about two million carers. Of these four-fifths are aged 60-74 and one fifth is aged 75 years and above.

It is also clear that older carers are 'ageing' and that many experience health problems as a consequence of age.

Changes in household composition coupled with the shift from institutional care to community based care have resulted in larger numbers of frail elders remaining at home being cared for by (often equally frail) older relatives or friends. Of particular note is the substantial increase in the numbers of older people living at home with a chronic illness such as dementia, whose need for care is substantial and intensive.

# Who do older carers support?

As might be expected, the overwhelming majority of those people receiving care from older people are old themselves; only about a tenth are under 60 years old. In fact, over a third of the total number of older people in need of family care are cared for by same generation relatives or friends.

In terms of which relatives or friends are supported: a third of older carers care for spouses; a fifth are adult children caring for elderly parents; a fifth care for friends/neighbours; just under a fifth care for 'other relatives'; and just under a tenth are parents caring for a child with physical and/or learning disabilities.

Analysis also suggests that over two thirds of those being cared for have physical disabilities, about a sixth receive care because they are 'old', just over a tenth have physical and mental 'impairments' and just under a tenth have 'mental impairments' only. Many of those with a 'physical disability' and those with both a 'physical and mental impairment' will be frail elders whereas those receiving help 'because they are old' are likely to have more minor ailments.

The vast majority of those with a physical disability will have an age related chronic disability such as arthritis. Most of those elders with a mental impairment will have dementia; this is a deteriorating condition and is widely considered to be particularly stressful for carers to manage (Askham, 1995).

## Groups of Older Carers

Older carers cannot be viewed as a single group. However, two particular groups can be identified: co-resident and extra-resident carers. (Co-resident means sharing the same household; extra-resident means living in a different household.) Two fifths of older carers are co-resident whilst three fifths are extra-resident. This profile dovetails with the other distinguishing feature of caring in later life, the relationship with the cared-for person. These two combine to form a third feature, which is intensive caring versus helping.

## Co-resident older carers

The GHS analysis confirms that spousal carers are the largest group of co-resident carers; equal numbers of spousal carers are male and female (Pickard, 1999). Spouse carers not only represent the largest proportion but also offer the most intensive level of support in the most demanding circumstances. A key aspect of spousal care is its mutuality and interdependence with the carer/cared-for roles being indistinguishable from one another. Caring within marriage, unlike most other caring relationships, tends to be regarded by carer and cared-for as an extension of the intimacy and companionship that characterises marriage. Spousal care also poses a challenge to a service allocation system that focuses on individuals rather than contexts.

Spousal carers of people with dementia face a particular set of challenges: they often care intensively over long periods and have the additional difficulty of dealing with challenging behaviour and the loss of companionship associated with a dementing illness. The cared-for individuals that require the most intensive care are older people with physical disabilities and dementia.

Parent carers are also co-resident; this small group of older carers care for an adult son or daughter with a learning disability or a mental health problem. The latter group receive very limited recognition of their

The review did not cover issues relating to older carers of people with a learning disability as a very thorough review of the needs of this group had recently been conducted by Walker & Walker (1998).

caring role, which tends to be supervisory in nature and is often very stressful (Perring *et al*, 1990).

Evidence suggests that adult children caring for their parents are either middle aged or older. They can be co-resident or extra resident depending upon proximity and intensity of need for support. It is likely that middle-aged carers will 'graduate' into later life caring as many will titrate their input as needed. There has been a shift away from co-resident care towards extra resident care in the last decade reflecting a change in household composition and increased social mobility. A higher proportion of carers in this group are women.

## Extra resident older carers

As noted above, three fifths of the total number of older carers are extra resident. There are two main groups: 'other relatives' and 'friends & neighbours'. Some adult children caring for their elderly parents may also be extra resident. Extra resident carers tend to be associated with 'helping' rather than caring. Many are friends and neighbours who tend to be involved on a limited basis and commit less time to caring. They are likely to offer practical support such as shopping, and care for a few hours per week.

Whilst many 'other relatives' are also involved on this basis, some are providing more intensive care. The survey data does not specify who these relatives are but the group is likely to include siblings, nieces, nephews and cousins, as well as half- and step-relatives. It may also include ex-spouses, ex-parents-in-law and other 'ex' relatives.

This finding suggests two things. One is that further work needs to be done to explore who 'other relative' carers are. Secondly, it may be that instead of abandoning caring, the reconstructed family continues to care for its members, albeit along different lines of reciprocity and in a different constellation from the 'traditional family' (Twigg & Atkin, 1994). Such conjecture requires exploration but may lend weight to the argument that people offer care on the basis of affection and attachment as well as out of a sense of duty and obligation.

# The roles and commitment of older carers

The GHS analysis reveals that the key caring tasks of older carers are: personal care, 'other practical help'; help with 'paperwork/finances'; and 'physical help' e.g. help with mobility problems. A significant proportion of older carers are providing this type of care for many hours

per week; nearly 40 percent are providing care for over 50 hours per week, most of these are spouse carers. As intensive caring is a combination of task and time, these combined findings confirm earlier evidence that many older carers provide intensive physical and personal care for many hours per week. The majority of such carers are spouses although some are adult children.

Evidence also suggests that the older a carer is, the more likely he/she is to be spending long hours providing care. Whilst one fifth of carers aged 60-74 provide 50+ hours per week of care, one third of carers aged 75+ provide this level of care. This finding is likely to reflect the serious nature of the illness or disability of the cared for person, who is also likely to be very elderly. Many older carers have also been caring for over a long period of time. Well over one quarter of older carers-mainly those aged 75+—have been caring for ten years or more. As these fourth-age older carers are likely to have health problems themselves and the extent and nature of their caring activities is likely to be onerous and stressful, caring may well be placing them at considerable physical and psychological

# Services and support for older carers

Evidence strongly suggests that older carers welcome support from health and social care services, but welfare policies, which target help towards those who live alone, may overlook their needs (Pickard, 1999). Those services that specifically improve carer well-being are respite care, day care and sitting services. A number of specialist services are also helpful for carers of people with dementia such as the admiral nursing service and memory clinics. Carers' groups are widely accessed and are invaluable sources of advice, information and support (Moriarty & Webb, 2000).

Despite this, the GHS analysis makes it clear that under a half of older carers receive support from services. There are also some interesting differences between the two types of residency. Namely, less than a quarter of older carers who are co-resident and under three fifths of older carers who are extra-resident regularly receive support from a health or social care worker. One third of intensively involved older carers who have been caring for between 5-14 years have not had a break of two days or more since they started caring.

Support from family and friends also plays an important role in maintaining carer well being. Networks seem to act as 'stress buffers' for carers and protect them against social isolation. Paradoxically, many older

carers—particularly those looking after someone with dementia—have limited social networks as a result of the demands of caring and receive limited support from family members.

## Conclusion

The review makes clear a number of trends. There are increasing numbers of older carers and they form an increasing percentage of the total number of carers. They are also ageing as a group in parallel with the population profile of the UK and are caring for increasingly frail relatives. Older carers can be distinguished from other groups of carers in a number of unique ways: they are more likely to live with the person they care for; care-giving is likely to take place within the context of a long term relationship; and there is a greater chance of carers having health problems of their own. Dementia is also more likely to be a feature of caring in later life.

The review confirms the previously noted distinction between older carers who offer support on a co-resident basis and those who are extra-resident. It also confirms that there is a strong correlation between type of relationship, type of household, and nature of caring activities. There is clearly a high level of devotion to caring amongst many co-resident older carers; they often provide intensive care over a long period of time in very demanding circumstances with little or no support from services. Most of these carers are spouses, although some are parents or adult sons and daughters. It is also clear that there is a growing group of less involved extra-resident carers who tend to offer help to friends and more distant relatives. Of particular note is the increasing number of 'other relatives'.

The review also suggests that older carers are increasingly involved in providing intensive care as a result of the shift of care from institutions to the community and the parallel shift of responsibility for care from formal services to informal sources. The consequences of picking up the 'tab' for caring are likely to be long term social and health problems for many older carers (Milne & Hatzidimitriadou, in press).

Up until now older carers have been invisible to both researchers and policy makers. The National Service Framework for Older People (Department of Health, 2001) alongside the National Carers Strategy (H.M Government, 1999) offers a good opportunity to focus attention on this group. This analysis highlights the particular needs and circumstances of older carers, and suggests that more should be done to develop understanding of the nature of caring in later life and improve the health

and quality of life of some of the most H.M. Government (1999) Caring about committed and intensively involved carers in UK society.

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Full copies of the report Caring in Later Life: Reviewing the Role of Older Carers are available from Help the Aged on 0207-278-1114

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## **BUPA Foundation Awards Scheme 2002 Call for Entries**

The BUPA Foundation has launched a new Care Award for excellence in the development of care for older people and the winning entry will receive £10,000. The winning work will address any need or service development designed to improve the delivery of care to Britain's older people.

Says BUPA's medical director and governor of the BUPA Foundation. Dr Andrew Vallance-Owen: "The care that Britain's elderly receives is increasingly coming under the spotlight and it is vital that our elderly people receive care that is appropriate to their needs. For this award the BUPA Foundation would particularly like to receive applications that address areas raised by the National Service Framework for Older People, for example, intermediate care services for stroke patients. dementia and other specialist care.

"The standard of submissions for the BUPA Foundation Awards is always very impressive and the Foundation is looking forward to receiving applications that will make a real difference to the care Britain's elderly receive," says Dr Vallance-Owen.

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J. Community Appl. Soc. Psychol., 15: 319–337 (2005)

Published online in Wiley InterScience (www.interscience.wiley.com). DOI: 10.1002/casp.830

# Dementia Care-giving in Black and Asian Populations: Reviewing and Refining the Research Agenda

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#### ABSTRACT

Despite the increased prevalence of dementia little work has been done to explore the extent and nature of care-giving in black or Asian-UK populations. Evidence that does exist suggests that the consequences of care-giving are significant but different from those experienced by white carers and are mediated by a number of culture-related factors. These include: ethnically specific conceptualisations of dementia; expectations of family duty; religiosity; the adoption of positive re-appraisal strategies, and beneficial outcomes. Present approaches to research are narrow, do not take account of cultural dimensions and employ terminology and care-giving frameworks which are of limited relevance. That the evidence base is characterised by small-scale studies, and weak methodology further undermines its validity. Research deficits are systemic and fundamental and are both conceptual and methodological. A key contribution would be the development of a multi-dimensional theoretical model that takes account of the role played by culture, ethnicity and structural inequality in shaping care-giving experiences and profiles. Incorporating the perspectives of black and Asian carers, and the influence of the life course of individuals and communities and employing qualitative methods would also influence the direction of research, improve its quality and generate knowledge in this underdeveloped field. Copyright © 2005 John Wiley & Sons, Ltd.

Key words: dementia care-giving/caring; black; Asian; culture

### INTRODUCTION

There is an increasing interest in the role of family support and the needs of carers from black and Asian populations in Western Europe and America (Daker–White, Beattie, Gilliard, & Means, 2002; Dilworth–Anderson, Williams, & Gibson, 2002). This reflects the ageing profile of these populations and the implications of age-related health conditions, particularly dementia, for family care-giving (Milne, Hatzidimitriadou, Chryssanthopoulou, & Owen, 2001). That the impact and consequences of dementia care-giving on the lives and health

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of minority carers may be as significant as those of white carers is a key driver. Despite this, there remains a fundamental knowledge deficit in this field, especially in the UK. The research paradigm lacks coherence, is constrained by very limited theoretical and conceptual development and fails to accommodate cultural or contextual location; it is also marginal to the arenas of both care-giving and dementia-related work (Hinton, 2002; Lampley–Dallas, 2002). The narrowly constructed frame of reference of current research undermines the advancement of understanding; it contributes to cultural myopia and to approaches which fail to take account of the perspectives of minority carers themselves. Exploring and addressing these barriers and improving the quality of research in this emerging field are the twin objectives underpinning this paper.

Focusing specifically upon black and Asian carers of people with dementia (PWD), the paper aims to provide an overview of existing evidence about care-giving, identify key themes from the literature and offer a critique of UK research. Its scope is limited to dementia care-giving as it represents the most significant challenge to family support, and its focus to black and Asian populations as these represent the largest ethnic minority groups in the UK (Briggs & Ashkam, 1999; Dilworth–Anderson et al., 2002). The authors conducted a specific electronic search to inform the review; databases include BIDS, PsycARTICLES, Medline, CareData, EBSCOhost and SOCIG. Where useful and for reference, evidence from UK is supplemented by US research. Whilst US work is considerably more developed, it is important to note limitations to comparisons between the two countries (Daker–White et al., 2000). An overarching deficit of UK research relates to the very limited extent of enquiry in black communities.

The paper is presented in three sections. The first Section offers context, and the second reviews the literature relating to dementia care-giving in black and Asian populations. The third section is a critique of the nature and dimensions of UK research including proposals for a number of improvements to the construction of the research paradigm and the direction and nature of future work.

## BLACK AND ASIAN POPULATIONS IN THE UK & DEMENTIA PREVALENCE

Overall, ethnic minorities constitute 8% of the total UK population (Scott, Pearce, & Goldblatt, 2001). Approximately half are South Asians of Indian, Pakistani or Bangladeshi origin and almost a third identify themselves as black; the Chinese population and 'other Asians' comprise 10% (Office for National Statistics, 2002). In parallel to the mainstream population, minority groups are ageing. Recent estimates suggest that approximately 11% of South Asians, 15% of black and 3% of Chinese are aged between 60 and 74 years old; 3% overall is aged 75 and over (Evandrou, 2000). In 2001 there were 350 000 ethnic minority elders in the UK (Office for National Statistics, 2003). Of particular significance is the predicted rise in the number of people aged 85 and over (Age Concern England, 2001).

<sup>&</sup>lt;sup>1</sup>The particular keywords used for these searches were as follows: 'dementia', 'Alzheimer's disease', 'caregiving', 'carer', 'minorities', 'ethnicity', 'race', 'culture', 'cultural differences', 'ethnic minorities', 'Asian', 'black' and 'Chinese'. These keywords had to be present in the title or abstract in papers. Papers were then sorted as relevant specifically to Asian and black populations.

<sup>&</sup>lt;sup>2</sup>In Britain, 'black' refers to individuals with at least one parent originating from either Africa or the Caribbean (Evandrou, 2000).

As longevity is the most significant risk factor for developing Alzheimer's disease which accounts for over 60% of all dementias—dementia prevalence in black and Asian groups is set to increase<sup>3</sup> (Audit Commission, 2002; Harvey, 1998), Although it is known that there are approximately 750 000 people with dementia in the UK, data on dementia prevalence in minority populations is limited and lack specificity (Office for National Statistics, 2002; Patel, Mirza, Lindblad, Amstrup, & Samaoli, 1998). The Alzheimer's Society (2004) estimates that at least 5000 people from ethnic minority groups have dementia but acknowledges that this figure is likely to be a considerable under-representation. In terms of differential rates, there is some evidence that the African-Caribbean population and certain sub-groups within the South Asian population are at increased risk of vascular dementia due to enhanced levels of hypertension and diabetes (Baker, 1996: Department of Health, 2002; McKeigue & Charturvedi, 1996; Modood et al., 1997). At present, there are a higher number of older men with dementia than women in both these populations as a consequence of patterns of migration; many young men came to the UK in the late 1950s and 1960s for employment in 'blue collar' industries (Bowes & Dar, 2000).

#### DEMENTIA CARE-GIVING IN BLACK AND ASIAN POPULATIONS

Despite the fact that the 2001 UK Census estimates there to be at least 285 000 carers from ethnic minorities overall, little is known about the extent of dementia care-giving (Office for National Statistics, 2003). This relates in part to lack of knowledge about dementia prevalence (Adamson, 2001; Maher & Green, 2002). The widely held stereotype that care-giving in ethnic populations is not only 'normal' but unproblematic, is also a contributing factor (Boneham et al., 1997; Department of Health, 1998). That few black and Asian carers use services further suggests that they are not 'in need' of support and that their experiences do not warrant research enquiry (Bowes & Dar, 2000; Hicks & Lam, 1999). Estimates for the white community suggest that over half of people with moderate to severe dementia are cared for in the community by a close relative (Townsend & Godfrey, 2001). Due to the unacceptability of residential care in minority populations, it is likely that this proportion is significantly higher (Adamson, 1999; Hicks & Lam, 1999). This view is supported by a number of recent small-scale studies in the UK which suggest that Asian families remain reluctant to contemplate care-home admission even for a relative with advanced dementia (Patel et al., 1998; Seabrooke & Milne, 2004; Townsend & Godfrey, 2001).

Research from both the UK and US suggests that culture and ethnicity play a significant role in defining dementia care-giving and in influencing the patterning and experiences of black and Asian carers. Evidence can be located around four themes: Illness Meanings of Dementia; Care-giving Patterns and Relationships; The Impact of Care-giving; and Social Support and Coping. These will now be reviewed.

<sup>&</sup>lt;sup>3</sup>Dementia is a term used to refer to a particular clinical condition that is characterised by widespread brain pathology with consequent global impairment of intellect, memory and personality (Miller & Morris, 1993). The most common forms of dementia are Alzheimer's disease and vascular dementia. Other less common dementias include: frontal lobe disorder such as Pick's disease and Parkinson's disease, and Lewy Body dementia. There are also a number of rare dementias including Wilson's disease, Korsakoff's syndrome and Creutzfeldt-Jacob Disease (CJD).

## Illness meanings of dementia

It is known that cultural norms and beliefs influence conceptualisations and definitions of mental illness: this also extends to dementia (Dilworth-Anderson & Gibson, 2002). These act as powerful determinants of carers' experiences, mediate the impact of care-giving on well-being, and influence approaches to illness management and help-seeking behaviour (Janevic & Connell, 2001).

Two key findings emerge from work done with South Asian communities in the UK. Dementia is widely understood as 'an act of God' or the result of normal ageing and as a mental illness—is regarded as shameful (Patel et al., 1998). No conceptual distinction is made between functional and organic mental illness. PWD are routinely stigmatised, families may deny the existence of dementia, keep the PWD hidden or present dementia symptoms as related to a physical illness (Kleinman, Eisenberg, & Good, 1987). If help from General Practitioners (GPs)<sup>4</sup> is sought at all, dementia diagnosis tends to occur at a late stage when the capacity of treatment to prevent deterioration and improve function is limited (Patel et al., 1998). The fact that early intervention is particularly effective for treating the remedial risk factors for vascular dementia is a particular loss (Powell, 2002). As a consequence of reluctance to seek help from services, or the wider family, South Asian carers tend to care unaided and often alone, keeping the PWD apart from the wider community (Seabrooke & Milne, 2004).

Similar observations have been made by US researchers studying Chinese carers (Dilworth-Anderson & Gibson, 2002). Specifically, research has shown that Chinese families tend to view dementia as part of a non-pathological ageing process (Elliott, Minno, Lam, & Tu, 1996). As it is expected that PWD will be cared for within the family, seeking medical treatment or help from services is not customary and is often viewed as unacceptable (Dilworth-Anderson & Gibson, 2002). Where dementia is viewed as a mental illness—and this is more likely when the PWD is displaying challenging behaviour—stigma and shame may be associated with it (Smith, 1996). As with South Asian communities, the family will tend to minimise contact between their relative and 'outsiders', including non-family members of their own community (Elliott, Minno, Lam, & Tu, 1996).

A very different perspective is adopted by African American culture. The behavioural symptoms commonly associated with dementia are conceptualised as 'worration', 'falling out' or 'high blood' (Dilworth-Anderson & Gibson, 2002; Gaines, 1989). 'Worration' reflects a combination of worry and stress and is rooted in the cultural theme of survival (Dilworth-Anderson, 1997; Gaines, 1989). Specifically, as a result of exposure to hardship and oppressive conditions, African American elders are regarded as more vulnerable to mental and physical ill health, and are regarded as needing protection and support (Dilworth-Anderson, 1997). Unlike the South Asian or Chinese communities this conceptualisation does not create a stigma for either the PWD or their carer although the emphasis on family care does act as a disincentive to help seeking from services (Dilworth-Anderson & Gibson, 2002). No evidence exists for the UK black community.

## Care-giving patterns and relationships

To date, only one study has specifically investigated dementia care-giving patterns in ethnic minority communities in the UK (Townsend & Godfrey, 2001). Focusing on South

<sup>&</sup>lt;sup>4</sup>General Practitioner in Britain refers to primary care physicians.

Asian carers, Townsend and Godfrey (2001) found that care-giving is significantly influenced by gender role stereotypes and filial responsibility. They observed that the vast majority of personal care is provided by female relatives, particularly daughters or daughters-in-law, whilst male relatives retain responsibility for decision-making and the organisation of care. Daughters/in-law seldom regard themselves as 'carers' and the support provided to the PWD is not defined as care-giving but rather considered a part of normal kinship responsibilities (Townsend & Godfrey, 2001).

Similar findings have been reported in research originating from the US focusing on Chinese carers (Braun & Browne, 1998). Confucian values underpin family care and much emphasis is placed on a gender-based family hierarchy; men are responsible for arranging care, whilst women provide the care itself. Care of PWD tends to fall to daughters-in-law as it is usually the eldest son who adopts formal responsibility for supporting his parent (Braun & Browne, 1998). There is, however, some evidence that responsibility for decision-making around care-giving is a family issue and that as the PWD deteriorates caring tasks are shared between family members (Hicks & Lam, 1999). A number of observers have described the management of PWD in Chinese communities as a process of 'containment rather than care' (Yu, 2000).

In African American families there is a powerful expectation that families will provide care to their frail elderly relatives, including those with dementia (Cloutterbuck & Mahoney, 2003). Despite the fact that the majority of carers are daughters or daughters-in-law, care is often shared within a family network and it is acceptable for the care-giving role to be assumed by a range of relatives, including spouses and sons (Haley et al., 1995; Lawton, Rajagopal, Brody, & Kleban, 1992). PWD may also receive support from wider family or community members and contact with others is encouraged (Dilworth–Anderson, Williams & Cooper, 1999). Although no work has charted dementia care-giving in UK black communities, the fact that a significantly higher proportion of African-Caribbean elders live alone, than is the case for Asian populations, has implications for the nature and pattern of family support (Office for National Statistics, 2003).

## Impact of care-giving

In the mainstream literature, it is widely noted that dementia care-giving, particularly over the longer term, significantly impacts on carer well-being and quality of life (Aneshensel, Pearlin, Mullan, Zarit, & Whitlach, 1995; Carers UK, 2004). Negative mental and physical health consequences include, depression and anxiety, musculo-skeletal injury, fatigue and cardiovascular problems; loneliness and poverty are also prevalent risks (Fuller-Jonap & Haley, 1995; Hirst, 2004; Milne et al., 2001; Ory, Yee, Tennstedt, & Schulz, 2000; Schulz, O'Brien, Bookwala, & Fleissner, 1995). Although limited, UK research suggests that the experiences of African-Caribbean and South Asian carers may be similar to those of white carers (Adamson, 1999). Certainly, reported health problems and levels of burden, distress and isolation appear to be as, or more, prevalent in these groups although how they are experienced and expressed may be very different (Atkin & Rollings, 1996; Haley et al., 2004).

The impact of care-giving on ethnic minority carers has received more attention in the US. Most research has focused on the African-American community (Dilworth–Anderson et al., 2002) and on negative psychological outcomes such as depression, burden and stress. Overall, findings are mixed (Gonzalez, Gitlin, & Lyons, 1995). A number of studies detect no significant differences in depression or burden scores between

African-American and white carers (Cox, 1993; Knight & McCallum, 1998; Wood & Parham, 1990), whilst other research shows that African-American carers experience lower levels of depression and are less burdened (Haley et al., 2004; Hinrichsen & Ramirez, 1992; Roth, Haley, Owen, Clay, & Goode, 2001). It has been suggested that this may be in part, due to the positive perceptions that shape the meaning of care-giving in this culture; this pertains particularly to the view that care-giving is a rewarding experience as well as the fulfilment of a traditional expectation and role obligation (Dilworth–Anderson & Gibson, 1999). Another explanation is that carers from cultures that value emotional expressiveness more than intellectual ability may retain higher levels of attachment to, and links with, the PWD (Gaines, 1989). A third proposition is that the negative impact of care-giving may not be expressed in terms of psychological morbidity but somatised as a physical illness (Calderone & Tennstedt, 1998; Haley et al., 2004).

## Social support and coping

Research on social support and coping among ethnic minority carers has been grounded primarily in the stress-process theoretical frameworks which have been developed in work with white care-givers (Pearlin, Mullan, Semple, & Skaff, 1990). Within these models, social support and coping responses are viewed as key determinants of an individual's adjustment to the care-giving role. Indeed, these factors have been shown to significantly influence carers' emotional and physical well-being (Goode, Haley, Roth, & Ford, 1998; Schulz et al., 1995). Of particular note is the knowledge that support may be forthcoming if needed; this has been evidenced as a potent stress-reduction factor (Goode et al., 1998; Wethington & Kessler, 1986).

Research suggests that black and Asian carers have larger and more diverse kinship networks than their white counterparts (Dilworth–Anderson et al., 1999). Despite the fact that such networks are widely conceptualised as offering mutual aid and reducing carer burden, very little is actually known about whether they are helpful to carers or have a positive effect on well-being (Department of Health, 1998; Wood & Parham, 1990). Recent work by Fox, Hinton, and Levk-off (1999) found little evidence that African-American carers received support from their kinship network; for some this deepened feelings of distress and isolation (Fox et al., 1999). The fact that we have reviewed evidence suggesting that in UK-based South Asian and Chinese communities care-giving for a PWD appears not to be shared between relatives in a network—or even a family—raises the question of the role it does—or does not—play in supporting carers. This is an issue which requires further exploration.

Whilst there is no UK research exploring coping responses amongst black or Asian carers, researchers in the US have looked at coping amongst African-American carers (Haley et al., 2004). This literature identifies African-Americans as having a significantly greater ability to manage the emotional and physical demands of care-giving and to protect themselves from negative consequences. Further, they are less likely to perceive caregiving as intrusive, tend to hold more positive views about the obligation to care and are able to retain their sense of self (Dilworth–Anderson et al., 2002; Haley et al., 2004; Ulbrich, Warheit, & Zimmerman, 1989). Knight and McCallum (1998) suggest that this may be a result of African-American carers' adoption of a positive reappraisal strategy. They argue that adaptation to long-term oppression, segregation and socio-economic deprivation, has resulted in the 'reframing of difficult life experiences' equipping African-Americans to deal more effectively with the demands of caring (Ulbrich et al., 1989; Wood & Parham, 1990).

US research has also highlighted the important role spirituality and religiosity play in supporting African-American carers (Dilworth–Anderson & Anderson, 1994; Haley et al., 2004; Levkoff, Levy, & Weitzman, 1999; Navaie-Waliser et al., 2001; Nkongho & Archbold, 1995). Overall, it has been argued that religious belief provides an explanatory framework resulting in greater acceptance of the challenges of care-giving and enhancement of carers' ability to manage stress (Farran, Paun, & Elliott, 2003). For example, in their study Wykle and Segall (1991) found that African-American carers were very likely to mention prayer and faith as their 'special aid' to coping. Similarly, Wood and Parham (1990) and Steritt and Pokorny (1998) showed that many regard God as an equally significant source of informal support as family and friends. It is important to note that these findings are not universal. In a recent investigation Cloutterbuck and Mahoney (2003) found that religion did not constitute an important aspect of African-American carers' coping repertoire and that the role of the church as a source of support is diminishing (Fox et al., 1999).

Having reviewed the current evidence base, the authors now turn to critiquing the nature, dimensions and deficits of UK research and identifying future directions.

## REFINING THE RESEARCH AGENDA

Whilst there are examples of high quality studies in the field under review, the evidence base is characterised by considerable variation in size, approach and focus and by a number of inherent weaknesses. If knowledge is to be generated and the research agenda develop, it is essential that researchers address existing limitations. Discourse is presented under five interlocking topic heads.

## Illness meanings of dementia

Ortiz, Simmons, and Hinton (1999) suggest that discourse about dementia in minority populations is polysemous embodying cultural information not only about local and personal constructions of illness, but also incorporating dimensions about the nature of family and community, place and personhood (Ortiz, Simmons, & Hinton, 1999). Whilst this is reflected in the earlier discussion of illness meanings of dementia, criticism has been made of the overly simplistic dichotomous representation of ethnic versus biomedical definitions (Iliffe & Manthorpe, 2004). This approach emphasises distinctions not only between the mainstream dominant ideology and minority perceptions, but also assumes an 'anachronistic view of culture as a top-down hegemonic patterning of health related beliefs, attitudes and practices' (Hinton & Levkoff, 1999, p. 546). Further, it takes no account of the more flexible reality. There is some US evidence for example, that ethnic minority communities accept both the organic nature and incurability of dementia whilst placing the experience of the illness on a continuum of psychosocial distress that serves to destigmatise it (Hinton & Levkoff, 1999). This acculturated 'locally grown' model influences the management not only of dementia symptoms but also the experience of care-giving. Researchers have yet to explore how far this conceptual fusion exists amongst black and Asian communities in the UK and if it does, what form it takes and how it impacts on caring. At present, studies are not located in a paradigm that aims to explore illness meanings of dementia or work with a community to identify how it is understood and responded to (Milne & Seabrooke, in press).

## Race, culture and ethnicity

Research into family care-giving tends to adopt relatively simplistic and global definitions of ethnicity, race and culture (Connell & Gibson, 1997; Janevic & Connell, 2001). Recent evidence suggests that the widely held view that culture is a shared set of ideas espoused equally by all members of a specific ethnic group is inaccurate (Hinton, 2002). Similarly, ethnicity is not usually experienced or expressed as a single autonomous and self-sufficient category of identity (Husband, 1996). Instead, culture and ethnicity need to be viewed as concepts which vary considerably between countries, places, communities, families and even individuals; they are situational, contested, diverse and subject to temporal change (Barth, 1994; Hinton, Fox, & Levkoff, 1999; Reicher & Hopkins, 2001; Wallman, 1986). Migration, for example eads to acculturation so that responses attributed to a presumed stable ethnic identity may be ohort effect, confined to one or two generations only (Iliffe & Manthorpe, 2004).

Difficulties in defining and measuring ethnicity has led to the use of race as a convenient—albeit oversimplified—proxy term. Not only is this conflation unsatisfactory but so fails to take account of the multi-faceted nature of ethnicity and conceals the significance of its macro level—personal, individual, family—meso level—group, community and macro level—historical, economic, political—dimensions (Barth, 1994; Hinton et al., 1999). Given the mutually interlocking and interpenetrating nature of these dimensions and the relevance of past and current contexts in influencing the meaning and experience of care-giving, the importance of employing accurate and reflexive definitions of ethnicity cannot be overstated (Hinton et al., 1999; Rait & Burns, 1997). Further, using terms which are not clearly defined confuses the focus and validity of research and undermines the potential to compare findings and develop a coherent evidence base (Dilworth–Anderson et al., 2002; Iliffe & Manthorpe, 2004).

The use of single indicators of race or ethnicity has also led to a challenge about the definition and management of intra-racial diversity; constructions of collectivity mask considerable heterogeneity (Yeo, 1996). Even within the same racial group there is tremendous diversity in terms of acculturation, migration and associated patterns of settlement and adaptation, education, income, religious affiliation and length of residence in the UK. For instance, South Asians in Britain come from a variety of cultures and represent different languages, dialects, religions, histories and customs (Gunaratnam, 1993). Furthermore, their cultural norms and traditions have undergone a number of transitions according to where they originally settled and levels and rates of assimilation and work opportunities (Seabrooke & Milne, 2004). A related issue is the research assumption that carers are inevitably of the same ethnic/racial background as the PWD; this excludes the rising numbers of interethnic and interracial families in the UK (Hinton, 2002; Janevic & Connell, 2001).

Modelling multiple indicators of ethnicity may assist in achieving a definition that encompasses these variables (Manuel, 2000) and work from the field of social anthropology may also be illuminating (Bhopal & Donaldson, 1998). Frameworks such as the 'contextual approach' (Dilworth–Anderson & Anderson, 1994), and the 'acculturation continuum' employed in work exploring diversity amongst ethnic groups (Valle, 1998) may also contribute to the development of a more sophisticated definition of ethnicity which is applicable to research in this field (Barth, 1994).

## Social inequalities and the life course

A powerful dimension of the experiences of black and Asian populations relates to their history, life course, structural status and socio-political context; the macro-level influences identified in the framework noted above (Janevic & Connell, 2001; Wilkinson, 1995). Lifelong and cumulative exposure to oppression, segregation, racism and socio-economic disadvantage have been identified as significant determinants of poor health and reduced quality of life amongst minority elders; the so-called 'double jeopardy' hypothesis in ageing (Fox et al., 1999). Specifically, evidence suggests that people from black and Asian groups in both the US and UK are more likely to live in poor housing conditions, have lower incomes, live in deprived neighbourhoods and have limited access to healthcare resources (Butt & O'Neil, 2004; Evandrou, 2000; Milne & Williams, 2000; Modood et al., 1997). Black people have also been shown to have a higher incidence of certain chronic physical illnesses including heart disease and diabetes, and both black and Asian populations are at greater risk of experiencing functional mental illness, particularly depression (Balarajan, 1993; Hirst, 2004; Simmons, Williams, & Powell, 1989). It is axiomatic that these inequalities will exert a distinctive influence on dementia care-giving. Although some US research has incorporated this dimension in its lens of analysis, it is entirely absent from UK work (Hinton et al., 1999). Fox et al. (1999) accounts of African-Americans caregiver, for example show how large-scale forces such as racism and economic inequality, come to be 'embodied as individual experience' and become 'translated into personal distress and individual symptomology' (Fox et al., 1999, p. 519). Additionally, it is important to acknowledge the ongoing influence of discrimination and disadvantage (Leavy, Sembhi, & Livingston, 2004). Racism for example continues to be a daily reality for many ethnic minority elders and their carers in both the UK and US and is, at present, regarded as entirely lateral to work on dementia care-giving (Iliffe & Manthorpe, 2004; Leavy et al., 2004; Modood et al., 1997).

Conceptualising and assessing dementia care-giving in Black and Asian communities

As the core of this paper, analysis of the nature and understanding of dementia care-giving warrants detailed critical attention.

Firstly, although the term 'caregiver' has gained widespread currency in the white population, it is not routinely understood by members of the black or Asian communities (Adamson, 1999; Moriarty, Sin, Brockmann, Butt, & Fisher, 2001). Indeed, as noted earlier, Townsend and Godfrey (2001) found that, in addition to problems in translating and describing 'caregiver', South Asians found it hard to relate to the term and struggled to distinguish between care-giving responsibilities and normal kinship relations. Failure to adopt an approach that takes account of the perspective of black and Asian carers contributes to their marginalisation within the research arena (Milne, 2003). It may also lead to under-representation of ethnic minority carers in national and local assessments of the extent of dementia care-giving and mask distinctions between ethnic populations, communities and geographical areas (Patel, et al., 1998; Townsend & Godfrey, 2001). As has been evidenced in a number of studies in the US—and to a lesser extent in the UK—working with the grain of a community to develop a shared conceptual picture offers a foundation for effective research which can then be built upon (Downs, 2000; Hicks & Lam, 1999). Research which incorporates a perspective familiar to the community is, in any event, far more likely to enhance co-operation from carers and increase rates of participation (Seabrooke & Milne, 2004). This is a complex issue and—as is discussed above—cannot be meaningfully achieved without taking account of the multi-faceted influence of ethnicity and culture (Barth, 1994).

A second issue concerns the cultural relevance and sensitivity of conceptual measures (Dilworth-Anderson et al., 2002; Iliffe & Manthorpe, 2004). For instance, the concept of 'caregiver burden' has been drawn primarily from research with white carers (Zarit, Reever, & Bach-Peterson, 1980). Evidence reviewed in this paper suggests that this may be limiting and culturally dissonant for black or Asian carers; conceptualising care-giving as burdensome may be regarded as unacceptable and, for some, represents an abandonment of family duty (Dilworth-Anderson & Gibson, 2002). Similarly, the employment of global constructs such as 'stress' and 'coping' may be ill-applied and have limited ability to take account of cultural variation (Dilworth-Anderson et al., 2002; Janevic & Connell, 2001). Indeed, if some black and/or Asian communities cope more effectively and are more resilient to the demands of care-giving (Roth et al., 2001), understanding the specific factors that mediate its negative aspects would be an invaluable contribution to the literature (Lawton et al., 1992). Additionally, although evidence from the US indicates that black and Asian carers attach positive meaning to their care-giving role current measures pay scant attention to this issue (Farran, Miller, Kaufman, & Davis, 1997; Nolan, Grant, & Keady, 1996; Picot, Debanne, Namazi, & Wykle, 1997).

A related third issue concerns temporal-frameworks for understanding dementia caregiving. As no UK research on black and Asian dementia care-givers has been conducted on a longitudinal basis, it is impossible to say how the trajectory of care is understood or if the staged template commonly applied to dementia care-giving in mainstream work has meaning for minority carers (Nolan et al., 1996). Whether black or Asian carers conceptualise themselves as having a 'care-giving career' is unknown, and the intersection of ethnicity and culture with intensive dementia care-giving over a sustained period remains entirely unexplored (Aneshensel et al., 1995).

A fourth criticism relates to the almost universal adoption of a comparative approach in research contrasting the dominant white experience with that of one or more minority groups. Whilst this has the benefit of allowing researchers to distinguish the universal elements of dementia care-giving from those that are specific to a particular ethnic group, it may also lead to overly simplistic conclusions and to outcomes which are regarded as significant only as they relate to the majority experience (Janevic & Connell, 2001). The development of a coherent body of work with black and Asian dementia carers would address this issue to some degree as would the adoption of approaches which build up a culturally relevant picture of the nature and features of care-giving, particularly in the UK (Katbamna, Ahmad, Bhakta, & Baker, 2004). This is explored further in the following section.

A fifth point relates to who provides care in black and Asian families. Whilst it is clear that daughters and daughters-in-law provide the majority of care, in the African-American community care-giving may be shared between relatives and sometimes, neighbours and friends (Dilworth–Anderson & Burton, 1999). Although patterns of care-giving in the black-British context have yet to be explored, it is reasonable to assume that the primary caregiver—or dyadic—model which dominates the UK research paradigm may not be applicable. It is likely to obscure important information about the role of kinship networks, the management of care-giving and the impact of 'shared care' on the PWD and carer health, particularly levels of burden and stress (Janevic & Connell, 2001). UK research may be able to draw upon recent US work which has successfully accommodated the wider family in its lens of enquiry (Maties-Carrelo et al., 2003).

A sixth issue relates to the changing nature and patterns of care-giving in black and Asian communities and the significance of cohort membership (Ahmad, 1996). Recent

changes to the family and social life of minority communities have undermined traditional support systems. In the UK, for example the extended family is now relatively uncommon among African-Caribbean communities and is diminishing in the South-Asian and Chinese communities (Adamson, 2001; Atkin & Rollings, 1996; Chiu & Yu, 2001). Although statistics continue to show that most South-Asian elders live with, and are being cared for, by close relatives; socio-economic and demographic changes suggest that this pattern is breaking down (Evandrou, 2000). Of particular note is social and occupational mobility, smaller family size and women's increasing participation in the labour market, particularly among Hindus and Sikhs (Daker-White et al., 2002). These factors influence the willingness and ability of families to provide support to relatives with long-term health care needs, including dementia (Nazroo, 1997; Seabrooke & Milne, 2004). Despite evidence that most Chinese families continue to be highly motivated to provide care, a similar pattern is observed in this community. Many families are engaged in the catering industry where working hours are very long and inflexible; this creates particular difficulties for daughters/in law caring for elderly parents (Chiu & Yu, 2001). Overall, these changes suggest that the care-giving capacity of black and Asian families is not as strong as is often assumed and will diminish in the future. Although researchers have started to acknowledge these changes, their specific course and consequence for care-giving patterns, and the experiences and needs of carers from different communities, remains largely unexplored (Chiu & Yu, 2001; Dilworth-Anderson & Anderson, 1994). Within the UK the 'acculturation continuum' may offer a useful framework for recognising the accommodation of individuals to local beliefs and practices, as well as explaining differences in care-giving attitudes and patterns between cohorts and generations (Iliffe & Manthorpe, 2004).

## Methodology and research design

In terms of research design, it is clear from the above review that the evidence base is very limited. Overall there are relatively few studies on dementia care-giving based in the Asian community and none conducted with black carers. The field is characterised by small-scale studies of non-representative samples; they are also very diverse in terms of socio-economic characteristics and geographical areas and tend to focus on a specific community (Patel et al., 1998; Townsend & Godfrey, 2001). These limitations impede comparisons between studies and severely limit the generalisability of findings (Haley et al., 2004). In addition, many studies have adopted a service perspective focusing almost exclusively on problems related to the accessibility and appropriateness of health and social services (e.g. Daker-White et al., 2002; Patel et al., 1998). There is thus a primary requirement to extend research in both communities, particularly the African-Caribbean, and to develop research projects on a larger-scale (Dilworth-Anderson & Anderson, 1994; Shadlen, 2002). National and European funding may offer opportunities to extend the size and remit of work and enrich data sources (Nolan et al., 1996; Patel, 2004; Townsend & Godfrey, 2001); that there is increased incorporation of issues about dementia in wider gerontological and carer-related research is also a positive trend.

Increased funding may also extend the remit and focus of research. At present, projects tend to be conducted at a single point in time or, at best, pre and post a particular intervention. These designs do not have the capacity to accommodate the lifecourse perspective of carers; the dementia care-trajectory; the temporal-order of changes to patterns of

care-giving or provide data on a longitudinal basis which may illuminate associations between caring, health and quality of life (Hirst, 2004). If, for example black care-givers are less burdened as a consequence of sharing the caring-task with a wider network this could be explored, as could the specific role of network members in alleviating stress.

There is a clear need to invest in research, employing qualitative methods if knowledge is to be generated and—as is identified above—theory is to be developed (Sin, 2004). Ethnographic and anthropological approaches, in particular, have the capacity to illuminate the role of family and community processes in under-girding understandings of dementia and experiences of care-giving, and elucidate the influence of cultural identity and ethnicity (Braun & Browne, 1998; Hinton, 2002; Rempusheski, 1999). The developing arena of ethno-gerontology offers opportunities in this regard. Fox et al. (1999) highlight the importance of 'caregiver stories'-narrative analysis-to understand meaningful connections between historical experiences of migration and settlement, racial oppression, cultural representations of the carer role and management of care-giving. For example if black carers do indeed gain more benefits from care-giving, data gathered from in depth case studies may offer opportunities to explore sources of motivation, resilience and satisfaction (Dilworth-Anderson & Burton, 1999; Hinton, 2002). That qualitative approaches are more appropriate at an early stage in the conceptual trajectory of this emerging field is also relevant as is their capacity to engage with the research community's perspective (Blakemore, 1999; Bowes & Wilkinson, 2003).

Operational barriers to implementing effective dementia research in black and Asian communities also need to be addressed. The fact that PWD are stigmatised and hidden from view is an obvious primary challenge. That dementia care-giving is an issue which, by default, tends to be invisible and is regarded by many families as an exclusively private matter is a further complication (Elliott et al., 1996; Kleinman, Eisenberg, & Good, 1987). Whilst the authors have already noted the importance of employing researchers who speak the same language(s) as the research community(ies), the importance of taking account of cultural norms in decisions about methods is equally important. For example, the gendered norms of a particular culture may preclude an 'outsider' interviewing an older woman alone. Further, many Asian women would regard questions of a management nature best answered by their husbands; this may include issues related to caring (Patel et al., 1998). In UK, whilst provisions are usually made to meet the linguistic—and other cultural—requirements of Asian communities, much less consideration is made to accommodate African-Caribbean respondents' language needs despite the fact that there are 'a multiplicity of island dialects and enunciations' in the West Indies (Chessum, 2000). Another important issue relates to engagement with potential research participants; organising health-related workshops about dementia and care-giving can be effective as a means of raising awareness, informing people about research aims and recruiting carers (Seabrooke & Milne, 2004). Other 'tips for success' include building links between communities and specific research units, designing research in partnership with carers and ensuring findings are fed back to participants (Dilworth-Anderson & Anderson, 1994; Sin, 2004).

Establishing coherent baseline evidence about the prevalence of dementia and care-giving in black and Asian populations would make a pivotal contribution to research. Whilst there is some evidence of prevalence in local studies (e.g. Bhatangar & Frank, 1997), PWD tend to remain invisible in national studies, including surveys (Brownlie, 1991; Elim, McMunn, & Nazroo, 2001; Patel et al., 1998). Whilst the Census did collect some data on family caring in minority populations, it did not delineate dementia care-giving

(Office for National Statistics, 2003). Technical problems include the fact that language differences impair detection of dementia symptoms; even those black or Asian elders who speak English tend to revert to using their language of origin when they become demented (Manthorpe, 1994; Sin, 2004). Further, screening instruments have been criticised as insufficiently sensitive to cultural differences and as unreliable measures of cognitive function or change (Lindesay et al., 1997; Rait et al., 2000; Stephenson, 2001). The development and validation of culturally appropriate measures for dementia and care-giving—a previously noted deficit—remains one of the major methodological challenges facing researchers in this field (Maties-Carrelo et al., 2003). US evidence suggests that the ideal is to achieve a approach that incorporates cultural flexibility alongside linguistic, semantic and technical equivalence whilst retaining cross-cultural generalisability and psychometric validity (Matias-Carrelo et al., 2003; Nazroo, 1997; Opaku, 1998). Very little attention is being paid to this complex methodological issue in the UK.

#### CONCLUSION

Care-giving for PWD in black and Asian population is of growing significance in the UK and constitutes a considerable research issue for the 21st Century. As it is clear from this paper, UK research community is under-prepared to meet this challenge. The evidence base is small, piecemeal and localised; the complete absence of work conducted within the African-Caribbean community is a primary deficit. Further, the research lacks theoretical location; it is neither informed by, nor informs the development of socio-cultural or conceptual frameworks, and its capacity to take account of ethnicity is constrained by superficial recognition of its meaning and relevance. Whilst more has been done in the US—in particular the development of more sophisticated understandings of care-giving in minority contexts and acknowledgement of the multi-dimensional impact of ethnicity, culture and life course experiences—no efforts have been made to replicate this approach in UK. The service oriented methods employed in most projects reflects this limited commitment to exploring dementia care-giving through the 'lens of culture' and from the perspective of the black or Asian community, family or individual care-giver. The resultant narrow understanding of the nature of dementia care-giving undermines the generation of coherent and ethnically relevant knowledge and marginalises the significance and impact of context, culture, history, and current and past inequalities in shaping caring experiences, patterns and profiles.

The overarching research task is three fold: extending the breadth and depth of research enquiry; developing a theoretical framework to underpin and inform research activity and addressing structural and methodological limitations. Shifting the focus of research activity away from service development and into the arena of knowledge and theory generation would be a positive step forward as would funding of larger-scale projects which engage with a wider range of—particularly black—communities. Employing qualitative methods which have the capacity to elucidate the 'mosaic of meaning' surrounding dementia care-giving in black and Asian communities would be of particular benefit. Collecting accurate epidemiological data would also be helpful. That a number of studies have recently been conducted in the UK implies some commitment to work in this field; that dementia related issues, including care-giving, are on the international research agenda is also important. What this paper makes clear is that UK research community has much to

do to advance the development of a robust and culturally coherent evidence base. The fact that the number of PWD in minority populations is increasing and that changes to traditional family structures threaten future commitment to family care-giving suggests that the time is ripe to explore the nature and needs of dementia care-givers from black and Asian populations and invest in research which extends understanding and knowledge and is meaningful and relevant to carers, those they support and the communities in which they live.

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# Carers of Older Relatives in Long Term Care: Support Needs and Services

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## **Abstract**

Carers of relatives in long-term care are beginning to be recognised as a distinct group facing specific challenges and having particular needs. Despite the fact that many struggle to adjust to the admission of their relative to a home and experience high levels of emotional stress, former carers receive mixed levels of support from care homes and carers organisations. Evidence suggests that they need support in the following key areas: learning to live again. health and finances, care home issues, caring role and relationship, and information. Whilst examples of good practice exist these are not shared and there is limited policy focus on former carers either nationally or locally. Current emphasis on care home standards and caring in later life may offer an opportunity to develop a service strategy to address the needs of this under-researched and 'invisible' group of carers.

## Introduction

Recent years have seen a growing recognition of the important role that older carers play in maintaining vulnerable adults in the community (Milne et al, 2001). Current estimates suggest that approximately a quarter of the 7 million carers in the UK are aged 60 years and over; half of all care to older people is provided by older people (Arber & Ginn, 1990). A growing sub-group of older carers are those who support a relative in a long-term care setting 1(Royal Commission on Long Term Care, 1999). Of the half million care home residents in the UK at least two thirds received care from a relative prior to admission and contrary to popular perception, most wish to have continued involvement (Relatives Association, 1997; Grant & Nolan, 1993). Work on the nature of caring in later life alongside enhanced policy emphasis on the provision of high quality residential care has highlighted the needs of this underresearched group (www.csci.org.uk).

This paper aims to offer an overview of the roles and support needs of former carers. It draws on evidence from a pilot study conducted in 2002/03 in one area of South East England, and a supplemental literature review. It is presented in three sections: the needs and roles of former carers; service provision and support related needs of former carers; and service development.

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## The Needs and Roles of Former Carers: Evidence from Literature

Although there is some evidence of a shift from institutional to community based care over the last twenty years, the changing profile of caring suggests that those people who are admitted tend to be extremely frail, most have dementia and many have been cared for intensively for a sustained period prior to admission (Milne & Hatzidimitriadou, 2002). Most former carers are older and the majority are spouses although some are filial carers, mainly daughters (Milne & Hatzidimitriadou, 2003). At least one in 10 care home residents are married at the time of admission (Relatives Association, 1997).

Impact of Admission on Carers

Although limited, some work has explored the effects of care home admission on carers. Evidence suggests that most struggle to come to terms with their changed situation and status and report feelings of loss, grief, guilt, anger, sadness and loneliness (Lewis, 1998; Almberg et al, 2000; Seddon et al, 2002). Despite the fact that institutionalisation brings relief from the physical demands of care-giving, psychological stress may remain; many continue to 'be a carer' in an emotional and psychological sense and are particularly vulnerable to developing depression (Moriarty & Webb, 2000)

## Post Admission Roles of Former Carers

For carers the most challenging aspect of care home placement concerns changes to their caring role (Seddon et al, 2002). No longer responsible for the day-to-day care of their relative, they are required to renegotiate their involvement in caregiving; they also have to redefine their relationships with family and friends, and revisit their identity as 'carer' (Aneshensel et al, 1995).

A number of studies have reviewed the post admission roles of carers (Wright, 1998). These suggest that they adopt a number of new roles: safeguarding the individuality of the cared for person, creating a personalised and homely environment within the care home, communicating their expertise to the care home staff, monitoring the quality of care provided, and helping to maintain family and community contacts (Seddon et al, 2003). Spouses visit frequently, some as many as five times per week reflecting the strong attachment and interdependency that underpins long term marriage (McKenzie & McLean, 1992). Additionally, carers maintain some of the roles they had prior to admission: protecting the dignity and self esteem of the care-recipient, advocating on their behalf, managing their financial affairs, offering companionship, and contributing to care planning (Seddon et al, 2002). Some carers, especially spouses,

continue to provide personal care, albeit in a reduced form (Wright, 2000).

Being able to 'continue to care' depends in good part on the carer adjusting to the regime of the care home and establishing good relationships with staff (Dellasega & Nolan, 1997). This does not always happen. Trusting others to provide care to their relative and taking on a reduced caring role can be difficult for some carers especially spouses, especially when they feel they are excluded from care decisions (Duncan & Morgan, 1994). Certainly there is evidence that where carers are treated as 'expert partners' in planning and implementing care both the carer and the cared for person adjust better to the placement (Woods & Matthison, 1996).

## Support for Former Carers

As is clear from existing evidence former carers face a number of challenges when their relative enters long term care. They have often spent many years caring for a close relative and their life has, up until admission, been defined by caring and organised around care related demands (Nolan et al, 2001). Despite the likely impact of such a significant decision on carer well being little is known about their need for support; even less on the extent of support provided by services or professionals (Burton-Jones, 2001; Seddon et al, 2002). It was this knowledge deficit that underpinned the pilot study conducted by the authors; it is to this that we now turn.

## The Pilot Study

The study aimed to explore the support needs of carers whose relative is placed in long-term care; identify the range of types of services available; and explore ways to support former carers more effectively. It was conducted in one area of Southeast England over a 10-month period in 2002/03 and had three linked stages. The first stage constituted a literature review, key themes from which have already been presented; the second stage involved mapping services accessed by former carers; and the third stage gathered evidence from a sample of former carers and local and national service providers (see Table 1). Qualitative

Table 1

STUDY SAMPLE	
National Organisations	Help the Aged Age Concern Carers UK Residents and Relatives Association Alzheimer's Society Admiral Nursing Service
Regional/Local Organisations	Alzheimer's Society – South East Region Alzheimer's and Dementias Support Service - Dartford Carers First - Tonbridge Carers' Voice – Herne Bay Age Concern – Canterbury Carers Support Scheme - Medway and Swale NW Kent Carers Support Service—Dartford
Individuals/ Groups	2 Professionals; 3 Former Carers 2 Support groups for former carers – 1 in a care home; 1 in the community

approaches were employed, primarily semi-structured interviews and focus groups (Bowling, 2002). Participants were identified via existing links the lead researcher had with carers' organisations, carers and care homes in the study area. Interview notes and transcribed data from the focus groups were analysed using a content analysis technique (Patton, 1990). Confidentiality was assured at all times.

## **Findings**

Findings will be presented under two heads: services for former carers and support needs.

## Services for Former Carers

Statutory Services

Former carers receive very mixed levels and types of support from services. In terms of statutory support, only Admiral Nurses<sup>2</sup> - who exclusively work with carers of people with dementia - and psychologists - where there must be evidence of 'clinical need' - provide support to former carers. Both professionals regard their role as helping the carer to re-integrate and re-engage with family and community and deal with their feelings of guilt and loss. Admiral Nurses also see themselves acting as 'a bridge' between the carer and the care home. Other health and social care workers withdraw once the dependent person has been admitted into a care home. As one respondent observed: 'Once my wife went into a home. I was lost to the services that used to come and visit 100 times a day... I simply dropped out of sight as far as they were concerned'.

## Local Carers Agencies

Local carers agencies tend to either include former carers in their existing support group or run groups specifically for them (See Box 1). Whilst continuing to

## BOX 1: Example of a Local Former Carers Service

## Carers Support Scheme for Medway and Swale

This small voluntary organisation offers a number of services for former carers. Over half the carers 'on their books' are former carers; the majority are carers of people with dementia and are spouses. The services they offer include: groups for former carers; 1:1 support; advice and information on care home choices, dealing with the challenges of becoming a 'former carer, quality of care issues and financial problems and also have a programme of external speakers addressing topics such as 'understanding dementia' and 'educational opportunities in Medway'. In addition to meeting practical and emotional needs related to caring, the organisation aims to help former carers 'move on', make new friends and develop a social life. For example, one of the support groups regularly goes on outings and for weekly pub lunches. Carers Support Scheme staff have links with statutory agencies and care homes and will refer carers for professional help if they think s/he is in need and is eligible. The organisation employs two staff and uses a number of volunteers.

belong to the original group can work well in the period following admission, it often fails in the medium term as the needs of former carers are very different from those with community based responsibilities. Former carers groups can be very effective and have a number of features. They focus on the challenges of providing care in partnership with a care home, offer an opportunity for carers to share experiences and discuss problems, provide an arena to disseminate information and advice, and provide a 'safe place' to develop a social life. For some carers seeking support post admission is the first time they have come to the attention of a carers' service (Nolan et al, 2001).

#### National Agencies

National carers agencies do not have policies specifically addressing the needs of former carers although they are aware of their needs. They offer advice about choosing and paying for a care home, and advocating on behalf of the carer and cared for person around quality of care. The Alzheimer's Society is far more aware of the needs of former carers of people with dementia and has funded a number of projects specifically for this group (See Box 2). National older people's charities have barely engaged with the issue.

# BOX 2: Example of a National Former Carers Project

#### After Dementia Millenium Awards

The Alzheimer's Society is managing a UK wide programme of awards in partnership with Carers UK and Alzheimer Scotland. It is funded by the Millenium Award Scheme. Awards are given to carers and former carers of a person with dementia with the aim of helping them to rebuild their lives and make links with their community. Over the last two years 131 projects have been funded at a total cost of £820,000. Although it is not a criterion that the project must be linked to caring, many are. Projects for former carers include: an arts and crafts club, educational outings to historical sites, a 'community quilt', setting up a telephone support service, a mobile information unit in a rural area, and a video about managing the care of a relative with dementia. The programme is due to report on its role June2004.http:// and successes in www.alzheimers.org.uk/About\_our\_work/ About the Society/ADMA.htm

The Relatives and Residents Association aims to meet the needs of care home residents and their relatives (www.relres.org.uk). The agency offers training to care home staff and runs a Helpline; this is often manned by former carers and provides emotional and practical support. It also deals with enquiries about choosing a care home and standards of care and runs support groups in partnership with carer's agencies and care homes. At present it is conducting a piece of research on developing good practice in working with spouses of care home residents building on earlier work (Burton-Jones, 2001).

#### Care homes

Support from care homes varies; some actively engage with carers and offer a range of support, whilst others fail to even recognise the contribution the carer could make to the ongoing care of their relative (Woods & Matthison, 1996). For those homes that do offer support, this can range from quite informal overtures of inclusion such as taking meals alongside their partner, to facilitating a support group (See Box 3). Sometimes carers become involved in the whole life of the care home. This can include activities such as running fundraising raffles, doing the gardening and

# BOX 3: Example of a Carers Support Group in a Nursing Home

#### Darland House Former Carers Group

Darland House is an NHS funded specialist nursing home for people with dementia in Medway. It hosts a former carers support group, which meets bi-weekly or monthly. The group offers a mixture of emotional support, advice and information and a social venue. Carers report that they feel able to 'share their story' of caring and admission, gain support from other carers and learn to cope more effectively with their feelings of guilt and upset. Dealing with their relative persistently asking to 'come home' and criticism from sons/daughters about admission are two specific issues that the groups have been able to help with. Sharing knowledge about the rules and regime of the home, advising about how to work with the care home staff to ensure ongoing involvement in their relative's care, dealing with welfare benefits issues, and advocating on behalf of a carer are also important roles of the group.

organising outings (Nolan & Dellasega, 2000). As might be expected, those homes that recognise the needs of carers also tend to treat them as a partner in the process of care. Carers groups based in care homes tend to offer similar types of support as those in the community although the primary focus is care of their relative rather than activities unrelated to caring (Seddon et al, 2001).

## Former Carers' Support Needs

#### Statutory Services

Findings indicate significant levels of physical, psychological and practical need amongst former carers. These can be located in a number of linked, but separate, spheres.

#### Learning to live again

Former carers report that as a consequence of intensive long term caring, they have become isolated from family, friends and interests and often need support to pick up the threads of life again (Milne, 2004). Building up social links and developing new interests are key aspects of a carer's re-engagement. Whilst some carers adopt quasi-formal roles in the 'caring system'; others wish to separate from caring completely and go on a course or take up a hobby (Pearlin, 1992). As one carer in Medway observed: '... joining the group gave me a chance to do things I had forgotten how to do like going to the pub and having a laugh and not worrying constantly about Masie (his wife). I have also taken up painting, which is something I used to do as a young man.... I feel I've had a new lease of life.'

#### Health and Finances

Data gathered in this study confirm existing evidence that carers have often damaged their own health as a result of providing long-term care. They are often physically and mentally exhausted and suffering from sleep deprivation (Moriarty & Webb, 2000; Lewis, 1998). They also worry about their own mortality and who will look after them when they become frail. For example, a carer whose husband is in a care home said: 'Nobody supports me, that worries me to death. I have a lot of acquaintances but there is nobody that could actually look after me ..... I got no children so there is no younger generation. I sometimes wake up in the middle of the night and think what on earth is going to happen to me?'

A key concern of many carers relates to money; older carers are known to be one of the poorest groups in UK society (Carers National Association, 2000). Primary issues are paying for care home fees, transport and managing money in the longer term. Clear advice about money matters including welfare benefits and contributions to care home fees is identified as very helpful.

#### Care Home Issues

As noted above, most carers feel very quilty about placing their relative in a home and need reassurance that 'they have done the right thing'. They are often also dealing with pressure from their families to continue to provide care at home. Having an opportunity to talk about the admission decision, associated feelings of guilt and sadness and being helped to re-frame the placement as having 'positives' as well as 'negatives', are all identified as facilitative of carers' adjustment to the changed situation (Seddon et al, 2002, 2003). A carer in one of the focus groups supports this contention: 'I felt so guilty when B (the husband) first went into the home and I got a lot of grief from my sons who kept telling me how I was abandoning their dad. But honestly I have had so much help... the care home staff, the group we have here and S (the Admiral Nurse) have all supported me and although I still feel bad leaving him when I go home of an evening I can see that he is happy here, he is well cared for and I can come whenever I like..'.

In terms of adjusting to the care home placement findings of this study suggest that help is needed in the following areas: communicating with care home staff; understanding the rules and regime of the home; and taking forward complaints about the quality of care. One carer got advice from a local carers organisation about how to complain about her relative's care: 'I used to go and see her everyday in the nursing home... the place there was absolutely appalling, they wouldn't do what the specialist said, they wouldn't serve herfood, she nearly died. Through H (manager of a carer's organisation) I got the inspectors in'.

#### Caring Role & Relationship

Whilst we know that most carers wish to continue to provide care for their relative post admission, findings highlight two issues. Carers often need encouragement to be clear about their new caring roles and responsibilities; care homes must avoid making assumptions about these. It is important for the agreed roles to be recorded in case files and for regular reviews to be conducted to ensure the level of carer involvement remains appropriate. Readiness amongst care home staff to utilise carer's knowledge of their relative's needs and preferences is very important in care planning, particularly when the resident has dementia (Seddon et al, 2002).

Ongoing recognition that they are 'still a carer' is also an important issue (Zarit & Whitlach, 1993). One respondent spoke for several when she complained that: 'you feel invisible to professionals and not a proper carer as far as other carers are concerned'.

The importance of maintaining family relationships has been demonstrated by research and is echoed in this study (Nolan et al, 2001). The role of 'private space', sharing meals alone, and being able to spend time together were identified by respondents as important facets of companionship (Wright, 1998). This is illustrated by a husband from a focus group: 'I can spend time with my wife whenever I want, we can go to her room and watch TV, no one bothers you. I also eat at the home with her three times a week.... this way I can keep the feeling that we are man and wife, that we still have a relationship....'

#### Information

Carers report needing advice and information about care home fees and regulations, how to make a complaint about care standards and services including support groups. This is particularly useful if given at an early stage (H.M Government, 1999).

# Addressing the Support Needs of Former Carers

There are a number of ways in which support for former carers can be developed and delivered. Care homes play a key role in enabling the involvement of the carer in the care of their relative as well as facilitating the continuation of their relationship. The following appear to be particularly important:

- Linking with the carer at an early stage to ensure they are involved in the admission process
- Creating a welcoming environment, which encourages and supports visiting, and working with carers to accommodate their involvement in the care of their relative. It is important to recognise the different roles that carers may wish to adopt
- Recognising and clarifying roles and responsibilities for both parties
- Valuing and accessing the carer's knowledge and expertise and utilising this as an important component of care planning
- Helping carers to create a positive perception of the admission, acknowledging their need to both receive and provide help, and dealing with emotional reactions
- Providing private space for couples to use; this is particularly important if the resident does not have a single room (Nolan and Dellasega, 2000)

In addition, it is clear that former carers can benefit from support in their own right. Although this can be delivered by community-based carers' organisations or by care homes, it is important that it specifically addresses their needs. A support strategy needs to engage with the following issues: helping carers to deal with guilt and loss, consider their approaches to coping, recognise their care giving achievements, dealing with concerns about the quality of care and planning for the future (Nolan et al, 2001; Burton-Jones, 2001). Access to information and advice is also important and is a key plank of the National Strategy for Carers (HM Government, 1999). Support should be tailored to the needs of individual carers and delivered in accordance with their personal preferences. Some carers prefer to talk on a one-to-one basis, some in a group, whilst others feel more comfortable contacting a telephone helpline (Seddon et al, 2002).

In order to develop effective support on a more coherent and universal basis a number of issues need to be tackled. There is clearly evidence of good practice in care homes and in carers' organisations; this needs to be documented and disseminated within the care home and carers sectors (Burton-Jones, 2001). The Commission for Social Care Inspection has provided some impetus for the recognition of the needs of carers by care homes but more needs to be done (www.csci.org.uk). Specific standards are required relating to: linking with and working alongside carers; incorporating carers in care decisions and plans; offering

direct support to carers; and ensuring that they can gain access to advice and information. As noted by existing research supporting carers takes time and training; both tend to be in short supply in care homes and will not be prioritised unless funded appropriately and accorded sufficient status by inspection bodies, training agencies and the care home sector. Similarly, former carers need to be prioritised by national carer's agencies. The present uneven approach by local carers' organisations underpins the need for a national focus on this group.

Few statutory services recognise former carers as legitimate recipients of welfare support. In part this is a consequence of resource constraints in health and social services but is also a reflection of limited national and local policy attention (Department of Health, 1996; HM Government, 1999). Evidence reviewed here would suggest that much could be done for carers by those agencies and workers that have been visiting the household prior to admission. Not only is the care manager or community nurse familiar with the carer but also is usually aware of the caring challenges they faced, the nature of the care relationship, the context of the admission, and the likely needs of the carer for support, guidance and information. This role is very

effectively performed by Admiral Nurses; the essence of this model needs to be replicated for former carers more widely.

#### Conclusion

This paper has reviewed the evidence base relating to former carers and extended understanding of their support needs and the role of services in meeting these. Overall, it is clear that they receive mixed levels of support from care homes and/or carers agencies and have need for support in the following areas: learning to live again, health and finances, care home issues, caring role and relationship, and information. Whilst examples of good practice exist these are not widely developed or shared and there is little evidence of a coherent policy or 'service strategy' for former carers at either a national or local level. The enhanced focus on the needs of caring in later life, quality of life in care homes and care home standards may offer an opportunity for such an approach to be developed bringing former carers out of the shadows and into the service arena (Nolan et al, 1996; Department of Health, 2001).

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#### **Footnotes**

- ¹ Carers in this situation will be referred to as former carers. Long-term care includes nursing and residential care but excludes hospital care.
- <sup>2</sup> Admiral nurses are specially trained nurses who support carers of people with dementia. The service was developed by the charity 'For Dementia' <a href="http://www.fordementia.org.uk/">http://www.fordementia.org.uk/</a> admiral.htm

# Planning ahead

Meeting the needs of older people with intellectual disabilities in the United Kingdom

dementia
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VOL 4(3) 341-359

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Abstract Despite the acknowledged increase in the number of older people with intellectual disabilities (ID) in the UK, the age-related health and social care needs of this population have yet to be fully understood and addressed. Although there is some evidence of positive development, the current picture of service provision is characterized by fragmentation and limited choice of resources and specialist care. Policy aims are variably met and inconsistently applied. Research suggests that service planning is often incoherent, that many older people with ID and their carers receive poor quality non-specialist care and that staff are inadequately trained to manage the often multiple and complex needs of this user group. There is a considerable co-joined service development and research challenge in this emerging field. If older people with ID and their carers are to receive quality provision, a coherent and well-funded service planning system is required which is underpinned by articulated agency partnerships, informed by good practice developments in the fields of ID, gerontology and dementia care, and linked to evidence about effective models of care and services. The incorporation of the perspectives of users and carers in the planning process is an essential pre-requisite as is a commitment to the development of effective support across the life course of all individuals with ID.

**Keywords** ageing; intellectual disability; policy; service provision

#### Introduction

Despite the noted phenomenon of the ageing population in western societies, old age has only recently been conceptualized as a separate and distinctive life stage for people with an intellectual disability (ID) (Erikson, 1998; Hughes, 1995). This emerging population presents new and particular challenges for policymakers and services and the evidence base is

limited in extent and quality; the majority focus of research to date has been childhood and early adulthood (Hogg & Lambe, 1998; Robertson, Moss, & Turner, 1996). This article aims to review existing evidence regarding the older<sup>1</sup> population with ID and their family carers, with a view to highlighting their health and social care needs and exploring the policy and service context of their care. A particular focus will be upon identifying the core elements of effective service planning and development. Although the focus of the article is the UK, the issues explored have wider relevance particularly in western societies. We begin by offering an overview of the epidemiology of the population under review.

# The older population with ID

Improvements in standard of living and access to medical treatments have resulted in better health and enhanced longevity for the population with ID, particularly amongst those with lower levels of disability (Haveman, 2004; Herr & Weber, 1999; Tinker, 1997; Victor, 1997). According to a 2002 British report, life expectancy has increased dramatically from 20 years in 1930 to 70–74 years in 1990 (Foundation for People with Learning Disabilities, 2002). Approximately 12 percent of the 210,000 people with severe and profound disabilities and 28 percent of the 1.2 million people with mild/moderate disabilities are aged 50 and over (Department of Health, 2001c). The greatest increase has been among ambulatory women with mild disabilities (McDonald, 2002; Moss, Lambe, & Hogg, 1998).

In addition to higher incidence, older people with ID are becoming more visible; this is as a consequence of community care policies, particularly the substitution of institutional care with community-based services. In the past, those who did reach old age tended to be hidden in long-stay hospitals or kept at home with their families 'out of sight' (Holland, 2000; A. Walker & C. Walker, 1998).

# Health and ageing with an ID

Whilst there is no definitive agreement about when 'old age' begins in the population of people with ID, the consensus is that 50 years marks the threshold (Grant, 2001). There is, however, widespread acceptance that age-related problems impact on populations with ID at an earlier chronological age than the general population (Jenkins, Brooksbank, & Miller, 1994; McDonald, 2002). Differential morbidity is a notable trend; people with more severe disabilities or complex needs tend to experience age-related ill health from the age of 30, whereas people with higher levels of

functional abilities are likely to remain fit until at least the age of 50 (Foundation for People with Learning Disabilities, 2002). This tendency results in a particular demographic pattern: the population of older people with ID is relatively able with good health and functional skills (Cooper, 1997a; Hogg & Lambe, 1998; Moss et al., 1998; C. Walker & A. Walker, 1998). People with profound and multiple disabilities and people with Down's syndrome are particularly at risk of premature death; this is often associated with the presence of serious medical conditions, as well as low levels of functioning and limited mobility (Haveman, 2004; Holland, 2001).

# **Physical health**

Although studies differ in their outcomes, there is broad consensus that older people with ID are at greater risk of experiencing a range of physical health problems; specifically, arthritis and rheumatic illnesses, cardiac and pulmonary conditions. These are the main causes of loss of mobility. Sight and hearing also decline (Janicki & Dalton, 1998; McDonald, 2002). That the impact of symptoms tends to be greater for older people with ID as a consequence of limited opportunities to maintain fitness and prevent deterioration, is a secondary but significant issue (Bland, Hutchinson, Oakes, & Yates, 2003).

Despite these findings, general practitioners do not routinely monitor the age-related health status of people with ID; it is unclear whether this is due to a lack of interest or knowledge (Grant, 2001). What evidence there is suggests health checks are useful in detecting a number of manageable or treatable medical conditions such as sight or hearing loss (Duff, Hoghton, & Scheepers, 2000; Evenhuis, Henderson, Beange, Lennox, & Chicoine, 2000). Evenhuis and colleagues (2000) summarize the barriers that may prevent older people with ID from accessing health care. Although some factors derive from the nature of the person's intellectual - and physical - disabilities, others relate to the structure and culture of services. Environment-related barriers include: minimal training of staff in assessment, diagnosis and treatment; lack of consent procedures; limited time for informant-based medical history taking or capacity for accommodating behavioural challenges (Grant, 2001; Jenkins et al., 1994). Grant concludes (2001) that urgent attention needs to be focused on addressing these structural barriers if older people with ID are to receive health care for treatable age-related medical conditions and to ensure the prevention of deterioration.

## Mental health

Overall, there is evidence that, at all ages, people with ID – including people with Down's syndrome – are at enhanced risk of developing psychiatric disorders, particularly psychosis (Cooper, 1999; Driessen, DuMoulin,

Haveman, & van Os, 1997; Gustafsson, 1997; Moss et al., 1998). For the ID population aged 65 years and over, there is a prevalence rate of 20 percent for major psychiatric disorders; the majority are depression and/or anxiety (Bland et al., 2003; Cooper, 1999; Day & Jancar, 1994). A significant proportion may be experiencing reactive depression to age-related physical illness, or bereavement associated with loss of a carer. Behaviour disorders are also identified in a third to a half of cases of psychiatric illness (Davidson et al., 1999; Day & Jancar, 1994). Many behavioural problems develop – or are observed for the first time – in old age. Minor psychiatric symptoms have also been reported in an additional 25 percent of cases.

Despite the relatively high occurrence of psychiatric conditions amongst the population under review, few people are referred to mental health services for help (Cooper, 1999; Day & Jancar, 1994; Moss et al., 1998; Moss & Patel, 1995). A British survey of moderately and profoundly disabled people aged 50+, found that although two thirds of participants were experiencing mental health difficulties, only a quarter had been referred for psychiatric assessment (Moss et al., 1998). A major barrier relates to the challenge of identifying a mental health problem: lack of cooperation and communication problems make assessment and diagnosis difficult and co-morbidity issues further complicate the picture (Bouras, 1999; Deb, Thomas, & Bright, 2001; Holland, 2000; Janicki & Dalton, 1999a). As a result, high levels of unmet psychiatric need exist and the challenge of ensuring access to, and support from, mental health services for this population remains a significant challenge for service development.

# Ageing and dementia

Dementia is predominantly a disease linked with longevity and tends to be manifested in those areas of function that may already be impaired in people with an ID. Although it is difficult to determine the prevalence of dementia in older people with ID, existing epidemiological studies suggest that it is comparable to (Janicki & Dalton, 2000), or higher (Cooper, 1999), than the age-matched general population. Occurrence increases with age; whilst only 6 percent of people aged 40–64 years have case level dementia, there is a 70 percent prevalence rate amongst those aged 85–94 years. As with the general population, Alzheimer's disease is the most prevalent type of dementia (Cooper, 1997c, 1999; Dalton & Janicki, 1999).

People with Down's syndrome have been identified as particularly vulnerable to developing Alzheimer's disease; at least 9 percent of people with Down's syndrome aged 40–49 years, 36 percent aged 50–59 years and 54 percent aged 60–69 years are affected (Holland, 2001; Hutchinson, 1999; Turk, Dodd, & Christmas, 2001). The precise link is yet to be fully understood, although it is known that the chromosomal anomaly present in

people with Down's syndrome plays a significant role (Holland, 2000, 2001). Dementia-related symptoms tend to be equally severe in people with Down's syndrome as in the general population. These may include impairment of activities of daily living, abnormal emotional and social behaviours, wandering or pacing, aggressive behaviour, apathy or loss of drive, and eating and sleep disturbances. People with ID who develop dementia may also be prone to developing depression; this is often overlooked or not sufficiently distinguished from dementia-related symptoms (Cooper, 1997b; Evenhuis, 1997; Janicki & Dalton, 1999a; Moss & Patel, 1995, 1997).

Early assessment and appropriate interventions are of paramount importance in developing effective support for people with ID who develop dementia; evidence suggests that much can be done to modify dementiarelated symptoms or behaviours and alleviate stress amongst carers (Janicki & Dalton, 1999a; Janicki, Heller, Seltzer, & Hogg, 1995). Models of best practice indicate a need for: regular assessments of an individual's functioning beginning in early adult life to monitor cognitive, behavioural and social change; accurate and careful diagnosis where dementia is suspected; access to medical treatment and support services titrated according to the level and nature of need – this is particularly important in the later stage of the illness when physical and mental health needs are likely to be multiple and complex and care packages may require considerable coordination (Holland, 2000; Turk et al., 2001). Materials to aid professionals and care workers supporting older people with ID and dementia have recently been developed in the UK, drawing, in part, on work from the USA (Dodd, Turk, & Christmas, 2002; Janicki & Dalton, 1999b; Janicki et al., 1995; Kerr, 1997; Kerr & Wilson, 2001). These initiatives are underpinned by a wider emphasis on 'good practice'. Drawing together experts from the UK and USA, a set of guidelines for working with this population was devised in 2001. They are underpinned by a number of principles<sup>2</sup> relating to the rights and needs of people with an ID and dementia, and are structured around four key dimensions: adopting a workable philosophy of care; adapting practices at service delivery point; coordinating diverse systems; and promoting relevant research (Janicki et al., 1995; Wilkinson & Janicki, 2002). We return to this issue later in the article.

# **Family carers**

Half of all adults with ID are cared for by relatives in the family home. Also, it is estimated that one third of them live with a family carer aged 70 or over (Foundation for People with Learning Disabilities, 2003; Hogg & Lambe, 1998; McGrother, Hauck, Bhaumik, Thorp, & Taub, 1996). A

quarter of people with ID become known to statutory agencies only in later life when there is a crisis and their older family carer is no longer able to continue to care (Foundation for People with Learning Disabilities, 2003). Most carers are parents, although a few are grandparents or siblings (Department of Health, 2001c; Ward, 1998). For parents in particular, caring is often the main focus of their lives and they are more likely to be sole carers (Haley & Perkins, 2004; C. Walker & A. Walker, 1998).

As a consequence of intensively caring for many years, older carers are at enhanced risk of becoming physically ill; familiar aspects of caring can become difficult and mobility problems may undermine the carer's capacity to offer personal care (Milne, Hatzidimitriadou, Chryssanthopoulou, & Owen, 2001; C. Walker & A. Walker, 1998). Social networks tend to diminish with age as relatives and friends die or move away; a particular loss may be that of other carers with whom a long history of mutual support often exists (Bigby, 1997). There is some evidence to suggest that as carers age, the caring relationship is partially reversed with the cared-for person taking on domestic tasks such as cleaning or cooking (Magrill, Dagnan, & Fitzgerald, 1997). Carers of older people with ID face exceptional challenges such as extended duration of caring, additional health issues of aging for carer and person cared for, and psychological stress that can be precipitated by anxiety over future arrangements of care after carer's death.

Having presented an overview of the profile and needs of the UK population of older people with ID and their carers, we now explore issues arising from the policy and service framework.

# **Policy context**

There are a number of UK policy developments of primary relevance to the population under review.

The White Paper Valuing People constitutes a major strategy document, which reviews existing services for people with ID in England and Wales and provides a 'new vision' for service development (Department of Health, 2001c).<sup>3</sup> It is based on the principles of rights, independence, choice and inclusion, and emphasizes the importance of effective partnership between people with ID, their families, statutory agencies and the independent sector. The strategy specifically recognizes the needs of older people with ID. It identifies person-centred planning as a key mechanism for ensuring age-related changes in physical and mental health are monitored and addressed:

... there are some people with learning disabilities over the age of 75, who have shown significant physical and mental deterioration with age, who have

high dependency needs and who make considerable demands on health and social services . . . Person-centred plans for these individuals should be developed in the context of services for elderly people. (2001c, Section 8.45, p. 104)

It also highlights local agency responsibilities to ensure 'appropriate residential care' is in place for those who require it and that the needs of family carers are met. Further, it acknowledges that people with ID are not a homogeneous population and that fitter, more able users need packages of care which incorporate occupational and recreational activities as well as care services. Mental health services are tasked with ensuring they meet the needs of people with ID who develop dementia or a functional mental illness and the strategy is underpinned by a planning framework which views partnership between services for older people, mental health services and services for those with ID as being at the heart of service development.

In parallel, developments in generic policy for older people and policies for carers highlight the needs of older people with ID and their families. The National Service Framework for Older People (Department of Health, 2001b) echoes Valuing People's emphasis on person-centred care and sets standards around a number of core themes, including tackling age discrimination, promoting older people's health and independence, and tailoring local services to meet age-related changes in user and carer need. The Carers and Disabled Children Act 2000 extends existing support to carers; it empowers local Councils to provide 'any services which, in their view, will support the carer in their caring role and help them to maintain their health and wellbeing' (Department of Health, 2001a, p.1). A number of recent 'Carers Grant' initiatives have been directed specifically at providing respite and other 'relief' services for carers of people with ID (H.M. Government, 1999).

Learning Disability Partnership Boards (LDPBs), <sup>4</sup> established in 2001, are tasked with implementing policy aims and represent the strategic vehicle for inter-agency service planning and commissioning for people with ID living in the locality (Department of Health, 2001c). The Boards bring together public, private, community and voluntary sector organizations as well as user representatives and family carers. A specific responsibility in relationship to older people with ID is ensuring coordination between ID and older people's services. Whilst recognizing the inter-agency complexities inherent in planning for a population with multiple needs, a UK survey in 2003 concluded that this mechanism was unsuccessful to a great extent in addressing the needs of older people with ID and their aging family carers and, although there is strong evidence that collaborative working is extending the support available to these groups, there are serious concerns over lack of resources and capacity (Foundation for People with

Learning Disabilities, 2003). Failing to meet the needs of, or even identify, older family carers is noted as a particular deficit (Towell, 2002). Additional evidence that few local authorities have fully developed plans for meeting the needs of older users with ID, suggests that this group is at risk of becoming marginalized from the benefits of strategic service planning, and dislocated from policy intent (Department of Health, 2004b; Learning Disability Task Force, 2004). The impact of this on the nature and pattern of provision is significant as is discussed in the following section.

# Service provision for users and carers

As might be expected, there is a mixed picture of the range, quality and effectiveness of services for older people with ID across the UK. A key challenge of reviewing the evidence base relates to the fact that the majority of UK studies are descriptive rather than systematic (Grant, 2001). One common theme, however, is the expectation that once they reach 'old age' most users are expected to 'leave' ID services and make use of services for older people. These are often less specialized, of lower quality and are imbued with a restrictive dependency culture which is at odds with the ideology of independence and normalization which underpins services for people with an ID (McDonald, 2002). As A. Walker and C. Walker (1998) note 'as soon as a person is transferred from one service provider category to another, merely as a result of chronological ageing, the orientation of services shifts from supporting independence to reproducing dependence' (p. 127).

In her study on service provision for older people with ID, Fitzgerald (1998b) found considerable variation in the provision of services and widespread confusion about which agencies - and professionals - are responsible for providing services for older people with ID. Noted problems included: lack of investment in specialist services for older people; low expectations of users by staff; limited commitment to maintaining user independence; low levels of stimulation or rehabilitation; and few opportunities for users to develop networks with others of similar age or who share similar interests (Aspray, Francis, Tyrer, & Quilliam, 1999; Dagnan & Ruddick, 1997; Duff et al., 2000; Hassiotis, Barron, & O'Hara, 2000). Specific concerns of professionals working with this user group are: limited access to psychiatric and general health care services; lack of access to recreational or leisure activities; limited awareness amongst care staff of agerelated health difficulties; and practically no opportunities for user consultation (Bailey & Cooper, 1997; Stalker, Duckett, & Downs, 1999). There is also evidence that older people with ID receive lower levels of day and respite care and are less likely to have an allocated social worker or receive structured activities outside the home compared with their younger counterparts (Cooper, 1997a). In a study of staff views, two thirds of those working with ID people over 50 thought that the general level of service available to this user group was 'poor' or 'very poor' (A. Walker & C. Walker, 1998). A specific deficit relates to care for older people with ID who develop dementia. Evidence suggests services vary considerably with many providers having no guidance for managing dementia-related needs or accessing dementia expertise (Wilkinson & Janicki, 2002).

Although there are no UK-wide statistics relating to the living situations of older people with ID, a growing number are being placed in care homes for older people. A survey conducted by the Foundation for People with Learning Disabilities in 2000 revealed that they are often admitted for reasons unrelated to their ageing and earlier than the specified age of admission, usually set at 65 years (Thompson & Wright, 2001). Further, many homes are ill prepared to meet the specific needs of people with ID, staff receive limited training and have infrequent contact with professionals from ID services. The survey also identified that, before being admitted, half of the individuals were living in non-residential settings, either with their families (39%) or on their own (11%), while the remaining resided in residential settings. Surprisingly, the impact of living situation on quality of life amongst this population has received little research attention in the UK, although there is evidence that effective person-centred care can ameliorate some of the negative consequences of ageing (Grant, 2001; Jones, Dagnan, Trower, & Ruddick, 1996). US research clearly demonstrates that 'type of residence' can have a major impact on important quality of life domains for older people with ID. Anderson (1989) concludes that:

the smaller community-based residential option such as foster care and small group homes offer considerable advantages, including greater potential integration with the community and more normal living conditions, than other settings, together with moderate costs and value orientations that emphasise habilitative rather than medical definition and solutions. (p. 240)

As already noted above, UK policy emphasis on community-based responses reinforces this view.

Research exploring the everyday life experiences of older people with ID suggests that they often perceive themselves to be living on the margins of society (Grant, McGrath, & Ramcharan, 1995). Many users are wholly dependent on welfare benefits, report difficulties in forming and maintaining personal and social relationships, have limited opportunities for taking part in ordinary activities, and have very limited influence on lifealtering decisions such as where they live, when to retire or which services to use. This status can be compounded by services whose key concern may

be to minimize risk for those older users with the most severe levels of need. Due to a narrow 'one size fits all' conception of need, services tend to constrain the activities of all users limiting the occupational, social and educational opportunities for those with lower levels of disability. There is a related tendency to minimize the significance of health-related losses such as reduced mobility, and the impact of needing help with activities of daily living, particularly personal and intimate care. Despite the present and likely future extent of provision of personal care services to this population, the issue is almost entirely unexplored in either research or practice literature (Hatzidimitriadou & Milne, in press).

The nature of support for older carers is also inadequate. Although limited, the evidence that does exist suggests that older carers struggle to gain access to appropriate and flexible services for themselves and the person they support. Of particular importance to elderly parents are concerns about what will happen to their son or daughter when they die or become too ill to provide care (Grant, 1990, 2001; Hatzidimitriadou & Forrester-Jones, 2002). Few carers actually make concrete arrangements; in one study only a third of parents had made plans for long-term care, although these were regularly altered due to changes in the family or financial circumstances, illness of carer, and availability and quality of substitute services (Foundation for People with Learning Disabilities, 2003). What is clear from research is the very limited nature of information available to carers at an earlier stage in the caring trajectory, particularly about residential care options (Grant, 2001). As the death of their relative results not only in the profound loss of their primary source of support and care but also a familiar lifestyle and home, it is crucial that more is done to engage carers and users at a stage when future plans can be thoroughly considered (Foundation for People with Learning Disabilities, 2002). It is to directions for service development that we now turn.

# **Directions for service development**

As the number of older people with ID increases in western societies, the case for developing coherent, planned, effective services for this population grows (Davidson, Heller, Janicki, & Hyer, 2004; Janicki, 2001; Thompson, 2002).

The above review highlights a number of issues that, although mostly relevant in the UK context, are equally pertinent in other developed and developing regions. At present the majority of agencies in the UK respond reactively to the emerging needs of older people with ID, rather than putting in place a proactive cooperative needs-led service system that has the capacity to take account of current and future age-related needs.

Evidence identifies the following as essential pre-requisites for effective service development: an established strategic framework for planning (such as LDPBs) to which all key relevant stakeholders are committed and contribute; a partnership between ID agencies and older people's services with support from mental health trusts and housing agencies; a service plan for older people with ID and their carers underpinned by dedicated funds; evidence of the extent and nature of existing service provision; flexibility of commissioning; and recognition of workforce and training issues. Challenges have been identified as: coordinating diverse care systems; and developing partnerships between a variety of providers and agencies (Janicki, 2001; Wilkinson & Janicki, 2002).

An effective service development strategy needs to be underpinned by national and international epidemiological data on the older population with ID; their living situations including family carers; past, current and likely future demands for support from services; and individualized needsbased data from recent person-centred planning reviews. The Valuing People guidance produced by the UK Department of Health (Department of Health, 2001c) recognizes the importance of proactive individualized planning which incorporates an assessment of both physical and mental health needs. It suggests that a detailed person-centred plan should be put in place when a person with ID reaches the age of 50, or earlier if agerelated health-care needs develop. This process should begin at age 40 for people with Down's syndrome. For providers to respond effectively to agerelated issues they need clear information about health, the user's situation. care needs, family situation and management of changes related to ageing. This will be particularly important if the person has dementia or another chronic health condition (Stalker et al., 1999).

The inclusion of family carers in the planning process is also essential and, as noted above, needs to take place well before the curtailment of care due to death or illness. A number of the Growing Older with Learning Disabilities (GOLD) projects, conducted by the UK Foundation for People with Learning Disabilities, identified positive ways to help family carers plan for the future care of their relative (Foundation for People with Learning Disabilities, 2002). Of particular note is recognizing that most older carers want to continue caring for as long as possible and need support from services to do so; the importance of planning ahead with a 'trusted worker' who has in-depth knowledge of carer and cared-for is also key.

In order to be comprehensive, the person-centred planning process needs to be supported and complemented by input from agencies other than those providing services for ID and older people. Hogg (2000) suggests that general practitioners have a pivotal role in assessing and monitoring changes in the general health status of older people with ID while Jenkins and

colleagues (1994) note that psychiatric services should assess mental health need (Hogg, 2000; Jenkins et al., 1994). Early detection of dementia is particularly important in people with Down's syndrome. Whilst the development of reliable and robust assessment tools and practice guidance has received some attention in the US, evidence suggests there is still some way to go in the UK (Wilkinson, Kerr, Cunningham, & Rae, 2004).

Although unhelpful to be prescriptive about the range and types of services needed to support the older ID population, evidence reviewed in this article suggests that both residential and community-based services are required. The provision of appropriate day and respite care have been identified as particular deficits and the development of supported housing that can accommodate the needs of people with ID and dementia is an emerging challenge (Department of Health, 2004a). As the quality of 'hands on' day-to-day care primarily defines the effectiveness of that service for users and carers, the twin issues of staff training and adequate remuneration need to be addressed (Dening & Milne, 2005). Generic care staff require training about the needs of people with ID and staff working in services for people with ID need training about the ageing process and agerelated ill health. Particular issues include communication, personal and intimate care, managing loss and bereavement, and supporting users with complex and challenging needs (Cambridge & Carnaby, 2000; Carnaby & Cambridge, 2002). Recognition of the age- and disability-related disadvantages accruing to older people with ID and the role of 'double jeopardy' in oppressing and marginalizing this population is also a component of good practice (Bland et al., 2003).

Underpinning ideology and the role of models of care is also significant, as it is these which provide a framework within which service development occurs. A. Walker and C. Walker (1998) question whether normalization - which is the key principle underpinning the development of services for younger adults with ID – continues to be as relevant, or appropriate, for services for older people. They propose that a model of 'social integration' may be more meaningful; specifically, adoption of the 'supportive environment model' as outlined by Zarb and Oliver (Zarb & Oliver, 1993). This provides a basis for extending the principles of social integration whilst accommodating the need for support arising from age-related ill health. As Wilkinson & Janicki (2002) state, older people with ID 'should be treated with respect and given the opportunity to remain in their community with sufficient and appropriate support and services to compensate for personal losses in function and decline' (p. 280). Current developments in the field of dementia care are also worth highlighting. These suggest that a shift away from a biomedical model towards a social and interpersonal model incorporating person-centred care not only enhances quality of life for users but reduces challenging behaviours and contributes to greater involvement of users in care and treatment decisions (Cheston & Bender, 1999; Kitwood & Bredin, 1992).

The contribution of older people with ID themselves to the developing discourse on service development is noteworthy (Grant, 2001). Although some work has been done in this field in the USA (Ansello & Coogle, 2000), little research attention has been focused on this in the UK (Fitzgerald, 1998a, 1998b; Grant, 1997). Studies have shown that older people with ID who have verbal skills do display insights into age-related changes in their personal and social lives. Much like the general population, they have varied perceptions of growing older; some wish to disassociate themselves from the process whilst others have more concrete concerns about occupation, health problems and loss of mobility (Erickson, Krauss, & Seltzer, 1989; Felce, Grant, & Todd, 1998). Other key research deficits include robust evaluations of: different models of care, particularly long-term care; effective care packages; innovative services, especially those which work across 'traditional' agency boundaries; and services which meet the needs of users with multiple or complex needs, such as those with dementia. Dissemination of such evidence would also help inform the development of services and 'good practice'.

## Conclusions

In both the UK and the wider western world, growing numbers of people with ID survive into later life and develop a range of age-related needs. Those charged with designing policy, and developing, funding and providing services are increasingly obliged to acknowledge, and meet, the specific and multiple needs of the older population with ID and their carers, and recognize their right to quality care. Despite some evidence of positive development in this field, much work remains to be done to ensure continuity of care across the life course, particularly in the later stages; consistency of provision within and across areas and agencies; a coherent, effective and well-funded service planning system; access to flexible care for users and carers when it is needed; and, where required, the development of dedicated provision. The current picture is one of inconsistency and fragmentation characterized by limited choice, access, resources and specialist care; this is particularly acute in long-term settings. A lack of underpinning principles and frameworks and a mixed evidence base articulating 'what works' hampers development and undermines commitment; this is made worse by the marginal status of older people with ID and the invisibility of many family carers. There is a considerable co-joined service development and research challenge in this emerging field. Much can be

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learnt from services for younger adults with ID, the extensive sphere of gerontology and from developments in dementia care; drawing on good practice in the USA also offers considerable opportunity. Understanding the experience of ageing with an ID and evaluating the effectiveness of services are two of the main research deficits. By drawing together evidence about the nature, extent and quality of policy and services and exploring future directions, this article offers a contribution to the developing discourse of how best to meet the current and upcoming needs of the older people with ID and their ageing family carers.

#### **Notes**

- 1. One of the challenges of reviewing literature in this field is that researchers do not employ a consistent definition of 'old' nor is evidence gathered around the same age cohorts or in the same way by different groups or agencies. The authors have been obliged to accept those definitions employed by researchers and have summarized evidence taking account of definitional and geographical variation.
- 2. These are known as the 'Edinburgh Principles' (Wilkinson & Janicki, 2002)
- 3. A major service and policy review was also conducted in Scotland in 2000, acknowledging the needs of older people with ID and highlighting similar issues to be addressed 'The Same as You? Scottish Executive, 2000'; cited in Foundation for People with Learning Disabilities, 2002.
- 4. Learning Disability Partnership Boards operate within the Local Strategic Partnership Framework.
- 5. See Hatzidimitriadou & Milne (in press) for a discussion of the implications of meeting the intimate and personal care needs of older people with ID.

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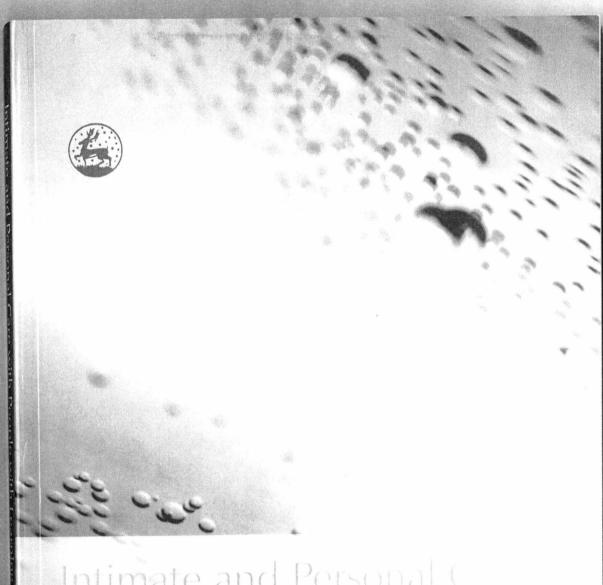
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Intimate and Personal (
with People
with Learning Disability

Edited by Steven Carnaby and Paul C

# Providing Care for Older People with Learning Disabilities

# Eleni Hatzidimitriadou and Alisoun Milne

#### **OVERVIEW**

Changes in lifestyle, improvements in care and better access to medical treatment have resulted in increased longevity among people with learning disabilities. Despite wider recognition of this 'new' older population by policy-makers and service providers, the needs arising from the cumulative challenges of ageing with a learning disability have yet to be fully understood and addressed. In this chapter, the authors explore the care implications of growing older with a learning disability, offer an overview of the main age-related needs and discuss the service context of their care. They also highlight the needs of family carers. The key challenges facing service provision are also explored and a number of recommendations made, focusing particularly on the development of effective and safe intimate and personal care.

#### INTRODUCTION

Old age has only recently been conceptualised as a distinctive life stage for people with learning disabilities. Enhanced longevity is a consequence of changes in lifestyle, improvements in care and better access to medical treatment (Herr and Weber 1999; Tinker 1997; Victor 1997). For the learning disabled population as a whole, life expectancy has increased from 20 years in 1930 to 70–74 years in 1990 (Foundation for People with Learning Disabilities 2002). The greatest increase has been among people with mild learning and physical disabilities – mainly women (McDonald 2002). Life expectancy of people with Down's Syndrome has increased spectacularly with over 40 per cent now

surviving to the age of 60 years (Holland 2000). In addition to higher numbers, older people with learning disabilities are also more visible as they live in community settings instead of being 'hidden' in institutions or within family homes (Walker and Walker 1998).

Despite this emerging 'new' population, limited attention has been paid to reviewing or meeting their needs; the majority focus of work in the learning disability field has been on childhood and early adulthood (Hatzidimitriadou and Milne 2005; Hogg and Lambe 1998; Robertson, Moss and Turner 1996). In this chapter, we present an overview of existing evidence about the needs of older people with learning disabilities and their family carers, and discuss the service context of their care. We also highlight key issues for addressing the intimate and personal care needs of this group and make a number of recommendations for future service developments.

#### HEALTH, AGEING AND LEARNING DISABILITY

Although there is no definitive age at which 'later life' begins in learning disabled populations, 50 years is generally accepted as the threshold. That age-related problems impact at an earlier age than for the general population is more widely recognised (Jenkins, Brooksbank and Miller 1994; McDonald 2002). Differential morbidity – the tendency for people with more severe levels of disability to experience age-related ill health at an earlier age than their more able counterparts – produces a particular demographic pattern (Foundation for People with Learning Disabilities 2002). The population of older people with learning disabilities tends to be relatively able with good health and functional skills (Cooper 1997a; Hogg et al. 2001; Moss, Lambe and Hogg 1998).

The most common physical health problems are arthritis, rheumatic illnesses, cardiac and pulmonary conditions. These difficulties usually lead to loss of mobility and sight and hearing may also decline (McDonald 2002). The impact of such age-related health symptoms tends to be greater for this group as there are limited opportunities to maintain fitness and prevent deterioration (Bland et al. 2003). Yet general practitioners do not routinely monitor the age-related health status of people with learning disabilities; it is unclear whether this is due to a lack of interest or knowledge (Grant 2001). Evenhuis et al. (2000) suggest a number of service-related barriers to accessing health care; these include minimal training of staff in assessment, diagnosis and treatment; lack of consent procedures; and limited time for informant-based medical history-taking or capacity for accommodating behavioural challenges. Mental health issues have particularly attracted the attention of researchers. Evidence can be located around two areas: functional mental illness and dementia.

#### Functional mental illness

Similar to the general older population, there is a prevalence rate of 20 per cent for major psychiatric disorders in learning-disabled people aged 65 years and over (Day and Jancar 1994). The majority of reported cases are diagnosed with depression or anxiety; in particular, people experience reactive depression due to age-related physical illness, or bereavement related to loss of their carer (Cooper 1999). Behavioural problems also account for a third to a half of cases with psychiatric disorders (Davidson *et al.* 1999). At all ages, people with learning disabilities are at enhanced risk of developing psychosis and autism (Cooper 1999; Driessen *et al.* 1997; Gustafsson 1997; Moss *et al.* 1998).

Despite the relatively high prevalence of mental ill health in this population, few people are referred to psychiatric services for help (Cooper, 1999; Moss et al. 1998). Identification of mental health problems in people with learning disabilities can be complex: lack of cooperation and communication problems make assessment and diagnosis difficult, while co-morbidity issues further complicate the picture (Bouras 1999; Holland 2000; Janicki and Dalton 1999). As a result, high levels of unmet psychiatric needs exist and ensuring access to, and support from, mental health services remains an ongoing challenge.

#### Dementia

Dementia is the global impairment of higher mental functioning including the loss of memory, problem-solving ability, the use of learned skills, social skills and emotional control (Alzheimer's Society 2003). It is progressive and usually irreversible. Longevity is the key risk factor for Alzheimer's disease, the most common form of dementia in the general as well as learning disabled populations (Dalton and Janicki 1999). Prevalence is the same as (Janicki and Dalton 2000), or higher than (Cooper 1999) that of the general population; it increases with age from 6 per cent in the 40–64 years cohort to 70 per cent in the 85–94 years age group (Holland 2001). People with Down's Syndrome are evidenced as particularly at risk of developing dementia: of those aged 50–59 over a quarter is affected whilst for those aged 60–69 over a half have dementia (Hutchinson 1999; Turk, Dodd and Christmas 2001).

Dementia-related symptoms such as impairment of daily activities, abnormal emotional and social behaviours, aggressive behaviour, eating and sleep disturbances, are likely to be similarly severe in people with learning disabilities as in the age-matched general population. Symptoms tend to manifest themselves in those areas of function that are already impaired. Depression is also common, a co-morbidity often overlooked (Cooper 1997b; Janicki and Dalton 1999). US work suggests that early assessment and appropriate interventions can alleviate symptoms and help with care planning (Janicki *et al.* 1995; Wilkinson and Janicki 2002).

## Profile and needs of older people with learning disabilities

- Improvements in care and treatment have resulted in many more people with learning disabilities reaching old age.
- The greatest increase has been amongst people with mild learning and physical disabilities mainly women.
- Older people with learning disabilities tend to be relatively able with good health and functional skills.
- Common age-related physical illnesses for this population are arthritis and rheumatic illnesses, cardiac and pulmonary conditions.
- Key age-related mental health problems are depression, anxiety and dementia.
- Dementia is at least as prevalent amongst older people with learning disabilities as the general age-matched population; it is more prevalent in people with Down's Syndrome. Prevalence increases with age.
- There are a number of disability and service-related barriers to accessing health care; primary care does not routinely monitor the health status of people with learning disabilities as they age.
- Few older people with learning disabilities are referred to psychiatric services for help; however, evidence indicates that early assessment and support from professionals can alleviate symptoms.

#### **FAMILY CARERS**

It is estimated that a third of adults with learning disabilities live with a family carer aged 70 or over; the vast majority of them are parents, while the remainder are grandparents or siblings (Department of Health 2001a; Foundation for People with Learning Disabilities 2003; Magrill 2005; Ward 1998). These carers tend to have limited social networks as a consequence of relatives and friends dying or moving away to 'retire'; many are also widowed (Bigby 1997). Due to providing intensive care over many years they are at significant risk of becoming physically and/or mentally ill; familiar aspects of caring can become difficult (Foundation for People with Learning Disabilities 2002; Milne *et al.* 2001). For some older carers the caring relationship may be partially 'reversed', with the cared for person taking on domestic tasks such as cleaning or cooking that used to be done by the carer (Hatzidimitriadou and Forrester-Jones 2002; Magrill *et al.* 1997).

The ageing profile of the learning disabled population often results in the loss of their primary carer during their middle or later years. As many will not have spouses or children, they are not only bereft of a familiar lifestyle and,

often their lifelong home, but also their primary source of emotional support and care (Foundation for People with Learning Disabilities 2002; Magrill 2005). The consequences are immense. It is often at this 'crisis point' that formal services become involved, with residential care often being the only option for people with complex or challenging needs (Herr and Weber 1999; Robertson *et al.* 1996). It is to service provision that we now turn.

# CARE PROVISION FOR OLDER PEOPLE WITH LEARNING DISABILITIES AND THEIR CARERS

#### Policy context

Over the last few years there have been major learning disability policy reviews by governments in England, Wales and Scotland (Foundation for People with Learning Disabilities 2002). The white paper *Valuing People* (Department of Health 2001b) is a key strategy document, which provides a new vision for learning disability services based on the principles of rights, independence, choice and inclusion. The importance of person centred planning for older people with learning disabilities is specifically highlighted; learning disability partnership boards (LDPBs) are tasked with planning and commissioning services for this population, including long-term care (Foundation for People with Learning Disabilities 2003; Towell 2002).

Valuing People also draws attention to the need to support older family carers (Department of Health 1999, 2001b). The Older Family Carers Initiative (OFCI) – launched by the Foundation for People with Learning Disabilities in 2002 – aimed to support LDPBs identify and meet the needs of older family carers (Magrill 2005). It offers a number of examples of good practice.

#### Summary of policy context

- The white paper Valuing People highlights a need for agencies to develop services for older people with learning disabilities and their carers.
- The importance of person centred planning is specifically highlighted.
- Learning disability partnership boards are tasked with planning and commissioning services for users and carers.
- The 'new vision' for learning disability services extends across the life span incorporating the principles of rights, independence, choice and inclusion.
- The Foundation for People with Learning Disabilities, Older Family Carers Initiative offers a number of examples of good practice with carers.

#### THE IDEOLOGICAL CONTEXT OF SERVICE PROVISION

In addition to the role played by policy, a number of ideological influences are also significant in underpinning service development for the population under review. Space only permits a brief review of two key issues: social construction of ageing and social integration.

## The social construction of ageing

The 'social construction of ageing' refers to the relationship between attitudes to old age, our conceptualisation of ageing and the care and treatment of older people. Ageism is a particularly powerful influence on attitudes, treatment and services for older people. It is defined by Hughes (1995, pp.42–43) as:

a matrix of beliefs and attitudes which legitimises the use of age as a means of identifying a particular social group which portrays the members of that group in negative, stereotypical terms and which consequently generates and reinforces a fear of the ageing process and a denigration of older people.

The consequences of ageism are observable everywhere – in the social and economic policies that discriminate against older people, in the attitudes and values of people generally and the ways these shape the treatment and behaviour towards older people in both personal and professional encounters. The ways in which old age, and attitudes to it, interact with other aspects of social identity such as race, gender, sexuality and disability has also been noted. It has been suggested that older people with learning disabilities are doubly disadvantaged by the combined effects of ageism and discrimination related to learning disability (Walker and Walker 1996, 1998). This 'double jeopardy' has the affect of lowering expectations and legitimising the provision of inadequate services.

There is evidence that ageism and the social construction of ageing underpin both the development of services for older people and the delivery of care (Hughes 1995). Many services are imbued with a dependency culture, which characterises old age as associated with inevitable decline in functioning, passivity and withdrawal from 'life' (Biggs 1993). This limited perspective is echoed in work with older people, which is routinely regarded as requiring lower levels of skill, knowledge and qualification than work with other user groups. For example, the needs of older people, as constructed by social services, emphasise the 'routine' nature of the work, and the delivery of short-term instrumental, standardised packages of care. This practice is then perpetuated by the habitual allocation of older service users to unqualified or assistant staff. These trends combine to form a reinforcing cycle of disadvantage; the low status attached to older users reinforcing the low status attached to unqualified staff. This issue

is linked to the devalued status of intimate and personal care, an issue that is explored later in this chapter.

#### Social integration

Walker and Walker (1998) extend this argument into the service delivery arena, critiquing the ideological shift experienced by people with learning disabilities once they become 'older' service users. They note that: 'as soon as a person is transferred from one service provider category to another, merely as a result of chronological ageing, the orientation of services shifts from supporting independence to reproducing dependence' (p.127). The ageist assumptions and dependency culture that underpin services for older people results in older people with learning disabilities facing more restrictive and segregated lives than was the case when they were in receipt of services for younger adults (McDonald 2002; Thompson 2002).

Whether normalisation – the key principle underpinning the majority of services for people with learning disabilities – continues to be as relevant, or appropriate, for services for older people is, however, debatable (Walker and Walker 1996). Walker and Walker (1998) propose a model of 'social integration', an adaptation of the 'supportive environment model' outlined by Zarb and Oliver (1993). This provides a basis for extending the principles of integration whilst accommodating the need for support arising from age-related ill health. The key components of this model – proactivity; creative provision; services that anticipate crises and reflect user need; user-led services; and an emphasis on user rights and entitlements – would ensure improved service quality, the maintenance of independence and the provision of support in a community-based setting.

Space does not permit discussion of the relevance of recent developments in dementia care but evidence suggests that a shift away from a biomedical model towards a social and interpersonal model enhances quality of life and reduces challenging behaviours amongst people with dementia (Kitwood and Bredin 1992). There may be lessons to be learned from innovative services in this field particularly, long-term care (Wilkinson *et al.* 2004).

# Summary of the ideological context of service provision

- Ageism is a powerful influence on our attitudes towards, and treatment of, older people.
- Older people with learning disabilities are disadvantaged by the combined effects of ageism and discrimination related to disability.
- Work with older people is regarded as requiring lower levels of skill and interventions tend to be 'standardised'.

- The ageist assumptions and dependency culture that underpin services for older people results in older people with learning disabilities facing restrictive and segregated lives.
- Whilst normalisation continues to be relevant a model of 'social integration' may be more appropriate; this provides a basis for extending the principles of integration while accommodating the need for support arising from age-related ill health.
- Recent developments in dementia care may also be relevant, particularly innovations in long-term care.

# SERVICES FOR OLDER PEOPLE WITH LEARNING DISABILITIES

As might be expected, there is limited consensus about whether services for older people with learning disabilities should be integrated with generic older people's services or whether specialist services need to be developed. What is clear, however, is that at present, when people with learning disabilities reach 'old age' they are expected to 'leave' specialist learning disability services and make use of services for older people. As noted above, these tend to be of lower quality and are often imbued with a dependency culture; few have specialist expertise in learning disability (McDonald 2002; Thompson and Wright 2001)

The present picture of service provision for this population is mixed. In her study of service provision for this user group, Fitzgerald (1998b) found considerable geographical variation and widespread confusion about which agencies are responsible for providing services. Common problems include lack of investment in services; low expectations of users; limited commitment to maintaining user independence; very low levels of consultation with users; and few opportunities for users to develop social networks (Fitzgerald 1998a, 1998b; Learning Disability Task Force 2004). A 2004 report by the Learning Disability Task Force confirms that these shortcomings of service provision are still evident despite the significant changes in policy-making (2004).

Severe criticisms about the lack of, and low quality of, services for older people with learning disabilities have also been made by professionals working in the learning disability sector (Aspray *et al.* 1999; Duff, Hoghton and Scheepers 2000; Hassiotis, Barron and O'Hara 2000). Specific concerns focus on limited access to psychiatric and general health care services, lack of access to recreational or leisure activities, and staff's limited awareness of age-related physical and mental health difficulties (Bailey and Cooper 1997). In a study that examined disparities in service provision between different groups of people with learning disabilities living in the community, two-thirds of those working with people over 50 thought that the general level of service for this user

group was 'poor' or 'very poor' and included the almost 'routine' practice of placing people with learning disabilities aged 50 and over in residential care (Walker and Walker 1998). A specific deficit relates to care for older people with learning disabilities who develop dementia. Evidence suggests many providers have no guidance for managing dementia-related needs or accessing dementia expertise (Wilkinson and Janicki 2002).

#### Choice and control by service users

Of core relevance to any discussion about service development are issues of choice and control. Despite the priority accorded the enablement of younger people with learning disabilities to exercise control over their lives, this emphasis is largely absent in work with older people (Fitzgerald 1998a; Grant 1997).

A study by Stalker and colleagues found wide variations in the opportunities available for older users to express their views and be involved in care or treatment decisions (Stalker, Duckett and Downs 1999). While a limited degree of choice over everyday matters is common, for example, what to eat at meal times, involvement in more significant choices is often restricted, partial or contested. Specifically, there is limited or no choice about accommodation, day activities or types of support. The study concludes that there are a number of barriers and facilitators to user involvement in decision-making. Barriers include negative staff attitudes; carers' views being regarded as more important than those of the service user; and lack of time. The factors that facilitate choice are knowledge of the service users' tastes and needs; time to explore ways of communicating; accessible information; and acknowledgement that the vast majority of people - however old or frail - can express their preferences given appropriate support and encouragement. Evidence from the US reveals that older people with learning disabilities who have verbal skills do display insights into age-related changes in their personal and social lives and can be engaged in discussions about the nature of services they want to meet their needs (Ansello and Coogle 2000). As noted above, lessons about effective engagement can also be learned from the field of dementia care. For example, the development of person-centred care has led to a much greater level of involvement of people with dementia in care and treatment decisions (Cheston and Bender 1999; Marshall 1996).

Failure to recognise the heterogeneity of the learning disabled population is a central barrier to creative service development. This tendency results in the whole user group receiving an unnecessarily restrictive level of care and standard packages of support – the 'one size fits all' philosophy. There is also an accompanying tendency to minimise the significance of losses such as mobility or incontinence, and to underestimate the impact of 'needing help' with

activities of daily living (Wilkinson et al. 2004). As noted earlier, packages for older people tend to be routine and practical in nature; whilst many contain elements of personal and intimate care this issue is rarely addressed, or even acknowledged, in any meaningful way. The older person with a learning disability is more likely to need help with activities of daily living and personal care as a consequence of suffering from a range of age-related illnesses. S/he is also more likely to be admitted to a care home. Issues relating to personal and intimate care are thus of core relevance to service provision for this group and are the focus of the next section.

## Summary of services for older people with learning disabilities

- There is limited consensus about whether services for older people with learning disabilities should be integrated with older people's services or whether specialist services are needed.
- When people with learning disabilities reach 'old age' they are expected to access older people's services, which tend to be of lower quality and are often imbued with a dependency culture; few have expertise in learning disability.
- Service provision is fragmented and piecemeal and it is not clear which agencies are responsible for service development.
- Professionals working in the learning disability sector have been very critical of the low quality of services for older people with learning disabilities.
- There is very limited opportunity for older users to express their views and be involved in care and treatment decisions.
- Barriers to user involvement include negative staff attitude, the dominance of carers' views, lack of time and the 'one size fits all' approach.
- Factors that facilitate choice are knowledge of the service users'
  wishes, time to explore ways of communicating and full assessment of
  changing needs.
- Person-centred care has improved the engagement of people with dementia care and may be applicable to older people with learning disabilities.
- As this group is more likely to need help with activities of daily living and personal care as a consequence of suffering from a range of age-related illnesses, personal and intimate care is of core relevance to service provision.

#### INTIMATE AND PERSONAL CARE

A key component of high quality care for the group under review is the provision of effective and appropriate intimate and personal care. Personal care is a contentious and contested arena; it lies on the fault line between the medical and social care spheres and is delivered by a range of workers with widely differing status, roles, pay and employers (Twigg 2000). It is also the focus of much debate concerning the long-term care of older people – including those with learning disabilities – as it constitutes a significant and costly proportion of the overall cost of care.

Despite its centrality to the care of adults with dependency needs, good practice in intimate and personal care has received little attention by service planners or care providers. Twigg (2002) offers two reasons for this negligence: the non-bodily nature of social work, which traditionally focuses on psychosocial aspects of care, and societal taboos concerning the body and its management. Body care is widely regarded as a 'private matter' that should be dealt with alone or in the company of intimates. Furthermore, as noted earlier, personal care tasks are devalued by health and social care agencies and are delivered by low status frontline staff whose needs for support and training go largely unrecognised (Twigg 2000, 2002). In part, this is explained by the gendered nature of informal care. There is a widespread belief that as women ordinarily provide unpaid care to their children and dependent relatives it is not only unproblematic as a task but also unworthy of financial recompense when delivered in the formal sector.

However, there is significant evidence that failing to address this issue increases the risk of staff engaging in inconsistent and institutionalised practices and exposes people with learning disabilities – especially those with complex age-related needs – to potential abuse (Cambridge and Carnaby 2000b; Garner and Evans 2000). This risk is magnified by the 'private' and 'closed' nature of the majority of long-term care settings (Garner and Evans 2000) and is compounded by the multiple vulnerabilities experienced by older people with learning disabilities. These include: high levels of dependency; the likely prevalence of dementia; severely impaired communication; the fact that most older users have few relatives; and very limited service options. Reliance on care staff for survival is a particularly notable dimension of risk. The double jeopardy status discussed earlier may also increase vulnerability to abuse or neglect.

# Summary of intimate and personal care

 A key component of high quality care for older people with learning disabilities is the provision of effective and appropriate intimate and personal care.

- Personal care is a contentious and contested arena and is the focus of much debate concerning long-term care.
- Despite its centrality to the care process, good practice in intimate and personal care has received little attention by service planners or providers.
- However, failure to address the issue increases the risk of staff engaging in inconsistent and institutionalised practices and may expose older people with learning disabilities to potential abuse.
- This risk is magnified by the 'private' and 'closed' nature of long-term care settings.
- It is also compounded by the multiple vulnerabilities experienced by older people with learning disabilities. These include significant dependency, dementia and impaired communication, physical frailty, few relatives, limited care options, and reliance on service providers.

#### RECOMMENDATIONS

Recommendations are located around the following themes: planning and service development; assessment of need; family carers; and intimate and personal care.

#### Planning and service development

Strategic service planning lies at the heart of high quality service development (Hogg 2000). Guidance accompanying *Valuing People* suggests that the most effective model for developing services for older people with a learning disability is for strategic planning on a local or regional basis to ensure partnership between learning disability trusts, older people's services and social services (Department of Health 2004a). Housing departments also have a role in providing housing with care for people who are relatively able bodied. Barriers between agencies and a weak culture of collaboration undermine joint working in many areas (Department of Health 2004b).

Learning disability partnership boards need to take account of the growing number of older people in the learning disabled population in their area. This requires acknowledgement of the fact that 'old age' begins earlier and that ageing is associated with a number of physical and mental health risks. Taking account of those users who are upcoming elderly is also important, particularly when they are living with an older family carer. A particular group that requires attention is people with Down's Syndrome; many will need services that can accommodate the challenges arising from Alzheimer's disease. Recent evidence identifies relatively few local authorities as having fully developed plans for

meeting the needs of the population under review: this suggests that the *Valuing People* guidance is timely and urgently needed (Towell 2002).

Whilst it is difficult to stipulate the range and types of services needed, it is clear that *both* residential and community-based services are required. The local service context will be important in influencing decisions about where to develop new services or adapt existing ones. Whilst there is mixed evidence about whether services for this user group are best located within older people's services or learning disability services, some needs can only be met in specialist care settings, for example, older people with complex needs and challenging behaviour. The development of appropriate psychiatric services, including early detection of, and appropriate care for, dementia, for older people with learning disabilities is a particular requirement, especially in people with Down's Syndrome.

#### Assessment of need

The Valuing People guidance proposes that a specific person-centred plan should be in place for every service user with a learning disability when they reach 50. This may need to be done earlier if the user already has a number of age-related needs or has Down's Syndrome (Department of Health 2004a). There is an accompanying need for primary care to assess proactively the health care needs of the population under review. Improved monitoring has the potential to identify health problems at an early stage and offer preventive treatment and advice (Hogg 2000). The advantage of general practitioners conducting the assessment is that they are very likely to be familiar with the service user and their carer, have knowledge of their health history, and awareness of their care needs These assessments should dovetail with the person centred planning process as well as with any specialist assessments.

Assessment of mental health needs is a specialist priority. Jenkins *et al.* (1994) suggest that all people with a learning disability aged 50 and over receive a regular psychiatric assessment to prevent the onset of functional mental problems; ensure early treatment for depression and anxiety; and minimise the effects of long-standing psychiatric disorders. Early detection of dementia is also important (Janicki and Dalton 1999). Whilst there is some way to go in terms of developing appropriate assessment tools, Janicki and Dalton propose that initial evaluations are done for all people with Down's Syndrome from the age of 40 years and for all other people with learning disabilities from the age of 50 years. These need to be done by psychiatric services as they are often complex and require specialist-skill.

## Family carers

There is a pressing need to plan care and support systems with both carers and cared for well before the curtailment of care, or death of the primary carer. A number of the 'Growing Older with Learning Disabilities' (GOLD) projects and the 'Older Family Carers Initiative' (OFCI) identified positive ways to help family carers plan for the future care of their relative (Foundation for People with Learning Disabilities 2002, 2003; Magrill 2005). Of particular note is recognising that what many older carers want is to continue caring for as long as possible; and the services that most help carers are respite care, support in an emergency, support groups and access to information. Further, the majority of older carers are prepared to engage in future planning for their relative, if the issue is dealt with sensitively and carefully by a known and trusted worker.

## Intimate and personal care

Providing quality intimate and personal care to older service users with a learning disability is a complex challenge, which, to date, has received very limited attention. Research evidence suggests that minimal guidance is offered to care workers (Carnaby and Cambridge 2002). Where policies do exist, they tend to be very general, taking little account of differences between user groups, age, life stages, gender issues, or cultural or dependency needs. Carnaby and Cambridge (2002) recommend the development of both specific policy guidance and staff training and have developed a training 'resource pack' upon which service providers and workers can draw with the aim of developing 'best practice' (Cambridge and Carnaby 2000a). The pack contains sections on supporting older people with learning disabilities, incorporating a number of the issues that have been reviewed here such as taking account of declining physical and mental health and supporting users and family carers to continue living a full and independent life.

The little work that has been done in this area indicates that delivering appropriate intimate and personal care requires detailed understanding of an individual's needs and wishes, for example, preference for a particular soap (Cambridge and Carnaby 2000b; Carnaby and Cambridge 2002; Dodd, Turk and Christmas 2002). Knowledge of this nature depends to a large extent on effective communication between the care worker and user and familiarity with the user's views and character traits (Carnaby and Cambridge 2002). We have noted that the health needs of many service users with learning disabilities change and multiply when they become old. Staff who do not have a pre-existing or well-established link with the service user are likely to find it much more difficult to offer sensitive and individualised care. Trust and effective communication are key elements of good practice in this intimate arena and are particularly significant for service users who develop dementia. That residential care

workers are unlikely to know a user before admission and that staff turnover is very high in both community and residential settings undermines the acquisition of personal knowledge, the development of intimacy and continuity of care.

Recent policy emphasis on raising the standards of service provision and staff may offer an opportunity to enhance practice. The National Minimum Standards for Care Homes for Older People state that 'arrangements for health and personal care must ensure that the service user's privacy and dignity are respected at all times' (Department of Health 2002, 'Privacy and Dignity', Standard 10.1). Training initiatives such as the Learning Disability Awards Framework (LDAF), introduced by the Department of Health, also address issues relating to personal care and unlike care standards guidance, locate it within a 'good practice' framework. These awards emphasise the role of underpinning principles in enhancing all care practice: user empowerment, collaborative communication between staff and service users and the development of an inclusive model of care. They also confirm the importance of quality of life principles such as choice, rights and self-actualisation in training staff to work effectively (Alcoe, Carnaby and Duerdoth 2002).

User involvement and empowerment are significant dimensions of quality care. Much like their minimal involvement in care and treatment decisions, older people with learning disabilities are very unlikely to be involved in service development. Whilst in part this reflects communication difficulties, it is also a consequence of their disempowered and dependent status (Ansello and Coogle 2000). While there is some expectation that their views will be taken account of in the person centred planning process, issues of body care are often neglected. Frontline staff should be actively encouraged to facilitate users to voice their preferences in personal care matters and independent advocates should be used in situations where the user's capacity is compromised. Flexible methods of working and allocating sufficient time to personal care tasks are essential pre-requisites for the delivery of a service, which promotes user dignity, individuality and independence (Fitzgerald 1998a, 1998b).

There is considerable scope for developing collaborative, individualised and flexible approaches to personal care, drawing on experience from other fields, and other countries. Work in the dementia field has already been noted, as has work from the USA specifically focusing on the needs of older people with learning disabilities. There is additional scope to take account of work with younger adults with learning disabilities, complex needs and challenging behaviour (Carnaby and Cambridge 2002).

A significant training agenda exists for health and social care staff – and agencies – if quality personal care is to be assured for the population under review. At the very least generic care staff require training about the needs of

people with learning disabilities and staff working in services for the learning disabled need training about the ageing process and age-related ill health. In addition to a focus on personal and intimate care the training agenda needs to incorporate work on communication, managing loss and bereavement, and supporting users with complex and cumulative needs As agencies are dealing with an increasing number of people in this group, more staff will need training in the recognition, assessment and management of dementia, including intimate and personal care (Wilkinson and Janicki 2002).

## Summary of intimate and personal care recommendations

- Personal care needs to change and multiply as the service user ages;
   dementia poses a particular challenge to the delivery of user-led care.
- Intimate and personal care needs should be reviewed as a part of the PCP process, taking full account of the views of the user.
- The delivery of effective care depends on detailed knowledge of the service user's wishes and preferences, effective communication, familiarity and trust.
- Responsibility for taking this forward rests with policy-makers, agencies providing care and those charged with implementing national care standards and training.
- Staff training for intimate and personal care issues should be based on quality of life principles including empowerment, choice, rights and self-actualisation.
- Staff should be encouraged to work flexibly and collaboratively with users in defining the parameters of intimate and personal care.
- Much can be learned from the dementia care field and from work with younger adults with learning disabilities with complex needs.
- Generic care staff require training about the needs of people with learning disabilities and staff working in services for the learning disabled need training about age-related ill health, including dementia.

### CONCLUSION

While there is some recognition of the growing number of people with learning disabilities surviving into old age, little account is taken of the implications of this demographic trend for the development of appropriate care (Hatzidimitriadou and Milne 2005). The multiple and often complex nature, of the physical and mental health needs of this population is a significant challenge

for services. That they experience the double jeopardy of being old and learning disabled and are rarely coherently provided for by agencies compounds their disadvantage. The review of evidence offered in this chapter suggests that the provision of quality care requires a multi-agency proactive approach, which involves both strategic and individualised planning with service users and their carers before 'old age' is reached. The provision of intimate and personal care is identified as pivotal to the delivery of effective support. While training can go part way to addressing the current skill deficit, the twin agendas of resourcing services appropriately and developing models of care that can accommodate the voices and choices of older users, are equally important dimensions of developing safe, effective and individualised intimate and personal care for one of the most vulnerable groups in UK society.

#### NOTE

1 Controversially, in the learning disabilities field there is no consistent definition of 'old' and evidence is not gathered around similar age cohorts or in a similar method by various groups or agencies; therefore, we are obliged to accept the definitions employed by researchers and summarise evidence taking account of definitional and geographical variation.

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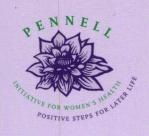
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# **WOMEN AT THE CROSSROADS:**

A literature review of the mental health risks facing women in mid-life

## Written by Alisoun Milne and Jennie Williams

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## Women at the Crossroads:

# A literature review of the mental health risks facing women in mid-life

#### SUMMARY

Women at the Crossroads: A literature review of the mental health risks facing women in midlife will be published in August 2003. The review was commissioned by the Pennell Initiative for Women's Health and undertaken by Alisoun Milne of the Mental Health Foundation and University of Kent, and Jennie Williams of Inequality Agenda Ltd. Mid-life is defined as 45-60 years.

The lives of mid-life women are distinct from younger and older women in a number of key ways. They face a range of specific challenges including: multiple family and caring commitments, employment challenges, current and future concerns about reduced economic status, and physical health problems. Many women are combining a variety of roles inside and outside the home and changes to social, family and economic situations are common. Whilst there is little evidence that mid-life women experience higher levels of mental illness, the combined and cumulative nature of managing numerous demands, alongside lifelong and age-related disadvantages, places them at enhanced risk of psychological and emotional distress.

### **BACKGROUND**

Despite the significance of mid-life as a pivotal stage for many women, it is largely invisible in policy and research arenas. Though some data exists about the extent of psychological problems in women aged 45-60, far less has been gathered about the causes of such difficulties or the challenges to mental health associated with mid-life. Women at the Crossroads draws together evidence from a range of sources to address this knowledge deficit. The authors pay particular attention to the implications social inequalities - including gender, race, class, and poverty - have for mental health outcomes.

The review is divided into a number of sections; these reflect the key areas of relevance to psychological well-being.

#### FINDINGS

#### Resources & Status

- Money and Poverty: One of the most significant influences on psychological well-being is access to money. Many women find themselves in the 'poverty trap' in mid-life. This is primarily as a consequence of lifelong gender-related circumstances including lower pay, part-time working and family caring. Widowhood is another cause of financial difficulty; as women tend to marry older men a significant proportion are widowed in their 50s. Other disadvantaged groups include: divorcees, ethnic minority women, and those from the lowest socio-economic cohorts. In addition to impacting on current financial status, these patterns also combine to reduce women's access to an adequate pension.
- Home ownership: Housing is a well-documented determinant of psychological
  well-being. At all ages women are less likely to own their own homes than men;
  this is particularly the case for women who have retired early or are on low
  incomes. Even when women are homeowners the quality of housing is likely to
  be inferior. Women also disproportionately occupy substandard public and
  privately rented housing.
- Employment: Fulfilling work can promote women's self esteem and independence, although for those 'obliged' to remain in low status jobs to support a family or boost pension contributions, work can be demoralising and stressful. Stereotyping, segregation and discrimination are common experiences for mid-life women employees with little account taken of family responsibilities.
- Status and power: Gender inequalities mean that women are systematically accorded less status and power than men. Additionally, the social process of ageism is experienced by many women in their 50s. As long as women are primarily charged with the task of reproduction, nurturing and the transmission of values to the next generation, they risk being perceived as 'redundant' and of limited social value when that work ends. This has significant implications for mental well-being.

#### Roles and Relationships

#### Unpaid work:

- Caring: Mid-life women make up the single largest cohort of family carers in the
  UK. A quarter of women workers ages 50+ retire early to look after a dependent
  relative reducing their access to an adequate income and pension. Intensive caring
  is a known cause of emotional stress and depression; it also affects physical health,
  social activities and finances.
- Housework: Mid-life women carry the primary responsibility for housework
  within their households. Women who have primarily worked inside the home are
  at enhanced risk of becoming depressed, an outcome which is suggested to be
  mediated by low self-esteem, helplessness and poverty.



#### Relationships:

- Marriage and divorce: Although marriage is generally evidenced as protective of
  mental health, it is the quality of the marital relationship which is key rather than
  marriage per se. The mental health benefits of marriage are greater for men than
  women. Marital dissolution negatively effects mental health; separated people are
  three or four times more likely to be depressed. Although the divorce rate for
  those aged 45+ is much lower than younger age groups, the social, psychological
  and financial impact is greater and longer term.
- Widowhood: Although only about 10% of women are widowed in mid-life, the
  loss of a long-term partner can be devastating. It represents a multiple loss: loss of
  confidante, sexual partner and social role as well as loss of status and income.
  Living alone also raises the risk of isolation and loneliness.
- Relationships with other women: These are reported as universally protective of
  mental health. Women friends often represent a source of therapeutic support,
  particularly in times of adversity, loss or change.

#### Abuses of power

Physical and sexual abuse: Whilst mid-life women do not appear to be at high risk
of abuse when compared with younger women and children, a significant
number arrive at mid-life with past experiences of sexual or physical abuse. The
effects of abuse are known determinants of mental ill health; for most women,
past abuses remain unresolved and their long-term impact goes unrecognised.

#### Health

- Physical Health: Although about 45% of women in mid-life report a longstanding
  illness or disability, little is known about the nature and impact of these. What is
  known however is that chronic illness and disability has a profoundly negative
  impact on mental health.
- Menopause: The menopause is the headline 'health issue' for mid-life women and
  its 'treatment' with HRT has recently been heralded as of massive benefit to
  women. There is increasing concern about HRTs long-term impact on health
  and growing opposition to the 'medicalisation' of the menopause. Little is known
  about direct links between the menopause and mental health.

## Mental Ill Health

24% of mid-life women suffer from anxiety or depression; rates for women are
double those for men. As the key risks for developing depression begin to
accumulate in mid-life, this group of women may be at particular risk. Risks
include: retirement, bereavement, recent divorce, isolation, and poverty. There is
also evidence that particular groups are at risk of alcohol abuse including
depressed women and homeless women.



#### THE IMPLICATIONS

The review highlights the key dimensions of the lives of mid-life women which door might be expected to – have an impact on their emotional and psychological well-being. A number of dominant themes emerge. There is a powerful sense that mid-life women are at a crossroads – between past and future, and between youth and old age. Some decisions are set, such as whether to have children or not, and there are core facets of the lives of mid-life women which are unlikely to substantially alter, such as career choice and economic status. Equally, she is facing a number of changes – retirement, health challenges, widowhood, reduced income – which she must adjust to and accommodate. Further, she is often juggling several roles: wife, mother, worker and carer for an ailing parent/parent in law. The experience of social inequality: of oppression, segregation, ageism, and discrimination, also marks out mid-life for many women. That she feels herself to be increasingly 'invisible' and disempowered is a personal reflection of this social process.

## **SUMMARY OF RECOMMENDATIONS**

Opportunities to alleviate distress and disadvantage and reduce the mental health costs on mid-life women lie in the arenas of research, policy, and services. Having identified some of the key parameters of the debate it is important that investment is made in: building up a more coherent and robust evidence base around the mental health of women in this cohort; developing policy that focuses on the needs of this group, and developing services that explore ways to support and meet their needs. These changes need to be underpinned by the voices of women. If we are to meet the needs of future generations of mid-life women it is imperative that we gain a much clearer understanding of their lives and experiences, and their management of the mental health challenges that mid-life presents.

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## **WOMEN AT THE CROSSROADS:**

A literature review of the mental health risks facing women in mid-life

Commissioned by the Pennell Initiative for Women's Health from the Mental Health Foundation and undertaken by Alisoun Milne and Jennie Williams.

**The Pennell Initiative for Women's Health** exists to champion the cause of women's health by researching and addressing the physical, emotional, mental and spiritual needs of women over the age of 45. They seek to improve every women's prospect of living well into healthy old age by promoting understanding of health issues and taking action to benefit women from middle age to very old age.

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## INTRODUCTION

This review focuses upon women aged 45-60: an under-researched subgroup of the adult female population. Women in mid-life occupy a unique position in the lifespan at the intersection of a number of age-related and lifelong pathways. The lives of these women can be distinguished from those of both older and younger women along a number of important dimensions including their family and working lives, economic situation, general health, and the complexity of their roles both inside and outside the home. Personal and economic changes are common at mid-life as are physical changes; all have particular and distinct implications for women's emotional and psychological health.

The aim of this review is to address a knowledge deficit. Though some evidence exists about the extent of psychological distress in women aged 45-60, far less has been gathered about the causes of such difficulties or the challenges to mental health associated with mid-life experience. The lifespan is routinely conceived as containing a number of discrete stages: women's lives are characterised by experiences that have overlapping threads and meanings and these combine with age-related issues in ways that warrant focused attention. This review draws evidence from a range of sources to identify the key parameters of mid-life women's lives. These include: the areas and types of risk to their mental health from a range of sources, the extent of psychological distress, and the ways in which research and policy could reduce the challenges that commonly face women in mid-life and alleviate or prevent mental ill health.

It should be noted at the outset that the age group 45-60 years does not map perfectly on to the existing field of research: researchers and national statisticians punctuate the life span in whatever ways they see fit. So, although we have tried to locate research which matches the age span of interest, inevitably we also draw upon the findings of research which only offers a close approximation.

# A SOCIAL INEQUALITY FRAMEWORK

There is now a wealth of evidence that points to the inappropriateness of discussing women's mental health problems in terms of individual pathology. It is both more accurate and useful to conceptualise women's mental health problems as responses to – and sometimes as creative ways of coping with – damaging experiences that are rooted in their lived experiences of inequality and abuses of power. Accordingly this review will be carried out from a social inequality perspective, which means that we will be particularly attentive to the mental health implications of gender, class, and race. This framework will be used to identify the ways that social inequalities can impair the mental health of women in this age group, and to focus attention on the ways that women survive and thrive.

Social inequality exists when an attribute such as gender, race or class affects access to socially valued resources including money, status and power. Dimensions of social inequality are hierarchies of domination – power relationships that limit and restrict some people while privileging others. They do not merely represent different lifestyle preferences or cultural beliefs, values and practices: there is a fundamental conflict of interests at their core. This perspective alerts us to the fact that many of the taken for granted institutional, social and domestic arrangements in our society are structured to meet men's needs at women's expense. Thirty years ago there was very little research evidence, or published work, making connections between inequalities in society and the psychological well-being of individuals. Now there is extensive literature, and there can be no doubt those social inequalities are major determinants of women's mental health (Busfield, 1996; Ussher, 1991; Williams, 1999).

We shall begin with a reminder of the main ways in which social inequality can impact on the mental health of women.

- First, through inequitable access to resources known to affect mental health, which include money status and power.
- Second, through processes of subordination that sustain and hide social inequality, including discrimination, exploitation and oppression.
- Finally, through serious abuse of power including sexual and physical violence and abuse.

Each of these overlapping topics will now be considered, and what is known or can be inferred about the psychological well-being of women in mid-life, reviewed.

# INEQUALITY, RESOURCES AND MENTAL HEALTH

In the first instance we shall consider the effect of inequality on mid-life women's access to a range of resources known to affect mental health, most notably money, status and power.

## Money and poverty

One of the most significant influences on physical and psychological well-being is the availability of, and access to, money. The positive association between poverty and mental health problems is one of the most well established in all of psychiatric epidemiology (Buck, 1997). Furthermore, research has consistently documented that low income is associated with high rates of mental disorder amongst women (Belle, 1990; Bruce et al., 1991; Platt et al., 1990), though few studies (e.g. Butler and Weatherley, 1992) have directly examined the mental health implications of poverty for mid-life women.

The existence of inequalities in our society means that as a consequence of their gender, race, class, and age, many women in mid-life have restricted access to money. 'Gender, rather than an individual's skills and abilities, continues to be a major determinant of individual economic prosperity'. (Equal Opportunities Commission, 2000a. page 7).

### **Education**

In a society which values education, a woman's educational attainment is likely to be directly linked to her identity and self-esteem. Additionally, having low or no qualifications is strongly related to low-skilled and low-paid work or unemployment, lack of money and poor housing. All of which are predictors of poor physical and mental health. It is noteworthy, therefore, that a higher proportion of women than men aged between 45 and retirement age has no qualifications: 30 % of women compared with 20 % of men (Figure 1).

Other data indicates that the ages at which women and men have children are strongly related to qualification levels: those who are most highly qualified being more likely to delay having children. In the age group 25 to 34, 84 % of women without qualifications had dependent children compared with only 29 % of those with degrees or equivalent. The situation had reversed by the age of 45 to 54, so that 22 % of women with no qualifications had dependent children, compared with 42 % of women with degrees (Equal Opportunities Commission, 2001d).

We also draw attention here to the findings of an American study (Elman and O'Rand, 1998) designed to determine who is most likely to seek re-training at mid-life (45-61 years). This study found that individuals already in occupations requiring high skill levels were most likely to re-enter training, while those with the fewest resources and rewards were least likely to do so. The authors argue that this is one of the ways that education operates to preserve occupational advantage, and to impede women and people from ethnic minority groups from accessing opportunities and increasing their income.

## Income and pay

As a result of the combined disadvantages of lower income and reduced levels of full-time employment, many mid-life women have significantly lower incomes – and as a consequence have less choice and power than their male peers and partners (Figure 2).

Overall, women's gross income is 49% of men's (Office for National Statistics, 2002) and the differential earnings of the sexes explains some of this discrepancy. Although both women and men aged 55+ have lower levels of economic activity than their younger counterparts, there is a clear gender differential in terms of earning capacity within the 55-59 year old age group. In this cohort, women's incomes are nearly two fifths lower than those of men (Equal Opportunities Commission, 2000a). It is also the case that in all ethnic groups men have higher average hourly earnings than women in this, and indeed all other, age groups (Equal Opportunities Commission, 2000a).

Two and a half million employees have weekly earnings below the Lower Earnings Limit (LEL); the majority of this group are women (Equal Opportunities Commission, 2001b). This is both age and gender related. Whereas 15 % of female employees in the 40-54 age group earn below the LEL, only 1 % of males in this group is in the same position. Amongst the group of employees aged 55 who are below the LEL, 28% are female and 6% are male (Figure 3).

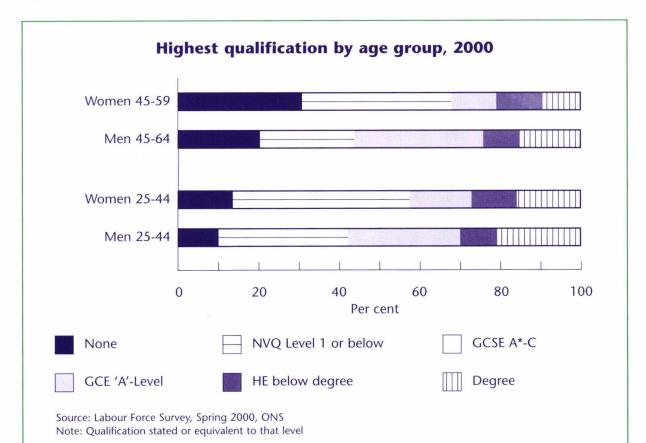


Figure 1: Highest qualification by sex and age

Figure 2: Median individual gross income by sex and age

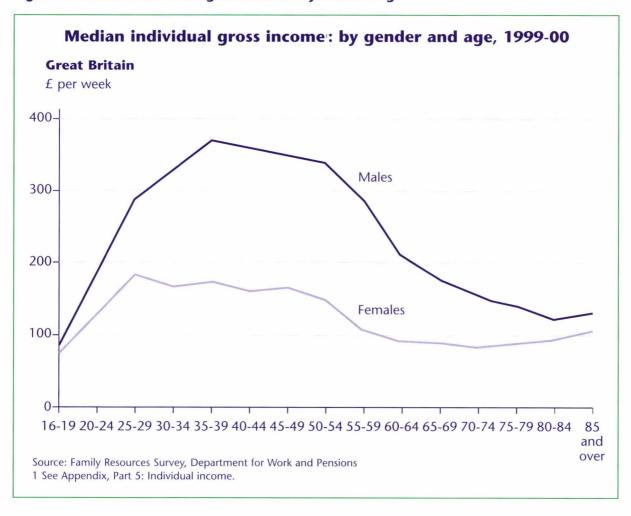
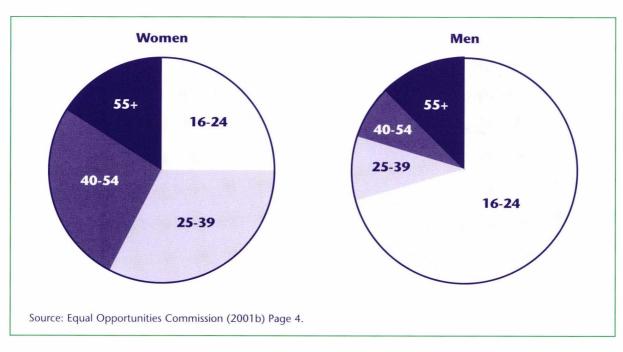


Figure 3: Employee earning below the Lower Earnings Limit by sex and age



Changes in marital status and household composition after the age of 50 can also affect a woman's standard of living. The period between the ages of 50 and 74 years is one when many married women will become widows. The financial consequences of widowhood are an important aspect of the income dimension of transitions after 50. Given the greater mortality among the poor than the rich, widowhood at a relatively young age may be particularly likely to result in poverty.

## **Patterns of employment**

Over the last two decades the employment participation of women of all ages has steadily increased (Table 1). These days just under a quarter of women aged 55-59 are in full-time work, with a slightly higher proportion working part-time.

In terms of both the types and patterns of work there are some distinct gender-based patterns and differences between men and women. In 2001 44% of women in employment in the UK worked part-time compared with only 9% of men (Dench et al, 2002). As they get older more women tend to work part-time: two fifths of female employees aged 16 to 44 work part-time compared with around half of those aged 45 to 64. The most common reason for working part-time are family commitments. The relationship between part-time working and having dependent children for women is very clearly demonstrated in Figure 4.

Working part-time has a huge impact on women's earning potential both in the present and future. Age and number of children compound the situation with older workers and those with higher number of children being the worst off. An additional factor is the status of much part-time work. Part-time workers are more likely to be found in low paid, low status jobs with fewer prospects for career advancement or higher incomes, they also have less opportunity than younger women to benefit from the equality strategies of recent years. Further, women tend to remain in these jobs in the long term and often for the majority of their working lives.

The ways in which education, the family, and access to the labour market interact are complex, but women have different opportunities and experience different types of discrimination throughout their lives. The resulting inequalities can clearly be seen in employment and income (Equal Opportunities Commission, 2001d). Overall, women remain disadvantaged compared to men, as occupational segregation means they are concentrated in lower skilled and lower paid jobs with less access to vocational training and education (Equal Opportunities Commission, 2000a). Bearing in mind these structural difficulties, it is interesting to draw attention to a large US survey (Carr, 1997) which found that women have higher levels of positive mental health and lower levels of depression when they have achieved the goals that they set for themselves earlier in life.

## **Unemployment**

There are few women in mid-life who define themselves as unemployed: who are without a job and seeking work. The unemployment rates in 2001 for women 45-54 and 55-59 were 2.4% and 2% respectively (Office of National Statistics, 2002). These are amongst the lowest unemployment rates for any age/sex group. It is, however, the case that many mid-life women are housewives and carers for dependent relatives: they are not unemployed in any sense but tend not to be actively earning an income.

Table 1: Economic activity of working women by age

	Economic inactivity rates of working age women by age: UK 1984-2001					
	Working age %	16-24 %	<b>25-34</b> %	35-49 %	<b>50-59</b> %	
1984	33.0	30.3	38.8	28.9	41.2	
1985	33.0	29.1	37.2	27.9	41.6	
1986	32.0	27.9	35.5	27.4	41.2	
1987	31.1	27.0	27.0 34.2 2		40.3	
1988	30.1	26.8	32.0	25.3	40.6	
1989	29.1	25.9	30.9	24.9	39.0	
1990	28.7	27.2	29.8	23.5	38.6	
1991	29.0	28.2	30.1	23.6	38.6	
1992	29.4	32.1	30.0	22.7	37.9	
1993	29.4	33.6	29.0	22.9	37.5	
1994	29.4	4 34.8 28.8		22.9	36.6	
1995	29.4	35.2	28.4	23.3	36.5	
1996	28.9	34.3	27.8	22.7	36.9	
1997	28.6	34.0	26.6	23.0	36.6	
1998	28.5	34.6	26.3	22.8	35.7	
1999	27.9	35.0	24.9	22.4	35.1	
2000	27.5	34.4	24.7	22.2	34.0	

24.9

21.7

33.7

Source: UK Labour Force Survey Spring Quarters Historical Supplement, 001

35.8

27.6

Data for figures 3.2 and 3.5

2001

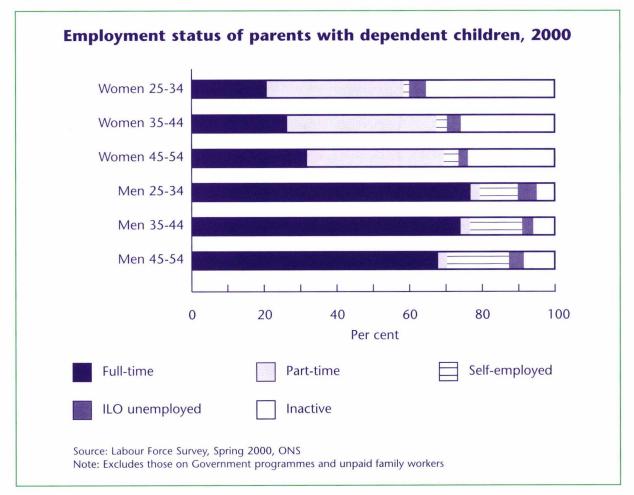


Figure 4: Employment status of parents with dependent children by sex and age

## Gendered work to gendered retirement

Increasing numbers of people, both men and women, are leaving work before state retirement age. Existing evidence suggests that while the minority of individuals who retire 'early' make a choice and are happy with their decision, a larger proportion is forced into early retirement through health problems, redundancy and family demands (Bone et al, 1992) (Table 2).

Caring responsibilities are a key reason for many mid-life women to leave work (Table 6). This group is more likely to experience problems in adjusting to and coping in retirement (Barnes et al, 2002). Recent research suggests that a significant number of women find retirement challenging; many miss their work which provided social and personal support as well as an income (Milne and Williams, 2000). Women with a strong social attachment to the workplace tend to be less willing to retire than those without, and are less likely than men to be positively oriented to retirement (Mooney et al, 2002). Despite the fact that most mid-life women will never 'retire' from domestic and family responsibilities, the role of paid work as a source of independence and identity should not be underestimated. This is a consistent finding regardless of the nature or status of the work (Phillips et al, 2002). Many older women still expect their 'retired' years to be predominantly organised according to traditional gender roles, supporting the contention that both women's working lives and retirement are structured by gender considerations (Barnes and Lakey, 2002; Milne and Hatzidimitriadou, 2002).

A particularly powerful feature of gender relations relates to the societal expectation that men should marry women younger than themselves, a tradition associated with the maintenance of a power differential within marriage. Due to different retirement ages, women tend to retire before or at the same time as their husbands. There is some evidence that older husbands are uncomfortable with their wives continuing to work and also that wives themselves prefer to retire at the same time as their husbands in order to be able to 'look after' them (Arber and Ginn, 1995). Where the household depends on the income of the wife she will continue to work beyond her husband's retirement: this is almost exclusively the case for poorer households, households where children under 21 still live and/or families where the husband has long-term health problems (O'Rand, 1992). The fact that over a quarter of women workers aged 50+ retire to take care of a dependent family member further reinforces the influence of patriarchy on retirement. As noted by Arber and Ginn (1995) these 'decisions' reflect constraints on women rather than choices. The gender culture embedded in many organisations also has implications for retirement; there is evidence that many women leave work before their state pension age due to ageist employer policies.

## **Gendered pension patterns**

Table 3 shows current pension membership among women and men, by type of pension and age. The total figures show that men are more likely than women to have personal pensions, a factor clearly linked to women's work patterns and the recent changes in employer pension provision. While 23% of men working full-time have personal pensions, 14% of women working full-time and 9% of women working part-time have such pension schemes. For those groups in mid-life it is clear that about the same numbers of women as men belong to a pension scheme; slightly more men belong to personal pension schemes and slightly more women in the 55+ age group contribute to an occupational pension scheme. It is interesting to note that between two fifths (45%) and under a tenth (8%) of women working part-time also contribute to a pension scheme. What needs to be borne in mind in interpreting these figures is the fact that the total number of women working full-time is far lower than the total number of men. Furthermore, fewer women will have worked full-time for the duration of their working lives and thus will have accrued lower pension contributions.

Table 2: Reasons for retirement by sex

	AII (%)	Men (%)	Women (%)
Own ill-health	26.6	26.0	27.7
Ill-health of others	5.2	4.1	7.5
Involuntary redundancy	14.5	15.0	13.7
Voluntary redundancy – reasonable financial terms	17.8	23.6	7.1
Spend more time with family	5.4	2.5	10.7
Enjoy life while young and fit	5.7	5.8	5.4
Fed up with work or wanted a change	5.3	4.4	6.9
Other	12.7	8.5	20.5
Fixed retirement age	6.9	10.3	0.7

Access to money and resources in mid and later life is pre-eminently a life course issue. The impact of lifelong employment patterns and reduced income in youth and early adulthood has a long-term impact on pension status for women. Research has shown that the financial inequalities inherent in work structures are reproduced in retirement for many women; it is also likely that they influence wider issues concerning the marginalisation of women in mid and later life and their ability to act independently and make choices (Bardasi and Jenkins, 2002) – all key determinants of mental health.

In terms of access to the state retirement pension, at present only 28% of older women receive a full state pension in their own right. Because of low pay and part-time employment, two million women currently earn too little to pay national insurance contributions and therefore will not qualify for a State pension in their own right. As this is a gendered pattern which is likely to continue in the future, the potential for many women in mid and later life to find themselves ineligible for the state pension, is considerable (Pension Provision Group, 1998; DSS, 1999).

37% of women receive a pension of less than £40 per week and 75% of pensioners claiming income support are women. Women who are single, divorced or widowed are particularly at risk in this respect (Pension Provision Group, 1998; DSS, 1999), as are women from ethnic minority groups and the lowest socio-economic groups (Vincent, 1995). A recent review of take up of the MIG (minimum income guarantee) by the National Audit Office reveals that of the 2 million eligible pensioners only 200,000 claim this benefit (ONS, 2002). This powerfully indicates not only that there are considerable levels of poverty amongst older people but that means testing in retirement are not effective ways to alleviate poverty; this will have a particular and acute impact on older and upcoming retired women (Table 3).

## Pensions policy and women

Recent changes to pension policy are having a particularly negative impact on women's incomes: of particular note is the emphasis on private or occupational pensions, and the raising of the state pension age to 65 years. We have already reviewed the numbers of women in receipt of private or occupational pensions. The current emphasis placing increasing responsibility for pension status on employers and individual workers particularly disadvantages mid-life women who for a range of gender-based structural reasons, have little opportunity to benefit from work-based pensions or build up a private pension fund (Bardasi and Jenkins, 2002).

The raising of the state retirement age to 65 for women is being phased in from the year 2010 (HMSO, 1994). Women will need an extra five years National Insurance contributions or credits in order to be eligible for a full state basic pension than is the case at present. This expectation places additional pressure on mid-life working women:

'To the extent that there are pressures to avoid contravening the norm of male economic dominance, in addition to lack of employment opportunities, wives will continue to retire well before the new pension age of 65, thus reducing their chance of fulfilling eligibility requirements for a full state pension as well as the value of any other pensions' (Page 85).

If women continue to leave the labour market mainly in their late 50s – as we have identified – the gap between their retirement and pension age will be widened, making the majority of wives wholly financially dependent on their husbands until aged 65 (Arber and Ginn, 1995). This status has clear implications for women's well-being: financial dependence is a known risk factor for compromising mental health.

Table 3: Current pension scheme membership by sex and age

	Age						
Pension scheme members	16-17	18-24	25-34	35-44	45-54	55 and over	Total
	%	%	%	%	%	%	%
Women full-time							
Occupational pensions	(0)	32	60	66	65	61	58
Personal pensions	(6)	4	17	20	13	11	14
Any pension	(6)	35	70	78	71	68	66
Men full-time							
Occupational pensions	(0)	24	52	64	63	55	54
Personal pensions	(0)	4	26	29	26	19	23
Any pension	(0)	27	68	79	77	65	67
Women part-time							
Occupational pensions	1	4	35	40	41	23	31
Personal pensions	0	1	13	13	9	8	9
Any pension	1	4	44	48	45	29	37

Note: Figures in brackets denote small numbers of cases

Source: Living in Britain: Results from the 2000/01 General Household Survey

There are two other changes which are likely to have an impact on mid-life women. In April 2001, stakeholder pensions were introduced that are designed to provide a second tier pension for those on moderate incomes who are unable to join an occupational scheme or for whom personal pensions are not suitable (DSS, 1998). This applies to many women and may be of considerable benefit to those who have compromised their earnings through breaks of service and part-time working: once they have 'bedded in' the impact of stakeholder pensions on women in mid-life will need to be reviewed to evaluate how far this is the case.

The government also plans to replace the State Earnings Related Pension Scheme (SERPS) with a State Second Pension from 2002, aiming to target additional resources at carers and those on incomes of up to 10K. This is likely to assist the many mid-life women on low incomes or who give up work to care for dependent relatives; time will tell how far they counteract the cumulative disadvantages that we have identified in this review.

Overall, present policy emphasis on individual responsibility for pension status and the raising of state retirement age condemns increasing numbers of current and future women pensioners to an impoverished later life. Unless there is a change of policy direction, the pension penalties of motherhood, caring for dependent relatives and retiring early to support a disabled or sexist husband, will persist for the foreseeable future. These disadvantages are further accentuated for lone mothers, and divorced and widowed women (Milne and Williams, 2000).

## Savings

Wealth is much less evenly distributed than income in mid-life. In 1997-98 half of all households in Britain had less than £1,500 of savings and 30% had none (Women and Equality Unit, 2000). Women are far less likely to have stocks and shares. Older women living alone are generally much poorer and have fewer savings than older men, because they are far more likely to solely rely on state pensions for their income rather than both state and occupational pensions (Milne et al, 1999).

## **Property ownership**

Housing and living arrangements are well-documented determinants of health and psychological well-being (Sixsmith 1990). Research consistently shows that home ownership is commonly associated with a wide range of physical (Gurney and Means 1993) and psychological benefits (Clark et al 1998). An individual's capacity to retain their social networks and adjust to mental or physical ill health is greater if they live in a permanent housing situation under their 'control' (Matheson, 2002).

At all ages women are less likely to be home owners than men (Arber and Ginn, 1995) and despite the fact that increased age tends to be associated with increased numbers of people owning their homes outright, this trend is biased towards men (Matheson, 2002). Analysis of the 1995-6 Family Resources Survey suggested that women aged 55-59 years who are early retired or have been sick long term are less likely to be owner occupiers (Baker and Harris, 2000). Even when women are homeowners the quality of housing is likely to be inferior to that of men. Forrest and Leather (1998) conclude on the basis of their review of homeownership that:

'Just as some of the worst housing conditions are experienced by female-headed households in the early stages of the lifecycle, it is also likely to be women who make up a disproportionate number of disadvantaged home owners in old age' (p.35).

It is also women who disproportionately occupy substandard public and privately rented housing (Leather and Morrison, 1997; Matheson, 2002.)

## Status and power

Gender inequalities mean that women are systematically accorded less status and power than men, and the consequences of this are ameliorated or accentuated by the interactive effects of other aspects of a woman's life such as her class, race and age. Whilst many women in mid-life will not experience the full range of disadvantages associated with later life, age as a dimension of inequality cannot be ignored (Milne and Williams, 2000). The tentacles of late life disadvantage have powerful roots in mid-life and the social process of ageism is experienced by many women in their 50s. Many writers have drawn attention to the fact that ageing is a gendered social process which men and women experience differentially (Walker 1993; Arber and Ginn 1998). As long as women are primarily charged with the task of reproduction, nurturing and the transmission of values to the next generation, they risk being perceived as socially redundant and of limited social value when that work ends. As de Beauvoir (1972) notes, older women are often seen as 'past it' and useless, whereas older men are often perceived as mature, distinguished and desirable. A 'double standard of ageing' operates which combines ageism with sexism and accords older women a doubly oppressed status in mid and later life. The significance placed on youth, appearance and reproductive capacity

undermine the contributions of women in mid-life, fuel a negative image of their roles and marginalise their views and position in a range of economic and social contexts.

'Because a lot of women do manage to look younger now, if you look your age when you're 50, it feels like a failure. I keep thinking when will I be allowed to give up and stop trying so hard – when I'm 60? 70?' (SIRC, 2001)

That older and mid-life women often experience themselves as socially 'invisible' has been widely reported (Greer, 1991; Apter, 1996). Other writers make the point that class and race also determine the nature and experience of ageing, and Arber and Ginn (1991) have identified black older women as being particularly disadvantaged by the triple jeopardy of ageism, sexism and racism. The differential impact of social inequalities on women's lives means that there is huge diversity in experience of oppression and privilege. What we need is research that will substantiate and offer understanding of the particular implications for women at mid-life.

## Relationships with other women

The effects of social inequalities on women's access to material, social and psychological resources, is typically detrimental. However, an exception to this is their potential access to valued relationships with other women. Like members of any disadvantaged group, women are well placed to seek support and value from each other. That these relationships are a source of therapeutic support for women both within and outside of mental health services is well documented (Bernardez, 1996; Harris, 1998a; Watson et al., 1996). In contradistinction this type of resource is less readily available to men (Miller and Bell, 1996). Indeed women between the ages of 45-60 may be particularly sensitised to the value of relationships with other women having been young during the re-emergence of the feminist movement in the 1960s and 1970s. There is also good evidence (e.g. Williams and Windebank 2000) of the benefits of community development work with women, especially those living in deprived communities (Holland, 1995).

## Summary and priorities for change

In this section we have traced ways in which women's psychological well-being can be affected by their access to material and social resources and have linked 'being female' with a range of gender and age-related disadvantages that impact on opportunity, income, status and power. We suggest the following priorities for action:

## Research

• The challenges facing mid-life women: Qualitative studies to explore the relevance and meaning for women of the issues that to date have been mainly identified through surveys. Mapping the cumulative ways in which women are disadvantaged socio-economically and how they manage the consequences of disadvantage would extend knowledge and illuminate ways to develop coherent and effective responses. Adopting a life course approach would reveal the threads of disadvantage in women's lives and the links between the separate strands.

• The emotional well-being of mid-life women: Research that explores the emotional well-being of women in mid and later life, including poor women and those from disadvantaged social groups. Hearing the voices of mid-life women – a time of life largely unexplored in research – would be very valuable.

## **Policy**

- Retention: Policy initiatives aimed at facilitating the development of organisations cultures that are sensitive to the needs of mature women workers and that challenge discriminatory practices and pay differentials.
- Retirement: Policy initiatives that increase the possibility that women will be supported and enabled to make a positive choice to stay in work. Guaranteeing the continued provision of a universal state pension would offer some protection for women.
- Poverty: Measures to prevent the widespread income poverty which currently exists amongst
  women in mid and later life. The benefits system is widely regarded as an area requiring reform.
  Women who are retiring should be able to access an income that allows them to live comfortably;
  it is regarded as demeaning to claim means tested benefits particularly when women have
  contributed significantly to child rearing, family and community life.

## Mental health

- Support from other women: Ensure that mental health services provide mid-life women with opportunities for group work with other women with whom they share important life experiences. This should include ensuring that mature women workers are able to contribute to supporting their counterparts with mental health problems.
- Mental health promotion: Work preventatively through community development initiatives in areas of social deprivation including identifying the roles played by mid-life women in supporting others and opportunities for them to be supported.

# INEQUALITY, OPPRESSION AND MENTAL HEALTH

In addition to socio-economic disadvantages, mid-life women also encounter challenges and potential disempowerment rooted in processes of discrimination and oppression. It should be noted that while discrimination and oppression exist in all areas of life, and are imbedded in many practices and systems and take on many forms, they are often invisible and hence are viewed as irrelevant by perpetrators.

## **Unpaid work**

## Housework

Women as the chief carers in families also hold most responsibility for household tasks, and this is particularly likely to be the case for older women. Research shows that married men report doing about 9 hours of 'housework' per week while their wives report an average of 24 hours (Seymour, 1992; Pilcher, 2000). Over recent decades there has only been a very gradual shift towards equality in this sphere. Additionally, there is evidence that women's personal or spare time is conflated with household tasks (Seymour, 1992), and that as a result many women feel that they have 'no time to call my own'.

Women's home roles are often characterised by considerable responsibility, a lack of power, and blame: there is now ample evidence that these exact a mental health cost from women (Brown and Harris, 1978; Williams and Watson 1996; Williams 1999). In mid and later life women who have primarily worked within the home appear more likely to experience depression than women who have also been employed, an outcome which is suggested to be mediated by low self-esteem, helplessness and poverty (Rodeheaver and Datan, 1988).

## Gender and caring in mid-life

## **Overview**

The likelihood of becoming a carer increases with age (Figure 5). Whilst only 9% of those aged 16-29 are carers, 37% of those aged 45-64 are carers, 25% are aged 60-74 and 6% are aged 75+ (OPCS, 1998). Approximately half of all carers are aged between 50 and 64 years old; most people take on the caring role between their mid-30s and mid-50s and many continue to care for the rest of their lives (Carers UK, 2002). By their late 60s almost one woman in three will have cared for a dependent adult at some point in her life. The mid-life group predominantly care for elderly parents (52%), although they also provide care to older spouses/partners (20%) and grown up children (18%). It has also recently become recognised that grandparents make a significant contribution to meeting childcare needs: surveys show that care by grandparents is the most common form of care used by women who work (Phillips et al, 2002).

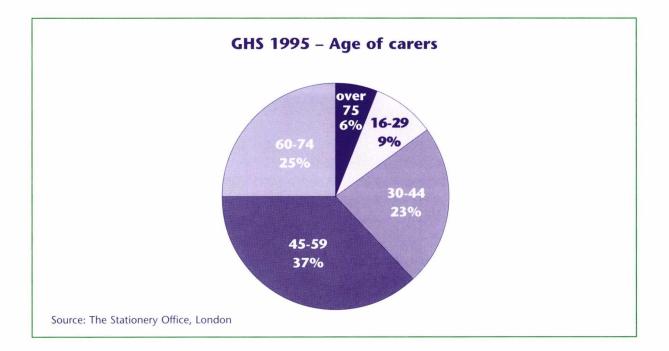


Figure 5: Age of Carers in the 1995 General Household Survey (GHS)

The responsibility for caring in mid-life falls predominantly on women (Maher and Green, 2002; Milne and Hatzidimitriadou, in press). Two thirds of carers are women and one third male. Women are also particularly likely to become a co-resident carer – caring for someone in the same household and women also predominate in those groups with the heaviest commitments (Parker, 1992). About double the number of women carers provide intensive care than men – care that involves bathing and personal care; a third (30%) spend 20+ hours caring per week including an eighth (12.5%) caring for 50+ hours (Maher and Green, 2002). In fact under the age of 65 women provide an average of twice as much care as men (Mooney et al, 2002). Women also appear more likely to be the sole or primary carer for a dependent relative rather than being a member of a network. There are indications that these patterns can be accentuated amongst some ethnic minority groups (Adamson, 1999; 1996; Atkin, 1992; Katbanna, et al, 1998).

Married people not in paid work, part-time employees and those in low status, poorly paid jobs are more likely to become carers than more advantaged groups; most of these are women. While being employed does not affect whether or not women start caregiving, women who do start are more likely to reduce employment hours or stop work altogether (Pavalko and Artis, 1997). As Pavalko and Artis 1997 conclude:

'Thus, the causal relationship between employment and caregiving in late mid-life is largely unidirectional, with women reducing hours to meet caregiving demands.' (Page 170).

## The pivot generation

What makes the needs of the mid-life carer unique is that many are combining paid work, home commitments – which may include supporting children – and care for an elderly relative. By the age of 50, three fifths of people still have a living parent and just over a third are grandparents (Grundy et al, 1999). At the same time 69% of men aged 50-64 and 63% of women aged 50-59 are in paid employment. This 'sandwich' or 'pivot' generation typically has a multiplicity of roles in both their work and family lives.

## The consequences and impact of caring

Most of the evidence relating to the consequences and impact of caring relates to carers providing intensive support and has been gathered from small-scale research projects. Many of this group are women carers aged 45-60. This literature indicates that the consequences of caring are far-reaching and long term, these include:

- Psychological and emotional consequences
- Effects on employment
- Financial consequences
- · Physical and social consequences.

Whilst the main focus of this section is the psychological and emotional consequences of caring, it is important to recognise the interlinked and cumulative nature of the range of effects caring has on a carers' health and well-being.

## Psychological and emotional consequences

There are no grounds for suggesting the process of caring for others in itself damages psychological well-being. However, the work of women carers is typically undervalued, associated with powerlessness, isolation, and financial hardship: all known determinants of mental health difficulties.

Evidence linking caring and emotional well-being is well established (Parker, 1990; Draper et al, 1996). Co-residency, intensive caring, and length of caring are all positively correlated with poor mental health as is being the sole or primary carer (Evandrou, 1996; Hirst 1998). Evidence from the General Household Survey (Office for National Statistics, 2002) suggests that compared to women in general, women carers are 23% more likely to have symptoms of psychological stress (Singleton et al, 2002). Recent work using the British Household Panel Survey has suggested that caring has a significant negative impact on the emotional health of carers (Hirst, 1998; Henwood, 1998). Stress among carers is widely reported and is particularly associated with depression; the GHS 2000 evidenced that a third of mid-life carers report feelings of stress (ONS, 2002).

Around one-third of those caring for a disabled spouse experience clinical level depression (Levin et al, 1994; Ballard et al, 1994). In Liston et al's study (1995), one third of the 93 carers interviewed felt their health was affected by caring, with nearly two thirds reporting stress and half reporting depression. In a recent survey undertaken by Carers UK (formerly Carers National Association), 65% of carers said their emotional health had been significantly affected by caring (CNA, 1992) with 52% being treated for stress related illnesses (Henwood, 1998). The combined negative effects of carers'

having less time for themselves, suffering from poor concentration and tiredness, and being unable to pursue career advancement cause mid-life carers great stress (Hutton and Hirst, 2001). The psychological consequences of caring are most prevalent among people caring for a spouse or parent with a serious disability, dementia or with a chronic mental health condition like schizophrenia (Mooney et al, 2002).

## **Effects on employment**

The relationship between employment and care is not straightforward (Glendinning, 1992; Parker and Lawson, 1994; Caring Costs Alliance, 1996). Caring responsibilities can impact on employment in a variety of ways with reduced levels of participation through fewer hours of work, movement from full-time to part-time employment or withdrawal from the labour market altogether (Department of Social Security, 1999). This is a particular feature of caring amongst mid-life women carers (Phillips et al, 2002). Unlike childcare, the onset of eldercare, its course and duration is more uncertain and unpredictable (Martin-Matthews and Campbell, 1995). Care may be intermittent and demanding, and therefore, both difficult and stressful for an employed person to provide.

Analysis of the Family and Working Lives Survey (1994-5) found that the onset of caring did not affect work for two thirds of respondents, but 16% had stopped work altogether and 10% had reduced their hours (Evandrou and Glaser, 2001). However, as time spent caring increases, there is a greater likelihood that those in work at the onset of caring will stop working (Hutton and Hirst, 2001). In 1995, Joshi et al (1995) found that one in seven of the workforce were involved in caregiving and that the majority of caregivers (80% of men and 60% of women) were in paid employment.

Significant changes in the UK population have led to there being fewer younger people, and a larger number of older people requiring support and care. Future predictions suggest that this situation will continue. The number of people aged over 75 is projected to increase by over 70% over the next 35 years or so (Carers UK, 2001). Over the same period, the number of people most likely to provide care – those aged between 45 and 65 – is projected to rise by only 11% (Mooney et al, 2002). The implications of this for employment are that employers try and retain older workers, particularly women. This results in a situation whereby women in their forties and fifties are being targeted by employers to enter and/or remain in the labour market, while at the same time there are more care demands being made on them.

The nature of work is also changing. As well as employers wanting to retain and attract women, both women and men are working longer hours. One in six employees now works in excess of 48 hours per week and 11% work over 60 hours (Ashdown, 2000). Between 1979 and 1999, there has been a threefold increase in the numbers of women aged 50-54 who are working 40 or more hours per week and increasing numbers of couples both work. Decreasing numbers of permanent jobs and increasing levels of job insecurity are also factors, which make the nature of the labour market different.

## Financial consequences of caring

Research indicates that carers providing substantial amounts of care face much financial hardship (Carers National Association, 1997). Half of these carers' incomes are within the lowest two fifths of income distribution (CNA, 1998) and one in five intensive carers have difficulty paying for essentials such as fuel bills (CNA, 2000). Housing is strongly correlated with income. Parker's research (Parker,

1998) suggests that those who care intensively are less likely than their counterparts to be in owner occupied accommodation. Some of this undoubtedly reflects the prolonged lowered income status of both the disabled person and their carer (Glendinning, 1992).

Caring can also involve extra costs (Glendinning, 1992). To meet these extra costs, carers often draw on their savings and those of the person they care for. Financial stress is also incurred by local authority charges for services such as home care, day care, meals on wheels, and respite care, which have greatly increased over the last decade (Hancock and Jarvis, 1994).

As has been noted many women lose the opportunity to make proper pension provision; one of the key reasons for this is interruptions to employment by periods of caring. This may be a second interruption following an earlier break for child rearing. Those carers who begin caring when they are employed, compromise their earning capacity for the remainder of their working lives as well as for retirement. As Evandrou points out, 'Lower pension rights may extend the employment impact of caring well beyond statutory retirement age' (Evandrou, 1995).

From a review of the literature on the reconciliation of work and family life, Devon et al (1998) conclude that many carers do not have an either/or choice between employment and providing care, but rather must adopt compromise solutions involving a number of strategies. Most mid-life carers aim to achieve a balance between work, family responsibilities and caring for an older relative, rather than giving up work completely.

Recent research funded by the Joseph Rowntree Foundation (Barnes at al, 2002) reveals that factors encouraging people to stay in paid work include: financial necessity, satisfaction with and commitment to work, and the potential of work to offer a respite from caring responsibilities. Factors leading people to leave work include: the increasingly demanding and stressful nature of many jobs, the negative impact of work on their health, the ability to take early retirement with a full pension, and life events which lead them to prioritise their personal and family lives over paid work (Phillips et al, 2002; Mooney at al, 2002). In addition, as we argue above there is a strong rationale for women employees in mid-life to remain in paid work. They need to build up their pensions and pursue work-based aspirations.

# Physical and social consequences of caring

Carers who care intensively are at increased risk of experiencing health problems or disabilities themselves (Arber and Ginn, 1991). The 2000 GHS found that of those mid-life carers caring for 20+ hours per week, a third report having a longstanding illness or disability and three quarters (72%) had consulted their GP about their physical health over the last year (Singleton et al, 2002). Despite this, many carers cannot afford to either be ill or be admitted to hospital due to the intensity of their caring role – particularly if they are not properly supported by services. Early discharge from hospital is of no value to a carer who is told to 'rest' but who must care for her disabled parent or husband. This is particularly the case for sole or primary carers who tend to have limited support from other relatives (Hirst, 1998).

Caring can also have social and personal costs. Leading a life constrained by caring is described by Twigg as 'restrictedness' (1994). This refers to facing a timetable of caring tasks, worrying about leaving the cared-for person alone as well as broader constraints such as a limited social life. Working carers often experience a 'time bind' resulting in less time for themselves and their family (Mooney at al, 2002).

## **Summary and commentary**

There is likely to be an increasing demand for both care of older people and grandchildren because of population trends and the current government emphasis on encouraging as many people as possible to enter and stay in paid employment. Yet, the same trends mean that there will be fewer people available to provide informal care. Women are increasingly moving into the labour market and working longer hours than in the past. Furthermore, one of the effects of the much discussed 'pension crisis' is to make early retirement, whether to provide care or for other reasons, an increasingly unrealistic option for many people.

A second concern is that the costs of caring are carried largely by individuals – primarily women – despite the value to society of the informal care they provide. As noted above, it is individual women who bear the financial consequences if they retire early without a full occupational pension, take a career break, forgo career advancement or reduce their hours of work in order to provide care. The financial consequences in terms of impact on pensions can be long-term, especially for women, who have often been less able to build up their pension entitlement over the years.

# The workplace

There is good evidence that women's physical and mental health can be enhanced by employment outside the home (Doyal, 1999; 2000). Paid work is a potential source of important determinants of mental health including, self-esteem, financial and emotional independence, and social support. However, as Doyal (2000) also observes, work can also be a source of stress when it is poorly paid, of low status, a source of high demands, and offers the person little opportunity for control. It is evident from the work reviewed below, that it is those women whose lives are already most disadvantaged by social inequalities that are most likely to experience the psychological disadvantages and least likely to experience the psychological advantages of paid work.

# Occupational stereotyping and segregation

Men and women do different jobs in different settings with women concentrated in certain areas. Around 31% of all employed women work in the public sector and four out of five public sector workers are female (Equal Opportunities Commission, 1999). In education and health care 69% of all employees are female, and women also predominate in clerical and secretarial work, personal and protective services and sales. Commenting on this segregation, Doyal (2000) points out that the most stressful occupations are those which require a worker to be responsible for the well-being of others: occupations which are predominately filled by women.

As well as vertical segregation between 'male' and 'female' jobs, there is also horizontal segregation between men and women in the workforce. Women are much more likely than men to be in the lowest positions in each occupational setting. They occupy only about one third of managerial and administrative jobs and within this category are likely to be in the lowest grades (Dench et al, 2002). This gender difference in occupational status is reflected in earnings. Despite the Equal Pay Act women still earn around 70% of the average male wage (Equal Opportunities Commission, 2002).

#### **Discrimination**

The evidence that has been reviewed in the sections on income, and employment suggest that women's employment patterns are powerfully determined by gendered structural and situational factors which are not of their own making (Bardasi and Jenkins, 2002). Disadvantage is deepened by discrimination within the workplace.

Women of all ages are affected by sex discrimination in employment and older workers, both male and female, are affected by age discrimination. These combine to result in 'gendered ageism' which is viewed as operating widely within the workplace and is linked to the development of a 'gender culture' (Bernard and Phillips 1998; Tyler and Abbott, 1994). The 'gender culture' has a number of distinct implications for mid-life women.

First, sex discrimination is deeply embedded within organisational cultures, structures and practices; for example women are routinely viewed as ageing earlier and as being 'older' at a younger age than men (Itzin and Phillipson, 1993, 1995; Itzin and Newman, 1995). There is clear evidence of age barriers limiting job opportunities for women aged 55+; which do not apply to men with equivalent qualifications and experience (Bone at al, 1992). Due to this discrimination women's careers are blocked with negative consequences for their income, status and prospects. This trend has implications for retirement; there is evidence that many women leave work before their state pension age due to ageist employer policies (Mooney et al, 2002). There is further evidence from the US (Auster, 2001) that mid-career professional women experience more stress in dual career households than their male counterparts. This study also found that the majority of women are not leaving professional jobs to spend time at home but because of the effects of gender inequality on their working lives

Second, the occupational profiles of women do not fit neatly with the expectations of the man made workplace; no account is made of their roles outside of the workplace or caring commitments. Attempts to improve the position of women employees through equal opportunities policies routinely meet resistance from men and cause conflict between, predominantly male managers and, predominantly female subordinates (Arber and Ginn, 1991; 1995). This pattern of individual and organisational discrimination is likely to be decisive in shaping a range of experiences affecting women in work and retirement; gendered work results in gendered retirement, an issue that we have already explored here.

The cost of age discrimination to the economy is estimated as £31billion in lost production; being without work can have a dramatic effect on physical and mental health: depression being a particular risk of unemployment. Leaving work early has profound implications for pension status and poverty as well as physical and mental health in late mid-life and post retirement (Help the Aged, 2002).

# Summary and priorities for action

In this section we have traced ways in which women's psychological well-being can be affected by processes of oppression and subordination, with a focus on women's lives at work and at home. On the basis of this review we suggest the following priorities for action:

#### Research

- Older women workers: Research to address the deficit of studies concerned with the psychological well-being of older women workers, including studies that explore the psychological survival of women who have worked for decades in jobs that are poorly paid and undervalued.
- Part-time work: Research to explore and compare the retirement experiences of women working full-time and part-time, and which aims to identify the determinants of successful transition.
- The impact of gendered patterns of work: Research to systematically investigate the ways in which gendered work affects other areas of the lives of mid-life women, including their friendships, housing, accommodation, leisure and education and the consequent implications for their mental health.

## **Policy**

- Caring: Much greater development of support for carers, including changes to benefits and pension entitlements, greater flexibility in the way work is organised and specific provisions within the work environment such as access to telephones and work-based counselling services.
- Family friendly policies: To date these have mainly focused on working parents with young children. Greater attention now needs to be given to those caring for dependent relatives or grandchildren. These could include, for example, phased retirement or career break without incurring pension penalties, extended lunch breaks, home working and opportunities for working in the evenings.
- Value and status: Greater public acknowledgement of the contribution made by those who care
  for vulnerable others. A change of culture within the workplace and wider society to recognise
  and value the contribution of mid-life carers and develop an 'ethic of care', so that the
  psychological and emotional consequences of caring are not to continue to fall inequitably on the
  pivot generation of women.
- Retirement: Protecting the universal state retirement pension as this ensures a minimum income for many women entering retirement with little occupational or private pension.
- Organisational policies and practices: Studies which increase understanding and appreciation of the
  ways in which age and gender interact in constructing present organisational policies and
  practices, which affect both work and retirement.

#### Mental health

- Carers: Preventative interventions including primary care support and enhanced support for the cared for person that are accessible to a wide range of carers. There is evidence of what is effective in supporting carers: more needs to be done to ensure women gain access to support at an early stage in the care trajectory and in a flexible and coherent way.
- Recognition: Service providers need to develop greater sensitivity to the psychological implications of the work and home roles of mid-life women; they need to provide interventions that are appropriate to juggling a range of responsibilities but do not pathologise women or medicalise their needs.

# INEQUALITY, SERIOUS ABUSES OF POWER AND MENTAL HEALTH

# Physical and sexual abuse

The existence of structural inequalities creates opportunities for very serious abuses of power. Physical and sexual violence and abuse, perpetrated overwhelmingly by men is a common and sometimes covertly sanctioned means of expressing and maintaining dominance in family and community settings. Research shows that between one in ten and one in three girls experience sexual abuse in childhood – depending on the definition of abuse and at what age childhood is deemed to end. Violence can and does occur over the lifespan, from childhood to old age, with elder abuse being the most recent aspect of domestic violence to receive sustained research attention. The lifetime prevalence rates for women experiencing domestic violence is one in four, and the peak incidence of physical and sexual violence occurs in young women (Domestic Violence Data Source, 2002). The mental health implications of these power abuses are now well substantiated (Goodman et al.,1999; Harris and Landis, 1997; Ristock, 1995; WHO 2000). Indeed, physical and sexual assault are normative experiences in the lives of women who have serious mental health problems, who are homeless or living in secure psychiatric services.

By mid-life substantial numbers of women will have experienced these kinds of trauma often in conjunction with other forms of exploitation and oppression. Those that have had the resources and opportunity to work through their psychological impact will be well placed to make the best of their futures. However, many will not be so fortunate: unfortunately as yet most statutory mental health services are ill equipped to support women and find some resolution to these profound experiences of disempowerment (Williams and Scott, 2001).

# Summary and priorities for action

While women at mid-life do not appear to be at high risk of physical and sexual abuse when compared with younger women and children, many women arrive at mid-life with histories of trauma. There is still much we need to know about how mid-life women survive and cope with these experiences, and the effects on many areas of their life including their education, work and relationships.

On the basis of this review we suggest the following priorities for action:

#### Research

• The impact of trauma: Studies to explore the ways that a history of trauma can affect the psychological well-being of mid-life women, including through the impact on education, work and relationships.

## **Policy**

• Tackling abuses of power: Public bodies and services need to continue to name the abuse of power as a serious problem for individuals and our society, and to work together to prevent and redress the problem.

#### Mental health

- Recognising abuses of power: Mental health services need to heed the research findings and name
  abuse of power as one of the key determinants of mental distress and the difficulties that are
  called madness.
- Competence in dealing with abuse: Mental health services need to develop competence to deal with the mental health implications of sexual, physical and emotional abuse. The understanding and skills needed to work with mid-life women will both be different from those needed to work with younger women although they will share a skill and knowledge base.

# INEQUALITY, MID-LIFE CHALLENGES AND MENTAL HEALTH

In 1996, Apter offered this observation:

'There is, for the generation of women now in mid-life, no typical family type or employment pattern. Different women report entirely different senses of constraint and opportunity'. (Page 558).

She queries whether it is reasonable to speak of general changes in mid-life. The data reviewed here would support the considerable diversity amongst women in their experience of mid-life, but suggest that there are also important patterns that are related to the existence of social inequalities in our society, and also to some shared challenges that characterise this particular phase of life.

# Relationships

# Marriage

At the ages of 50-54, the Family Resources Survey (Baker and Harris, 2000) found that 82% of men are married and 79% of women. Whereas 74% of men and only 48% of women are married amongst those aged 70-74.

Research consistently shows that the mental health benefits of marriage are greater for men than for women and that men who are married are less likely to report symptoms of depression than their unmarried counterparts (Earle et al., 1998; Williams, 1984). This is perhaps unsurprising when we take into account the fact that marriage is an institution like other social institutions, and as such tends to meet men's needs better than women's. Whilst generally speaking, marriage functions as a buffer against depression, evidence suggests that the quality of marital relationship in mid-life is the important mediating variable, rather then marriage per se. Unhappily married women are much more likely to be depressed than whose who report higher levels of marital satisfaction (Earle et al, 1998). Such findings indicate that marital status itself may be a less powerful indicator of emotional well-being at mid-life than marital satisfaction, self-rated health, and employment status. This has some common sense validity and is reflected in evidence relating to late-life marriage (Milne and Hatzidimiriadou, in press).

#### Children

When children leave home it is likely to have different emotional resonance for today's mothers than for their own mothers, largely because of shifts in women's roles and sources of identity. In the 1960s and 1970s there was much discussion about the 'empty nest syndrome' (e.g. Harkins, 1978), a syndrome for which there seems to be little evidence (Dennerstein et al, 2002). More recently there are indications that for a growing number of families, their children leaving home is a transitory rather than permanent phase due to the rising cost of housing and education. Interestingly, a large Australian study (Dennerstein et al, 2002) found that for the majority of women in their sample, their last child leaving home had a positive impact on their mood and their level of stress. Characteristically there were women who were not worried about their children leaving home.

#### **Childless women**

In 1998 16% of women aged 45 were childless – it is anticipated that this trend towards increased childlessness will increase. So that nearly a quarter of women born in 1973 will be childless when they reach the age of 45 (Women and Equality Unit, 2000). It should be noted that employment rates and hours of work are closely related to parental and caring responsibilities. For childless women these are likely to be higher than those for mothers. For fathers the opposite applies – men with children are more likely to be working and working longer hours than men without children (Equal Opportunities Commission, 2000b).

#### **Divorced women**

The significance of marital dissolution for mental health is well documented. For example, in their large US survey Earle et al, 1998 found that separated people are three to four times as likely to be depressed as the married. Divorced people now account for 8% of the adult population, compared with only 1% in 1971 (Equal Opportunities Commission, 2000c). In 1998 separated and divorced women together formed nearly three fifths of lone mothers, with single women comprising two fifths.

The divorce rates for women and men 45+ are much lower than for younger age groups (Dench et al, 2002) (Table 5). However, divorce at mid-life is likely to have different material and psychological implications than when it occurs at an earlier time of life. A longitudinal study carried out in the US in the 1980s (Wallerstein, 1986) found that most women in the sample who had divorced in their 20s and 30s had re-established themselves emotionally, socially, and vocationally 10 years post divorce. In contrast, many of the women who were aged between 40 and 55 when they had divorced had not. These women continued to suffer from losses of self-esteem and income and many were depressed and lonely. Although there were some women in this group who welcomed divorce, these women were in a minority. While this study was carried out in the US some time ago, many of the contextual challenges faced by women are likely to be generalisable to this country in the 21<sup>st</sup> century. This includes the loss of income and the decreasing social value and loss of self esteem which often accompanies divorce; this acts as a barrier to establishing new relationships and picking up the threads of a new life (Coone, 1991). Particularly at risk will be women whose employment history has been intermittent (Bogolub, 1991).

#### Widowhood and bereavement

The 2000-2001 General Household Survey indicates that significantly more women live alone in later life than men. A key cause of this is widowhood; as women tend to marry older men, they are more likely to be left widowed in their mid or later lives. In the age group 65-74 yrs, 37% of women live alone and in the 75+ age group this applies to 60% of women; corresponding percentages for men are 19% and 33%. In mid-life – 45-64 yrs – very similar numbers of women and men live alone; 15% and 16% respectively (OPCS, 2002; Dench et al., 2002) (Table 6).

The impact of grief caused by the loss of a long term partner can be serious and long term. Many studies indicate significant increases in mortality and morbidity follow the death of a loved one. Particular risks are associated with the first six months. Common feelings include: shock, numbness, disbelief, anxiety, sadness, a sense of meaningless, loneliness, confusion, anger, guilt and relief; the latter is usually associated with release after a long illness or very stressful long term caring for a person with dementia (Nolan et al, 1996; Briggs and Askham, 1999). Sometimes sufferers also

experience sleep and appetite disturbance and a preoccupation with thoughts of the deceased. Many newly bereaved people withdraw from social contact; some may do so permanently (Littlewood, 1992). The consumption of alcohol and tobacco may also increase.

Table 5: Divorce rates by sex and age

# Divorce rates by gender and age group, England and Wales, 1999

Rates per thousand of married population Age Women Men 16-24 30.3 29.0 25-29 32.3 31.5 30-34 27.3 28.4 35-44 19.4 21.7 45 and over 5.1 6.3

Source: Office for National Statistics

Data for figure 2.11

Table 6: People living alone by sex and age

People	living	alone	by	age	and	gender:
	Great	Britaiı	1, 2	000	200	1

Age	Women	Men
	%	%
16-24	4	6
25-44	7	17
45-64	15	16
65-74	37	19
75 and over	60	33
All ages	18	16

Base: All persons aged 16 or over

Source: General Household Survey, 2000-2001

Data for figure 2.9

The impact of widowhood on a woman's emotional and psychological well-being is significant. It represents a multiple loss; loss of a confidante, sexual partner and social role are all involved to a greater or lesser extent. These personal losses may be accompanied by economic deprivation associated with the loss of the partner's income or pension. A number of authors have suggested that the impact of bereavement may be particularly severe upon women who have occupied the traditional role of wife; when widows say their life has no meaning it is a literal truth, for it is through the relationship she defined herself and her identity (Littlewood, 1992).

#### Isolation and Ioneliness

As already noted a number of significant life changes occur in mid-life – retirement, relocation, widowhood, and bereavement; these tend to reduce the size and quality of an individual's social network (Victor et al, 2000; 2002). Of particular note is the consequence of living alone. Isolation and loneliness appear to be more common among those living alone (Andersson, 1998); higher numbers of widowed or divorced women report loneliness as a concern (Milne et al, 1999). Further, there is an increase in the number of people reporting loneliness with advancing age (Audit Commission, 2000). This suggests a causal link between living alone, isolation and loneliness as the proportion of people living alone increases with age (Wenger, 1996).

# Health and the menopause

The General Household Survey (GHS) collects a range of information about self-perceived health. There is little difference between males and females on these measures, but as people get older they tend to be more likely to report both longstanding illness and restricted activity. Around 45% of women aged between 45 and 64 years, and 61% of those aged 65 to 74 reported a longstanding illness (Table 7). 19 percent of those aged 45-54 report that they have a disability (Table 8).

There is widespread cultural approval for supporting the physical well-being of mid-life women through exercise and diet. As an approach to the menopause, it is widely favoured by those who are opposed to the medicalisation of the menopause and its 'treatment' through hormone replacement therapy (HRT). Cousins and Edwards (2002), for example, conclude:

'we show that active living is a worthy alternative – potent for health promotion, broader than hormones in its benefits, and is the more empowering and ethical route for women's long term health' (Page 325)

However, these authors rightly note that this strategy is not equally attractive and accessible to all women. The general trend in the recent SIRC study (2001) was one of improvement in women's lives post menopause, particularly for those taking HRT. The positive effects are particularly experienced by middle class well educated women. Research in this country (McCarthy, 2002) and Canada (Morrow, 2000) notes that women with disabilities encounter systemic barriers to information and help around managing menopausal symptoms. There are indications, therefore, that social inequalities also impact on the management of the menopause – advantaging some women whilst disadvantaging others. In the face of growing evidence that the health risks of HRT are greater than first anticipated, it would seem wise to increase our understanding of the menopause and its management through exploring it within its social context and from the perspective of non-medical intervention. Women are often only offered HRT as treatment for menopausal symptoms. More information about alternatives to HRT, which is evidence-based, should also be available to enable women to make an informed choice.

Table 7: Self-reported sickness by sex and age

Self-reported sickness: by type of complaint, gender and age, 2000-01

Great Britain

Percentages

	Poor general health	Longstanding illness	Limiting longstanding illness	Restricted activity <sup>2</sup>
Males				
0-4	4	14	4	11
5-15	3	23	9	10
16-44	6	23	11	10
45-64	18	45	27	17
65-74	22	61	38	20
75 and over	29	63	44	23
All	11	33	18	13
Females				
0-4	3	13	4	7
5-15	3	18	8	11
16-44	8	22	11	12
45-64	16	42	27	19
65-74	21	54	35	21
75 and over	26	64	48	27
All	12	32	19	15

Source: General Household Survey, Office for National Statistics 1 See Appendix, Part 7: Self-reported sickness

<sup>2</sup> In the 14 days before interview

Table 8: Disability by sex and age

Prevalence of disability by age – women: UK, 2001							
Women	16-24 %	25-34 %	35-44 %	45-54 %	55-59 %		
Any disability	9	11	16	23	39		
DDA disabled	6	8	12	19	34		
Work-limiting disabled	7	9	13	19	33		

Base: All people of working age

Source: Labour Force Survey, Spring 2001

Prevalence of disability by age - men: UK, 2001

Men	16-24 %	25-34 %	35-44 %	45-54 %	<b>55-64</b> %
Any disability	8	13	17	26	36
DDA disabled	6	11	14	22	31
Work-limiting disabled	6	10	13	21	30

Base: All people of working age

Source: Labour Force Survey, Spring 2001

# Summary and priorities for action

In this section we have considered some of the specific challenges that characterise the lives of many mid-life women.

#### Research

- Naming the risks: A longitudinal panel study that started with an inclusive sample of women aged 50 would provide an invaluable source of data for teasing out the causal pathways, interactions and effects of social inequalities on psychological well-being.
- Roles and relationships: The role of private 'choices' such as getting married, having children, getting divorced on women's well-being and the consequences of early life 'choices' on later-life issues such as widowhood would be valuable.
- Menopause research: Research on the effectiveness of alternative treatments to HRT is needed.
  Additionally, information about the menopause and treatment choices need to be offered to
  marginalised groups of women, e.g. ethnic minority groups, and those who have physical,
  psychiatric or learning disabilities.

## **Policy**

• Employment policy: Employment policies and practices that facilitate the inclusion of mid-life women with ill health or disabilities.

#### **Mental Health**

• Information about the menopause: Women find balanced and coherent information about the menopause empowering; thus it should be made accessible to all women in all situations. The long term benefits of HRT as the treatment for menopausal symptoms is not yet proven conclusively and alternative, evidence-based treatments should also be promoted.

# INEQUALITY AND VULNERABLE GROUPS

The data reviewed above suggests there are substantive grounds for identifying the groups of women who are especially at risk of mental health problems in mid-life. Included here would be women whose access to valued material and psychological resources have been seriously affected by inequalities such as race, class and disability. Also included are women who have not been able to protect themselves from experiences of oppression and discrimination, which leave them, feeling diminished, constrained and blamed. Finally, at risk are women whose childhood and adult lives have been marked by sexual and physical violence, abuse and trauma.

It is important to note at this point, that some women enter mid-life with the benefit of the accumulated privileges of class and race. They include women who are well educated, middle class and white and those who are materially and psychologically secure due to valued domestic and work roles. Women who feel able to rightfully exercise power and control in their lives are psychologically advantaged. They may face similar challenges to their less advantaged peers around the menopause; sexism and ageism, and continuing and emergent demands for family care. However, they are less likely to experience these demands as overwhelming, and more likely to have choices about how they respond to these challenges e.g. buying in childcare or support for ill parents (SIRC, 2001). Indeed, a number of women in this group are reported as finding a number of their mid-life challenges to be new, or additional, sources of satisfaction (e.g. Reid and Hardy, 1999). Retirement for example, may offer a middle class professional woman with financial resources and good health, a new set of social and educational opportunities.

There is insufficient space within this review to explore the mid-life challenges facing women from black and ethnic minorities in any depth but it is helpful to acknowledge that evidence from existing research suggests that racism extracts a mental health cost for women (Milne and Williams, 2000).

# Summary and priorities for action

Focusing specifically on the psychological needs of mid-life women from disadvantaged social groups, we suggest the following priorities for action:

#### Research

- Marginalised women: Comparative research that explores the experience of mid-life for different groups of women, including those who are socially marginalised
- Differences between women in mid-life: Differences in histories, life styles and futures amongst mid-life women need to be made more evident, rather than submerged, by research in this field. mid-life women are not a homogeneous group.
- *Hearing the voices:* The voices of women from these marginalised groups need to be amplified through research.

# **Policy**

- Challenging disadvantage: Policy interventions that increase mid-life women's access to money, work, choice and value, and which support them to find workable solutions to the challenges of mid-life.
- *Policy informed by women*: Policymakers need to ensure that policy is informed by the needs, views and experiences of women from marginalised social groups.

#### **Mental Health**

• Divergent groups of women: Mental health workers need to be aware of the consequence of further de-valuing mid-life women, and be responsive to the mental health needs of women across the social, racial and cultural spectrum.

# MENTAL HEALTH OUTCOMES

This sub-section will outline the prevalence of mental ill health amongst mid-life women and service responses.

# Patterning of distress in this group

Women aged 45-64 on average visit a general practitioner (GP) 6 times a year (Table 9). Women of all ages are more likely than men to contact a GP about a mental health difficulty. More specifically, 16% of women aged 55+ were estimated to visit their GP in 1999 for this reason, compared to 13 percent of men (Table 10). Interestingly the rates for these women are lower than those for younger women. Whether this reflects actual differences in psychological well-being, or GP insensitivity to distress in older women is hard to determine from these data. The model of ageing which dominates medicine assumes an inevitable decline in physical and mental well-being from middle age, may play a role in this context.

# **Anxiety and depression**

In terms of self-reported distress, 24 % of women in this age group report anxiety or depression (Women and Equality Unit, 2000). More specifically, a consistent finding in community studies of depression is that rates for women are approximately double those for men (Beekman et al, 1999; Copeland et al, 1999).

The key risks for developing depression lie in a range of social and economic vulnerabilities, many of which have been identified in this review. Bereavement; retirement; recent divorce; isolation and loneliness; and poverty, are all powerful determinants of depression. As they are regularly and cumulatively experienced by women in mid-life they are clearly at enhanced risk of experiencing depression (Bowling et al, 1997; Bowling and Browne, 1991). The lack of a confiding relationship appears particularly significant (Brown and Harris, 1978).

# Reliance on drugs and alcohol

Self reported average weekly alcohol consumption of women aged 45-64 in 2000 was 6.2 units a week; half that consumed by younger women (Table 11). However, there is evidence that alcohol abuse amongst women is largely hidden, and amongst mid-life women is rarely identified as a social or personal problem. There is some evidence that particular groups of women are vulnerable to both alcohol and drug abuse. These are isolated and depressed women who live alone (Corrigan and Butler, 1991; Davidson and Marshall, 1996), non-English speaking women who are culturally isolated (Russo, 1990), and those who are homeless (Kutza and Keigher, 1991). The extent to which mid-life women are dependent on prescribed drugs is unclear although it is likely – given older women are the largest sex-age group prescribed psychotropic medication – that this is a pattern established during mid-life. Finally, 27% of women smoke in the 50-59 age group, and while these are lower rates than for younger women they still represent a significant health cost.

# Service provision

As yet, mid-life women are not a defined group that demands – or appears to 'need' – a separate or distinctive response from mental health services, nor have they been identified as such within the recent mental health strategy for women's mental health services (Department of Health, 2002). However, the existence of this strategy, as well as other evidence (e.g. William et al, 2002), indicates that the majority of women are very dissatisfied with statutory mental health services. A primary concern is the lack of demonstrable interest shown in a woman's past life, those needs who's roots lie in social and economic disadvantage, or her current social and emotional context:

'Our needs are ignored, we are treated as illnesses'. (Williams et al, 2000, page 5).

'The responsibility that many women have, beyond themselves, is not really acknowledged, Most of the time it is not just the women in front of them they have to "treat" but the whole system that she cares for, supports emotionally and is needed by. Some women may need to get away from the "system" they are in but they will do this with enormous anxiety so that has to be addressed' (Williams et al, 2000, page 10).

Table 9: GP consultation by sex, age and year

<b>NHS GP consultations</b>	per vear.	by age.	Great Britain	1998 and 2000
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#### Average number of consultations per year

	Women 1998	2000	Men 1998	2000
All ages	5	5	4	4
0-4	6	4	6	6
5-15	3	3	2	2
16-44	5	5	3	3
45-64	6	5	4	5
65-74	6	7	5	6
75 and over	6	7	7	6

#### Base: All persons

Source: Living in Britain: Results from the 2000/02 General Household Survey

Data for Great Britain shows that women make greater use of GP services than men. When expressed in terms of the number of GP consultations per year, women average five such consultations, and men four.

Table 10: Help-seeking for a mental health difficulty by sex and age

Proportion contacting a GP about being anxious or depressed for a mental, nervous or emotional problem, by age, in the past year: England, 1999

	Wor	M					
16-34	35-54	55+	All ages	16-34	35-54	55+	All ages
18	24	16	20	11	18	13	14

**Base: All persons aged 16 and over** Source: *Health Survey for England, 1999* 

Table 11: Weekly alcohol consumption by sex and age

		Nui	nber of u	nits	
	1992	1994	1996	1998	2000
Women					
16-24	7.3	7.7	9.5	10.6	12.6
25-44	6.3	6.2	7.2	7.1	8.1
45-64	5.3	5.3	5.9	6.4	6.2
65+	2.7	3.2	3.5	3.3	3.5
All ages	5.4	5.4	6.3	6.4	7.1
Men					
16-24	19.1	17.4	20.3	23.6	25.9
25-44	18.2	17.5	17.6	16.5	17.7
45-64	15.6	15.5	15.6	17.3	16.8
65+	9.7	10.0	11.0	10.7	11.0
All ages	15.9	15.4	16.0	16.4	17.4

Base: All persons aged 16 and over

Source: Living in Britain: Results from the 2000/01 General Household Survey

Care management and the Care Programme Approach (CPA) were intended to be a key organisational mechanism for delivering the aims of community care policy. However, these systems for allocating and distributing welfare resources were not intended to address issues of structural inequality. The individualisation of need, which is at the heart of CPA, dislocates the woman from her social and historical 'world' and fails to define, and therefore, to meet, those needs with social, economic or historical causes. The status and value accorded mid-life women also makes it difficult for them to voice their needs and many lack the income, and social resources, to deploy creative choice.

This is a particularly powerful issue for those mid-life women whose histories are characterised by a high level of involvement with psychiatric services. Such women are highly likely to have survived traumatic childhoods, and an adult life of deprivation and disruption (Williams and Scott, 2000). The quality of mental health services means that most will have received little help to change the trajectory of their lives. Instead, they are likely to have been further re-victimised within services and over medicated (Warner and Ford, 1998; Williams and Keating, 2000). It is axiomatic that women who have already experienced abuse or trauma do not receive mistreatment or abuse within services.

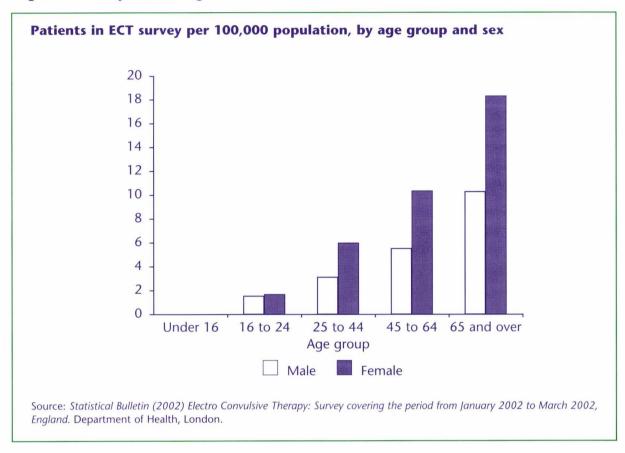
'I feel threatened by men, they get more angry and I've been sexually assaulted by a man on the ward. When I need to use the bathroom at night there are often men wandering in the corridor' (Williams et al, 2000 page 6).

In addition to the very real possibility that they will be sexually victimised or re-victimised within mental health services, most women have to endure inequalities within services which render them, as service users, dependent and powerless.

'Treatment and care generally involved women being powerless in the process. Not being listened to, or consulted, forced to take mediation or sectioned. Women need to be allowed to control their own lives'. (Williams et al, 2000, page 9).

We also note that the risk of ECT increases with age – almost twice as many women receive ECT as men (Figure 6). The difference between the rates for females and males is apparent in all age groups recorded in the survey, with a more pronounced difference in the oldest age groups.

Figure 6: ECT by sex and age



#### **Clinical interventions**

Whilst there is growing acknowledgement that women with mental health problems require individualised care, little attention has been paid to the existence and meaning of gender, class and race by professionals. They often fail to analyse the experiences of women and men separately, which presents as 'neutral' the gendered challenges of mid-life and ageing.

Whilst efficacy of treatment for depression suggest that mid-life women may be as responsive as younger people to talking therapies, recent evidence suggests that age is negatively correlated with the likelihood of patients receiving psychotherapy and family therapy; this suggests a persistence of a belief that older people are either not worthy of, or do not benefit from, therapy. Whilst some attention has been given to developing appropriate models of psychotherapy for work with people in mid-life, little work has been done to either develop gender appropriate models, or to evaluate the effectiveness of current therapy models for women (Milne and Williams, 2000).

# Summary and priorities for action

In this section we have summarised research relating to mental health outcomes for mid-life women and service responses to their needs. We suggest the following priorities for action:

#### Research

- Mental ill health amongst mid-life women: More work is needed both from an epidemiological perspective and an experiential one, to map the extent and nature of mental ill health amongst mid-life women. What women consider would ameliorate their mental ill health would also be valuable.
- Women with enduring mental health problems: Studies that help to determine the factors that differentiate women who first seek help from mental health services at mid-life, from those who have been long term users of these services.
- *Treatment regimes*: Gather more precise data about the use of physical treatments to manage the distress of mid-life women and in which contexts these treatments are delivered.
- Safety in services: Women-only facilities go only part way to ensuring safety for mid-life women receiving in patient care. More work is needed in partnership with women service users to identify how to make services safe for women.

## **Policy**

- *Mid-life women*: Ensure that women in mid-life who are experiencing mental distress are differentiated and identified explicitly in mental health policy
- Safety in services: It is likely that research into safety in services will result in a need to develop and implement safety policies for mental health services.

#### Mental health

- What women want: Find out directly from mid-life women using services what they want from services, professionals and others in their context e.g. family members.
- Extend talking therapies: Women find talking therapies helpful. It is vital to offer wider and easier access to a range of talking therapies in mental health service settings and in primary care.

# CONCLUDING COMMENTS

Women in mid-life are a complex, heterogeneous and diverse cohort. Their lives and health related challenges are unexplored and they are rarely conceptualised as a 'group' by services, researchers or policy makers. They remain largely invisible. Yet, much like women's relationships with their family, community and jobs, it is only when the focus turns to what is actually managed and achieved on a daily basis, that the sheer breadth and depth of the mid-life woman's 'lot' becomes apparent. This most often occurs when the woman 'fails' or is exposed as not 'coping' with her multiple roles.

This review has highlighted the key dimensions of the lives of mid-life women which do – or might be expected to – have an impact on their emotional and psychological well-being. The literature reviewed exists in a number of different domains and emanates from a number of sources. To date this group of women have received very little specific attention, and the literature reviewed here has been somewhat uneven; much evidence is 'hidden' in broader texts.

The authors have focussed on what is distinct or unique about mid-life women's lives and the mental health challenges they face, rather than what is shared with other groups. Some dominant themes emerge. There is a powerful sense that mid-life women are at a crossroads or in transition from one stage of life to another; some decisions have already been made e.g. whether to have children or not, and there are certain facets of life which are unlikely to substantially alter, such as career choices. She is often juggling several roles: wife/partner, mother, worker and is often asked – in addition to these demands – to support her ailing parent/parent in law. Mid-life carers are predominantly women. A core component of her life is providing care for others, often at immense personal and psychological cost. Divorce and widowhood are also significant life changing events which many mid-life women face; both exact a considerable mental health cost on women. She is also much less likely to remarry than a younger woman and must accept living in a single person household, most probably for the rest of her life. Her income status may be relatively established and it is at this stage of life that women are obliged to come to terms with decisions made earlier in life. For example, as a consequence of working part-time to look after children, a woman's pension will be significantly lower.

This is not to present a negative picture of mid-life, merely to be honest about the nature of this stage of life, the mid-life – between past and future, and between youth and old age. For some women the changes are beneficial. It is also useful to note that even the dominant themes need to be interpreted with care as there is much variety both within and across the mid-life period (45-60 years). Particular groups of women – black women, women with enduring mental health problems – will be facing additional and different challenges.

Another key theme relates to the role and impact of social inequalities. The literature does show that both lifelong and age-related social inequalities create and perpetuate psychological distress in mid-life women. This period of life is a point when the cumulative effects of lifelong privilege or disadvantage find expression in great diversity amongst women; these are revealed in their experiences, contexts, physical and emotional well-being, and future life opportunities. Whilst mid-life women will be facing common challenges such as discrimination and oppression in the workplace, and ageism, they will be more or less able to deal with these on the basis of their socio-economic status, work opportunities, personal histories and health. Those mid-life women with least resources face the greatest challenges to their mental health; they are the least powerful and the most marginalised.

There is a widespread societal assumption that this group of women will continue to absorb the impact of changes related to ageing, family life, the community and the workplace; that they will simply carry on shouldering the burden of an increasing and often complex range of demands, demands which may compromise their well-being and mental health. It is testament to their strength that so few appear to develop mental illness although we need to be cautious before making this assumption as we know little about the genuine prevalence and incidence of mental illness in this group. We know even less about the effects of juggling multiple roles on women's more general psychological health and quality of life and on ways that they avert or survive mental health crisis.

Opportunities to alleviate distress and disadvantage and reduce the mental health costs on mid-life women lie in the arenas of research, policy, and services. Having identified some of the key parameters of the debate it is important that investment is made in: building up a more robust evidence base around the mental health of women in mid-life; developing policy that focuses on the needs of this group, and developing services that explore ways to support and meet their needs. These changes need to be underpinned by the voices of women. If we are to meet the needs of future generations of mid-life women it is imperative that we gain a much clearer understanding of their experiences and views, and their management of the mental health challenges that mid-life presents.

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# Notes

# Notes



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# **Published August 2003 by**

The Mental Health Foundation 83 Victoria Street, London SW1H 0HW Tel: 020 7802 0300 Fax: 020 7802 0301 Email: mhf@mhf.org.uk

Scotland Office 5th Floor, Merchants House, 30 George Square, Glasgow G2 1EG Tel: 0141 572 0125 Fax: 0141 572 0246 Email: Scotland@mhf.org.uk

> www.mentalhealth.org.uk Registered charity number: 801130

© Pennell Initiative for Women's Health

ISBN 1 903645 47 6

Price: £12.00

# "ISN'T HE WONDERFUL?" EXPLORING THE CONTRIBUTION AND CONCEPTUALIZATION OF OLDER HUSBANDS AS CARERS

#### ALISOUN MILNE AND ELENI HATZIDIMITRIADOU

This paper explores the relationship between the dimensions of a debate cited at the intersection of ageing, gender, and family care. It draws together evidence from the General Household Survey for Britain 2000 and social research to explore the contribution and conceptualization of caring by older husbands. UK research on caring reveals that among older spouses, equal numbers of husbands and wives provide intensive care. It has been argued that within late-life marriage an over-riding desire to retain independence erodes gender-determined task allocation, suggesting not only similarity but equality between wives and husbands as carers. More recent qualitative research challenges this assumption and suggests two key findings: that older husbands are motivated to care by a combination of marital duty and reciprocal love, and that they manage the tasks of caring within an instrumental framework. Further, it is clear that pre-existing gender relations continue to be powerful determinants of the experience of caring, and that marital power is retained by men in late-life marriage. Overall, the caring contribution of older husbands is imbued with positive meaning, is highly valued, and offers a distinctive role and identity; this contrasts sharply with the caring experiences of older wives.

#### Introduction

The aim of this paper is to explore the unique nature of caring by older husbands (defined as 60 years of age or older), a group hitherto marginal to the research and policy agenda. It reviews evidence from sociological discourse and from social research to explore the contribution and conceptualization of caring in this context, and presents a synthesis of evidence. Current knowledge tends to be drawn either from large data sets such as the General Household Survey or from small-scale phenomenological studies. Critical analysis of evidence from a range of sources has not been at-

tempted previously, limiting understanding of the depth and breadth of caring by older husbands and presenting only a partial picture of this complex issue.

The paper is presented in three main sections. The first section provides an overarching context for the paper; the second section outlines evidence from the General Household Survey 2000; and the third section focuses on a review of the literature exploring the motivation and meaning of caring by older husbands. Key points and research directions are discussed in the conclusions. The majority of literature reviewed is from 1990 onward and the primary focus of the paper is the UK, although some relevant evidence is included from North America.

#### Older Husbands as Caregivers: The Context

A number of interlocking strands underpin the interest in older husbands: a renewed focus on family caregiving; caring as a gender- and age-related issue; and aspects of caregiving. These will be reviewed in brief before introducing caregiving in later life and spouse caregiving.

#### Family Caregiving

There is renewed state and professional interest in the whole issue of family caregiving, to which a number of interrelated factors have contributed. A significant issue is the increasing numbers and proportion of older people in the population, particularly those aged over 75 years, the group most at risk of developing a physical or mental frailty (OPCS, 1998). Given the established link between increased longevity and relative dependency, the challenges posed by the ageing population are inescapable (Askham et al., 1992). Another factor is the development of community care policy underpinned by a new vocabulary of individual autonomy and responsibility, and a shift in rhetoric from a focus on care in the community to care by the community (Department of Health, 1990; Johnson, 1995). This relates to a third factor, the erosion of public-sector support services and the capping of community care budgets. In an effort to achieve more cost-effective use of scarce resources, increasing emphasis has been placed on the role of the family as the mainstay of care provision, particularly in maintaining community-based living for frail older people (Arber & Evandrou, 1993). The fact that family carers save the British state about £57 billion per year (Carers UK, 2002) lends considerable support to the contention that there is a primarily instrumental motivation behind the current policy emphasis on increased support for family carers (Twigg & Atkin, 1994; Evers, 1995).

#### Caring as Gender and Age Issue

A crucial strand in the history of heightened consciousness around caring has been the evidence presented by feminist researchers from the late 1970s

and early 1980s, who conceptualized family care as primarily unpaid, unrecognized domestic labor for women (Dalley, 1993; Graham, 1991; Gerstel & Gallagher, 2001). Caring was viewed as reproductive work, and as such an integral part of the social division of labor (Evandrou, 1996). A succession of theoretical and empirical papers drew attention to three key issues: first, to structured inequalities in the distribution of caring between men and women that were embedded in social policies and practices; second, to the negative material, physical, and psychological consequences of being a carer, and third, to the ways that expectations around the provision of informal care reinforced particular gendered definitions or conceptions of male and female roles and identities (Dalley, 1996; Davidson, Arber, & Ginn, 2000). In particular, it was argued that through early socialization processes, women learn that it is "natural and normative" for them to provide family care.

Two important criticisms of these arguments emerged during the late 1980s and early 1990s. Evidence from the 1985 and 1990 General Household Surveys (GHS) suggested that substantially more men—particularly husbands—were involved in family caring than previously had been thought, and that a significant number were involved in providing intensive care for many hours per week (OPCS, 1989; 1993; Fisher, 1994). It revealed a particular pattern among older spouses: that as many husbands provide care for their wives as wives do for their husbands (Arber & Gilbert, 1989; Rose & Bruce, 1995).

A second criticism was based on the fact that most research emphasized the plight of filial caregivers (Manthorpe, 1994) and focused primarily on caring for a physically disabled older person (Finch & Groves, 1983). Only comparatively recently have we begun to understand how caring within the context of later-life marriage differs from intergenerational caring (Arber & Ginn, 1995a & b; Davidson, Arber, & Ginn, 2000). It was noted that this area remains under-researched, and that the care given by older men to their ailing spouses has been almost totally neglected (Thompson, 1993; Kramer & Lambert, 1999; Orme, 2001). The revelation that many older people are providers of care and that a great deal of mutual caring occurs between older couples has led to an acknowledgement that any analysis of family care must take account of age as well as gender (Rose & Bruce, 1995; Phillipson, Bernard, Phillips, & Ogg, 2001).

#### Aspects of Caregiving

Field research on carers has enhanced understanding of family caregiving and added depth to existing sociological definitions. Broadly, the concept of caring draws on five key elements: the performance of physical or personal care tasks; kinship obligation; association with emotion and feelings; co-residency (sharing the same household); and carrying primary responsibility for the person being cared for (Twigg & Atkin, 1994; Perring, Twigg, & Atkin, 1990; Askham, 1995). Three particular dimensions have been identified as

significant determinants of the caring experience: physical labor, emotional labor, and taking responsibility for the management/organization of care (Qureshi & Walker, 1989; Graham, 1983; Dalley, 1993; Holland & Adkins, 1996). Research exploring spouse care has reworked these core dimensions, distinguishing between "active sensibility" and "sentient activity" (Mason, 1996). In their study of spouse care, Davidson, Arber, and Ginn summarise the distinction as follows:

Active sensibility ... operates largely on a conscious plane in terms of physical care activities and decision-making in relation to performing tasks. Sentient activity, on the other hand, operates on a less conscious plane and entails consideration for another, sensitivity to likes and dislikes learned over time, and acquiescence to another's wishes through a desire to please (2000, p. 537).

The authors further state that invisible sentient activities are often carried out on "autopilot" so that they are underestimated and undervalued by both carer and care recipient. This is particularly notable in late-life marriage (Davidson, Arber, & Ginn, 2000).

For older spouse carers, caring is both a role and a relationship where all the elements of caring are combined and coexist. It is to caring in later life and spouse caring that we now turn.

#### Caregiving in Later Life

Increasing research evidence suggests that much care of older people is provided by other older people: 2 million of the 6 million family carers in the UK are aged 60 or older (Milne, Hatzidimitriadou, Chryssanthopoulou, & Owen, 2001; OPCS, 2002). More than one-third of people will become carers post-retirement (Rowlands, 1998).

Caring in later life differs in important ways from caring earlier in life in terms of the recipient of care, the duration of care, and the objective burden of care (Hancock & Jarvis, 1994). Older carers are more likely to live with the person they care for; caregiving is likely to take place within the context of a long-term relationship; and there is a greater chance of carers having health problems of their own (Hirst, 1998). Dementia is also more likely to be present (Lewis, 1998). Older carers tend to take on more onerous caring responsibilities and the physical demands are often more stressful (Draper, Poulos, Poulos, & Ehrlich, 1996). A significant amount of care in this context is spouse care; it constitutes a defining feature of late-life caring.

Spouse Caregiving in Later Life

The Caring in Later Life review (Milne, Hatzidimitriadou, Chryssanthopoulou, & Owen, 2001) confirmed existing evidence that about

equal numbers of older spouse carers are male and female. It is also known that a spouse is the most likely person to become the carer for his or her partner in the event of illness or disability that is more likely to occur in older age. Spouse carers particularly predominate where the cared-for person is severely disabled (Arber & Gilbert, 1989); nearly two-thirds of the carers of older people with dementia are spouses (Levin, Moriarty, & Gorbach, 1994).

Although UK research on older spouse caring is limited, a number of trends can be identified. Overall, evidence suggests that older spouse carers tend to offer the most intensive level of support in the most demanding circumstances with little or no support from other family members (Milne, Hatzidimitriadou, Chryssanthopoulou, & Owen, 2001; Maher & Green, 2002). They also provide long-term help with personal and physical care tasks, and do heavy nursing tasks associated with chronic illness (Wenger, 1992). Care is also less likely to be supplemented by formal services (Argyle, 2001).

A key aspect of spousal care is its mutuality and interdependence, with the carer/cared-for roles enmeshed and even indistinguishable from one another. Spouse care—unlike most other caring relationships—tends to be regarded by carer and cared-for as an extension of the intimacy and companionship that characterizes marriage; spouses often fear being separated from one another particularly institutionalization of the dependent partner (Parker, 1983; Lewis, 1998; Arskey, Hepworth, & Qureshi, 2000). Wenger's research findings demonstrate that powerful expectations for care underpin marriage: a spouse will provide "total help, support and personal care as needed" (1990, p. 200). Typically, older spouse carers demonstrate a high level of commitment and devotion to caring: it is central to their lives and based on mutuality and long-term shared residence. Askham reminds us that "one of the basic relationships retained by most people after they lose the fundamental one of employment is that of marriage" (1995, p. 87). Marriage in later life is viewed by many as a mark of constancy and continuity (Parker, 1998), hence, its significance as the bedrock of care for older spouses (Spitze & Ward, 2000).

Exploring the parameters of spouse care in later life is important in its own right, but it is also the arena in which the contribution of male carers was first recognized (Arber & Gilbert, 1989; Parker, 1993; Fisher, 1994). The spotlight of interest that illuminated the extent and nature of spouse care among older people also highlighted the caring contribution of older husbands (Spitze & Ward, 2000).

We now turn to unpublished analysis of data from the General Household Survey 2000<sup>1</sup> (OPCS, 2002), outlining evidence on older husband carers with a particular focus on roles and tasks. We begin with an update of the numbers of older spouse carers.

Gender, Caring, and Age

Of the 2,312 people who identified themselves as carers in the 2000 GHS, one-third are older, and more than half of the co-resident older carers support

spouses (Maher & Green, 2002). Statistically, there are more co-resident male carers (22%) than female (16%) ( $\chi^2$ (7)=22.34, p<.001) (Table 1). This may be explained in part by the higher numbers of older men who are married: in the 1995 GHS sample 88% of older men were married, whereas this was the case for only 72% of older women. A significant number of older carers also support a very elderly parent, a trend which is increasing with enhanced longevity (39% male carers and 45% female carers).

#### Caring Tasks and Length of Caring

Looking at the care provided by older husbands, it is clear that they predominantly provide personal care (48%), physical help (25%), and other practical help (14%). (See Table 2). While caring wives are providing similar amounts of help with personal care (49%) and physical help (24%), they offer lower levels of other practical help (6%) and higher levels of help in giving medicines (8%), keeping the cared-for person company (6%), and keeping an eye on the cared-for person (4%) (OPCS, 2000). Overall, there are no statistically significant differences in the caring tasks performed by male and female spouses ( $\chi^2$  (8)=12.01, p<.151).

One-third of all carers who provide 20 or more hours per week of care (intensive care) are aged 60 or over, and nearly half of all intensive care is provided within the context of marriage or long-term partnerships (Maher & Green, 2002). Among older carers, equal numbers of men and women provide very intensive care, i.e., spend 50 hours or more per week on caring activities (13% and 14%, respectively). Equal numbers of men and women have also been caring for 15 years or more (11% and 10%, respectively), while slightly more women (37%) than men (34%) have been caring for between 5-14 years.

Table 1

Relationship of older carer to cared-for person by gender of carer		
	Gender of carer	
	Male	Female
Spouse (n=95)	45 (21.9%)	50 (15.9%)
Friend/neighbor (n=67)	29 (14.1%)	38 (12.1%)
Parent (n=222)	80 (39%)	142 (45.2%)
Other relative (n=90)	40 (19.5%)	50 (15.9%)
Adult child (n=45)	11 (5.3%)	34 (10.8%)
Total	205	314

Source: General Household Survey 2000 (OPCS, 2002)

Table 2

Spouse Carers - Type of help given by gender of carer				
		Gender of carer		
	M	<b>I</b> ale	Fen	nale
Personal care (e.g. bathing)	21	(47.7%)	24	(49%)
Other practical help (e.g. shopping)	6	(13.6%)	3	(6.1%)
Physical help (e.g. with walking)	11	(25%)	12	(24.5%)
Paperwork or financial matters	2	(4.5%)	_	
Keeping company	1	(2.3%)	3	(6.1%)
Taking out	2	(4.5%)	_	
Giving medicines	_		4	(8.2%)
Keeping an eye on dependant	_		2	(4.1%)
Other help	1	(2.3%)	1	(2%)
Total	44		49	

<sup>\*</sup> Missing = 2(2.1%)

Source: General Household Survey 2000 (OPCS, 2002)

#### Disability of the Cared-For Person

The type of help given is strongly related to the nature of the cared-for person's disability or illness. The GHS 2000 analysis reveals that it is coresident carers—mainly spouses—who tend to support people with "both a mental and physical disability" (20%) and people with "mental disabilities" (8%) (Maher & Green, 2002). As many of the cared-for are elderly, it is likely that many have dementia and a physical frailty as well (Milne & Hatzidimitriadou, 2002; Moriarty & Webb, 2000). Caring for a person with dementia tends to involve intensive care, which is a combination of personal and physical care and is known to be very stressful (Lewis, 1998).

#### Health, Well-Being, and Support from Services

Half of older husband carers (47%) and nearly three-quarters of wives (73%) report that they have experienced a range of negative consequences to their well-being (See Table 3). Particularly noteworthy are feeling tired (22% of men, 35% of women); feeling depressed (7% of men, 10% of women); and disturbed sleep (9% of men, 12% of women). No statistically significant differences were found between the two groups ( $\chi^2$  (6)=11.50, p<.074).

As might be expected, the negative impact of caring is linked to the intensity of caring. Those caring most intensively are affected most: 60% of carers who spend 20-49 hours per week caring and 53% of those who spend 50

Table 3

Spouse Carers - Health status by gender of carer			
	Gender o	Gender of carer	
	Male	Female	
Feeling tired	10 (22.2%)	17 (34.7%)	
Feeling depressed	3 (6.7%)	5 (10.2%)	
Disturbed sleep	4 (8.9%)	6 (12.2%)	
General feeling of stress	1 (2.2%)	5 (10.2%)	
Short-tempered/irritable	3 (6.7%)	1 (2%)	
Other	_	2 (4.1%)	
None of these	24 (53.3%)	13 (26.5%)	
Total	45	49	

<sup>\*</sup> Missing = 1(1.1%)

Source: General Household Survey 2000 (OPCS, 2002)

hours or more per week are in this position. Among those spending 50 hours or more, just under a half (45%) report feeling tired or having disturbed sleep.

In addition, data from the 1995 GHS indicate that although 60% of older husbands stated that their health was generally "good," a third reported that they were suffering from a "long-standing illness or disability." Of this group, two-thirds said their disability limited their activities of daily living; it must therefore have had an impact on their capacity to provide care, although this is not directly evidenced in the GHS.

The GHS 2000 analysis suggests that older co-resident carers are significantly less likely than older extra-resident carers to receive support from services: 40% compared with 65%. As can be seen from Table 4, just over a third (35%) of co-resident older husbands and a third (31%) of coresident older wives receive regular support from a healthcare or social services worker ( $\chi^2$  (7)=4.43, p<.730). To illustrate, 64% of husbands, caring for 20 or more hours per week, have no access to respite care.

#### Discussion of GHS Findings

The GHS 2000 secondary analysis reveals a particular picture of men's contribution to spouse caring. First, it confirms the likelihood of an older man becoming a carer in the marital context. This is for two reasons: men tend to care in lower numbers for other groups of vulnerable adults, and a larger proportion of older men are married compared with older women. Caring for non-spouse kin tends to become established earlier in life, particularly during middle age, and women take the major responsibility for dependent parents,

Table 4

Spousal Carers - Visits from services by gender				
	Gender	Gender		
	Male	Female		
Doctor	4 (10.8%)	5 (11.1%)		
Community/district nurse	3 (8.1%)	3 (6.7%)		
Health visitor	_	1 (2.2%)		
Home help	3 (8.1%)	1 (2.2%)		
Meals on wheels	1 (2.7%)	_		
Other professional visitor	_	2 (4.4%)		
Don't know	2 (5.4%)	2 (4.4%)		
No regular visitor	24 (64.9%)	31 (68.9%)		
Total	37	45		

<sup>\*</sup> Missing = 13 (13.7%)

Source: General Household Survey 2000 (OPCS, 2002)

children and other relatives. Shorter life expectancy for men and the tendency for women to marry men older than themselves mean that men are more likely to remain married and women are more likely to be widowed (Drewett, Oldsen, & Parker, 1994). Thus, the older husband dominates the male caring paradigm as a result of the combined impact of two gender inequalities: that it is normative for women to care for dependent relatives, and that women tend to marry men who are older. The consequence is that many older men have wives to care for them, while conversely, many older women are left widowed and cannot rely on spouse care (Rowlands, 1998; Maher & Green, 2002). A related issue is that men who become spouse carers do so at a greater age than their female counterparts; thus they are generally more frail. If they become carers they also tend to care for longer periods, as their wives are younger (Wenger, 1990).

Second, evidence confirms earlier findings that older husbands offer similar levels and types of care, including intensive care over a long period (Pickard, 1999; Rowlands, 1998). In addition to providing much personal and intimate care, they provide physical help and other practical help to a significant extent. Wives appear to do similar amounts of personal care and physical help, but provide more help with medicines and keeping the cared-for person company. This is likely to reflect the fact that older wives may care for more frail, older husbands who need more medicines and supervision, particularly if they have dementia (Stoller, 1992).

Third, the health status of one-third of older husbands is a matter for concern; for many of them, their poor health impacts upon their daily lives and functioning (Pickard, Shaw, & Glendinning, 2000). The question of how they

manage to care intensively for a disabled wife is automatically raised. If we add to this the fact that only a third of older husbands receive support from services, the picture of daily struggle and isolation is complete. Of course, there are a number of reasons why an older husband refuses or fails to seek help: power of the marital bond, fear of intervention, and admittance of failure to cope will all play a part. It is also likely that over-stretched welfare agencies do not seek out extra work, nor do the targeting and allocation systems of social services departments lend themselves easily to the provision of support to a couple or a mutual caring situation (Pickard, 1999; Bauld et al., 2000).

Before leaving this discussion, it is useful to identify some of the limitations of the GHS and its capacity to shed light on an issue as complex as that under review. One criticism is that the wording of the GHS questions² leads to an underestimation of care by both older spouses (Arber & Ginn, 1991; Parker & Lawton, 1994). As noted, spouses tend to regard caring as normal reciprocity, and do not see themselves as carers. Linked to this is the likelihood that within a mutual-care situation, women are more likely than men to underestimate their contribution; the male of a partnership may be erroneously identified as the "primary carer" (Finch, 1995). In terms of the nature of the questions asked, it is likely that there is significant under-reporting of caring tasks of a non-instrumental nature, such as "feeling responsible for" or "meeting the emotional needs of" the cared-for person (Milne & Hatzidimitriadou, 2002; Maher & Green, 2002).

It is to this more sentient and less obvious dimension of spouse care that we now turn. By looking beyond the instrumental face of caring in this intimate and private world, we can explore the motivation of older husbands and what gives meaning to their caring role. The contribution of more qualitative research will be reviewed alongside arguments offered from sociological discourse.

#### Older Husbands as Carers: Motivation and Meaning

This section constitutes a literature review. It focuses on four interlinked issues: the motivation of older husbands to care; managing care; gender and caring in late-life marriage; and the meaning ascribed to caring.

#### Motivation to Care

The motivation of older husbands to care is predominantly explained through the framework of marriage (Thompson, 1993). On the one hand, it is argued that husbands have a desire to "pay back" or reciprocate the love and care they have received from their wives earlier in married life (Fisher, 1994). Grant and Nolan (1993) consider that husbands view caring as an indication of an enduring and still highly significant bond; that caring will strengthen

emotional ties and confirm marital love. On the other hand, it has been argued that care expectations for husbands operate on a model of fixed obligations: this reflects both the legal nature of marital commitment and the long-term sharing of a household (Finch, 1995). Others have described older husbands as accepting their obligation to care, and explain it as the fulfillment of a duty implicit within marriage. In this framework, husbands' motivation to care stems from a commitment to the marital contract rather than a more generalized duty of care to other family members (Hirsch, 1996). Motenko (1988) suggested that these two motivations coexist; husbands view caring as both a tangible representation of their marriage and as a manifestation of love and affection.

The literature exploring developmental changes in sex-role differences provides some support for this argument. Gutmann (1987) suggests that older women become more instrumental and assertive over the life course, while older men tend to become more nurturing and expressive. As a result of these shifts, the caring role may be better suited developmentally to older husbands. Ciambrone and Allen (2002) also argue that caregiving may provide them with a vehicle to maintain social connectivity with other family members and the cared-for person's network.

#### Managing Care

Of a related nature is the approach men take to caring (Finch & Groves, 1983). Men tend to adopt an employment template to managing care, and use working practices to process caring demands (Twigg & Atkin, 1994). It has even been suggested that the role of carer may substitute for the loss of employment, and that caregiving offers an opportunity to extend male authority from the workplace into the home (Kaye & Applegate, 1994).

Evidence relating to the emotional consequences of caring, particularly the gendering of coping, is also relevant (Arber & Ginn, 1995b; Fuller-Jonap & Haley, 1995). Research consistently shows that the emotional impact of caring is far more negative for wives than for husbands (Rose-Rego, Strauss, & Smyth, 1998). Wives are more likely to perceive caring as a burden and identify loss of autonomy, "being trapped in the house," and exhaustion as the key consequences of caring (Wenger, 1994; Levesque, Cossette, & Laurin, 1995). Men, however, appear more likely to feel effective in dealing with the demands of caring, including financial, personal, and health-related problems. They describe themselves as being "active" copers "in control" of the caring situation (Barusch & Spaid, 1989; Fisher, 1994; Miller, 1987).

Zarit et al. (1998) explain this by arguing that men tend to be more emotionally detached from their wives and thus are able to separate the functional aspects of caring from the emotional aspects of marriage. Men also appear more able to set limits on their caring involvement, and view their need for support from other family members as legitimate (Bywaters & Harris, 1998).

It also has been suggested that, for women, caring may have a wider impact outside of the caregiving context that affects the whole of their lives, while for men it may have a more compartmentalized and less global impact (Morris, Woods, Davies, & Morris, 1991; Hirsch, 1996).

An additional factor relates to the attitude of the cared-for person; there is evidence that wives tend to make better patients than husbands (Davidson, Arber, & Ginn, 2000). As women have grown up believing that one of their primary functions is to provide care, many feel guilt about the role reversal. The socialization of women into caring also promotes their ability to understand the perspectives of others and the effort involved in caring (Holland & Adkins, 1996). The gratitude women feel as care recipients manifests itself in their being obliging and less demanding than husbands, for whom being cared for is considered routine (Kramer & Thompson, 2002).

#### Gender and Caring in Late-Life Marriage

We have noted that a dominant source of difference between older husbands and wives as carers has been located in gender-based socialization patterns and pre-existing gendered divisions of domestic labor in marriage (Pollitt, Anderson, & O'Connor, 1991; Arber & Ginn, 1990; Finch & Groves, 1983; Fear, 2000). An opposing school of thought suggests that old age may reduce the significance of gender-determined task allocation and that gender divisions of care hold less rigid. This is particularly the case where the independence of the marital unit may be undermined by the dependency of one partner (Arber & Ginn, 1991; Wenger, 1994; Arber & Evandrou, 1993; Martin-Matthews, 2000).

Davidson, Arber, and Ginn (2000) specifically explored the interactions of dependency, gender, and caring in late-life marriage. Their research revealed that the same act—the provision of care to a disabled spouse—results in quite different consequences for the autonomy and independence of the care provider, depending on the carer's gender. This study showed that husbands retain control within the marriage even when they become dependent: they continue to manage finances and make major decisions including those relating to care outcomes, many of which have implications for both themselves and their wives. In fact, the researchers observed that control is retained by husbands in all contexts except when the man has dementia, regardless of whether they are the carer or the cared-for. The team concluded that the concept of dependency in a caring relationship has a different meaning for men and women, and cannot be understood in isolation from the social construction of gender. Marital power is gendered, and the relationship between caring and dependency also is gendered. When one partner becomes ill and in need of care, the caring relationship must be considered within the context of the gendered nature of later-life marriage (Wilson, 1995; Bowers, 1999).

Meaning Attributed to Caring

So how might the evidence reviewed here impact on the meaning of being a carer for older husbands? Older husbands appear to gain a number of benefits from caring; there is evidence that they not only derive a "sense of identity," but also considerable self-esteem from their caring activities (Fisher, 1994; Rose & Bruce, 1995; Davidson, Arber, & Ginn, 2000). This emanates from a number of sources: pride in their own achievements; the admiration of kin and wider society; and the gratitude of their wives (Pickard, Shaw, & Glendinning, 2000; Moriarty & Webb, 2000).

Their role as carer also tends to be more highly valued (Collins & Jones, 1997). This relates in part to the fact that they retain greater control over caring tasks, experience fewer problems in coping with caring, and feel more positive about it (Rapp & Chao, 2000). Substantially, though, it relates to the fact that for a man to adopt a caring role is regarded as special and even heroic (Allen, 1994). In Davidson, Arber, and Ginn's study of spouse carers, women viewed their caring role as an extension of the "invisible daily routine of noticing, interpreting and responding to the needs of a partner" (2000, p. 546). However, for husbands, caring for an ailing spouse was taking on something "abnormal," highly visible, and much acclaimed. Virtuous behavior noted in a male carer could easily be passed over as an accepted part of a woman's ordinary domestic responsibilities. Arber and Ginn observe that the "superior gender brings esteem to a task undervalued when done by women, particularly old women" (1991, p. 110). As long as caring is viewed as a feminine activity-or at best gender-neutral-the contribution of older husbands will always attract accolade, imbue the caring role with positive meaning, and ensure that the label of "Mr. Wonderful" remains firmly attached.

#### **Conclusions**

This paper has offered a review of evidence about the contribution and conceptualization of older husbands as carers. The authors have drawn upon quantitative and qualitative research evidence, as well as sociological analyses of gender, marriage, and caregiving, and have explored a number of interlocking perspectives contributing to this debate.

Overall, evidence supports two key and apparently contradictory conclusions. The Caring in Later Life review (Milne, Hatzidimitriadou, Chryssanthopoulou, & Owen, 2001) and follow-up GHS 2000 analysis confirm that older husbands offer similar types of care and to the same extent as their female counterparts, while qualitative evidence identifies that their motivation to care, the management of their caring role, and the meaning ascribed to their caring role is significantly different. The GHS analysis paints a picture of many older husbands as devoted carers. They provide many hours of intensive care to their wives over sustained periods of time with little or no

support from services. It also indicates that they perform a wide range of caring tasks including personal and physical care, and that they suffer a number of negative health consequences related to caring.

However, evidence from research literature indicates that there are clear differences between husbands and wives in the experience of being a carer and the meaning of caring. Caring offers older husbands considerable benefit, status, and self-esteem, and accords these men both a role and a vehicle for reciprocity within marriage and an expression of commitment to their wives. Their ability to manage caring tasks and cope with caring demands more effectively reflects their different motivation to care as well as their capacity to adopt an instrumental approach to caring, separate the functional from the emotional, and gain support and acclaim for caring. The lifelong expectations to provide family care that underpin women's roles do not underpin men's: caring is an obligation in fewer contexts and a choice, insofar as a marriage partner is chosen. As it is not normative for men to give care, and it is a role men appear less likely to perform for other relatives, their contribution in the marital context is conceptualized as being of higher value and as deserving of greater recognition and acclaim.

There is also evidence that caring is an arena in which older husbands exert control whether they are the carer or the cared-for, and that the gendered nature of dependency inherent within marriage continues to influence the caregiving experiences of both older husbands and wives. Although the overriding desire for independence and autonomy among older couples may erode gender-determined task allocation, the equality this suggests is a chimera. Gender is a crucial factor mediating the experiences of caring within late-life marriage, where it has long been assumed to be of minimal relevance. This is a topic which deserves wider exploration.

Older husband carers may be widely regarded as wonderful, but this is not a gender-neutral label. While their devotion to caring is not in question, this paper has identified the importance of understanding the multidimensional nature of caring in late-life marriage and the significance of understanding what lies behind and beyond the instrumental provision of care. As caring occurs in a lifelong relationship on the basis of marital commitment, as a representation of love, as a social role, as an occupation, and within a gendered social context, it is necessary to explore it by taking account of these dimensions before coming to firm conclusions about the contribution of older husbands as carers and the conceptualization of their role.

This paper has woven together literature and research evidence from a number of sources, and has identified the nature and extent of knowledge about older husbands as carers. A number of deficits remain in this field. While some analysis has been done around the age-related and lifelong impact of gender roles within marriage—and of gender itself—on spouse caring, additional illumination of gender inequality could contribute depth to the developing discourse. The influence of other structural inequalities on spouse care—

in particular race and class—is a notable research limitation (Spitze & Ward, 2000). Additional exploration of the roles of male carers (Kramer & Thompson, 2002) and research that explores the interactions between male identity, masculinity, and caring will illuminate the gendered nature of caring by male carers and the ways in which caring identities influence the older husband's transition into caring (Gollins, 2001). Particular areas for future investigation include developing models of family caregiving which take account of older husband carers; ways in which both policy and services can be developed to support this unique group of carers; studies that include larger samples of male carers, including older husbands as current and former carers (Wright, 1998); and work that explores the impact of the changing nature of marriage on caring patterns and commitments (Houde, 2002; Gollins, 2001).

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#### **Author Note**

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#### Notes

- From the 19,266 people interviewed for the GHS 2000, 12% identified themselves as current carers.
- 2. The GHS 2000 adopted a particular definition of carer and cared-for person. Specifically, according to the guidelines for using the carers' data, all adult respondents were asked whether they, "cared for someone who was sick, disabled or elderly." Certain types of caring were excluded for analysis of the data: those caring for someone in their capacity as a volunteer for a charity or other organization; those caring for someone receiving care in an institution; those providing financial support only, and those caring for someone with a temporary illness or disability (as defined by the respondent).

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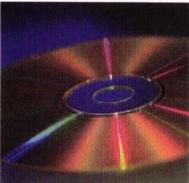
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Centre for Health Services Studies

# Caring in Kent: Patterns and Profiles, Evidence from the Kent Health and Lifestyle Survey, 2005









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**Commissioned by Kent County Council** 

March 2008

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Commissioned by Richard Spoerry, Kent County Council

The Tizard Centre (www.kent.ac.uk/tizard/) is located within the top-rated School of Sociology, Social Policy and Social Research at the University of Kent. It is one of the leading academic groups in the UK working in learning disability and community care

#### **Funding and Acknowledgements**

Acknowledgements are due to many people for their support and advice. These include the residents of Kent who responded, the Kent Public Health Network, the Public Health Information team at Kent & Medway Strategic Health Authority, and Richard Spoerry and Debbie Smith at Kent County Council



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#### **Abstract**

'Carers provide unpaid care by looking after an ill, frail or disabled family member, friend or partner'. The increasingly recognised importance of the role of the 'informal carer' is - in good part - due to the rising proportion of older people in the UK population. Not only do people live longer but many experience a number of chronic conditions; these require support from family members if the older person is to remain living in the community.

The 'Caring in Kent' report draws on the results of a Kent wide 'Health and Lifestyle Survey' conducted in 2005; this included a module on caring. This enables a picture of caring to be reported including: a general profile of carers, levels and types of care-giving, carers' health, and the level and types of support they receive.

5800 people responded to the survey (27% response rate), of whom 19.7% identified themselves as carers. 28% were aged 65 and over; 40% were male. In contrast 45% of the cared for were aged 65-84 and 27% were aged 85 and over; 66% of the cared for were female. 42% of carers were looking after a parent/in law and 16% a spouse or partner.

66% of cared for people were reported as suffering a physical disability or illness, 10% dementia, 9.5% another type of mental health problem and 6.2% a learning disability. 62% were living in their own home, 25% with their carer, and 7% in a care home or hospital. Men (44%) were more likely to be living with their carer than were women (19%). 78% of parents/in law were extra-resident.

Carers were classified according to whether they were providing 'intensive care' (help with washing, dressing, feeding and toilet),

'moderate care' (help with walking, stairs, getting in and out of bed, taking medicines) or 'tending' (help with forms, finances, meal preparation, housework etc). The classification used combined these with the number of hours – 73.4% of carers were providing tending and moderate levels of care for less than 20 hours a week; 7.2% were providing moderate levels of care for 20 hours or more and 19.4% of carers were providing intensive care.

30% of people providing intensive care were themselves aged 65 and over, 32% were caring for 50 hours or more a week. 53% were coresident carers; 37% were spouses and 41% sons/daughters; 51% had a learning disability. Overall, 84% of people providing intensive care for 50 hours or more were co resident. This is also the case for 70.9% of people providing moderate care for 20 hours or more per week although 21.5% of people receiving moderate care for 20 hours or more a week were living in their own home. 72.2% had a physical disability; 49.4% were spouses; 22.8% were parents, and 15.2% were sons/daughters.

Providing tending or moderate care for less than 20 hours a week was the majority care pattern and 87% was delivered on an extra-resident basis. 49% of tending or moderate care for less than 20 hours was provided to parents, 7.3% to spouses and 5.1% to sons/daughters. 82% of parents were receiving tending/moderate care for less than 20 hours a week whereas 41.3% of spouses were receiving intensive care, 32.9% for 50 hours a week.

The 2005 survey demonstrated an increase in the proportion of older people in Kent who were caring and a reduction in younger carers compared to the 2001 survey. The number of hours spent caring increased for all age groups over the age of 45 years.

43.5% of all carers in the 2005 survey were aged 40-59 i.e. 'mid-life

carers'. These people often continue caring with paid work and family commitments; they are twice as likely to be women as men, and 64% of the cared for were aged 75 and over; 81% were living in their own home; and 66% were suffering a physical health problem.

15.8% of carers were 'betwixt and between' aged 60-64 years, an equal proportion of men and women. 27% of carers in the 2005 survey were older people aged 65 and over; at this age male carers begin to predominate; older people were increasingly providing more intensive levels of caring. Nearly a half of older carers had been caring for 5 years or longer.

Effects of caring include financial, health, emotional and social consequences. In the Kent survey 50.1% of carers reported caring had adversely affected their health. These effects included tiredness (66.1%), depression (30.2%), disturbed sleep (36.9%) and general feelings of stress (51%). Interestingly 36.7% of carers reported caring affected their health but in the question on general health status (SF-36) they also reported they were in good to excellent health. 24% of carers emerged as being at risk of major depression, 45% reported a longstanding illness or disability.

Carers were less likely to be employed than were non-carers and those who were employed were less likely to be in managerial positions.

The survey found important differences in the amount of support provided; in particular that support for health and social services was more likely to be provided to those caring for people living alone rather than those who are co-resident, and that very few carers were in receipt of services in their own right.

70% of support from services was provided to those in the groups receiving the lowest support (tending) from their carers. 6.7% of carers reported receiving no support from family and friends or from health and social services.

In conclusion, whilst the Kent survey may not be completely representative of all carers in Kent it provides a comprehensive overview of caregiving patterns and profiles. Evidence about intensive carers and its effects on carers' lives and their lack of access to support is particularly interesting. Recommendations for future work include further analysis of the 2005 survey, a supplementary survey to the forthcoming 2008 'health and lifestyle' survey, and additional qualitative work looking at groups such as employed carers, mid-life carers, and the development of the 'caring trajectory'.

#### Introduction

'Carers provide unpaid care by looking after an ill, frail or disabled family member, friend or partner. People from all walks of life and backgrounds are carers - over 3 in 5 people in the UK will become carers at some time in their lives. Caring can be a rewarding experience, yet many face isolation, poverty and ill-health. Carers give so much to society yet as a consequence of caring, they experience ill health, poverty and discrimination'

Recent years have seen a growing recognition of the important role that carers play in maintaining vulnerable adults in the community. This is due in part to the increasing proportion of older people in the population who require support from relatives, as well as the development of community care and related policies which emphasise the positive role of the family as the mainstay of care provision for dependent adults<sup>2</sup> <sup>3</sup>.

The Kent Survey 2005, which was primarily a Health and Lifestyle Survey, included questions relating to whether the respondent was caring for 'family members, friends, neighbours or others because of long-term physical or mental, ill-health or disability, or problems related to old age'.

This report offers a review of the epidemiology, characteristics and needs of family carers in Kent drawing on analysis of data from the Survey<sup>4</sup>. The survey included a specific module on carers adapted

<sup>&</sup>lt;sup>1</sup> Carers UK <a href="http://www.carersuk.org/Aboutus">http://www.carersuk.org/Aboutus</a> accessed 24/12/07

<sup>&</sup>lt;sup>2</sup> Carers UK (2004) In Poor Health: the impact of caring on health, London: Carers UK

<sup>&</sup>lt;sup>3</sup> Department of Health (2005) The Carers (Equal Opportunities) Act 2004, London: Department of Health

<sup>&</sup>lt;sup>4</sup> Jenkins L, Hastie C, Palmer A. (2007) Kent 2005 Survey of Health & Lifestyle: Geographical Report, Canterbury: CHSS, University of Kent

from the national General Household Survey<sup>5</sup> <sup>6</sup>; this is the most recent GHS to collect detailed data on carers<sup>7</sup> <sup>8</sup>. The report focuses its analysis and commentary in four key areas:

- a general profile of carers in Kent
- levels and types of caregiving
- > carers' health including the impact of caring
- > support from formal and informal sources

It also offers analysis of data around specific groups of carers including mid life carers, older carers and co resident carers. The report begins by placing caring in Kent in its wider national context.

<sup>&</sup>lt;sup>5</sup>Maher J and Green H (2002) Carers 2000 London: Office of National Statistics, The Stationary Office.

<sup>&</sup>lt;sup>6</sup> Office of National Statistics (2002) Census 2001 London: The Stationary Office

<sup>&</sup>lt;sup>7</sup> The GHS adopted a particular definition of carer and of cared for. Specifically, according to the instructions given to interviewers, the specific part of the survey referring to informal carers "is intended to cover those informants who look after chronically sick, handicapped or elderly people – eitherrelatives or non-relatives, adults or children. Also included are those who provide some regular service e.g. shopping or doing odd jobs, for someone who is sick, handicapped or elderly" <sup>8</sup> The GHS offers respondent carers the following categories: spouse/cohabitee, own/adopted child, foster child, parent, parent-in-law, other relative, friend/neighbour

#### **National Context**

The level and nature of caring activity has increased incrementally over the last 20 years

The 2000 General Household Survey reveals that across the UK 16% of the population - 6 million people - provide unpaid care<sup>9</sup>. Thus, one in six people aged 16 and over is caring for a sick, disabled or elderly person; one in five households contains a carer<sup>10</sup>.

... a growing proportion of carers are older

In addition to a growth in the total number of carers, longitudinal data suggests that since the 1980s the profile of 'who provides care to whom' has changed. Intensity of care, i.e. the level and nature of caring activity, has increased significantly<sup>11</sup>. Of particular note is the growing number of carers providing 50 or more hours of support per week and the growing proportion of older carers <sup>12</sup>. Further, there are more carers with sole responsibility for care and there is an increase in the number of co-resident carers - carers who live with the person they support. Evidence also indicates that compared to the late 1980s, the people receiving care tend to be significantly older and frailer and are more likely to have a mental impairment, primarily dementia <sup>13</sup> <sup>14</sup> <sup>15</sup> <sup>16</sup>.

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<sup>&</sup>lt;sup>9</sup> Carers UK (2004) In Poor Health: the impact of caring on health, London: Carers UK

<sup>&</sup>lt;sup>10</sup> Office of National Statistics (2002) General Household Survey 2000 London: HMSO

<sup>&</sup>lt;sup>11</sup> Office of National Statistics (2002) General Household Survey 2000 London: HMSO

<sup>&</sup>lt;sup>12</sup> Office of National Statistics (2002) Census, 2001 London: The Stationary Office

<sup>&</sup>lt;sup>13</sup> Office of National Statistics (2002) General Household Survey 2000 London: HMSO

<sup>&</sup>lt;sup>14</sup> Wanless (2006) Securing Good Care for Older People, taking the long term view London: Kings Fund

<sup>&</sup>lt;sup>15</sup> Milne, A., Hatzidimitriadou, E., Chryssanthopoulou, C and Owen, T (2001) Caring in Later Life: Reviewing the role of older carers, London: Help the Aged

<sup>&</sup>lt;sup>16</sup> Milne, A., and Hatzidimitriadou, E (2003) Isn't He Wonderful? Exploring the contribution and conceptualisation of older husbands as carers, *Ageing International*, Vol. 28(4), p389-408

#### Ageing and the Need for Care

the population is ageing...

The UK population is ageing. Not only has the population aged 65 and over increased from 13% to 16% between 1971 and 2005 but also the proportion of people aged under 16 has fallen from 25% to 19%. The number of people aged 85 and over has grown by 64,000 (6%) to 1.2 million. Whilst ageing is partly due to a decline in fertility rates, it is mostly a result of the decrease in mortality amongst older people<sup>17</sup>

the population aged 65 and over increased from 13% to 16% between 1971 & 2005 At all ages the mortality rate for men is higher than for women; in men the risk of dying increases from 3.6% a year at 65 - 74 to 11.1% at 75 and over whilst in women it increases from 2.1% at 65 - 74 to 8.6% aged 75 and over. Women still live longer than men although there is some evidence that the gap may be closing. Although 50% of all male deaths take place before the age of 75 years; 70% of all women live to at least this age. Despite the fact that the ratio of male to female deaths has reduced in the under 75s over the past 20 years, the reduction in mortality between men and women is less marked in the 75 and over age group. There has, however, been a significant increase in the number of people living to old age with an increase in 'senescent deaths' 18 from around 40% to over 80% for women and 70% for men.

the prevalence of chronic disease and disability increases with age

Despite medical and social advances and the fact that many older people report being in 'good health', morbidity statistics reveal that the prevalence of chronic disease and disability increases with age <sup>19</sup>.

<sup>&</sup>lt;sup>17</sup> ONS <a href="http://www.statistics.gov.uk/cci/nugget.asp?id=949">http://www.statistics.gov.uk/cci/nugget.asp?id=949</a> accessed 16/8/07

<sup>18</sup> i.e. deaths in old age

<sup>&</sup>lt;sup>19</sup> Taken from Palmer A. (1997) Ageing and the Elderly Population: Epidemiology and Sociology of Health in Older People. West Kent Health Authority

Over the last twenty years trends in 'self-reported sickness' suggest an increase both in the 65-74 year age group and the cohort aged 75 and over. 60% of 65 - 74 year olds and 67% of those aged 75 and over report a 'long standing illness'. Further, 40% of those aged between 65 & 74 and 50% of the group aged 75 and over report 'limiting long standing illness'; commensurate figures for 'restricted activity' are 18% and 21%. The increase has been proportionately greater in the younger age groups<sup>20</sup>.

Many older people suffer multiple chronic conditions which make it likely they will need support

Many older people suffer multiple chronic conditions. The number of chronic conditions increases with age, making it increasingly more likely the person will require support and less likely they will be able to offer care themselves.

Between the ages of 65 and 74 years older people have an average of 4.6 conditions; for the cohort aged 75 years and over the average rises to 5.8. By the age of 75 and over only 10% of people have no chronic conditions. For the group aged 65 -74 the commonest conditions are: arthritis (50%), forgetfulness (34%), back pain (33%), poor vision (32%), indigestion (29%) and breathless on exertion (28%). Sleep patterns are often affected by age; the prevalence of insomnia increases with up to 1 in 3 people aged 65 and over suffering, women more so than men.

A tenth (10%) of all carers support a person with dementia

The increase in the prevalence of dementia is a dominant trend and one that has particular implications for caregiving. A tenth of all carers support a person with dementia. Dementia increases with age, from 1.4% in the 65-69 age group to 23.6% amongst those aged 85

<sup>&</sup>lt;sup>20</sup> Soule, A., Babb, P., Evandrou. M., Balchin, S and Zealey, L (eds) (2005) Focus on Older People, London: Office of National Statistics

and over<sup>21</sup>. Most studies show there is no sex difference. Whilst there is no evidence of any actual change in dementia prevalence in recent years, because of the increasing number of older people the actual number of people with dementia is predicted to increase from 700,000 today to 940,000 by 2021 and to 1.7 million by 2051.

#### Carers & Policy

Since the 1990 NHS and Community Care Act<sup>22</sup> (Department of Health, 1990) concern with supporting carers has become an increasingly important policy priority. One of the Act's key objectives was to ensure that service providers made practical support for carers a high priority. Continued concerns about provision for carers culminated in the Carers (Recognition and Services) Act 1995<sup>23</sup> which offered an assessment of their ability to care and gave local authorities a duty to take into account carers' capacity when looking at services for the user. Publication of the National Carers Strategy in February 1999<sup>24</sup> represented the government's response to long-term campaigns to secure more support, increased rights and improved recognition for carers.

The Carers & Disabled Children Act introduced a right for carers to receive an assessment of need The Carers & Disabled Children Act came into force in April 2001; it introduced a right for carers to receive an assessment of need, whether the cared for person receives services or not<sup>25</sup> The Act includes carers supporting relatives with mental health problems. Further, it gives local authorities discretion to meet carers needs with any service that will genuinely help them to continue to care and maintain their well-being. It also empowers local authorities to make direct payments to carers<sup>26</sup>

<sup>&</sup>lt;sup>21</sup> Alzheimers Society (2007) Dementia UK. London Alzheimers Society

<sup>&</sup>lt;sup>22</sup> Department of Health (1990) The 1990 NHS and Community Care Act London: HMSO

<sup>&</sup>lt;sup>23</sup> Department of Health (1995) Carers (Recognition and Services) Act 1995 London: HMSO

<sup>&</sup>lt;sup>24</sup> HM Government (1999) National Carers Strategy London: HMSO

<sup>&</sup>lt;sup>25</sup> Department of Health (2001) The Carers & Disabled Children Act London: HMSO

<sup>&</sup>lt;sup>26</sup> Department of Health (2001) Carers and Disabled Children Act 2000 London: Department of Health

The 2004 Carers (Equal Opportunities) Act extends carers' rights to receive as 'assessment of need', access social care services and direct payments, and obtain support from health - as well as social care - services if the carer's ability 'to provide care might be enhanced by such services' The subsequent Work & Families Act extends the right of working carers to request flexible hours from their employer A 'New Deal for Carers' is being developed by the Department of Health and is due to be launched later in 2008.

As the population ages and the need for family support of frail elders increases, there is a pressing need to extend understanding of family care and to ensure the full inclusion of carers in social and economic life and that carers are supported appropriately and effectively by care agencies, friends and relatives.

#### Kent Health & Lifestyle Survey 2005

The 2005 Health and Lifestyle Survey in Kent, was commissioned by Kent County Council. It was a postal survey of 23,000 people across Kent. The sampling frame was the GP registration list from the Kent Primary Care Agency. Names, addresses, date of birth and NHS number for patients aged 16 and over registered with the Kent Primary Care Agency were downloaded and a one in fifty sample obtained electronically.

The people in the derived sample were sent a postal questionnaire together with an information sheet and a stamp addressed envelope for returning the questionnaire. Non-responders at three weeks were sent a reminder postcard. Further contact was made with non-responders at six weeks when they were sent a letter and

<sup>28</sup>Department of Health (2007) Work & Families Act 2006. London: Department of Health

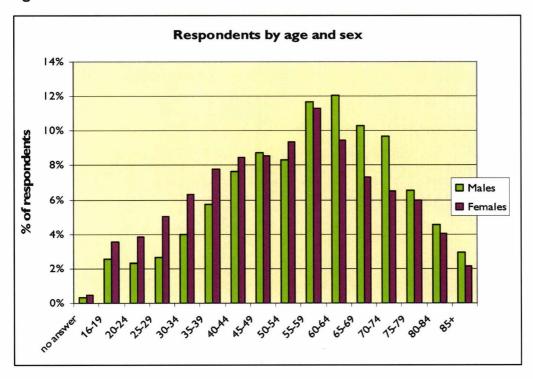
<sup>&</sup>lt;sup>27</sup> Department of Health (2005) The Carers (Equal Opportunities) Act 2004, London: Department of Health

questionnaire, and again at three months (and after Christmas) when they were sent a further reminder post card. The survey results were analysed using SPSS.

5800 people in Kent responded to the survey

5800 people in Kent responded to the survey; 66 (1.1%) of these did not give their sex and 86 (1.5%) did not give their age; 63 declined to give either age or sex; 8 males and 15 females did not give their age. There are 5714 respondents who gave both age and sex and in some analyses the people who did not respond to age and/or sex have been excluded. There are estimated to have been 1,077,421 people in Kent in 2004; this includes a bulge in the population aged 35-45 and aged 55-59. There were fewer people in the younger age groups. Survey respondents were older, increasing steadily in numbers to age 60-69 and then falling off again (Figure 1). The number of women respondents exceeded men until the age of 44, then from age 60 the number of men exceeded women until the age of 85 and over.

Figure I

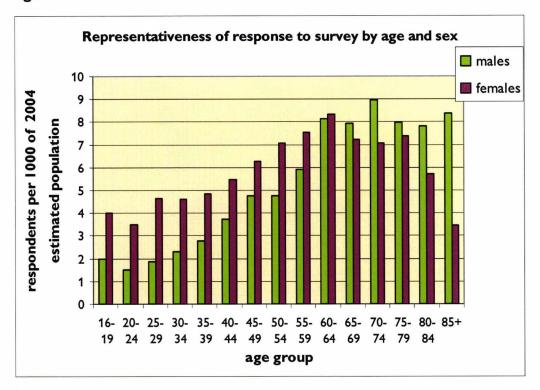


women were better represented up to the age of 64; from this age onwards men were better represented

In this survey, women were better represented up to the age of 64; from this age onwards men were better represented (Figure 2). However the survey is more representative of older people than younger people and of young women than of young men, and older men than of older women.

The distribution of respondents may be affected by the fact that although women are more likely to live longer than men they are also more likely to be chronically ill (and therefore less likely to be able to complete a questionnaire especially as this one was particularly long).

Figure 2



The survey is also more representative of married (6.9/1000), separated or divorced (4.6/1000) and widowed (5.4/1000) people than of single or never married people (2.8/1000); this fits with the finding that older people are better represented because older people are more likely to be currently married or widowed. Men in the survey were more likely to be married and less likely to be widowers.

Most respondents aged under 25 were still single (96% of men and 86% of women); in the age group 25-44 72% of men and 71% of women were married. At 45-64, 81% of men and 77% of women were married; by 65-74 85% of men but only 62% of women were married. 70% of men aged 75 and over were still married and 23%

were widowers, compared to only 33.5% of women who were still married and 54% who were widowed reflecting the tendency for women to marry older men and for men to die younger than women.

#### The Profile of Carers in Kent

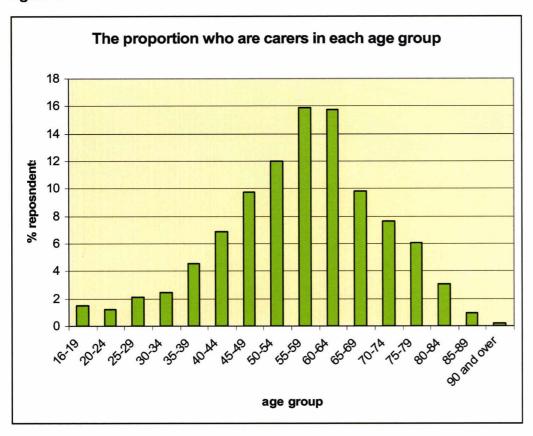
#### **Number & Characteristics of Carers**

19.7% (N=1142) of the total number of survey respondents (N=5800) identified themselves as carers<sup>29</sup>. 3% of carers were aged 16-24, 16% were 25-44, 53% were 45-64, 18% were 65-74 & 10% were aged 75 and over. 70% of carers aged 75 and over cared for relatives in the same age group (Figure 3). Over half of carers were thus in the mid life group. This profile mirrors national trends; the majority group of carers nationally are middle aged with an increasing proportion being aged 60 and over. There may be higher numbers of older carers in Kent than is the case nationally as it is a popular retirement area. The observed age distribution may reflect the better response rate amongst older people and a possible bias introduced by carers wishing to use the survey to identify themselves.

20% of respondents identified themselves as carers, 40% were men; over half were in the midlife group

<sup>&</sup>lt;sup>29</sup> 201 (3.5%) did not reply to the question

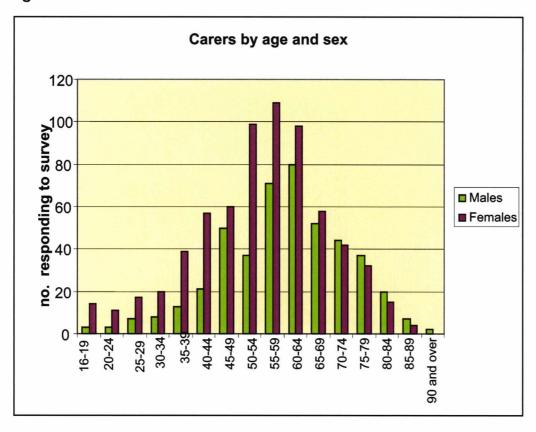
Figure 3



In the Kent Survey 40% of carers identified themselves as men and 59% as women (1% is unknown); this gender split mirrors the national figure<sup>30</sup>. With increasing age, in this survey male carers predominated (Figure 4). This mirrors the national picture and reflects the fact that amongst men, spouse carers predominate; there are proportionately more husbands caring for their wives amongst the older population.

 $<sup>^{30}</sup>$  Young H, Grundy, E & Kalogirou, S (2005) Who Cares? Geographic variation in unpaid caregiving in England and Wales: evidence from the 2001 Census London: population Trends 120, ONS.

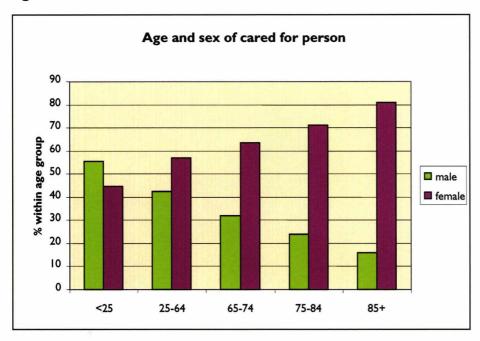
Figure 4



#### Who Cares for Whom?

In terms of age, 5% of the cared for population were aged under 25 years, 15.5% were aged 25-64, 13% were 65-74, 32% were 75-84 and 27% were aged 85 years or older. Overall two thirds (66%) of the cared for were female and a quarter (26%) were male; there are also 6% who are both. The vast majority (91.5%) were caring for one person; a small number (8.4%) were caring for more than one. In the younger age groups the cared for was more likely to be a male; with advancing age the cared for person was increasingly likely to be female (Figure 5).

Figure 5



Two thirds of people cared for were women, in the older age groups (85+) this rose to 81%

In the older groups women predominated with 71% of the cared for aged 75-84 being female and 25% male; in the age group 85 and over women constituted 81% and men only 16%. 75% of men were caring for someone aged 65 and over compared to 70% of women. This is consistent with national patterns. It is well documented that the vast majority (71%) of care recipients are aged 65 and over; in Kent the total is 72%.

With increasing age of the carer the person being cared for became more and more likely to be aged 65 and over (Figure 6). At all ages after 25 years more than 50% of persons cared for were aged 65 and over. At age 45-54 76% of persons cared for were aged 65 and over; at 75 and over this was 82%. There were 31 carers aged under 25 in the survey; 60% were caring for someone aged under 65.

one in four had been caring for 5-10 years and 17% for ten years or more

Carers in this survey had been caring for a long period of time. One in four had been caring for 5-10 years and 17% for ten years or more. Only one in ten carers had been doing so for less than one year (Table 1).

Figure 6

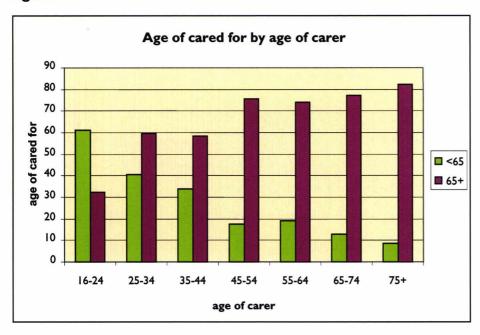


Table I
For about how long have you been providing support or care to your relative/friend

	Frequency	Percent
no answer	24	2.1
under a year	121	10.6
I - 3 years	307	26.9
3 - 5 years	209	18.3
5 - 10 years	285	25.0
more than 10 years	196	17.2
Total	1142	100.0

Two fifths (42%) of cared for people were parents/parents in law, 16% were a spouse or partner, 9% were a disabled son or daughter,

Two fifths (42%) of cared for people were parents or parents in law

7% were 'other relatives', 16.5% were friends or neighbours and 3% were grandparents (Figure 7).

Young carers were more likely to be caring for a parent/in law whereas caring for a spouse increased with age from 10% aged 45-64 to over 40% aged 75 and over. Caring for a child was less likely with increasing age, but caring for a friend or other relative increased with age (Figure 8).

In terms of the type of health problems the cared for person had, over two thirds (65.8%) had a physical disability or illness, a tenth (10%) had dementia, a tenth (9.5%) had 'another type of mental health problem', and 6.2% had a learning disability. Another fifth (21.5%) had 'another' unspecified health problem.



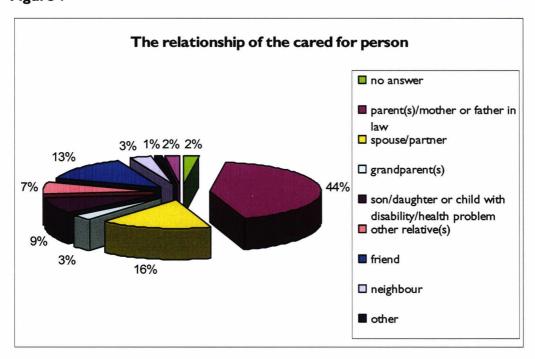
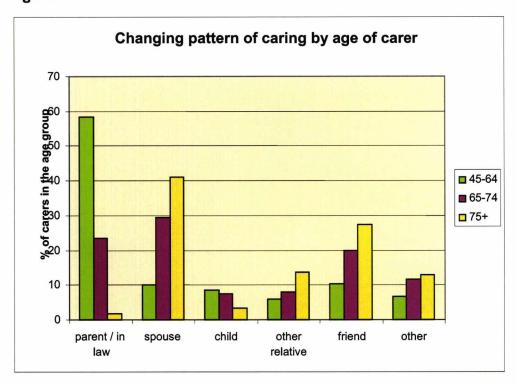


Figure 8



#### Where does the Cared for Person Live?

Three fifths (62%) of people who were supported by carers were living in their own home, a quarter (25%) with their carer, 7% in a care home or hospital and 2% were living in sheltered housing<sup>31</sup>. Carers providing longer hours of caring were more likely to have the cared for person living with them (Table 2).

 $<sup>^{\</sup>rm 31}$  This category also subsumes housing with extra care

Table 2
Where does the cared for person live?

Hours of care	I-19 hours a week (n=26)	20-49 hours a week (n=845)	50 + hours a week (n=80)	No answer (n=191)	Total (n= 1142)
In their own home	76.4%	38.8%	10.5%	34.6%	61.8%
With me in the same household	9.1%	47.5%	81.7%	42.3%	24.7%
In a care home / hospital	8.3%	6.3%	1.0%	11.5%	7.0%
Sheltered housing with extra care	0.0%	3.0%	0.0%	0.0%	2.3%
Other	2.2%	3.8%	2.6%	7.7%	2.5%
No answer	0.9%	2.5%	4.2%	3.8%	1.7%

Carers tend to fall into two household types: co and extra resident carers

Although carers cannot be viewed as a single group, they do tend to fall into two sub groups:

- > co-resident, that is carers sharing a single household with the cared for
- extra resident, that is carers living in a separate household to the relative they support.

In turn, household type dovetails with the type of relationship the carer & cared for person have

This profile dovetails with the other distinguishing feature of caring, the type of relationship the carer has with the cared for person i.e. if you are a spouse you will be living with your partner. The overall proportion of co-resident carers identified in the survey was 24.7%, compared to 73.6% who were identified as extra-resident carers.

58% of disabled sons
/daughters we living with
their parent carer

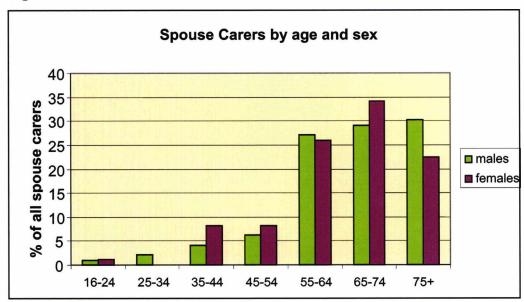
a quarter (27%) were living in their own home

#### Co resident Carers

In this survey 86% of spouses were living with their carer – their husband or wife. For disabled sons and daughters, the picture was mixed. Over half (58%) sons / daughters were living with their parent carer and a quarter (27%) were living in their own home; another 10% were living in institutional care.

A higher proportion of men (44%) were living with the person caring for them than women (19%). This is likely to reflect the fact that there were a higher proportion of older men being cared for by younger wives (Figure 9); there may also have been more widower men living with their daughter or son than widowed women.

Figure 9



#### **Extra Resident Carers**

78% of cared for parents/in law were extra resident

78% of cared for parents/in law were extra resident with only 10% being co-resident; another 10% of parents/in law were in a care home, hospital or living in sheltered housing. The vast majority of friends (84%) and all of the cared for neighbours, were living in their own homes; this was also the case for two thirds (66%) of 'other relatives'.

Most people with physical ill health/disability, dementia and functional mental illness were not living with their carer. A half (54%) of people with dementia were living in their own home, a tenth (11%) with their carers and a quarter (24.5%) were living in a care home/hospital or housing with extra care.

## The Nature of Caring - Types and Levels

The distinguishing features of caring, the relationship with the cared for person and whether or not they are co-resident combine to form a third feature, the nature of care; intensive caring - which involves providing personal care and many hours of care - versus tending - which describes 'lower levels of instrumental care' such as shopping. As might be expected, in this survey co-resident carers tended to offer more intensive care whilst extra resident carers were more likely to be tending (Table 3).

Table 3

Proportion of carers who are co-resident or extra-resident and the intensity of their caring

Intensity	Co-resident	Extra-resident
Tending and moderate 1-19 hours per week	12.0%	87.5%
Moderate 20+ hours per week	68.8%	31.3%
Intensive I-19 hours per week	18.5%	80.0%
Intensive 20-49 hours per week	42.9%	52.4%
Intensive 50+ hours per week	87.3%	11.1%

#### How we categorised levels and types of caregiving

Drawing on the wider literature, care was classified into three categories: intensive care, moderate care and tending.

Respondents were classified as providing 'intensive' activities if they said the care they provided included one or more of the following: washing, dressing, feeding and using the toilet (see Appendix for precise definitions and reference to the questionnaire).

Of all those caring:

- > 12.7% were helping to wash,
- II.7% were helping with dressing,
- > 7.6% with feeding, and
- > 7.1% with using the toilet

Care was classified as 'moderate' if carers said their care included one or more of the following: help with walking, getting up and down stairs, getting in and out of bed, giving medicine.

22.5% of all carers provide Of all those caring: help with walking, 9% with getting up and down stairs, 10% with getting in and out of bed and 19% with giving medicines

- > 22.5% were providing physical help with walking,
- 8.8% provided assistance with getting up and down stairs,
- 10% with getting in and out of bed
- 19.1% with help to take medicines.

Care was classified as 'tending' if carers said their care only included one or more of the following activities: help with filling in forms, dealing with bills, banking, preparing meals, laundry, housework, gardening, taking to doctors/hospital, keeping him/her company, taking them out, keeping an eye on them.

In the survey the following emerged on tending related activities:

- Regarding financial matters: 51.1% needed help with filling in forms, 35.6% with managing bill payments, and 34% with banking,
- > 34% received help with preparing meals and 54% with shopping,
- > 30.6% were helped to do laundry and 36.8% with housework,
- > 33.8 received help with gardening,
- > 53.1% required help to be taken to the doctors, and
- > 53.7% were keeping the cared for person company, 51.4% took him/her out, and 60.9% were keeping an eye on him/her.

73.4% of carers were providing tending or moderate levels of care for less than 20 hours a week

In addition to the levels of care described above, carers reported the number of hours per week they devoted to caring. The analyses provided in this report are broken down into 5 categories (Figure 10).

7.2% were providing moderate care for more than 20 hours and 19.4% were providing intensive care

Men are more likely to be providing tending or moderate levels of care women are more involved in intensive care and for longer periods

In Kent overall:

- > 73.4% of carers were providing tending and moderate levels of care for less than 20 hours per week
- > 7.2% of carers were providing moderate levels of care for 20 hours or more
- ➤ 19.4% of carers were providing intensive care. 7.8% of carers were providing intensive levels of care for 1-19 hours per week, 2.3% for between 20-49 hours and 9.3% for 50 hours or more.

This survey demonstrates that the level of caring is more likely to be intensive with increasing age (Figure 11). Men were more likely to be providing tending or moderate activities and a greater proportion of women were involved in intensive activities for longer periods (Table 4).

Figure 10

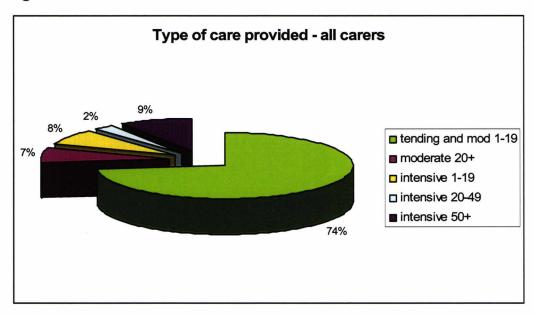
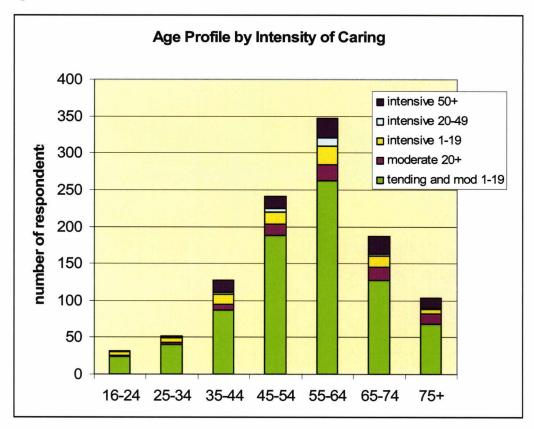


Table 4

Level of Care	Male (n=438)		Female (n=651)	
	Age 16-64	Age 65+	Age 16-64	Age 65+
Tending and moderate 1-19 hours	79.7%	67.1%	72.9%	68.1%
Moderate 20 + hours	5.9%	11.2%	6.0%	9.4%
Intensive 1-19 hours	7.0%	8.6%	8.8%	5.8%
Intensive 20-49 hours	2.1%	1.3%	2.9%	1.4%
Intensive 50+ hours	5.2%	11.8%	9.4%	15.2%

Figure II



Additional qualitative commentary suggested that carers provide support with a range of other activities in addition to those activities specifically identified as care related. For example, carers reported liaising with care agencies (including social services departments, education department, care home staff, GP); monitoring self funded services (e.g. paid live-in carer); providing social support; organising the cared for person's affairs (e.g. getting her papers sorted; arranging power of attorney) and transport issues (e.g. taking the person to and from hospice by car, transporting people to carers meetings).

#### Intensive Levels of Caring

Overall, a fifth (19.4%) of all who identified themselves as carers in the Kent survey were providing intensive care. In terms of type of condition, half (51%) of those being cared for who had a learning disability, a quarter (25%) of people with dementia (13%) and a fifth (20%) of people with a physical health problem or disability were receiving intensive care.

Of those providing intensive care:

- > Over half (54%) were helping with getting in and out of bed,
- > Three quarters (77.5%) were helping to wash,
- Nearly three quarters (72.5%) were helping with dressing,
- > A third (36%) with feeding and
- Two fifths (41%) with using the toilet

Two thirds of all carers who were providing intensive levels of care were female and a third male. 20% were aged 35-44; 22% were 45-54, 26% were 55-64, 20% were 65-74 and a 10% were aged 75 years and over. 53.1% of the intensively cared for were sharing a household

A half (51%) of those cared for who have a learning disability, a quarter (25%) of people with dementia and a fifth (20%) of people with a physical disability receive intensive care

You just feel like you have no time to yourself and when you do you are too tired to even socialise let alone take exercise'

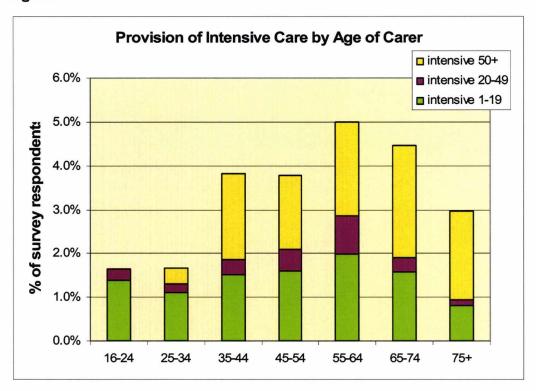
with their carer, and 44.6% were extra-resident. As might be expected carers who were caring intensively for longer hours (50+ hours per week) were more likely to be sharing a household with the person they cared for (84%)

Co-resident spouses (37%) and adult sons/daughters (41%) were receiving considerably higher levels of care than the extra resident cared for groups

In terms of types and levels of care, the survey evidence reflects the national picture with co-resident spouses (37%) and adult sons/daughters (41%) receiving considerably higher and more intensive levels of care than the extra resident cared for groups.

More detailed analysis makes it clear that intensive care for 20-49 hours per week is more likely to be provided by those aged 55-64 than other age groups (Figure 12); more people aged 65-74 were providing intensive care. Although these age groups do a great deal of intensive care for 50 hours or more per week, it is striking that many younger carers (35-54) and older carers (75+ years) also provide this very high level of care.

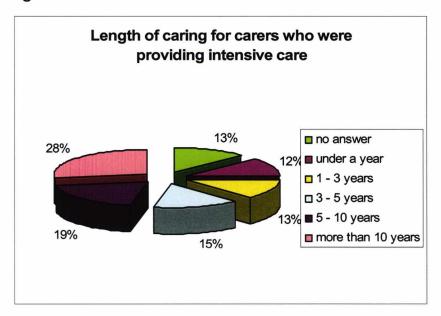
Figure 12



One third of people providing intensive care for 50 or more hours a week (32%) had been caring for over 10 years

One third (32%) of people providing intensive care for 50 or more hours a week said they had been caring for over 10 years, the same number for between 5 and 10 years, a sixth (16%) between 3 and 5 years, a sixth (16%) between 1 and 3 and 3% for under a year (Figure 13). Thus overall, two thirds of people providing intensive care for 50 hours or more per week had been caring for over 5 years. Of those who have been caring for over 10 years (68 carers, a third of the total), a third (33%) have been caring for between 11 and 15 years and a third (32%) for over 24 years.

Figure 13



7.4% of intensive care is provided to relatives living in care homes

7.4% of intensive care is provided to relatives living in a care home or hospital. These are likely primarily to be spouses as there is evidence that, of all the cared for groups, spouses tend to remain intensively involved with their wife or husband even when they move into long term care.

#### **Moderate Levels of Caring**

Of those receiving moderate levels of care (20 or more hours a week):

- > A half (54.4%) needed physical help with walking,
- A third (27.8%) with getting up and down stairs
- > 15.2% needed help getting in and out of bed, and
- 60.8% needed help to take medicines

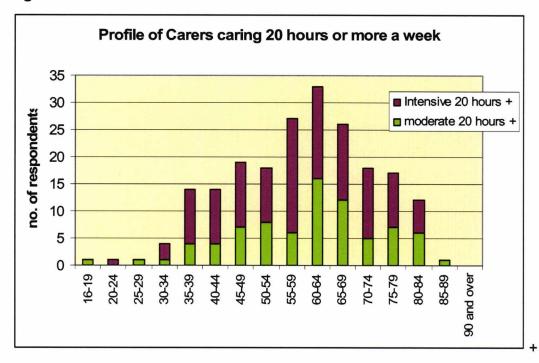
For all carers in the survey, moderate care activities (those that require physical support) were provided by relatively few. 23% of all

carers provided help with walking, 19.3% with giving medicines, 8.9% with getting up and down the stairs, and 10.1% with getting in and out of bed. It is important to note that many carers providing intensive care will be providing help with physical care activities alongside intensive care. For example, 70% of carers providing 50 or more hours of care per week give medicines.

The proportion of people providing moderate care rose steeply from 2.5% aged 25-34 to 27.8% aged 55-64; it fell to 21.5% for those aged 65-74 and to 17.7% for those aged 75 and over. This rise is steeper than is seen for intensive care (Figure 14).

Most people (70.5%) providing moderate care for 20 hours or more were caring for someone living with them on a co-resident basis. A fifth (21.5%) of those in receipt of moderate care live in their own home, a small number (2.5%) were living in a care home or housing with extra care; most of the latter group would be elderly parents; a smaller number spouses.

Figure 14



In terms of the type of health condition of the person receiving moderate care (20 hours or more a week), 72.2% had a physical disability, 13.9% were suffering from Alzheimer's disease or dementia, 12.7% had 'another kind of mental health problem', and 8.9% had a learning disability. A quarter (22.8%) of care recipients were parents, half (49.4%) were spouses, a sixth (15.2%) were sons/daughters and a few were 'other relatives' (1.3%) or friends (5.1%).

The key distinction
between intensive and
moderate levels of caring
is the provision of personal
care

The key distinction between intensive and moderate levels of caring is the provision of personal care. Intensive carers provide support with physical care alongside personal care with personal care being its defining feature whereas the role of a moderate carer is characterised by physical care activities. It is also the case that whilst more intensive care is provided on a co-resident basis and more

moderate care on an extra resident basis, for some relationships the latter situation simply represents an earlier stage on the caregiving trajectory. Filial carers for example, may provide moderate care to a parent living in their own home for a number of years before shifting the locus of care to sharing a household when they become more dependent and need intensive care.

'... driving around to appointments takes up a lot of time and is tiring' The majority of intensive care recipients are spouses or sons/daughters and this is consistent with earlier findings about links between co-residency, type of care and the relationship between carer and cared for. The fact that more parents featured in the moderate care category than the intensive reflects the fact that parent carers tend to have lower levels of need for support.

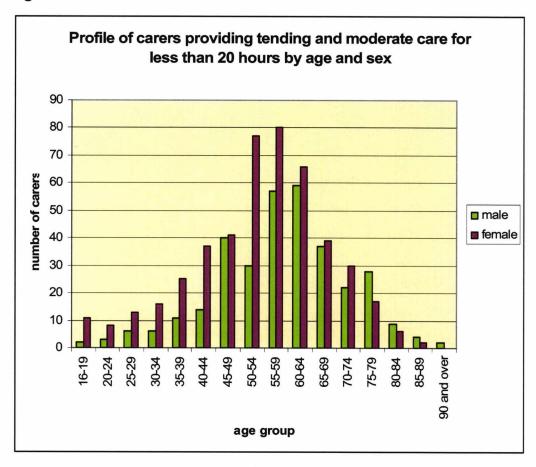
#### **Tending**

Overall, 73% of carers
were providing tending or
moderate levels of care for
less than 20 hours a week

Providing low levels of instrumental or physical care – (tending activities only for any number of hours or moderate care activities for less than 20 hours per week) was the majority care pattern evidenced in the survey; this was the case for 73% of all Kent carers (Figure 15). Two fifths (41%) of this group were male, and three fifths female (59%). Younger women respondents were particularly more likely than men to be providing low levels of care.

As might be expected the majority of tending (69%) was being delivered on an extra resident basis. Tending is characterised by a few hours per day or even per week of relatively low level support tasks such as doing the shopping or taking the person to the doctor's.

Figure 15



Half of all those with dementia and those with physical ill health and a third of people with a learning disability receive tending Half (48.5%) of those care recipients with dementia, over half (53%) of those people with a physical health problem or disability and a third (35.5%) of people with a learning disability, were in receipt of tending. Many of those with a physical health problem (64.9%) were older people (65 or older), as noted above. In terms of relatives, nearly two thirds (60%) of parents, a quarter (25%) of all spouses, and nearly two fifths (38%) of the total number of sons/daughters were in receipt of tending. Three quarters (77.5%) of 'other relatives' and friends (78%) and 100% of neighbours were also in receipt of tending. Although tending was also provided for some close relatives

– parents, spouses – this often represents the early stages of dependency; it is consistent with wider trends that the vast majority of friends and more distant relatives receive low levels of tending type support over the longer term<sup>32</sup>. Only 35% of those caring for a spouse and 42% for a child were tending or providing moderate care less than 20 hours.

The proportion of carers carrying out tending activities is also different depending on the relationship. For example 72% took their spouse to the doctor or hospital compared to 29% who took their friend and 27% their neighbour. Further, 60% took their spouse and 57% their parent out compared to 34% their friend and only 5% their neighbour.

The vast majority of younger carers were providing tending

The vast majority (93.5%) of younger carers - those aged 16-24 years - were providing tending. There were only 31 young carers in the survey and 42% were caring for a parent.

<sup>&</sup>lt;sup>32</sup> Maher J and Green H (2002) Carers 2000, London: Office for National Statistics, The Stationary Office.

# Has there been any change in the pattern of caring in Kent since 2001?

It has been possible to do a comparison of some of the carer related findings from the 2005 survey with its predecessor. The 2001 Health and Lifestyle survey covered Medway as well as Kent; there was also an enhanced sample of older people. The 2001 survey asked one question about caring (the same key question used in the 2005 survey):-

'Do you look after, or give any help or support to family members, friends, neighbours or others because of: long-term, physical or mental ill-health or disability, or problems related to old age?'

In 2001, overall, 16.4% of respondents living in Kent said they were providing help or support for friends or family. 10.8% of people in the survey aged 16-24 were caring, rising to 27.0% aged 45-64 and then falling again to 10.4% for those aged 75 and over. In 2005, 8.7% of all those aged between 16-24 said they were caring, rising to 25.1% at 45-54 and 29.2% aged 55-64 falling then to 16.9% aged 75 and over.

In the 2001 survey 4.1% of people aged 75 and over were caring for 50 hours a week or more; this had increased to 4.6% by 2005

In both surveys and for all ages the proportion of women who were caring was greater than men (Table 5). The proportion who were caring rose to a peak at age 45-64 and remained high at 65-74 before falling again. There has been a reduction in the proportion caring aged under 65 from 2001 to 2005, but for men aged 45-64 there was an increase from 22.4% to 24.3%, a small reduction aged 65-74 and a small increase aged 75 and over. The proportion of women caring continued to fall until the age of 65 when there was an increase from 16.6% in 2001 to 21.5% in 2005 and from 8.3% in 2001 to 12.6% in 2005 (Table 5) (Figure 16).

In 2001 11.6% of carers were providing care for between 1-19 hours per week, 1.8% for 20-49 hours and 3.1% for 50 hours or more a week. By 2005 comparables figures were: 15.1%, 1.4% and 3.4%. The burden of additional hours of caring has primarily been borne by older carers. The numbers of hours spent caring has increased for all ages from 45 (Figure 16).

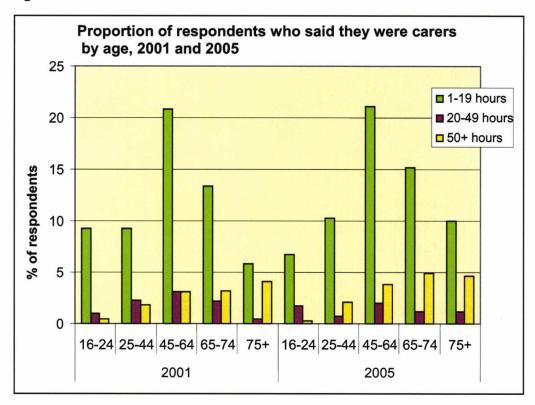
The intensity of caring has increased for all ages from 45 yrs; the burden of additional hours of caring has been borne by older people

There appears to have been an increase in the amount of caring amongst older people (65 and over) by 2005, both in terms of the proportion who are caring for 1-19 hours and those caring for 50 hours or more a week (Figure 16). In 2001 3.2% of people aged 65-74 were caring for 50 hours or more and in 2005 this had risen to 4.9%. In the 2001 survey, 4.1% of people aged 75 and over were caring for 50 hours a week or more compared to 4.6% in the 2005 survey.

Table 5
Proportion of respondents who said they were a carer by age, Kent 2001 and 2005

Age Group	2001		2005	
	Males Females		Males	Females
	N=3256	N=4815	N=2355	N=3172
16-24	8.2%	12.2%	5.2%	10.4%
25-44	11.3%	15.5%	10.3%	14.8%
45-64	22.4%	30.2%	24.3%	28.9%
65-74	21.05	16.6%	20.2%	21.5%
75+	13.6%	8.3%	13.9%	12.6%

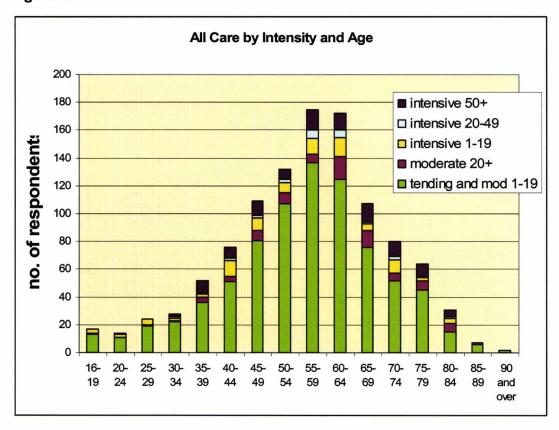
Figure 16



#### **Particular Groups of Carers**

The following section explores the survey findings around a number of specific groups of carers: Mid-life carers, 'betwixt and between' older carers, and parent carers. The distinguishing feature between these first three groups of carers is their age. Young carers are categorised as being less than 40 years old. Figure 17 shows the breakdown of the age of the respondents in the survey who said they were carers and the level of intensity of their care.

Figure 17



#### Mid Life Carers - The Pivot Generation

Mid life carers (carers aged 40-59) constitute the largest group of carers in the UK; they make up two fifths of the total and are the group increasing at the fastest rate<sup>33-34</sup>. They primarily care for elderly parents/in law. Mid life carers are at the forefront of recent policy and research developments and increasing attention is being paid to their needs by employers and local authorities<sup>35</sup>. What makes the needs of the mid life carer unique is that many are combining paid work, home commitments - which may include supporting children -

<sup>&</sup>lt;sup>33</sup> Milne A & Hatzidimitriadou E (2002) The Caring in ater Life Report: A Secondary Analysis of the 1995 General Household Survey, *Quality in Ageing*, Vol 3, Issue 3, pp3-15

<sup>&</sup>lt;sup>34</sup> Office of National Staistics (2002) Census, 2001 London: The Stationary Office

<sup>&</sup>lt;sup>35</sup> Mooney, A., Stratham, J., & Simon, A. (2002). The Pivot Generation - Informal Care and Work after Fifty. Bristol: The Policy Press

and care for an elderly relative. 81% of men aged 40-59 and 69% of women aged 40-59 are in paid employment in England and Wales<sup>36</sup>. For many older workers caring responsibilities emerge resulting in the challenge of 'juggling work and care'<sup>37</sup>. In the Kent survey a greater proportion of midlife carers (35.5%) had at least one child (aged 15 or younger) living in their household, compared to carers in other age groups (17.7%).

43.5% of all carers in Kent were aged 40-59; there were higher proportions in the older age groups of 50-54 & 55-59 years 43.5% of all carers in Kent were aged 40-59; there were proportionately higher numbers in the 'older' mid life cohorts - 50-54 years and 55-59 years. Three quarters (76%) of all mid life carers were involved either in tending activities or moderate levels of care for under 20 hours per week (Figures 18 and 19). This was the case across all the midlife cohorts: under 10% of each age cohort cares for 50 or more hours per week. There were nearly double the number of women to men in each age cohort of mid-life carers — overall the split was two thirds female (64.4%) and one third male (35.6%) for the mid-life carer group. Three quarters (79%) of all mid life carers were married, a tenth (12%) were divorced or separated, 5% are single and 3% were widowed.

<sup>&</sup>lt;sup>36</sup> Census 2001, downloaded from the NOMIS database <u>www.nomisweb.co.uk</u> 20/02/2008

<sup>&</sup>lt;sup>37</sup> Phillips, J., Bernard, M and Chittenden, M (2002). Juggling Work and Care, the experiences of working carers of older adults. York: Joseph Rowntree Foundation

Figure 18

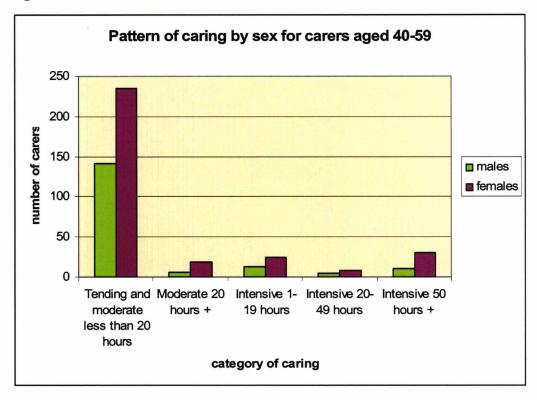


Figure 19a

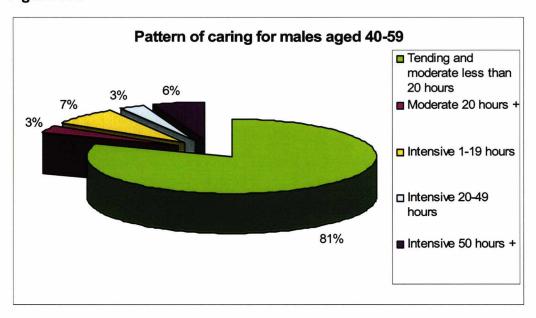
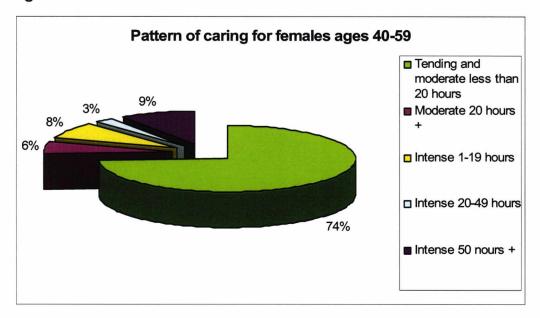


Figure 19b



Amongst mid life carers:

- Two thirds (64%) of the cared for were aged 75 and over; of these two thirds were aged 75-84 years and a third aged 85+. A sixth (14%) were 25-64 years, 9% were 65-74 and 5% were aged under 25 years.
- Four fifths (81%) of the cared for were living in their own home; one fifth were co resident (19%).
- Two thirds (66%) of the cared for had a physical health problem/disability, under a tenth (9%) had dementia, a tenth (10%) had 'another type of mental health problem', 7% had a learning disability and just under a quarter (23%) had 'other health problems'.

'...other people's looks and words can make

caring so much harder'

'... caring does get in the

Two thirds of the cared for

were aged 75-84 years

and a third were aged

way of life.... but its

family'

85+

Three fifths (61%) of mid life carers were supporting their parents/in law, a tenth (10%) support a disabled son or daughter, a tenth (9%) a friend, 6.5% a spouse and 5% 'other relatives'. In terms of which groups were supported intensively by mid life carers it is clear that it was primarily parents/in law or disabled sons/daughters who required this level of care.

3 out of ten people aged 60-64 were caring

#### Betwixt and Between - Carers aged 60-64

There is a group of carers, aged 60-64 who are 'betwixt and between' the group defined as mid life carers and those defined as older carers. In the Kent survey this group constituted 15.8% (N=172) of the total and 29.4% of all people in this age group. About equal numbers were male (49.5%) and female (45%) (the others not specified).

three quarters provided tending and two fifths were supporting a parent / in law

The cared for group was predominantly older with three quarters (74%) being aged 65 years or over. The majority of care (73%) was tending; only a tenth (10%) providing intensive care for 20 hours or more per week. Two fifths (44%) were supporting their parents/in law, a fifth (19%) their spouse/partner, a tenth (8%) a son or daughter, a tenth (9%) 'other relatives', and over a tenth (12%) were supporting friends. 8% of this 'betwixt and between' group were caring for more than one person; most would be parents/in law but for a few they would have been supporting a parent and a spouse.

As is the case nationally this growing group of 'betwixt and between carers' is made up of three distinct sub groups: those supporting friends, 'other relatives' and spouses who were likely to have been caring for a relatively short period of time, those who have been caring for their parents in the medium term and parent carers who have been supporting their son or daughter all their children's life. The former group (friends, relatives and spouses) is considerably larger and the care demands are relatively low level. The parent carers make up the majority of those doing intensive care<sup>38</sup>

<sup>&</sup>lt;sup>38</sup> Milne, A and Hatzidimitriadou, E (2002) The Caring in Later Life Report: A Secondary Analysis of the 1995 General Household Survey, *Quality in Ageing*, Vol 3, Issue 3, pp3-15

#### **Older Carers**

A quarter of all UK carers were aged at least 60 years old

Older carers are likely to be caring in the context of a long-term relationship

Over a third of people will become carers post retirement

'it's my duty to look after my husband' Although the number of carers declines with age, nearly a quarter of all carers in the UK are aged at least 65 years old; over a third of people will become carers post retirement<sup>39</sup>. Three quarters of those people receiving care from older carers are older themselves. A number of mid life carers 'graduate' into late life caring, titrating support to a dependent parent according to need.

The contribution of older carers has only recently been recognised. It is clear that there is a growing number of older carers in the UK and that they form an increasing percentage of the total number. They are also ageing as a group, in parallel with the UK population profile. There is also a trend towards evergreater numbers of older people being cared for by similarly aged or third age carers<sup>40</sup>.

Older carers can be distinguished from other groups of carers in a number of key ways.

- > Care-giving is more likely to take place within the context of a long-term often life long relationship,
- > Dementia is more likely to be present.
- > There is an increased risk of carers having health problems of their own<sup>41</sup>.
- Spouse caring constitutes a defining feature of caring in later life; nearly two thirds of the carers of older people with dementia are spouses<sup>42</sup>.

<sup>&</sup>lt;sup>39</sup> Milne, A., Hatzidimitriadou, E., Chryssanthopoulou, C and Owen, T (2001) Caring in Later Life: Reviewing the role of older carers, London: Help the Aged

<sup>40 &#</sup>x27;third age' is a term for those aged over 60 years.

<sup>&</sup>lt;sup>41</sup> Hatzidimitriadou, E and Milne, A (2005) Planning Ahead: Meeting the Needs of Older People with Intellectual Disabilities in the UK, Dementia: The International Journal of Social Research and Practice, 4(3): 341-359

<sup>&</sup>lt;sup>42</sup> Milne A & Hatzidimitriadou E, (2003) Isn't He Wonderful? Exploring the contribution and conceptualisation of older husbands as carers, Ageing International, Vol. 28(4), p389-408

aged 65 and over; 20% of these were caring intensively

27% of carers in Kent were Just over a quarter (27%) of carers in the Kent survey were aged 65 and over (N=314). Of these, a third (35%) were aged 65-69, a quarter (27%) were 70-74, a fifth (22%) 75-79, a tenth (11%) 80-84, 4.1% were aged 85 years and over. Just over a half of older carers (aged 65 and over) were male (52%) and just under a half (48%) were female.

'I regularly change his stoma bag'

Three fifths (63%) of older carers were providing tending and moderate caring 1-19 hours per week, a tenth (10%) were providing moderate levels of caring for 20 or more hours per week, 7% intensive care 1-19 hours per week, 1% intensive care 20-49 hours per week and as many as one in ten (12%) were offering intensive care for 50 or more hours per week.

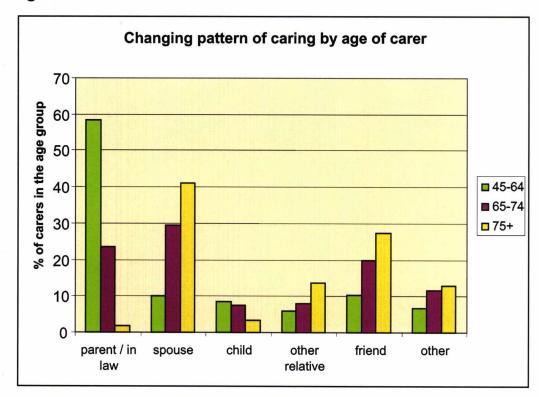
Older carers were most likely to be caring for their spouse (34%), their friend (23%) or their parent / in law (15%)

In terms of who was being cared for, nearly a sixth (15.3%) were parents/in law, a third (33.8%) were spouses/ partners, 6.1% were sons/daughters, a tenth (10.2%) were other relatives, a fifth (22.6%) were friends, 4.1% cared for a neighbour and 2.2% were 'other'.

It is interesting to note the changing pattern of caring with age of the carer. Carers aged under 65 were most likely to be caring for a parent / in law whilst older carers were increasingly likely to be caring for a spouse (41% of those aged 75 and over) or a friend (27.4% of those aged 75 and over) (Figure 20).

In terms of length of time caring, a tenth of older carers (9%) had been caring for under a year, just under a quarter (22%) for I-3 years, a fifth (20%) for between 3-5 years, a quarter (24.5%) for 5-10 years and a fifth (20%) for more than 10 years. 8% were caring for more than one person.

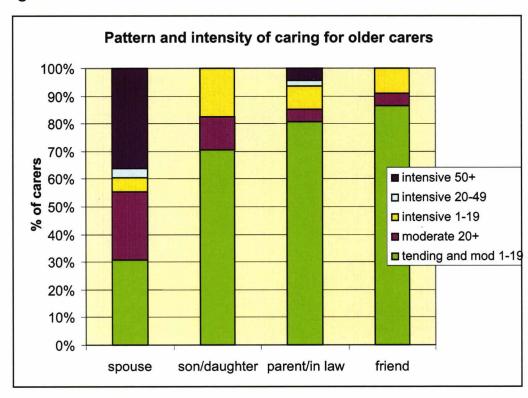
Figure 20



Nearly a quarter of all older carers were providing intensive care; spouses were most likely to be in receipt of intensive care

'As a couple we look after each other, you name it we do it!' Nearly a quarter (22.0%) of all carers aged 65 and over were providing intensive care (for any number of hours); this compares to 18.6% of carers aged under 65. Older carers were also more likely to be providing intensive care for 50 hours or more, primarily because a significant proportion were coresident. Spouses or partners were the cared for people requiring the most intensive levels of care; 36% were receiving intensive care for 50 hours or more. Most parents/in law, friends and 'other relatives' were receiving 'tending' (Figure 21).

Figure 21



29% of parent carers were aged under 45 and 70% were aged 45 and over; only 4% were aged 75 and over.

'I care 100% about my daughter; the difficulty I have is whether she abuses my love and willingness to do things for her'

#### **Parent Carers**

9% (N = 101) of all carers in Kent were parent carers; as a group they tended to be younger than spousal carers. 30 % of parent carers were aged under 45, a quarter (25%) were 45-54, a quarter (28%) were 55-64, a fifth (14%) were 17% were aged 65 and over. Over three quarters (78%) of parent carers were mothers. Three fifths (59%) of sons/daughters were living with their parent carers.

Whilst 40% of parents were providing tending and moderate care for less than 20 hours a week, 41% were providing intensive care, 29% for 50 hours or more a week (Figure 22). Younger parent carers were more likely to be providing intensive care; 54% of those aged 16-44 were caring intensively 50 hours or more per week compared to 22% aged 45 and over. Conversely 49%

of those aged 45 and over were providing tending and moderate care for 1-19 hours per week. 52% of the cared for were aged under 25. This group was likely to demand intensive care (Figure 23).

Figure 22

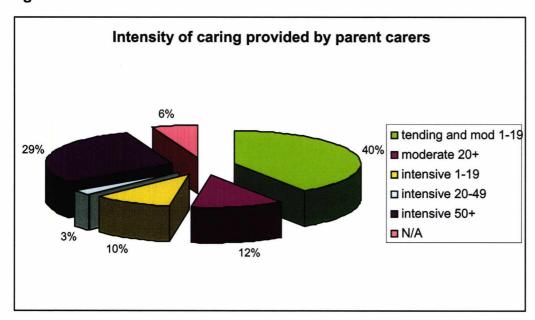
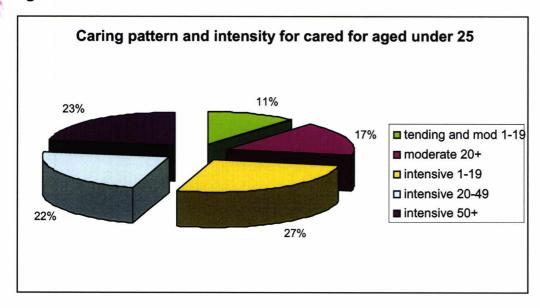


Figure 23



The health problems experienced by the son or daughter were available for 94.1% of cases; the majority of parent carers (59%) were supporting a son or daughter with a learning disability; fewer were caring for a child with a long term physical disability as a higher proportion of this group live independently. Long term care of a child with a learning disability is widely evidenced to be very stressful, time consuming and a considerable responsibility. Many older parents worry about what will happen to their son/daughter when they die or become too frail to care<sup>43</sup>.

## Caring & Health

Research evidence suggests there are financial, health, emotional and social consequences related to caring

'I tend to get swamped in the cared for person's needs and medical condition'

'My freedom of movement is severely restricted'

There is a considerable literature on the effects of caring on carers' lives. This shows that there are financial, health, emotional and social consequences related to caring; these are particularly pronounced for carers providing intensive care over the longer term<sup>44</sup>. Although the relationship between physical health and caring is complex, intensive carers appear at increased risk of musculoskeletal problems; the physical challenges such as lifting and bathing associated with caring increase their vulnerability to injury.

Analysis of the 2001 Census has shown that 22% of people providing substantial care are not in good health compared to 11% of people not providing care<sup>45</sup>. Health is more likely to be poor if they are caring for more than 50 hours a week. The younger a carer the more likely their health is to suffer; many younger carers are caring for disabled children and have a lifelong commitment. Additionally, there are a number of social costs related to caring for example, being unable to leave the person you are caring for as well as

<sup>&</sup>lt;sup>43</sup>Hatzidimitriadou E & Milne A (2005) Planning Ahead: Meeting the Needs of Older People with Intellectual Disabilities in the UK, Dementia: The International Journal of Social Research and Practice, 4(3): 341-359

<sup>&</sup>lt;sup>44</sup> Milne, A., Hatzidimitriadou, E., Chryssanthopoulou, C and Owen, T (2001) Caring in Later Life: Reviewing the role of older carers, London: Help the Aged.

<sup>&</sup>lt;sup>45</sup>Carers UK. In poor health: the impact of caring on health <a href="http://www.carersuk.org/Policyandpractice/PolicyResources/Research/InPoorHealth.pdf">http://www.carersuk.org/Policyandpractice/PolicyResources/Research/InPoorHealth.pdf</a>

broader constraints such as a limited social life, being kept at home, facing a timetable of caring tasks and worrying when leaving the cared-for person.

The negative impact of caring was particularly marked for those providing intensive care

Evidence about the link between caring and emotional health is much stronger. Recent work analysing data from the British Household Panel Survey suggests that older carers experience increased stress, with between one third and one half of all spousal carers of people with dementia suffering from depression<sup>46</sup>.

prevalence of mental health problems is higher amongst people caring for a spouse or partner A survey in 2001 as a follow up to the 2000 General Household Survey has shown that carers suffer greater levels of neurosis particularly those living in the urban situation; neurosis levels were higher in women than in men<sup>47</sup>. They also reported a strong association between levels of neurosis and self reported health status, long standing health problems and health problems that had led to restricted activity. The prevalence of mental health problems appears higher amongst people caring for a spouse or partner.

A prospective survey of 70 primary carers of severely brain injured people using the SF36, the Carers Strain Index and the Relative Questionnaire, <sup>48</sup> demonstrated a trend towards lower perceived health status which related to the level of disability of the injured person and interpersonal factors irrespective of the cause of the injury. Age related ill health – an issue discussed earlier in the report – is a particular risk factor for older carers whose health may also be damaged by intensive and/or long term care giving.

'I would really like more time to myself — if I have a day out with a friend I always feel guilty'

The Kent survey included many questions about health and lifestyle and the opportunity has been taken to use this data to look at the health of carers. Increasingly age enhanced the likelihood of carers reporting fair or poor health; 25.5% of carers aged 65-74 and 39.8% of carers aged 75 and over reported

<sup>&</sup>lt;sup>46</sup>Hirst, M (2002) Transitions to Informal Care in Great Britain during the 1990's, Journal of Epidemiology and Community Health, 56, 579-87

<sup>&</sup>lt;sup>47</sup> Singleton et al (2002) The Mental Health of Carers. ONS HMSO

http://www.statistics.gov.uk/downloads/theme\_health/Mental\_Health\_of\_Carers\_June02.pdf

<sup>&</sup>lt;sup>48</sup> McPherson KM, Pentland B, McNaughton HK (2000) Brain Injury – the perceived health of carers, Disability and Rehabilitation 22; 15. 683-689

either fair or poor health. Nearly three quarters (72%) of parent carers reported that their health had been adversely affected by caring.

'It just feels like you have no time to yourself and when you do you are too tired to even socialise let alone take exercise!' Overall however, nearly three quarters (73%) of all carers reported their health as 'good or excellent' and only a quarter (24%) were at risk of major depression. As nearly half (45%) of carers reported having a 'long standing illness or disability', these findings are perhaps surprising.

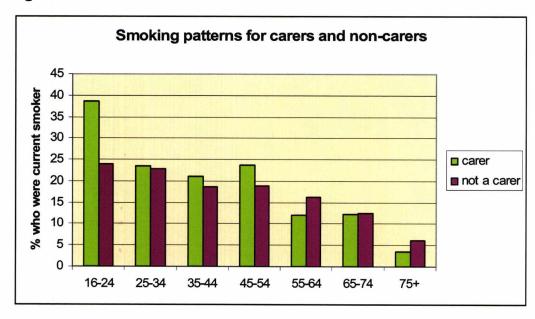
Although few carers (11%) reported their health as worse than it was a year ago, slightly higher proportions of those who were caring intensively were in this situation. 5% of carers who were providing care for 50 or more hours per week reported their health as 'much worse' than it was a year ago compared with 1% of those who were tending.

'the main problem is my feet, also back & kidney problems...'

Overall larger numbers of carers reported fair or poor health than non-carers. However for mid life carers and those aged 75 and over this was not the case (Figure 26). This may reflect two issues: that carers may be fitter than the person they care for and that 'admitting' to poor health implies an inability to continue caring. For many older carers, many of whom are spouses, this would be unthinkable as the need to maintain the 'caring dyad' is a primary motivator<sup>49</sup>.

<sup>&</sup>lt;sup>49</sup> Milne A & Hatzidimitriadou E (2003) Isn't He Wonderful? Exploring the contribution and conceptualisation of older husbands as carers, Ageing International, Vol. 28(4), p389-408

Figure 24

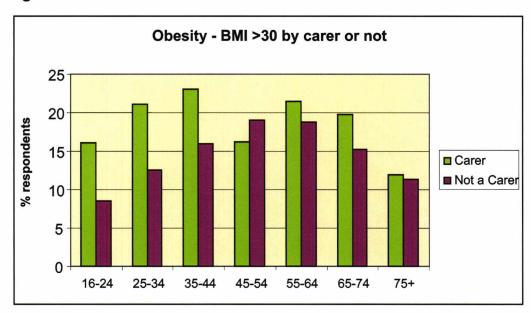


Smoking was more prevalent amongst younger carers than the general population....

Although half of older carers once smoked, only a tenth (8%) did so at the time of the survey. Smoking was more prevalent amongst younger carers than the general population, only reducing to lower levels after the age of 55 (Figure 24). Care related stress may be a contributory factor. As the survey includes a lot of information about attitudes to smoking and it would be interesting to explore this further.

....younger carers were at greater risk of obesity than younger non-carer It is well documented that exercise and diet are important in preventing obesity. Three quarters of all carers (72%) were exercising at least once a week for 30 minutes. A similar proportion (78%) had a BMI of less than 30. However analysis shows that younger carers were at greater risk of obesity than younger non-carer (Figure 25).

Figure 25



'Caring leaves me emotionally drained'

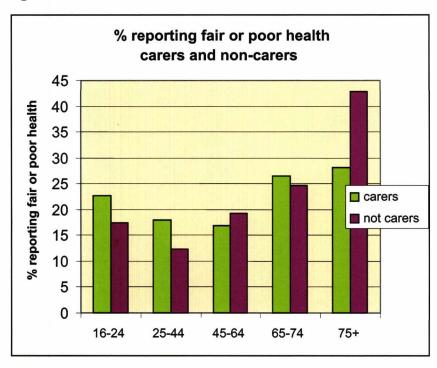
'I get swamped in the cared for person's needs and medical condition'

'long term stress on marital relations'

A particular pattern emerged around carers caring moderately for 20 or more hours per week. Findings suggest that, in general terms, this group tended to be at risk of poor health outcomes and reduced quality of life.

Extra resident filial carers supporting their parents for example, may also have been working and for some, looking after children. We found this to be the case compared to other carers in our survey with 59.7% of extra-resident filial carers being in paid work and 28.4% having children. This group are referred to as the 'pivot generation' and may be carrying a burden that significantly undermines health and quality of life. However in our survey we found coresident filial carers were also facing similar challenges with a similar proportion also saying they were in work whilst caring (57.1%).

Figure 26



One in two carers in the Kent survey said that caring had affected their health adversely

One in two (50.1%) carers in the Kent survey reported that caring had adversely affected their health. This was the case for the same proportion of men as women.

It is interesting to note that (36.7%) of carers reported their health had been affected but did not report fair or poor health overall. By contrast 7.5% of carers reported poor or fair health did not contribute this to caring (Table 6).

Table 6

Proportion of carers reporting their health has been affected by caring, by self reported level of general health

Health Affected	General Health Status		
by Caring	good to excellent	fair or poor	
yes	36.7%	13.2%	
no	42.6%	7.5%	

'anxiety about quality of care; stress caused me to develop ME'

The negative impact of caring was particularly marked for those providing intensive care. Overall the majority of intensive carers (79.9%) reported care as having a negative impact on their health in some way. This is the case for 84% of those caring for 20-49 hours and 86% of those caring for 50 hours or more per week. These findings contrast with those providing lower levels of care; only 42% of those providing tending said their health had been affected by caring. The differences between types of care is significant (Chi.sq=89.265; 3df; p<0.0001).

In terms of specific health conditions, of those carers who said their health had been adversely affected:

- 66.1% reported feeling tired
- > 30.2% reported feeling depressed,
- > 2.4% reported loss of appetite,
- > 36.9% reported disturbed sleep,
- > 51% reported general feelings of stress,
- > 23.4% experienced physical strain,
- > 33.7% were short tempered/irritable and

'At times I feel low and depressed ... but I soon pull myself together'

Further, 11.4% had been to see their GP as a result of caring. Women carers were more likely to report the ill effects of caring than men; they were nearly twice as likely to report tiredness and depression and were more than twice as likely to have been to see their GP (Figure 27) These effects on health were also increasingly reported with increasing intensity of care (Figure 28).

' its difficult but the attitude of the family gets us through'

Nearly a tenth of intensive carers reported 'other' effects of care giving; these included marital break up, bruises and scratches from pinching by the cared for person, reduced independence and limited opportunity to pursue leisure interests. Other qualitative comments emphasised the contribution of caring to: dermatitis; stress levels; migraine and a limited social life. One carer spoke for many when they complained that their 'freedom of movement is severely restricted' and another that they had 'no time to do things'.

'caring caused the break up of my marriage'

More positively, one or two carers reported that the family 'pulls together' to help them provide care — 'it's difficult but the attitude of the family gets us through'. Another commented that they were aware 'that others are in a far worse situation'.

Figure 27

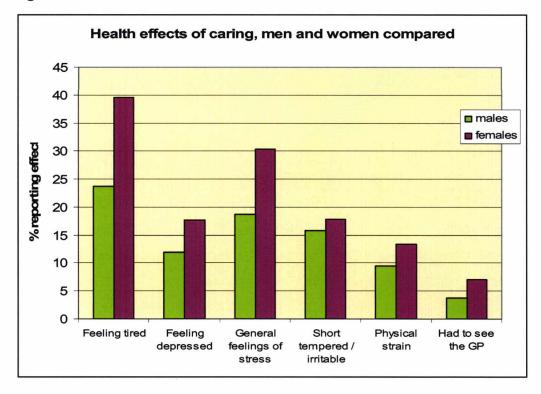
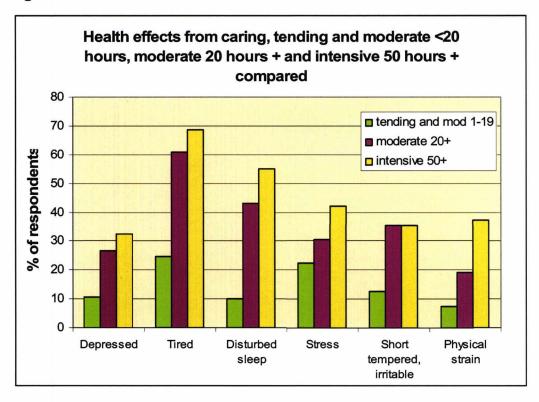
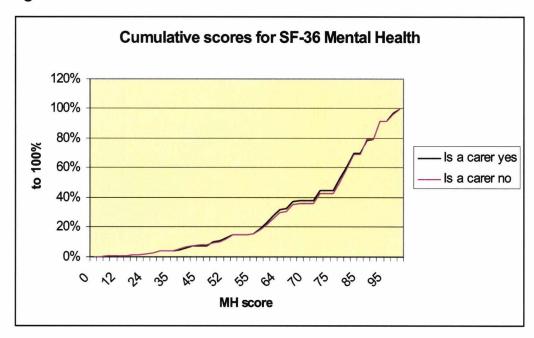


Figure 28



The survey included questions on mental health from the SF-36 which provided the mental health score, however analysis was unable to demonstrate any divergence between the scores for carers and non-carers (Figure 29).

Figure 29



The SF-36 depression screener was also included which measures respondents risk of depression. Survey evidence using the SF-36 depression screener suggests that a third of carers (32.3%) are at risk of 'major depression' compared to 27.4% of non-carers (p=0.001; Chi sq.=15.7, 3d.f.) (Table 7). Questions on anxiety were asked from the revised clinical review schedule (CIS-R) which measures psychiatric disorder<sup>50</sup>. Of all carers 16.1% had a CIS-R symptom score of 2 or more, indicating symptoms of severe anxiety among carers, however this compares to 14.2% of non-carers.

Table 7
Risk of depression for carers and non-carers

Depression screener:	ls a c	ls a carer		
Risk for depression	Yes	No		
	(n=1142)	(n=4457)		
no answer	.3%	.9%		
Major depression	32.3%	27.4%		
Dysthymia	.2%	.4%		
No risk	67.3%	71.3%		

<sup>&</sup>lt;sup>50</sup> Singleton et al. (1998) Psychiatric Morbidity among Prisoners in England and Wales. Office of National Statistics: Social Survey Division SS1417

## **Deprivation, Poverty & Caring**

Intensive carers have been identified as one of the poorest groups in the UK

Intensive carers have been identified as one of the poorest groups in the UK; research indicates that carers providing substantial amounts of care face much financial hardship. In particular, if caring begins during pre-retirement it impacts upon earning capacity and in turn pensionable status. There are also additional costs related to caring such as extra heating and washing, and transport costs<sup>51</sup>.

Overall the survey reveals
very little difference
between levels of
deprivation between carers
and non carers in Kent

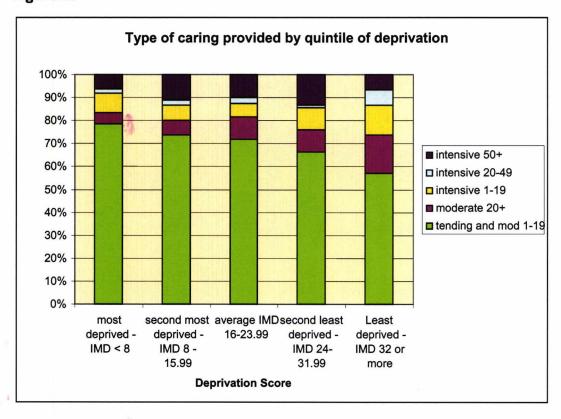
Overall, the Kent survey reveals very little difference between levels of deprivation amongst those providing care and those not (range 18.1% to 20.9%). However, in the more deprived wards the level of care provided appears more likely to have been tending or moderate care of less than 20 hours per week. Conversely, people in the least deprived wards were providing higher levels of moderate or intensive care, apart from those caring for 50 hours or more (Figure 30). In terms of geography, there were few differences between East Kent & West Kent.

There are higher numbers of younger carers and women carers in deprived wards

Additional analysis suggests that there was a higher number of younger adult carers in deprived wards than less deprived (27% compared with 16% in intermediate and 13% in least deprived). Further, there was a higher proportion of women carers in deprived wards (not significant) than in less deprived wards; this pattern was not reflected for men.

<sup>&</sup>lt;sup>51</sup> Buckner, L and Yeandle, S (2007) Valuing Carers: calculating the value of unpaid care London: Carers UK

Figure 30



Carers are more likely than non carers to be owner occupiers in Kent

Housing type and tenure are important indicators of deprivation. The survey data found that carers were more likely than non carers to be owner occupiers (78.5% compared to 75.1%) (Table 8). This was particularly the case if they are providing tending or moderate care for less then 20 hours per week (81.9%). Younger carers (16-24) were less likely to be living with parents/family (41.9% compared to 67.3%) than their non caring counterparts. Further, older carers aged 75+ were more likely to be owner occupiers compared to older people who were not carers (85.5% to 78.1%).

Table 8

Housing type by whether or not a carer

	ls a carer		
	Yes	No	
Housing Type	(n=1142)	(n=4457)	
Owner Occupier	78.5%	75.1%	
Privately Rented	4.6%	5.9%	
Renting from Housing Association	5.2%	5.0%	
Renting from Local Authority or Council	3.5%	2.9%	
Living with parents/family	3.9%	7.1%	
Other/No answer	4.4%	3.9%	

There is some recent
evidence that there are
higher numbers of carers in
socially deprived areas

Nationally, there is some recent evidence that there are higher numbers of carers in socially deprived areas such as North East England and some inner cities<sup>52</sup>. This is likely to reflect the fact that there are a greater proportion of people with a limiting long standing illness; poor health and poverty are independently associated with an increased propensity to provide family care.

Caring rates are higher amongst the economically inactive

Caring rates are higher amongst the economically inactive, including those who are retired (Maher & Green, 2002). A rural location is also an influential factor; rurality is linked with higher numbers of unsupported carers and those caring alone (Milne et al, 2007; Office of National Statistics, 2004). In the Kent Survey there were slightly higher numbers in rural locations providing tending and moderate care for less than 20 hours a week, whilst they were less likely to be providing intensive care (Table 9)

Table 9
Rurality and Type of Care provided

	Urban	Rural
	(N=546)	(N=510)
Tending and moderate 1-19 hours	72.5%	74.9%
Moderate 20+	7.5%	6.7%
All intense	20.0%	18.5%

<sup>&</sup>lt;sup>52</sup> Young H, Grundy, E & Kalogirou, S (2005) Who Cares? Geographic variation in unpaid caregiving in England and Wales: evidence from the 2001 Census London: *Population Trends 120*, ONS.

17.4% received Disability
Living Allowance

The key benefits received by carers in the Kent survey related primarily to disability. Small proportions of carers appeared to have made a claim: 17.4% received Disability Living Allowance, 1.5% Severe Disablement Allowance, 6.7% Incapacity Benefit, and 1.4% Industrial Injuries Benefit. A number of carers commented on carer related benefits. One carer felt bitter that he had cared for his wife for 30 years and worked full time but as he was receiving an occupational pension he was not eligible for a carers allowance. Older carers were ineligible for a number of benefits, or believed they were, due to being in receipt of a state retirement pension. A working carer wished the amount of money he was allowed to earn whilst retaining his benefits was greater.

## **Employment & Caring**

The 2001 Census found that over 3 million people combine work with caring

Caring has significant implications for employment, particularly for those under retirement age<sup>53</sup>. The 2001 Census found that over 3 million people combine work with caring<sup>54</sup>. This is approximately 1 in 8 workers in the UK; of these over 2 million carers work full time and 1 million work part time; nearly 500,000 of the full timers contribute at least 20 hours of care per week.

Combining paid work and care causes considerable stress and can result in carers giving up work; whilst being employed does not affect whether or not carers start providing care, those who do start are more likely to reduce employment hours or stop working altogether<sup>55</sup>. In 1996 49% of carers canvassed by Carers UK had given up work to care<sup>56</sup>. Nearly 73% said their earnings had been affected.

In the Kent survey 62.5% of carers aged under 65 were employed or self

<sup>&</sup>lt;sup>53</sup> Milne A & Williams J (2003) Women at the Crossroads: a literature review of the mental health risks facing women in mid-life. London, Mental Health Foundation

<sup>&</sup>lt;sup>54</sup> Office of National Statistics (2002) Census, 2001 London: The Stationary Office

<sup>55</sup>Yeandle S and Buckner L (2007) Carers, Employment and Services: time for a new social contract? London: Carers UK

<sup>&</sup>lt;sup>56</sup> Carers UK (2001) It Could Be You – A report on the chances of becoming a carer London: Carers UK

In Kent over two fifths (46%) of carers are employed or self employed

Far more carers who provide low levels of care are employed

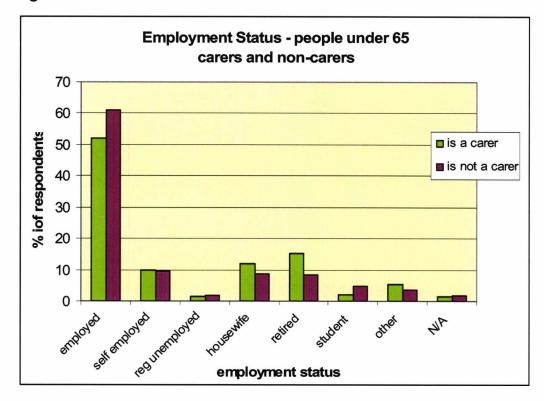
A higher number of non carers are employed than carers

employed. A third (36%) of all carers were retired (with just under a third of these being under the age of 65). A tenth (9.5%) of all carers described themselves as housewives. There was a clear relationship between employment profiles and intensity of caring in the survey. Far more carers who were providing low levels of care were employed; of those carers were who working over two thirds (68%) provided tending although it is interesting to note that nearly a tenth (8.8%) were providing intensive care for 50 or more hours per week. A very similar pattern was observed for those who were self employed. Amongst those who were retired nearly half (47.4%) were providing low levels of tending support.

Nearly half (47%) of all carers who were working were in 'managerial or professional occupations', a tenth (13.5%) are in 'intermediate occupations', a tenth in 'lower supervisory and technical occupations', one in 10 (11%) were working in 'semi routine or routine' occupations and one in 20 (4.5%) were working for small employers'.

A higher number of non carers were employed or self-employed than were carers for all ages (51.5% compared with 47.1%) (Figure 31). In terms of type of employment a higher proportion of moderate and intensive carers were in 'lower supervisory/technical occupations' or 'semi-routine/routine' occupations than non carers. Less than a quarter (24%) of non carers were in these two classes of occupation compared with 36% of moderate carers caring for 20 or more hours and 29% of intensive cares caring for 20-49 hours per week. 26% of people providing intensive care for 50+ hours or more per week were also in this category as were 20% of those providing tending. These findings resonate with national trends.

Figure 31



## **Support from Friends, Family and Services**

Overall, two thirds of carers were receiving support from family and/or friends

Evidence strongly suggests that long term carers appreciate support, and actively benefit from support from family, friends and services. Specifically, carers want: time off from caring; reliable support from services; information and advice and recognition of their caring role. Those services that improve carer well-being are respite care, day care and sitting services. A number of specialist services are also helpful for carers of people with dementia; this includes the admiral nursing service, specialist respite care and memory clinics. Carers groups are widely accessed and are an invaluable source of advice, information and support<sup>57 58</sup>.

49.3% of households were receiving support for the cared for person... and only 2.7% for the carer alone

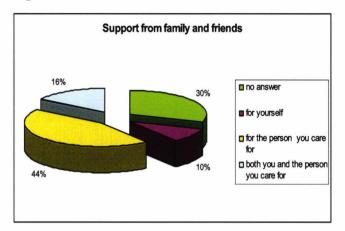
6.7% of carers were receiving no support at all

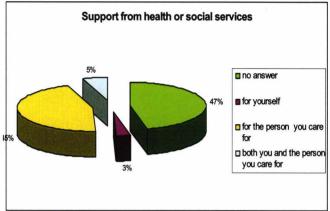
In the Kent survey overall, two thirds (67.9%) of caring dyads were receiving support from family and friends; 41.3% for the person cared for and 21.3% for both the carer and the cared for and 5.3% for the carer in their own right. Less than two thirds (62.7%) were receiving support from health and social services; 49.3% of households were receiving support for the cared for person, only 10.7% for both cared for and carer and only 2.7% for the carer alone (Figure 32). 6.7% of carers appear not to have been receiving support from either friends and family or health and social services.

<sup>&</sup>lt;sup>57</sup> Milne A, Hatzidimitriadou, E., Chryssanthopoulou, C and Owen, T (2001) Caring in Later Life: Reviewing the role of older carers, London: Help the Aged

<sup>&</sup>lt;sup>58</sup>Milne, A., and Hatzidimitriadou, E (2003) Isn't He Wonderful? Exploring the contribution and conceptualisation of older husbands as carers, *Ageing International*, Vol. 28(4), p389-408

Figure 32





Parent carers appear slightly more likely to receive support from health and social services for the cared for person (60.0%) compared to all carers (51.5%) and much more likely to receive support for themselves (13.4% compared to 6.0%). However 37.3% were unsupported.

The parent carer was in particular more likely to receive support from family and friends with 41.3% receiving support for the cared for son / daughter, 21.3% receiving care for both the cared for and themselves and 5.3% receiving support for themselves alone. Very few parent carers were not in receipt of some kind of support (Table 9)

Table 9

Parent Carers - support from health or social services by support from family/friends/neighbours

Carer/cared for gets	Carer/cared for gets support from family/friends/neighbours			Total	
support from health or			for the cared	for both the carer	
social services	no answer	for carer	for	and cared for	
no answer	6.7%	.0%	21.3%	9.3%	37.3%
for carer	.0%	.0%	.0%	2.7%	2.7%
for the cared for	22.7%	4.0%	17.3%	5.3%	49.3%
for both the carer and cared for	2.7%	1.3%	2.7%	4.0%	10.7%
Total	32.0%	5.3%	41.3%	21.3%	100.0%

40% of people with care related need who live in their own home get support from services;

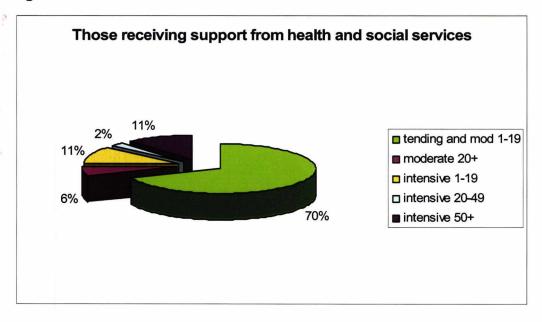
this is the case for only 20% of those sharing a household

40% of people with care related needs who live in their own home were getting support from services; this was the case for only 20% of those sharing a household with their carer. Very few carers were receiving services in their own right in either circumstance (under 3% for both). Two fifths of co resident households were receiving no support from friends, family or neighbours, or from services; this was the case for 24% of the carer/cared for dyad in the extra resident group.

- Of the carers and/or cared for who said they received support from health and social services:
- > 45% received support from home help or a care worker,
- > 43% received help from a district or community nurse,
- > 38% were provided support from a social worker,
- > 19% were provided support from a day centre or hospital,
- > 12.5% were provided support from a carers social or support group,
- > 12% were provided respite care,
- > 10.5% were provided support from meals on wheels, and
- > 3% were provided with a sitting service.

70% of all support from services appears to have been allocated to those in the lowest level care group whereas only 11% of the total was allocated to those providing intensive care for 1-19 hours per week and the same proportion (11%) to those caring intensively for 50 or more hours per week (Figure 33).

Figure 33



70% of all support from services appears to be allocated to those in the lowest level care group

Overall more disabled or ill people living in their own household, many of whom were receiving lower levels of care, received more support from services than those who were sharing a household with their carer, where intensive care was more likely. This appears paradoxical as many more co resident carers were providing intensive care than extra resident.

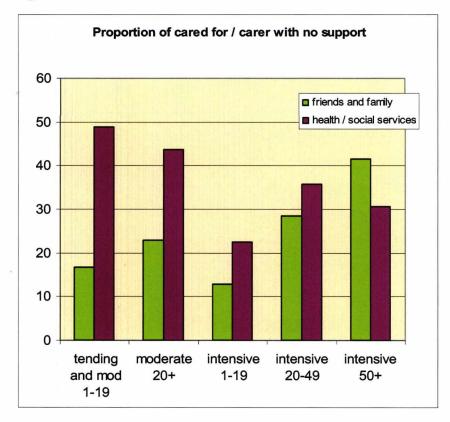
'I need to feel I am not on my own'

Those caring on a tending or moderate basis were also more likely to have been receiving support from family and friends Explanations may lie in three areas. A disabled person living alone may be more likely to be assessed as needing services by social services than one 'buffered' by a carer's support. Secondly, that living alone is considered a 'risk factor' by health and social services in eligibility for service allocation. Thirdly, the nature and type of co resident relationships may play a part. Spouses in particular are traditionally reluctant to ask for help from formal sources and tend to prize the independence of the couple above seeking support from others. Fear of institutionalisation of the cared for person is also a factor<sup>59</sup>

It also appears to be the case that those cared for on a tending or moderate basis, many of whom live in their own household, were *also* more likely to have been receiving support from family and friends than those in the intensive categories (Figure 34).

<sup>&</sup>lt;sup>59</sup> Milne A & Hatzidimitriadou E (2003) Isn't He Wonderful? Exploring the contribution and conceptualisation of older husbands as carers, *Ageing International*, Vol. 28(4), p389-408

Figure 34



These findings suggest that support tends to be concentrated on those living along receiving relatively low levels of informal care

These combined findings do suggest that both informal and formal support tends to be concentrated on those living alone receiving low or moderate levels of care on an extra resident basis. In part this may reflect the fact that disabled people living alone are more visible, perhaps at greater risk, and their carer may be more inclined to ask for, and accept, help from relatives or friends. Co resident intensive carers tend to be less visible, may be caring for a relative with challenging needs such as those associated with dementia, and may find it difficult to ask for help. Certainly we know that the group of carers who are most isolated are those supporting a relative, a spouse or parent with dementia in a shared household<sup>60</sup>. A third of older carers (30.4%) - a group over-represented in the long term co resident group of carers — receive no help at all from either informal or formal sources, underlines this issue.

'I only get 28 days per year of respite; I also need it at short notice rather than planned in advance' ....under 3% of carers receive support from services in their own right

That such a low proportion of carers (under 3%) receive support from services in their own right as 'carers' in *all* circumstances - including the most demanding - suggests that more needs to be done to:

- > seek out those carers providing intensive care
- > ensure that more carers are aware of their right to an assessment of need and support from services e.g. respite care
- ensure that agencies proactively alert carers, carers groups, primary care workers and specialist voluntary groups such as the Alzheimer's Society to the rights carers have and available services.

The widespread assumption that because a disabled person is living with a carer they, and their carer, are at reduced risk of threats to independence, also needs to be challenged.

<sup>&</sup>lt;sup>60</sup> Alzheimer's Society (2007) Dementia UK. London Alzheimer's Society.

'I want a day off now and again...'

'it took six months to sort out help from social services'

'I am not sure what help is available for me or my mother'

'If only my sister would help me out once in a while to enable me to attend an appointment or go shopping... if I go out I have to get a paid carer in'

'I get a lot from my carers support group — excellent'

Qualitative commentary suggests that carers often want relatively moderate inputs such as time off from caring; 'I want a day off now and again'. Getting information about, and accessing help from, social services is reported as difficult and time consuming. One carer commented: 'We were on a waiting list for a sitting service for 3 months; I needed it well before then', and another '... it took 6 months to sort out help from social services'.

Carers also found the number of different staff they have to see confusing and were not sure what was actually on offer, 'I am not sure what help is available for me or my mother'. They reported wanting accessible 'professional advice' and more respite care as well as respite at short notice; 'I only get 28 days per year of respite; I also need it at short notice rather than planned in advance'. Practical help such as aids and adaptations was in short supply; one carer commented, '....what we really want is a shower or bath lift'. Carers also wanted acknowledgement of their role; 'I need to feel I am not on my own'.

Nevertheless carers really valued and relied on help from services. One carer commented, 'I get a lot from my carers support group – excellent' and also in relation to support given to her relative, 'Social services carers are excellent at giving care to my mother'.

Help from family & friends was really appreciated although it was not routinely offered. One carer commented, 'If only my sister would help me out once in a while to enable me to attend an appointment or go shopping - if I go out I have to get a paid carer in'.

## Neighbourhood Involvement and Local Support

Intensive carers were less likely to be involved in local organisations

The survey asked a number of questions relating to respondents' involvement in local activities and the extent to which they could ask for help from neighbours e.g. :-

'Have you been involved in any local organisation over the past 3 years? (include school, religious, resident associations, support groups and charities)'

37.7% of people providing intensive care said they had been involved in a local organisation during the past 3 years; this was lower than the 43.9% of the general population. 21.8% of people providing intensive care were also involved in voluntary work; this compared with 25.7% of the general population. In terms of getting help in the event of a crisis e.g. illness, three fifths (61.8%) considered they could but a sixth (15%) felt they could not, this compared with 62.8% of the general population who could expect help.

One in five of intensive care givers had contacted someone to resolve a problem:

- > 20.9% had contacted a councillor or MP to resolve a problem, slightly more than the general population (19.4%)
- > 30.5% had contacted the appropriate organisation (e.g. the council) compared to 32.5% of the general population.

In terms of contact with neighbours, most carers reported that they spoke to or saw their neighbours at least 'once or twice a week'. 35.0% of intensive carers saw their neighbours 5 or more days a week, this compared to 40.3% of the general population. Twice as many male (36%) as female (17%) carers saw their neighbours every day.

These findings suggest that carers are at least as involved in their local community as other members of the general public and perhaps make use of

this opportunity to further their cause. People providing intensive care were slightly less likely to feel they could 'trust most people' (51.4%) compared to the general population (54%).

#### **Discussion and Conclusions**

This survey was the result of a random sample of I in 80 of the Kent adult population. The response rate was low, only 27%, more representative of older people than young, and of men than women. It is widely thought, in Kent, that the low response rate is partly due to the length of the questionnaire; however the additional pages relating to caring may have resulted in a higher response amongst people who do care in relation to the rest of the population. These factors need to be taken into account when drawing conclusions from the survey; in particular its transferability to the population of Kent as a whole (similarity of the results might be used as indicative of the national population of carers).

It has been tempting, in drawing conclusions from this survey, to assume that reported data on the cared for person is representative of the population of people who are being cared for; many reasons make this a difficult assumption – in particular it is a second hand report for the carer and not directly completed by the person being cared for.

It is also not possible to draw direct conclusions about the needs of the cared for person; firstly, the medical states reported are not exclusive, and people can be suffering more than one condition (e.g. dementia plus physical incapacity) as well as having multiple needs (personal care, physical needs, social needs etc).

The report barely scratches the surface in terms of analyses which are possible regarding both carers and the cared for and readers are urged to consider how the very rich data set might be used for further analyses.

This report, drawing on the Kent wide 2005 survey of health and lifestyles, offers a comprehensive picture of 'caring in Kent'. The population of Kent – as elsewhere – is ageing. The care related demands of an ageing population are inescapable. The increased number of elders with long term complex conditions such as dementia, and with multiple frailties living in the community is a particular challenge for both families and services. As carers have become a key foci of policy and research over the past decade and that they - rather than formal services - provide the majority care to disabled family members, underpin the need to develop a profile of carers in Kent.

A number of key trends is clear. A fifth of all survey respondents identified themselves as carers. Whilst this proportion is slightly higher than the estimated national prevalence, the older profile of Kent's population coupled with the age bias of survey respondents may explain this. As might be expected the majority of care recipients were elderly – many were parents/in law, some were spouses and also friends or neighbours.

As is consistent with national trends the largest group of carers were middle aged – a cohort referred to in literature as the 'pivot' or sandwich generation. The majority were women – daughters/in law supporting their elderly parents/in law. Many mid life carers were also caring for children and were working; it is this need to 'juggle' multiple demands that creates a high level of stress in this group of carers and places them at risk of giving up work and/or ill health.

Whilst currently just over a quarter of carers are older - aged 65 and over – it is important to note that this group is growing in number. Further, they tend to carry the most intensive care burden as they primarily support relatives of the same generation on a co resident basis. Although the proportion of parent carers is small, they also tend to care intensively for a disabled son or daughter on a lifelong basis.

The report reinforces a number of key carer related distinctions. Although carers cannot be viewed as a single group they do tend to fall into two sub groups: co and extra resident carers. Carers providing longer hours and more intensive types of care were much more likely to be co resident. This profile dovetails with the other distinguishing feature of caring – the type of relationship. That many spouse carers were providing intensive care, for example, is a consequence of the combined impact of household type and relationship type. The fact that most intensive carers have a life long, or at least very long term link with the cared for person is also key.

Levels of care have been so defined to cluster care tasks around levels of care input. In Kent three quarters of people who identified themselves as carers were providing extra low levels of care such a shopping, help with filling in forms and keeping the cared for person company, on an extra resident basis. This is consistent with the national picture where 'tending' pre-dominates. A small proportion of carers were providing moderate levels of care - care that involves physical support such as helping someone get in and out of bed or up and downstairs, in addition to the kind of cluster described as tending. However nearly a fifth of people identifying themselves as carers were providing intensive levels of care; this includes personal care such a bathing or help to use the toilet. It is clear that those with the most complex or chronic conditions such as dementia, learning disabilities, received the most intensive levels of care. That the number of hours spent caring has increased in Kent since 2001 underlies a growth in the number of intensive carers. That the burden of additional hours of caring has been borne primarily by older people is an additional finding - one worthy of additional exploration.

The majority of intensive care recipients were spouses or sons/daughters. This is consistent with findings earlier in the report about links between coresidency, type of care and relationship between carer and cared for. One third of all carers providing intensive care for 50 hours or more per week had been

caring for over 10 years. This is a notable finding and one that underpins a need to do further analysis of how they manage care related demands and what is, and may need to be done, to support this group in the future.

The key distinction between intensive and moderate levels of caring is the provision of personal care. Intensive carers provide support with physical care alongside personal care, with personal care being its defining feature, whereas the role of a moderate carer is characterised by physical care activities.

It is also the case that whilst more intensive care is provided on a co-resident basis and more moderate care on an extra resident basis, for some relationships the latter situation simply represents an earlier stage on the caregiving trajectory. Filial carers for example, may provide moderate care to a parent living in their own home for a number of years before shifting the locus of care to sharing a household when they become more dependent and need intensive care.

The adverse health consequences of caregiving, particularly over the longer term, are well established. It is noteworthy that over half of carer respondents reported that caring had affected their health. This finding is pronounced for those providing intensive care and amongst older carers; this is a concern given that nearly half of all carers themselves have a 'long standing illness or disability'. Specific health problems reported as linked to caring included: tiredness, depression, stress and physical strain. Marital breaks ups, a limited social life, no 'freedom of movement', and a general sense of being trapped were also reported. These echo findings in wider research.

In the Kent survey over two fifths of carers were employed or self employed. As might be expected and as is reported elsewhere, there was a clear relationship between employment and caring. Overall, caring reduces the likelihood of employment with fewer carers working compared to non carers. Further, far more carers who were providing low levels of care were currently

in work - and working full time - than more intensive carers.

Evidence strongly suggests that long term carers appreciate, and actively benefit from, support from both family/friends and services. Although two thirds of carer households were receiving support from family and/or friends and slightly fewer from health or social services, a small but significant number were receiving no help from either source. It is a concern that under 3% of carers were receiving services in their own right and it is a fact that only a fifth of co resident care households get support from services. Paradoxically, those carers were most likely to be providing intensive care on a long term basis seemed to be getting lower levels of input from formal services than those caring less intensively. Interestingly, it is also this group of carers who were getting the support overall from family and friends. Isolation of the caring dyad, dementia in the cared for person, mistrust of care agencies particularly of institutional care for the cared for, and lack of access to advice and information are all likely to play a part in explaining this situation.

A number of the challenges facing carers and those agencies tasked with supporting them are shared across the UK. The need to identify those carers at greatest risk of loss of independence and/or risks to health is a key issue; one that tends to be hidden by the fact that a significant number of co resident carers are 'invisible'. The fact that they may not wish contact with agencies and that eligibility criteria for social care services may give prominence to those 'living alone' amplify this tendency.

In terms of future direction for carer related research in Kent a number of possible areas emerge. Additional analysis of the survey data around health and caring and/or employment and caring would yield useful additional material which may inform public health targets and interventions, service planning and work related initiatives to support carers.

In terms of follow on projects surprisingly little is known about how people

'become' carers. Work exploring the process of engaging with the role of carer — objectively, emotionally, and role wise - has considerable practical and analytical potential. Specifically, explanation of when services may be of greatest value in the care trajectory would be a useful outcome of such work. Spouse carers, who are evidenced as carrying a particularly heavy burden are older, are a key group of carers who often collapse before accepting help from services. Exploring their particular needs and how they may be more effectively identified (e.g. via GPs surgeries) and supported may be a fruitful focus of enquiry. The needs and situations of rural carers is also of interest as are the roles and needs of carers - some of whom provide 'intensive care' - whose relative is placed in a care home. The Kent survey asked carers whether they would be interested in taking part in further research. This means that we have a ready made sample (or number of sub samples).

Further work recommended:-

- A: Deeper and more detailed analysis of the existing 2005 dataset around:
- (i) deeper analysis v. intensity
  - employment and caring
  - health physical and mental health of carers, especially those caring intensively
  - support formal and informal for carers and social engagement activities
- (ii) Specific groups of carers
  - older carers
  - parent carers
  - working / mid-life carers
- (iii) further comparisons with 2001

B: Follow up qualitative work

- intensive carers and spouse carers
- betwixt and betweens' (those aged 60-64)
- > the caring trajectory (people who have been caring more than 5 years and are moderate/intensive carers)
- > carers not receiving support from any source
- > carers supporting a relative in a care home

C: Conduct a 2008 survey (with those in 2005 who agreed to be followed up and a supplementary sample). This would involve:

- ➤ A question on caring in the Kent 2001 survey will be used this asks if they are a carer and number of hours they care per week.
- ➤ A question on intensity of caring (a short question asking if they carry out personal and/or physical care activities).
- ➤ A supplementary questionnaire on caring would be given to those who were identified as carers in the 2005 survey
- A supplementary questionnaire on caring would be given as a follow up to newly identified carers in the 2008 survey

#### **APPENDIX A**

#### Description of care intensity categories

#### Intensive activities for 50+ hours per week

Includes carers who said their care included one or more of the following: washing, dressing, feeding and using the toilet (q78ba, q78bb, q78bc, q78bd) and cares for 50+ hours per week (q73).

#### Intensive activities for 20-49 hours per week

Includes carers who said their care included one or more of the following: washing, dressing, feeding and using the toilet (q78ba, q78bb, q78bc, q78bd) and cares for between 20-49 hours per week (q73).

#### Intensive activities for I-19 hours per week

Includes carers who said their care included one or more of the following: washing, dressing, feeding and using the toilet (q78ba, q78bb, q78bc, q78bd) or any moderate or tending activities and cares for between 1-19 hours per week (q73).

#### Moderate activities for 20+ hours per week

Includes carers who said their care included one or more of the following: help with walking, getting up and down stairs, getting in and out of bed, giving medicine (q78aa, q78ab, q78ac, q78be) or any tending activities but **not** intensive activities **and** cares for between 20+ hours per week (q73).

#### Moderate activities for 1-19 hours per week

Includes carers who said their care included one or more of the following: help with walking, getting up and down stairs, getting in and out of bed, giving medicine (q78aa, q78ab, q78ac, q78be) or any tending activities but **not** intensive activities **and** cares for between I-19 hours per week (q73).

#### Tending activities for 20+ hours per week

Includes carers who said their care only included one or more of the following activities: help with filling in forms, dealing with bills, banking (q78ca, q78cb, q78cc), preparing meals, laundry, housework, gardening, taking to doctors/hospital (q78da, q78db, q78dc, q78dd, q78de, q78df), keeping him/her company, taking them out, keeping an eye on them (q78ea, q78eb, q78ec, q78ed) and cares for 20+ hours per week (q73)

#### Tending activities for 1-19 hours per week

Includes carers who said their care only included one or more of the following activities: help with filling in forms, dealing with bills, banking (q78ca, q78cb, q78cc), preparing meals, laundry, housework, gardening, taking to doctors/hospital (q78da, q78db, q78dc, q78dd, q78de, q78df), keeping him/her company, taking them out, keeping an eye on them (q78ea, q78eb, q78ec, q78ed) and cares for I-19 hours per week (q73).

## **APPENDIX B**

# Care Activities by Intensity of Care

# Personal care activities carried out by intensity of caring

	Washing	Dressing	Feeding	Using the Toilet
No answer	5	4	3	3
	11.4%	9.1%	6.8%	6.8%
Tending I-19	0	0	0	0
hours per week	.0%	.0%	.0%	.0%
Tending 20+ hours	0	0	0	0
per week	.0%	.0%	.0%	.0%
Moderate	0	0	0	0
Activities 1-19 hours per week	.0%	.0%	.0%	.0%
Moderate	0	0	0	0
Activities 20+ hours per week	.0%	.0%	.0%	.0%
Intensive Activities	46	40	34	30
I-19 hours per week	53.5%	46.5%	39.5%	34.9%
Intensive Activities	15	16	13	6
20+ hours per week	60.0%	64.0%	52.0%	24.0%
Intensive Activities	79	74	37	42
50+ hours per week	77.5%	72.5%	36.3%	41.2%
All Carers Total	145	134	87	81
	12.7%	11.7%	7.6%	7.1%

# Physical care activities carried out by intensity of caring

	Walking	Getting Up/Down Stairs	Getting In/Out of Bed	Giving Medicines
No answer	5	3	3	6
	11.4%	6.8%	6.8%	13.6%
Tending I-19	0	0	0	0
hours per week	.0%	.0%	.0%	.0%
Tending 20+ hours	0	0	0	0
per week	.0%	.0%	.0%	.0%
Moderate	115	21	7	47
Activities I-19	72.8%	13.3%	4.4%	29.7%
hours per week	0.3-0.00	100,000,000	18150 E55000	
Moderate	43	22	12	48
Activities 20+	54.4%	27.8%	15.2%	60.8%
hours per week	1000 0000 0000 0	A.7990 12918A U	0 Particular	
Intensive Activities	35	16	25	32
I-19 hours per week	40.7%	18.6%	29.1%	37.2%
Intensive Activities	11	6	12	14
20+ hours per week	44.0%	24.0%	48.0%	56.0%
Intensive Activities	48	33	55	71
50+ hours per week	47.1%	32.4%	53.9%	69.6%
All Carers Total	257	101	114	218
	22.5%	8.8%	10.0%	19.1%

# Tending activities carried out by intensity of caring

	Fill in forms	Bills help	Banking	Preparing Meals	Doing Shopping	Laundry	Housework	Gardening	Take to Dr/Hosp	Keeping him/her Company	Taking him/her out	Keeping an eye on him/her
No answer	10	6	8	11	15	9	11	7	1.1	8	8	H
	22.7%	13.6%	18.2%	25.0%	34.1%	20.5%	25.0%	15.9%	25.0%	18.2%	18.2%	25.0%
Tending I-	255	184	158	79	272	73	134	165	245	321	262	330
19 hours per week	43.4%	31.3%	26.9%	13.5%	46.3%	12.4%	22.8%	28.1%	41.7%	54.7%	44.6%	56.2%
Tending 20+	33	27	22	32	29	30	27	22	33	22	24	38
hours per week	54.1%	44.3%	36.1%	52.5%	47.5%	49.2%	44.3%	36.1%	54.1%	36.1%	39.3%	62.3%
Moderate	98	76	69	43	100	37	49	52	102	81	105	95
Activities 1- 19 hours per week	62.0%	48.1%	43.7%	27.2%	63.3%	23.4%	31.0%	32.9%	64.6%	51.3%	66.5%	60.1%
Moderate	54	54	41	57	54	53	57	42	66	41	52	56
Activities 20+ hours per week	68.4%	68.4%	51.9%	72.2%	68.4%	67.1%	72.2%	53.2%	83.5%	51.9%	65.8%	70.9%
Intensive	45	37	36	52	53	40	41	25	42	63	49	61
Activities 1- 19 hours per week	52.3%	43.0%	41.9%	60.5%	61.6%	46.5%	47.7%	29.1%	48.8%	73.3%	57.0%	70.9%
Intensive	19	16	17	22	15	17	20	15	21	14	15	19
Activities 20+ hours per week	76.0%	64.0%	68.0%	88.0%	60.0%	68.0%	80.0%	60.0%	84.0%	56.0%	60.0%	76.0%
Intensive	69	61	56	92	79	90	81	58	86	63	72	85
Activities 50+ hours per week	67.6%	59.8%	54.9%	90.2%	77.5%	88.2%	79.4%	56.9%	84.3%	61.8%	70.6%	83.3%
All Carers	583	461	407	388	617	349	420	386	606	613	587	695
Total	51.1%	40.4%	35.6%	34.0%	54.0%	30.6%	36.8%	33.8%	53.1%	53.7%	51.4%	60.9%

# EMPLOYMENT SUPPORT FOR CARERS

Sarah Vickerstaff, Wendy Loretto, Alisoun Milne, Elaine Alden, Jenny Billings, and Phil White

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## Acknowledgements

We would like to thank all those who agreed to be interviewed for this study, for the time they gave us and the good humour with which they participated. We would also like to thank Daniel Sweiry and Robert Lilly at the Department for Work and Pensions for their encouragement and support throughout the project.

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#### **SUMMARY**

This report presents the findings of a qualitative research study, commissioned by the Department for Work and Pensions (DWP) in April 2008, to examine and understand what employment support is needed for carers in order for them to take up and remain in work. Many carers who are not currently working would like to do so and the DWP is keen to understand the support they require to achieve this.

The background to the project is the DWP's aim to promote work as the best form of welfare for people of working age by ensuring that work is seen as the best way out of poverty, while protecting the position of those in greatest need. This summary provides an overview of the research findings and the policy implications of the study.

#### **Background and aims**

It is estimated that around 6 million adults in Britain are providing unpaid care to a sick, disabled or elderly person, and that three out of five people will be carers at some point in their lives. The challenges of combining paid work and informal care are substantial and affect the type of work that can be done, the hours of work, and the likelihood of gaining or remaining in employment. Caring, particularly intensive long term caring has been identified as a primary cause of decisions to reduce working hours and/or to give up work altogether (Milne et al, 2001). This is especially pronounced for women and for those offering intensive care (Palmer et al, 2008). Many carers who are not currently in work, wish to return to work and for those obliged to work reduced hours, a number would like to give up work to care (Arskey et al, 2005).

There is increasing policy emphasis and employment related interest in promoting and facilitating employment amongst carers. A number of recent policy initiatives - such as the 2004 Carers' (Equal Opportunities) Act, the Work and Families Act 2006, and European legislation on parental leave, flexible working and the organisation of working time - aim to encourage employers, carers and agencies which support carers to facilitate the continuation of employment amongst carers and/or a return to it.

In 2007 the Government launched its 'New Deal for Carers' in England and Wales, which was underpinned by a set of Task Force Reports one of which specifically related to employment (Department of Health, 2007). In 2008, the Government published its new ten-year vision for carers – its Carers Strategy – entitled 'Carers at the Heart of 21st Century Families and Communities' (HM Government 2008). The Strategy is underpinned by £255 million to implement some immediate steps, alongside longer-term plans. A wide range of commitments are set out, including: the provision of information and advice; respite provision; a review of carers' benefits; improved support from the NHS; and support to help carers better combine work and care.

In light of the policy background and research evidence, the aims of the research were to examine what employment support is needed for carers or those who have recently ended a spell of caring in order for them to take up or remain in work. It was designed to find out how caring responsibilities affect people's decisions about employment, to assess how DWP and Jobcentre Plus can effectively help claimants with caring responsibilities to return to the labour market. The research supports the DWP's aim to develop its strategy for carers and decide how and by whom any support should be provided.

The principal objectives of the research are to examine what employment supports are needed for carers currently in work or those who are currently caring or have recently ended a spell of caring and want to return to paid employment. Specifically:

- 1 To investigate how caring responsibilities affect people's decisions about employment
- 2 To begin to fill the evidence gap on the role and effectiveness of existing services for carers
- 3 To assess how DWP and Jobcentre Plus can effectively help claimants with caring responsibilities to return to the labour market
- To provide evidence to enable the DWP to develop its strategy for carers.

In total, 55 people in two regions were interviewed. The sample included men and women, across a range of ages, different working statuses and caring responsibilities.

The semi-structured interviews collected factual and biographical data as well as more qualitative data relating to carers' support needs and their experiences of different agencies and support providers, such as Jobcentre Plus, social services, carers centres and employers.

# How do caring responsibilities affect people's decisions about employment?

Caring places restrictions on the amount and type of paid work that carers can undertake: it may limit the hours they are available for work, how far from home they are prepared to travel and it impacts upon job mobility and career planning. Many of the carers interviewed for this research stressed the importance of work for financial, social and personal satisfaction reasons but in practice combining working and caring was far from easy. In particular the intermittent and unpredictable requirements of their caring role caused difficulties in working and work-related plans. Many respondents talked about the balancing and juggling that went on to stay at work, the stress this caused and the guilt they often felt both towards their employers and coworkers and the cared for person. An overarching theme was either a self-reliance or reliance on family and friends in order to be able to work.

For those not currently working the desire to work remained in principle but when explored practically they expected or encountered considerable problems: finding suitable work in terms of flexible hours; feeling that no employer would take them on because of their caring responsibilities; and concern about the impact on the wellbeing of the cared for person and their own health.

One of the key elements that facilitated the ability to work and care was work related flexibility; this took a number of different forms: part-time work, flexitime, shift working or term-time working, and locational flexibility (e.g. working from home). However, this formal flexibility was not necessarily sufficient it often needed to be reinforced by 'informal' flexibility, namely the willingness of line-managers or co-workers to accommodate shift changes or early or late arrivals according to the fluctuating and sometimes unpredictable demands of caring.

The past and current employment experience of our respondents revealed that very few employers had a formal policy of offering flexible working. 'Passive' employer support was more common, whereby it was up to the carer to ask for support and/or flexible working arrangements.

#### The role and effectiveness of sources of support for carers

Carers obtained support from a wide range of formal and informal sources: the NHS, social services, voluntary organisations, family and friends as well the DWP. With the exception of the DWP most other sources of support for carers did not conceptualise their role as supporting or enabling carers to work. For most carers contact with the NHS or social services focused on the needs of the cared for rather than their own circumstances; very few of those interviewed had had a social services assessment of their needs as a carer. There was a general sense of the fragmented nature of the support system available for carers and a strong desire for a single port of call for advice and help. The voluntary sector was highly valued by many of the carers who were interviewed because it came nearest to being a 'one-stop shop' for help but also because carers support groups were trusted sources of information, advice and support.

A few respondents reported that employers demonstrated an active approach to supporting employees who were carers. It was more typical though for there to be no specific policies for carers and little awareness of what the needs of a carer might be. It was up to the carer to ask for help if it was needed and many carers felt it was their individual responsibility to manage the balance between work and caring and hence made few demands on their employers.

As with other research into employment rights, respondents in our sample were very often unaware of their rights under the law (to request flexible working or to have time off for emergencies). Some had a general awareness of their legal entitlement but either it did not apply to them (e.g. not enough service to qualify) or they did not want to disrupt their employer and/or workplace. In general our respondents tended to view their caring responsibilities as private and were concerned not to effect a burden on employers or colleagues.

# The role of the DWP and JCP in supporting carers to remain in, or return to, the labour market

There were varying degrees of experience of DWP and JCP amongst the respondents, ranging from people who had had no contact to those who had experience of job search activities and/or benefit advice. There was a widespread

feeling, either through direct experience or hearsay that the JCP environment was unwelcoming and this was linked to the sense that carers were not really understood; that there were no specialists or experts on caring in the JCP offices. The issue of expertise is now being addressed with specialist training for JCP Advisers who deal with carers.

Many respondents felt that in relation to job search JCP did not have the right kinds of jobs to meet their needs: either because they did not have part-time or flexible jobs suitable to accommodate care related demands or because they were only offered access to jobs that did not reflect their level of experience or previous job status. There is now a system for flagging flexible jobs on the JCP system, which should help identify the flexible opportunities available. There has also been agreement to fund replacement care to enable carers to undertake relevant training.

Many carers who were interviewed complained about the complexity and inflexibility of benefit rules and wondered whether anyone really understood the system. This finding contributed to the widely noted view that there should be just one place that carers can go for advice on benefits and employment opportunities and that the advice needs to be provided by people who genuinely understand the situations carers are facing.

#### Conclusions and policy implications of the research findings

It is a safe assumption, given current demographic trends and developments in medical care, that the demand for informal care will increase in the coming decades and that the challenge of how to effectively support carers to continue working and/or facilitate their return to work will become increasingly important. Removing the barriers to employment for carers requires action on a number of different fronts and by a range of stakeholders. The DWP - as the main governmental policy agent in the field -, most particularly through JCP and PDCS, can play a number of roles in developing appropriate policies and procedures for their delivery. Employers will also have a pivotal role in providing and sustaining employment for carers. The NHS and Social Services, although primarily concerned with the needs of the cared for person, also have a role in supporting carers who wish to stay in, or return to, paid work. Lastly, the voluntary sector, which already does much to support carers on a day to day basis, may also be able to play an enhanced role in supporting working carers.

In all cases the situation and needs of carers needs greater visibility and recognition. As has now been recognised there is a need for specific expertise on carers within JCP and an enhanced ability to locate flexible working opportunities and match carers to those opportunities. With respect to welfare benefits for carers (which are currently under review by Government) there is a need for greater clarity over benefit rules and entitlements and the interaction of different benefits.

It is important that employers become more aware of carers and their needs, creating a network of sympathetic or care-friendly employers both nationally and locally may be one way of raising the visibility of carers as employees. Legislative rights for carers to request flexible working arrangements are insufficient by themselves as many people are not aware of their rights or if they are may not wish to invoke them for fear of a negative reaction from their employer.

At present, and not unreasonably, professionals in the NHS and Social Services are primarily focused on the needs of the cared for person and do not necessarily see their role as supporting the carer to remain in or go back to work. However, there clearly are roles for GPs in being alert to the health issues that carers combining work and caring may be experiencing and providing good advice and or referral to occupational health services. Social services need to be more aware of carers' rights to an assessment of their needs and this should be routinely offered and periodically revisited at every opportunity e.g. when a visit to the cared for person is arranged.

The voluntary sector is currently a well respected and trusted source of help, advice and support for carers. The barriers to involvement with JCP over employment support that many of our respondents expressed might be overcome by locating employment advice and support with third sector organisations that already command the respect and trust of carers.

#### 1 INTRODUCTION

It is estimated that around 6 million adults in Britain are providing unpaid care to a sick, disabled or elderly person<sup>1</sup>. About a third of carers are co-resident carers, while the remaining two-thirds are caring for someone in another household. Women are more likely than men to care for a sick, disabled or elderly person: 18 per cent of women and 14 per cent of men were carers, the difference mainly being accounted for by the fact that more women care for someone in another household. Among those spending at least 20 hours per week caring, seven out of ten were below state pension age and the likelihood of becoming a carer increases with age, peaking in the 45 to 64 year age group (see also HM Government, 2008: 34). One in 20 adults in Britain are spending more than 20 hours per week caring and half of those caring for this duration said that they themselves had a long-standing illness and a third said it limited their activities. Caring can be either long term in duration, with three out of ten carers providing care for at least ten years or short-term 2.2 million people enter or exit a caring role each year (Carers UK, 2006). This means that the total number of people who experience caring at some stage in their lives is very much larger than the snapshot figures recorded in the Census. Three out of five people will be carers at some point.

#### 1.1 Caring and employment

Just less than one in eight (13 per cent) adults aged between 16 and 64 in full-time employment were caring for a sick, disabled or elderly person. However, the incidence of caring is highest of all among the economically inactive, one in five (21 per cent) of whom were spending time caring for someone. Only about a half of carers spending the most time (between 20 and 49 hours) caring per week were in employment in 2001. The challenges of combining paid work and informal care seems to particularly affect those undertaking substantial hours of caring per week.

<sup>&</sup>lt;sup>1</sup> The background provided here, and all the figures quoted, is taken from DWP Research Report number 290, "Carers' aspirations and decisions around work and retirement", published in 2005.

Women carers were much less likely than men to be in full-time employment and much more likely to be in part-time employment. Co-resident carers were less likely to be in paid employment than either those caring for someone in another household or those who do not have caring responsibilities. Among women, caring for someone in another household was associated with a lower rate of full-time employment and a higher rate of part-time employment than non-carers.

The experience of being in work is much valued by many carers and many carers report that they enjoy work. Work can provide positive benefits in addition to the income it brings and having a job is associated with measurable psychological health benefits.

Most carers' feel that they have little choice in becoming a carer and evidence suggests that most carers did not want to leave work altogether; instead they wanted to achieve a reasonable balance between caring and paid employment. However, research suggests that most employers have given little or no consideration to the difficulties carers face in trying to combine substantial caring with paid employment. Inflexible working hours and the absence of 'care-friendly' employment policies have been found to be a major barrier to managing work and caring.

#### 1.2 Research aims of the study

The aims of the research were to examine what employment support is needed for carers or those who have recently ended a spell of caring in order for them to take up or remain in work. It was designed to find out how caring responsibilities affect peoples decisions about employment, to assess how DWP and Jobcentre Plus can effectively help claimants with caring responsibilities to return to the labour market. The research supports the DWP's aim to develop its strategy for carers and decide how and by whom any support should be provided.

The principal objectives of the research are to examine what employment supports are needed for carers currently in work or those who are currently caring or have recently ended a spell of caring and want to return to paid employment. Specifically:

1 To investigate how caring responsibilities affect people's decisions about employment

- 2 To begin to fill the evidence gap on the role and effectiveness of existing services for carers
- 3 To assess how DWP and Jobcentre Plus can effectively help claimants with caring responsibilities to return to the labour market
- To provide evidence to enable the DWP to develop its strategy for carers.

This research is intended to complement and build upon the research carried out in the report "Carers' aspirations and decisions around work and retirement" (DWP Research Report Number 290). An evidence gap on the role and effectiveness of existing services for carers was identified within the report which this research sought to address.

#### 1.3 Methodology

The research started with a brief literature review to set the study in context, followed by semi-structured qualitative interviews with some 55 people. The topic guide for the interviews was developed on the basis of the literature review and research specification; it was piloted before going into the field. The interviews were used to collect both factual and biographical data, about topics such as marital status, work history, employment status, health and caring responsibilities, income and wealth, benefit receipt, household composition and also more qualitative data relating to their support needs and their experiences of different agencies and support providers, such as Jobcentre Plus, social services, carers centres and employers. The interviews were be semi-structured and lasted on average, between one and a half and two hours.

At the beginning of the interview respondents were asked to complete a time line grid outlining the key events in their working and caring lives. This was important for capturing the history and nature of the individual's caring responsibilities and the interaction of caring with paid employment. See Appendix A for a copy of the topic guide for the interviews and the timeline grid.

#### 1.4 Recruitment of respondents

The study was interested in those who are currently working and those who would like to get back to paid employment. The aim was to recruit both women and men in the 25-60 age range, whilst acknowledging that women predominate in caring roles. To reflect the range of caring roles that individual's experience it was also desirable to get a mixture of resident and non-resident carers. Existing evidence from previous research suggests that public sector employers may be better able to provide flexible employment arrangements than the private sector (Loretto and White (2006). Size of employing organisation is similarly an important factor in employment opportunities; large companies may have greater potential to redeploy an individual or offer flexible hours whereas a smaller organisation might be more tightly geared in staffing terms and have less room for manoeuvre. Conversely, some small organisations may be keen to retain an individual's skills and experience and thus be willing to work around the employee's need for flexibility. In addition, self-employment may also afford opportunities for greater flexibility in location of work and distribution of working time across the week. It was desirable therefore to get a spread of respondents across different employment situations.

For those carers who are not currently working there are two distinct groups, which the research wished to cover the first is those who are currently not working but would like to if suitably flexible work could be found and second, those who have recently finished caring for someone and are looking to re-enter the labour market.

The target number for recruitment was 70 respondents from two regions:

28 Interviews in Scotland

42 Interviews in England

The main focus for interviews in Scotland was in and around Edinburgh, covering both well off and less affluent areas, urban and rural locations. In England the main focus was east and coastal Kent which includes a number of poorer towns, with higher than national average rates of unemployment.

In the absence of access to the DWP's Carer's Allowance Database and Jobcentre plus internal records due to embargos on data transfer the recruitment of respondents for interviews was achieved though a mixture of methods. The following recruitment routes were used:

- Carer's information and nursing support groups
- Local employers

- Care homes
- Adult training centres
- Local newspapers and free local newspapers
- Participant referrals

In practice it proved difficult to recruit the target number. Explanations for this may include firstly, that carers do not always define themselves as such, rather seeing their caring as being implied in the role of a husband, mother or daughter. Secondly, caring is a very emotive role and a willingness to participate in a study may be tempered by an unwillingness to share information with a stranger. Thirdly, carers are typically stretched for time, facing conflicting priorities and for these reasons may be difficult to reach; a number of potential respondents expressed initial willingness to take part in the study but a suitable time for an interview could not be achieved. In addition to the general difficulty of contacting carers it was more difficult to recruit men to the study, this is not untypical of qualitative research projects.

## 1.5 The Sample

Of the 55 respondents recruited to the study, 36 came from Kent and 19 from Edinburgh. There were more females than males. There was a good age spread of respondents with over 50s (31) and under 50s (24) in the sample, however, the real differences are in the gender breakdowns within these age groups. For the under 50s, it was extremely difficult to source males (2), and females (22) were more predominant. This was possibly due to the fact that most of the under 50 females were caring for children. For the over 50s there was a more even mix of gender with 20 females and 11 males participating.

Table 1-1: Gender and age composition of the respondents

	Gender			
Age	Women	Men		
Under 50	22	2		
Over 50	20	11		

**Total** 42 13

For many of the males it was presented during recruitment that there was a wish to participate so that others might be helped who were in a similar situation to them. For the women many commented at the end of the interviews that it had been very helpful to get their story out — the process had been cathartic. This could subtly suggest why we have more females participating than males; that the females were more willing to open up regarding this very personal part of their lives as opposed to the men who may not be so willing to do so.

Considering work status, the breakdown of the sample was spread across the three target groups: working, not working and ceased caring as follows:

Table 1-2: Work Status by Age and Gender

	Gend	ler
Work Status by Age	Women	Men
Caring & Working		
Under 50	13	1
Over 50	7	5
Caring & Not Working		
Under 50	6	1
Over 50	7	2
Ceased Caring & Working		
Under 50	1	0
Over 50	4	0
Ceased Caring & Not Working		
Under 50	2	0
Over 50	2	4

The numbers for ceased caring participants is comparatively low; there are several reasons why this may have happened to the sample. Initially, the definition of ceased carers was seen to be those who had ceased caring due to the cared for becoming well, dying or moving in to a home. In some cases these clear distinctions held true, and for those who had lost their cared for it is possible that they would be difficult to reach due to grief, however we had several participants who were in the early stages of bereavement. For the most part the definition of ceased caring had to be relaxed as most ceased carers were continuing to care for their loved ones when they moved in to a care facility.

When assessing the work status by age, there is one significant point, that all the ceased caring males were not working and over 50. This has been attributed to the fact that many of them were assessing their retirement options, either because they had been able to secure pensions or saving through work at an earlier stage of their life and had been left assets when their cared for died, or due to the fact they felt it unlikely they would be seriously considered by employers for employment at their age. In regards to gender differences there are just as many females over 50 as there were under 50 in work; however many of the over 50s had been able to maintain existing or similar work to what they had been doing prior to their caring episode. The problem for both men and women and all age groups was when they 'fell out' of work at some point in the caring episode or if the caring started before they were able to establish their career or prospects for a career.

For those who were working, the participants were either working for public organisations (10), medium/large private organisations (8), small private organisations (3), or were in self employment (10). Males predominated in the self employed category.

In regards to the caring environment, the majority of participants were co-resident with the cared for (34) and for the rest bar one the cared for person was not resident (14). One respondent indicated that they were semi-resident, in that it was a regular occurrence that he would spend the night in the house of the cared for person but he retained his own home. This was not an unusual transition stage for parental care, where the carer shifts from being extra residents to co resident in a similar way to this respondent. A key factor in extending the extra resident status was either the carer

or the cared for person wishing to maintain their independence for as long as possible before acknowledging the need for more intensive co resident care. There was also a transition almost in the other direction for those who had ceased actively caring when their relative was admitted to a residential care home. In this context although carers often continue to visit and attend to their relative's needs, they are effectively extra resident. In relationship to hours spent caring, it was most likely that those providing 50+ hours of care were caring on a co- or semi-resident basis.

With respect to who was being cared for, 20 were looking after one or both parents, 17 were looking after their spouse and 13 were caring for special needs children. There were 5 who were caring for others such as a neighbour, friend or grandparent. Except for one, all the carers for children were females. For the most part care for a parent or parents was provided by a daughter; if it was the son it seemed to be a choice of last resort either due to the other siblings being unwilling or there was no one else to provide care.

Whilst our sample is not, and was never intended to be, statistically representative of working carers, it does reflect the key dimensions - outlined above - of the broader population from which they are drawn. The gender and age profile nationally is mirrored on our sample. Further, we have a mixture of those who work full and part time, work in a range of employment situations, and tend towards the intensive end of the caring continuum (either now or in the future). The sample also provides a balance of self employed and employed carers and a range of different caring contexts with a higher number caring for disabled spouses or parent(s)/in law as is the case nationally.

#### 1.6 Data collection

Interviews usually took place at the respondent's home. The process of filling out the timeline and the answering of the questionnaire schedule was recorded and transcribed for qualitative data analysis. Short answers to questions in section 1 of the schedule and further notes were recorded by hand by the interviewer. Before the start of the interview respondents were given a financial gift to thank them for taking part (£25 per individual respondent).

One potential concern within the data collection process was the use of four different interviewers. To ensure consistency as far as possible, all interviewers were trained

by the lead researcher, with several follow up sessions to discuss process and findings. The semi-structured schedule contained detailed directions and prompts towards particular lines of questioning to further facilitate such reliability and the vetting of transcripts of the initial interviews was used to verify this was indeed the case.

#### 1.7 Ethics

The study received approval by the University of Kent Ethics Committee. Every effort was made to ensure respondents were consenting to taking part in a fully informed manner. The form and content of the interviews were explained to them on multiple occasions.

Due to the personal nature of the some of the questions, there were times when upsetting issues were raised. It was underlined to the respondents that they were free to pause or cease the interview at any stage. All interviewers were experienced in handling sensitive topics in such situations and were briefed beforehand. Respondents were also given a printed sheet detailing a number of agencies, which they could approach for further information on a range of topics.

Anonymity and data protection were also a prime concern and ensured by the transcriptions being coded and the identity of the respondents being kept separately in locked office space. All electronic data was stored on a secure, password protected computer system.

#### 1.8 Interpretation and analysis of data

All the interviews were transcribed and analysed using QSR NVivo 7, a qualitative analysis software programme. NVivo provides a set of tools which aid management and analysis of qualitative data such as interviews (Bazeley, 2007). First, each interview was analysed for a set of respondent descriptive attributes, i.e. age, gender, employment status, location, household income etc. Next, the interviews were coded for references or answers to direct questions that respondents were asked, for example what experiences they had of Jobcentre Plus. Third the interviews were coded interpretively for references to factors affecting continued working or ability to

return to work and respondents' experience of the support and help they received from informal and formal sources. Quotations from the interviews are employed in the report in two ways: primarily direct quotations are used in a representative manner to illustrate a commonly expressed point of view of a number of respondents; less frequently quotations are used to demonstrate an unusual or particular experience of an individual respondent. All the names of respondents quoted are fictitious.

#### 1.9 Report structure

Chapter 2 provides a summary of the existing literature on employment support needs of carers and the currently prevailing policy context. Chapter 3 provides an overview of the roles that carers play and the impact that caring has on their wider social life, health and finance. This chapter is important for locating the respondents in their caring context, which for many of them is the starting point for thinking about remaining in work or seeking work. Chapter 4 reports directly on how their caring responsibilities affected the respondents' decisions about employment. Chapter 5 gives an account of the role of employers, the experiences of the respondents in managing work and caring and the importance of flexibility. Chapter 6 looks at the role and effectiveness of non-employment based sources of support for carers namely: family and friends, the NHS, Social services and voluntary agencies. Chapter 7 presents the evidence on respondents' experience of and attitude towards the services of the DWP and in particular of the JCP. Chapter 8 offers details of a number of 'caring case histories'; these provide concrete examples of the pressures and conflicting priorities faced by carers in reconciling paid employment and caring duties. Finally, chapter 9 concludes by drawing the research findings together and considering the policy implications of the study.

#### 2 POLICY CONTEXT AND LITERATURE REVIEW

In this chapter we set the research in its policy and literature context by first reviewing the main policies designed to support carers in employment. Secondly, we provide a brief review of existing research on the factors affecting the labour market aspirations and participation of carers.

#### 2.1 Policy Context

There is increasing policy emphasis and employment related interest in promoting and facilitating employment amongst carers (Yeandle et al, 2007a; HM Government, 2008: chapter 4). Current estimates suggest that over 3 million carers combine work & caring. Caring, particularly intensive long term caring has been identified as a primary cause of decisions to reduce working hours and/or to give up work altogether (Milne et al, 2001). This is especially pronounced for women and for those offering intensive care (Palmer et al, 2008). Many carers who are not currently in work, wish to return to work and for those obliged to work reduced hours, a number would like to give up work to care (Arskey et al, 2005).

#### 2.1.1 Recent Legislation

A number of recent policy initiatives aim to encourage employers, carers and agencies which support carers to facilitate the continuation of employment amongst carers and/or a return to it. The 2004 Carers (Equal Opportunities) Act built on earlier legislation by aiming to give carers more choice and opportunity to lead a fulfilling life. In particular it places a duty on local authorities to consider whether or not a carer wishes to take part in paid work, education, training or leisure activities when they are carrying out a carer's assessment. The Work & Families Act 2006 specifically introduced the right of working carers to request flexible hours from their employer; this came into effect in April 2007.

Carers, like other groups of employees, can benefit from the 1999 Employment Relations Act which gave all employees the right to (unpaid) time off to deal with family emergencies. This measure allows carers, parents and others with dependants to take a 'reasonable' number of days off to deal with the immediate

situation and to make any necessary longer term arrangements. The 2002 Employment Act gave employed carers of disabled children under the age of 18 the right to request flexible working arrangements such as changing start and finish times, compressed working hours, part-time working and working from home after six months in post. This right was extended to certain groups of carers for adults under the Work and Families Act 2006. All three measures cover England, Scotland and Wales.

It is additionally notable that working carers also stand to gain from successive European Directives on parental leave, flexible working and the organisation of working time that have been put in place and translated into policy and legislation in the UK. Key initiatives include: the Employment Relations Act 1999 which entitles employees to take a 'reasonable amount of unpaid (unpaid) time off work' to deal with emergencies or unexpected situations involving a dependent relative. More recently, the flexible working regulations, included in the Employment Act, 2002, give parents of children under 6, or 18 if the child is disabled, the right to request flexible working. As of 6 April 2009 the right to request flexible working was extended to cover those with parental responsibility for children aged 16 and under.

#### 2.1.2 New Deal for Carers

In 2007 the Government launched its 'New Deal for Carers' in England and Wales, which was underpinned by a set of Task Force Reports one of which specifically related to employment (Department of Health, 2007). The package of measures introduced included a revision of the 1999 National Strategy for Carers, the provision of respite care cover in emergencies, the setting up of a national helpline and an 'expert carers programme' (now renamed 'Caring with Confidence'). In 2008, the Government published its new ten-year vision for carers – its Carers Strategy – entitled 'Carers at the Heart of 21st Century Families and Communities' (HM Government 2008). The Strategy is underpinned by £255 million to implement some immediate steps, alongside longer-term plans. A wide range of commitments are set out, including: the provision of information and advice; respite provision; a review of carers' benefits; improved support from the NHS; and support to help carers better combine work and care.

In relation to working carers the Strategy acknowledges that more than 3 million people currently combine paid employment with caring; it also recognises the need to support carers to get into, or return to, work (HM Government, 2008). The Government will try to ensure that all carers who want to work will be able to and commits an additional £38 million of additional funding to provide:

- A Care Partnership Manager in every Jobcentre Plus district
- · Training improvements for Jobcentre Plus advisors
- Funding replacement 'care for carers' receiving approved training
- DWP and Jobcentre Plus will investigate feasibility of providing 'return to work support'; this may be through third sector organisations
- Encouraging more flexible learning opportunities to be made available

The Strategy also states that employers have a responsibility to recognise staff who are carers and is investing in:

- An awareness raising campaign to ensure that carers and employers are aware of flexible working rights
- Plans for the Government to work with the business sector to produce a 'good practice guide' for all employers on benefits of employing carers
- A review of the definition of the term 'carer' in flexible working regulations<sup>2</sup>

The new Strategy applies in full to England; commitments on income and employment are UK-wide. Scotland and Wales have also developed 'Carers' Strategies' and committed additional funding to support carers' services; in Scotland this is part of local authorities' General Annual Expenditure allocation, while in Wales the Carers' Grant Scheme/Mental Health Carers' Grant have both been introduced (Yeandle and Buckner, 2007).

A number of welfare benefits are also available to carers the main one being Carer's Allowance. Carers may be entitled to Carer's Allowance if they provide at least 35 hours of care a week for someone who is in receipt of Attendance Allowance (AA) or Disability Living Allowance (DLA) care component at the middle or highest rate. Policy on carers cuts across a number of Government departments. Although this and associated research has been commissioned by the Department for Work & Pensions (DWP), the findings are also relevant to the Department of Health and the

<sup>&</sup>lt;sup>2</sup> The right to request flexible working applies only where the person being cared for is a spouse, partner, civil partner or specified relatives of the carer or where the person cared for lives at the same address as the carer.

Department for Business, Enterprise and Regulatory reform (BERR). Policy on social care support to carers is the responsibility of the Department of Health and policies on flexible working are the responsibility of the BERR. The DWP has a core commitment to creating a chance to work for all; a key part of this is ensuring carers have every opportunity to remain in work and return to work once a period of caring has ended (HM Government, 2008; Yeandle et al, 2006). The DWP, through the JCP Offices and the Pension, Disability and Carers Service (PDCS) is directly responsible for two forms of support to carers: the provision of employment support and advice and the payment of benefits. PDCS is the combined delivery arm for Pensions, Disability and Carer's Benefits and came into being on April 1st 2008, it is an executive agency of the DWP. The Disability and Carers Service is part of PDCS and delivers the following financial support: Disability Living Allowance, Attendance Allowance, Carer's Allowance and Vaccine Damage Payments (PDCS, 2008).

#### 2.2 Literature Review

#### 2.2.1 Working Carers

Caring has significant implications for employment, particularly for those under retirement age (Milne & Williams, 2003). According to the 2001 Census about half of the 6 million UK carers combine work with caring. Of these over 2 million carers work full time and 1 million work part time; nearly 500,000 of those in full time work contribute at least 20 hours of care per week. In 2001, just less than one in eight (13%) of adults aged between 16 and 64 years in full time employment were caring for a sick or disabled person.

There is a clear relationship between employment profiles and intensity of caring; far more carers who provide low levels of care are employed. Conversely, only about half of carers spending the most time – over 20 hours per week - caring were in employment in 2001 (Palmer et al, 2008; Yeandle et al, 2007). Among those caring for 50 or more hours per week, only three out of ten were in paid employment. The 2001 Census indicates that the incidence of caring is highest amongst the economically inactive, one in five (21%) of whom are spending time caring for someone. Currently, around one in five carers give up work to care and many more reduce their hours or pass up promotion opportunities (Yeandle et al, 2007a).

Table 2-1: Economic activity by provision of care among people aged 16-74

	Does not provide care %	1-19 hours %	Provides care 20-49 hours %	50+ hours %
Economically Active				
Employee or self employed	62	65	48	29
Unemployed	3	3	4	2
Student	3	1	1	<1
Economically Inactive				
Retired	13	16	17	26
Looking after home/family	6	7	18	27
Permanently sick/disabled	5	4	8	11
Other	8	4	5	4
Total	100	100	100	100

Source: Arskey et al, 2005 from Census 2001 data

Women carers are much less likely to be in full time employment than men and much more likely to be working part time (Milne and Williams, 2003). Further, co resident carers were less likely to be in paid employment than either those caring for someone in another household (extra resident) or those who do not have caring responsibilities. Amongst women, caring for someone on an extra resident basis was associated with a lower rate of full time employment and a higher rate of part time employment than non carers (Phillips et al, 2002; Nolan et al, 1996). Being able to retire early with a full occupational pension or favourable retirement deal can be a significant incentive to leave work in order to undertake caring duties, particularly for men (Arskey et al, 2005).

The vast majority (90%) of working carers are aged 30 years or over although it is important to note that a significant proportion are aged over 50. Being a Carer has been identified as a key contributory factor in lowering the labour market activity rates of those aged 50 years and over (Loretto et al, 2007). For women carers in

employment, 5% are aged 16-24 years, 57% are 25-49 years, 33% are 50-59 years and 4% are 60-64 years. Comparable figures for men are: 5%, 53%, 34% and 7% (Arskey et al. 2005).

#### 2.2.2 Combining Work and Family Caring

Combining paid work and care causes considerable stress and can result in carers giving up work; whilst being employed does not affect whether or not carers start caring those who do start are more likely to reduce employment hours or stop working altogether (Milne and Williams, 2003). In a recent survey of working carers almost half of those working part-time had reduced their hours from full time exclusively to accommodate care related responsibilities (Yeandle et al, 2007). Evidence suggests that those who are obliged to give up work to provide care do not wish to leave employment altogether. Instead most wish to achieve a reasonable balance between work and caring. However, research suggests that most employers give little or no consideration to the difficulties facing carers in trying to juggle caring with paid employment (Phillips et al, 2002). A recent study revealed that under two thirds of working carers - and only about a half of those working in the private sector regard their employer as 'carer-friendly' (Yeandle et al, 2007). It is co resident carers providing 20 or more hours of care per week who face the biggest obstacles.

As might be expected, of the total number of working age carers identified in the 2001 Census, only two thirds are in paid employment; around 1.5 million carers were not in employment who could have been. A recent representative survey suggests that more than two thirds of carers outside employment consider that their caring responsibilities were the cause of them leaving work (Yeandle et al, 2006). For those seeking work, finding a sufficiently flexible job, concerns about 'substitute' support services for the cared for person, refusal by the person they care for to accept help from services and loss of confidence have all been identified as 'barriers'. The cost of replacement care, lack of tax incentives, and an inflexible benefits system are also factors and, for some carers, these can mean they are financially worse off by working than by remaining a full time carer.

The experience of being in work is much valued by carers. It can provide positive benefits in addition to the income it brings, and having a job is associated with a range of measurable psychological health and social benefits (Arskey, 2002). Working can enable carers to avoid social isolation, can provide a break from caring,

facilitate social contact, offer a purposeful activity and provide an identity out with that of 'being a carer' (Becker, 2000; Seddon et al, 2004). Being in work - whether full or part time - has even been found to reduce the amount of stress carers experience (Hirst, 2003). Being out of the labour market even for a short time can result in 'opportunity penalties'- the loss of vocational skills, a reduction in self esteem, confidence and purpose.

Research suggests that particular barriers to carers staying in work include: restricted access to flexible working, limitations in the flexible arrangements themselves, reluctance to disclose caring responsibilities, variable responses from line managers and inflexible support services (Carers UK, 2004). The issues that research identifies as keeping carers in employment include: workplace support such as awareness of carers policies and flexibility in accommodating home based working; flexible working such as flexible start and finish times and part time working; a supportive work culture, and formal policies being in place (Pickard, 2004). There is also a developing evidence base supporting the 'Business Case' for employing carers. Arguments include increased motivation and productivity, reduced absenteeism and sickness, and enhanced levels of retention; this may be particularly relevant to older workers who tend to be those who have the highest level of skill and who are most likely to have care related responsibilities (Department of Health, 2008). Making it easier for carers to balance work and family life should also reduce premature retirement, which is important in the context of the need to sustain an ageing workforce in an ageing society (Confederation of British Industry, 2007; Loretto et al, 2007).

#### 2.2.3 Financial Implications of Caring

Reducing working hours - even over the short term - or giving up work altogether has significant implications for earnings and subsequent pension entitlements. This is particularly pronounced in contexts where the caring episode lasts for many years; it is also a more prominent issue for women (Carers UK, 2007). Research indicates that carers providing substantial amounts of care face much financial hardship; research conducted in 2007 found that a third of carers were in debt and one in ten could not afford their rent or mortgage (Buckner and Yeandle, 2007).

In 1996 nearly three quarters (73%) of carers canvassed by Carers UK reported that their earnings had been affected by caring (Carers Costs, 1996), a figure mirrored in more recent work which evidenced 72% of carers as 'worse off' as a result of taking

on a caring role (Carers UK, 2007). These findings are echoed in work by Yeandle et al (2006) who found that compared with working carers, carers who had given up work to care were 'struggling financially'. Most carers who leave paid employment to care are providing intensive care; a significant number are parents caring for a sick or disabled child. A reduced income not only means it is more difficult to make ends meet, it increases the risk of social exclusion for carers and cared for. It also means the carer is less able to save for their retirement or their own future care needs.

Since 2001 the Government has introduced a number of measures to help improve financial support for carers with a particular focus on those at risk of greatest hardship (HM Government, 2008). Some 229,000 carers in receipt of Income Support are now better off because they also receive a carer premium (£29.50 a week). To help carers who want to work part time the earnings limit in Carer's Allowance has increased every year since 2001 and it now stands at £95 per week net. One of the longer term aims of the Carers Strategy is to review the structure of benefits available to carers in the context of wider benefit reform and the fundamental review of the care and support system (HM Government, 2007).

Carers of working age in the UK have been estimated to save the economy £58.2 billion a year. When all carers across the whole of the UK are taken into account, the total saving to the economy is £87 billion (Buckner & Yeandle, 2005).

#### 2.2.4 Support for Working Carers

Evidence strongly suggests that long term carers appreciate support, and actively benefit from assistance from family, friends and services. Specifically, carers want: time off from caring; reliable support from services; information and advice and recognition of their caring role. Those services that improve carer well-being are respite care, day care and sitting services. A number of specialist services are also helpful for carers of people with dementia; this includes the admiral nursing service, specialist respite care and memory clinics (Milne et al, 2001; Milne and Hatzidimitriadou, 2002).

Recent research by Yeandle et al (2007) shows that amongst working carers:

 40% of those caring full-time said they would rather be in paid work but needed better support and services for the cared for person to achieve this

- The majority said they needed at least one type of formal service which they were not currently receiving
- One third of carers in full or part-time work were struggling financially
- Very few were getting breaks, and less than a quarter had access to respite care services
- Only a quarter of carers felt they had adequate support from formal services to enable them to combine work and care
- Between 40% and 50% reported a lack of flexibility and sensitivity in the delivery of services which undermined willingness to expand working hours
- A third of carers felt that they lacked information about what was available from services in their area. These findings underscore the pivotal importance of care services for supporting working carers. Their absence as noted above also hampers carers returning to work; recent evidence suggest that over 40% of those caring full time and not in work say that they cannot return to work because of limited availability of support services (Yeandle et al, 2006). On a more positive note, the same group of studies found that more than half of the working carers surveyed reported their employers as 'carerfriendly'. The fact that 93% of requests for 'flexible working' which carers have had the right to ask for since April 2007 had been granted, either in full or with an agreed compromise, is particularly noteworthy.

In terms of a coherent approach, very few local authorities have begun the process of mainstreaming their support for working carers across the full range of local agencies in health, social care, employment, and education. A recent survey of 10 localities reveals that the number of 'Carers Assessments' conducted among carers of working age is very small with even fewer local authorities proactively asking carers about their desire to work, or about the services they need to combine work and care (Yeandle et al, 2007a). The lack of a comprehensive 'needs assessment' leading to suitable, responsive services has been identified as a key factor in undermining the continuance or return to employment of working age carers (Commission for Social Care Inspection, 2008).

## 2.2.5 Carers aspirations and decisions around work and retirement

Arskey et al's recent report (2005) - Carers aspirations and decisions around work and retirement - conceptualised 'support' for working carers as falling into six categories:

- Jobcentre Plus
- Social services departments
- · Financial support
- · Workplace policies & procedure
- Carers centres
- Inter-agency collaboration

With regard to Jobcentre Plus, the research team found that only a few carers had taken part in a Work Focused Interview (WFI) with a Jobcentre Plus personal advisor. The interviews did not tend to influence carers' decisions about obtaining paid work as long as their current caring situation prevailed. However carers appreciated the advice, information and better-off-in-work calculations. Carers felt more critical of advisors' lack of knowledge about caring and the impact of caring on carers' ability to work. This deficit is, at least in part, a consequence of the very limited number of WFI personal advisors conduct with carers compared with other customer groups. This hampered their capacity to build up a knowledge base of care related challenges and issues, not helped by a focus on help that could be offered if the carer's care demands change.

In relationship to social services the report identified that although some carers were very positive about the support they received, others are more critical. Further, there seems to be little evidence of a link between the number of hours carers provide care and the level of support offered. Generally social services support was not essential to the ability of carers to undertake paid work partly because it did not easily accommodate work hours or patterns – for example day centre hours are rarely long enough to allow for a full working day. This is evidenced in other work (e.g. Phillips et al, 2002). Services that carers reported would make it easier for them to combine work and care included: longer day centre hours, childcare and after school clubs for disabled children and practical help with domestic responsibilities for older care recipients.

In terms of financial support Carer's Allowance (CA) is the main welfare benefit for carers. Both carers & professionals regarded the value of the benefit as too small and certainly insufficient to be a 'substitute' for paid work. Carers commonly agreed that the earnings threshold was low and, therefore, restrictive. There was evidence that the benefit might not act as an incentive to work, and that it could act as a barrier to working more hours. CA was not flexible enough for some carers, for example, paid work could jeopardise receipt of the benefit because of the rules regarding spreading earnings over a reasonable time period. The ceiling on earnings meant that carers who were working were unable to offer employers flexibility by occasionally working additional hours (Carers UK, 2007). This has been reported in other work and contributes to the impoverished financial status of many, particularly long term carers. One of the key aims of the Carers Strategy is to ensure a minimum level of income for carers who are unable to work (HM Government, 2008). The National Insurance carer's credit, due to be introduced in 2010, is anticipated to help militate against carer poverty. As 70% of all caring is done by women, they are likely to particularly benefit from this initiative (Yeandle et al, 2007b).

Arskey et al's report (2005) also evidenced that employed carers benefited from both formal and informal workplace policies and practices. For many, these were essential to their ability to combine work and care. Flexible start and finish times, together with the ability to take time off in emergencies or for planned hospital or doctor's appointments were particularly important. So too were sympathetic line managers and colleagues as has been demonstrated more widely with regard to family-friendly policies in general (Yeandle et al, 2002). Health and social care professionals - who were interviewed alongside carers as part of Arskey et al's study - believed that employment opportunities did exist for carers who wanted to combine work and care but such jobs were typically low paid, unskilled and possibly part-time and/or seasonal. Currently, the right to request flexible working is underutilised by carers; this is due to a combination of lack of awareness of its existence coupled with reluctance on the part of employers to provide flexible opportunities (Yeandle et al, 2007). The narrow scope of the definition of who is deemed to be 'a carer' is also an issue; as noted above this is due to be reviewed under the auspices of the Carers Strategy (HM Government, 2008).

Evidence from this research on the role of carers organisations and agencies supports wider evidence that, for those working carers who access assistance, the help received is much appreciated and valued (Milne et al, 2001). They provide

information & advice, a 'listening ear', counselling, advocacy, referral to social services and access to short breaks. Opening hours were a challenge for those carers working full time.

The research evidenced interagency collaboration between Jobcentre Plus, social services departments and carers' organisations as limited. The team suggested this reflects knowledge gaps about which agencies should and do support carers and what services they offer. Jobcentre Plus staff were the most isolated professional group; advisors knew little about what carers centres and social services provide. Wider work suggest that interagency collaboration is undermined by geographical variation, the liminal status of carers as part 'client' and part 'citizen', the complexity of differential 'support systems' and the lack of coherent attention paid to working carers as a group by any single agency.

A recent report by the National Audit office (NAO), which investigated the DWP's role in supporting carers to care, confirmed a number of the findings of the Arksey et al report, concluding that:

'The Department's [DWP] help to carers who wish to support themselves through combining paid work with their caring responsibilities is not sufficiently effective for carers.' (NAO, 2009:7)

#### 2.3 Summary

In recent years the work-life balance agenda has made huge strides, embedding the idea that all sections of the population should have access to work and a life outside work. This understanding of the crucial role that work plays should apply to those with caring responsibilities as much as to anyone else, yet until recently carers have not been recognised as having any specific rights at work and many continue to lack the support they need to combine working and caring.

As the population ages and the need for family support of frail elders increases there is a pressing need to extend support for working carers, reduce barriers to continue, or return to, work and ensure the full inclusion of carers in social and economic life. The challenge of how to effectively support carers to continue working and facilitate their return to work is considerable. Although some recent work has begun to explore support for working carers in depth understanding of what effective support is and

how different types of services may provide a single integrated 'package' is little understood. The economic case for maintaining carers in the workforce will become stronger as the number of carers grows.

## 3 THE ROLES AND IMPACT OF BEING A CARER

In this section we report on the roles and tasks carers perform and the impact of being a carer on their lives and health. There is a relatively well developed evidence base that charts carers' roles and the effect of caring on them, particularly for those providing intensive care and care for people with dementia. The impact of caring on the lives of working carers is only now becoming clear and is an issue that is foregrounded in recent policy changes and in plans to support carers in, or seeking, employment. This chapter adds to this evidence base.

Caring, especially over the longer term and intensively, has been widely reported as encompassing a range of instrumental activities such as bathing, and washing alongside responsibilities such as supervising the cared for person and ensuring they take their medication. In addition to these tasks carers also tend to perform a whole set of practical less 'hands on' activities such as shopping, cleaning and household management. For most carers they begin supporting the cared for person in relatively low key ways such as doing their shopping or taking them to hospital appointments, but gradually over time care activities become more intensive, time consuming and intimate. This reflects the fact that most causes of long term ill health are deteriorating conditions such as dementia or arthritis. Less often carers become carers overnight in circumstances for example, where the cared for person has a stroke, or car accident. Parent carers are in a different category again, most have been carers from the beginning of the disabled child's life. It is important to recognise that caring is embedded in a long term relationship that has a personal and individual history and biography.

Hours of care provided tend to be associated with type and level of care. Those carers who provide intensive types of care tend to provide care for longer hours per week than those who provide shopping; the latter category is often referred to as 'tending'. In the middle is a category referred to in research as 'moderate care'; this tends to include activities such as helping the cared for person out of bed or to get downstairs but not personal care. Intensive care is associated with 50 or more hours of care per week, moderate care with 20-49 hours and tending with less than 20 hours. Those providing intensive care tend to be supporting a disabled child, a partner or for more than one person; carers of parents with dementia may also fall

into this category of caring. The cared for person being co-resident is also a key feature.

Table 3-1 illustrates the number of carers who were in different caring contexts: 20 carers were looking after one or both parents, 17 were looking after their spouse and 13 were caring for children with disabilities or special needs. 5 carers were supporting 'others' including, a neighbour, friend and grandparent. Except for one, all the carers of children were mothers. The majority of carers of parents were daughters although there were also some sons.

Table 3-1: Who is Cared for by Relationship & Gender

Cared For	Women	Men	Total
Parent (s)	15	5	20
Spouse	11	6	17
Child(ren)	12	1	13
Other	4	1	5
Total	42	13	55

### 3.1 Caring Tasks

As can be seen from Table 3-2 most carers (34) were co resident i.e. they shared the household with the cared for person; 15 were extra resident i.e. they did not share the household. One respondent was 'semi-resident' in that he regularly spent the night in the house of his elderly relative although he retained his own home. In terms of hours of caring, as can be seen from Table 3-3, those caring for 50 or more hours per week tended to be co resident. Conversely, those caring for fewer hours tended to be extra resident. This was consistent with national trends.

In our sample, most carers (38) were providing over 50 hours per week of care; in other words they tended to provide intensive care. 11 carers provided moderate



levels of care between 20-49 hours per week and 6 provided tending or lower levels of care for between 1-19 hours per week. Interestingly, hours spent caring was not an indicator of whether the carer was working or not. There were as many working carers caring for 50+ hours per week as non working.

Table 3-2: Residency by Hours Caring

Hours Spent Caring per Week				
Residency	1 to 19	20 to 49	50 +	?Totals?
Resident	0	5	29	34
Semi- Resident	0	0	1	1
Not-Resident	6	6	3	15
N/A	0	0	5*	5
Total	6	11	38	55

<sup>\*</sup> Ceased Caring - Hours spent caring prior to change

Table 3-3: Work Status by Hours Caring

	Hours Spent Caring per Week		
Work Status	1 to 19	20 to 49	50 +
Caring & Working	3	5	18
Caring & Not Working	1	4	11
Ceased Caring & Working*	1	2	2
Ceased Caring & Not Working*	1	0	7
Total	6	11	38

<sup>\*</sup> Ceased Caring - Hours spent caring prior to change

#### 3.1.1 Low-level Caring or Tending

In terms of tasks, carers reported doing a wide range. At the lower, tending, end of the continuum a number of carers did laundry, helped with finances, took the cared for person out, kept them company, and generally made sure they were alright:

'Yes definitely, I helped him with paperwork and financial stuff. Also laundry, there's an awful lot of it. If he doesn't feel he can drive, which is quite often, then obviously I have to do the driving' (10KFNR, Female, under 50, caring, not working)

'Helping with paperwork, financial matters – well I did all of that. That was the other thing she stopped being able to do – she used to be actually very good with finances and looking after her bank account and all those things. Completely went to pot that did so I stopped in.'
(16KMNN, Male, over 50, ceased caring, not working)

Also carers often took the cared for person to medical appointments or to day services:

'If she goes to hospital I have to be there in order to give medical history and things like that'
(26KFWR, Female, under 50, caring, working)

'I used to drop him off at [name-special head injuries service) the other side of Ashford and then go to work and then pick him up... I then leave work a bit early and pick him up'

(14KFWR, Female, over 50, ceased caring, not working)

### 3.1.2 Moderate Caring

Many carers were also providing help with moving and handling the cared for person:

'If he can't get out of the bath and sometimes he needs help getting up and downstairs and in and out of bed' (10KFNR, Female, under 50, caring, not working)

'Physical help,yes. She can't manage stairs or walking except with a zimmer but I do help her stand up out of a chair, I put her into another chair, I help her in and out of bed, all that stuff'

(32EFWN, Female, over 50, caring, working)

Housework was regularly mentioned by carers, often as an *additional* job which, although they may do some of the chores anyway were part of the overarching caring role:

'Cooking, cleaning and washing, laundry and ironing... all of those lovely jobs.... I don't always do the meal but I now (always) pack it away and put it all in the dishwasher and stuff like that' (15KMWR, Male, over 50, caring, working)

'There's an awful lot of washing that goes on that I have to do in the morning (after she's got up)... it can be full of faeces which is not very pleasant' (21KMWR, Male, over 50, caring, working)

#### 3.1.3 Intensive caring

For most of the carers providing 50 or more hours of care per week, they were providing personal care of some kind:

'I go in every night and I shave him, clean his teeth, do his nails....sometime I feed him. He's doubly incontinent... he has to be moved with hoists, he's not even weight bearing. (Also) I cream him as he gets this funny condition, do his nails, give him drinks, give him his drugs. Just generally look after him, fuss around him really'

(14KFWR, Female, over 50, ceased caring, working)

'I do personal care for him because he's incontinent at night and he needs help to do .... Put pads on, changing the bed at night if it's wet. I have to give injections every day to him'

(19KFNR, Female, under 50, caring, working)

Some carers were required to do more evening and night related activities which may involve regular overnight stays:

'I stay overnight sometimes... I spend evening and nights at my mothers and days at my flat which has sort of become my office for work. So long as there is something for her to eat in the day she's ok and I like to be there at night in case there's a health issue'

(1KMWS, Male, over 50, caring, working)

Monitoring medications and doing quasi nursing care tasks was another role commonly reported by intensive carers:

'He (son with severe epilepsy) requires medication morning and night... we need to measure it out, keep it safe and make sure he takes it. Also we have to make sure if he goes anywhere to play or to a friend's house that the people are aware of the disability, of the consequences of what could happen and he has emergency medication with him and people are clear about what to do if he has a seizure'

(2EFWR, Female, under 50, caring, working)

'Also there's the medical things now that I take care of, there's the tube feeding and everything that goes with that. I do physio as well' (36EFWR, Female, over 50, caring, not working)

Most intensive carers did a wide range of care tasks. This carer summarised well what he does for his very dependent mother:

'Helping with financial matters - well I did all of that....other practical help, preparing meals, I did those, shopping, laundry, housework, gardening, all of that. Keeping her company, reading to her. Taking her out... walks, drives... taking her to visit relatives. Medication — she was really getting in a muddle with that... I do it all apart from personal care'. (16KMNN, Male, over 50, ceased caring, not working)

#### 3.1.4 Challenging Behaviour

Managing difficult behaviour was another facet of caring, particularly for carers of people with dementia:

'He used to unscrew everything.... the drain for the washing machine, he unscrewed the poles that kept it in place' (14KFWR, Female, over 50, ceased caring, working)

'I woke up and I could hear this beeping and I got up and looked outside. It was then I realised we had no power... and I got a torch and I was looking around and he'd weed all over the floor by the bathroom but not only on the floor, he'd weed down the wall and there was a socket and he'd fused all the lights!'

(34KFWN, Female, over 50, ceased caring, working)

Cared for people with memory and concentration problems posed a particular challenge for carers in terms of supervision and help:

'Memory, that's going now. His short term memory is going and ability to concentrate is now .... He can't concentrate at all now. Learn or understand. Crossing the road is hopeless, he needs help' (18KFNR, Female, over 50, caring, not working)

'Like when my daughter got married, she'd (elderly mum in law) be in every half hour asking me what was happening tomorrow and I'd have to go over it again and again and again, what she was going to do, what her part was, when she was coming home, the meal' (21KMWR, Male, over 50, caring, working)

#### 3.1.5 Other Care Related Activities

Another - under-recognised - care activity is related to emotional well being. Many carers recognised that the cared for person appreciated, or even needed, the impetus to look after themselves that a regular visit from a carer afforded:

'A visit from me gives her an emotional lift... I think people deteriorate very quickly if they feel they aren't being visited because suddenly it become less important for them to do things, like cooking. .... You can see the mental, emotional deterioration amongst elderly people when they are not visited' (1KMWS, Male, over 50, caring, working)

'One of worst points was mum feeling dead guilty about my sister (being sectioned) and part of my role was to keep her buoyed up so that she didn't get too depressed herself.... providing emotional support, just sitting there while she cried and trying to reassure her that she was a good person ... just trying to keep her spirits up basically' (37EFNN, Female, under 50, ceased caring, not working)

A linked activity was helping the cared for person to retain some level of independence:

'I'll give him (dad with dementia) a list of things to get, I'll tape the list to the dashboard.... because he's got to have his autonomy, his independence and he's got his pride as well' (26KFWR, Female, under 50, caring, working)

It was common for the demands of caring to increase over time; a carer often began by providing relatively low level types of support and ended up providing personal care:

'Personal care, washing, dressing, feeding and using the toilet. Plus filling in forms, financial matters, all of that. Having said that bearing in mind that if we went back to the beginning of 10 years I would have done hardly any of that for her.... She was perfectly capable of all that. All of the practical help I done, preparing meals, shopping, laundry, housekeeping, eventually I did all of those. It was progressive.... And keeping an eye on her all the time' (12KMNN, Male, over 50, ceased caring, not working)

The cared for person not being prepared to use a social care service or an aid was an additional stress for some carers:

'He won't go to the old age place, you know, because he doesn't want to go where all the people are old! It makes me laugh really. So that's another thing. If I could just have a day a week free it would be lovely for me' (25KFWR, Female, over 50, caring, working)

'She has a hearing aid but refuses to wear it.... She refuses to go into a home where at least her incontinence pads would be changed very regularly and all of that... she sends the district nurses away' (32EFWN, Female, over 50, caring, working)

#### 3.2 Carers Roles

Whilst a review of the tasks carers performed for their relatives paints a distinctive and detailed picture of what carers actually do - the physical and emotional labour associated with giving care- the roles they perform go beyond the performance of tasks. In this short sub section we offer an overview of carers' roles above and beyond care related tasks per se.

#### 3.2.1 Feeling and being responsible for the cared for person

This carer encapsulated well the all encompassing nature of her role as a carer; in particular the interlocking of physical labour with emotional labour and the performance of a wide range of tasks:

'He can't go upstairs so he sleeps downstairs in the chair. Feeding he can do. Shower I have to do. When he's bad then I have to shave him and do everything. I do all the financial side. I do all the meals, shopping, housework, gardening, taking him to the doctors, hospital. I also keep him company. I do all the medication. He likes to go out in the car so I do that sometimes. And I keep an eye on him when he's bad to make sure he doesn't do anything ... well he did have a turn once at turning the cooker on... well I changed it from gas but nevertheless. So I have to keep an eye out. I keep the doors locked if he starts to wander. But we're pretty good. He tends to wander up to the neighbours. And I got him a calendar so he can sort the days, it helps him to know what day it is and what he's done...'
(24KFWR, Female, over 50, caring, working)

#### 3.2.2 Interpreter

One of the greatest challenges faced by carers of people with dementia was the issue of communication. This posed problems for the carer but also for staff working in services; they sometimes had to rely on the carer to interpret what the user was saying:

'... with dementia, the ... understanding and the use of language kind of disappears so your communication is by other means. If you're a principal carer and you are attuned to that ... there's other ways of communicating. But in a hospital the staff are asked ... are trying to ask the patient every time what they want. Do you want me to do this? Do you want me to do that? Because dementia patients they can't answer... they can't properly

communicate and that is a problem... and the only person who can be the interpreter and translator is the carer and so you have to kind of be there ' (12KMNN, Male, over 50, ceased caring, not working)

#### 3.2.3 Monitoring self-care

Many carers need to ensure that the cared for person takes a degree of responsibility for themselves and there is often considerable tension in trying to empower the cared for whilst keeping them save and healthy. As a mother of boy with severe autism commented:

'He needs his routine, first thing in the morning, last thing at night. He needs chivvying about hair washing. ... I have to remind him to use the loo... and change his clothes because his attitude is 'I've got clothes on haven't I?' It's only recently he's realised what clothes to wear with regards to the weather... so yes some things have got easier in the fact he can dress himself but he still needs someone around to make sure things are safe and ok' (20KFNR, Female, under 50, caring, not working)

For carers who looked after people with dementia the need to monitor the well being and safety of their relative tended to increase over time:

'There was a point when I could go out for an hour, reliably and she'd fine. Leave her in the chair with a cup of tea and say 'I'll be back in an hour, don't move'. 'Yes OK, darling television's on, don't worry, I'll phone you if I need you'. That worked for quite a while. Even for 2 hours I could do that. Afterwards, later on, you couldn't leave her for 5 minutes, she just didn't remember that she'd had that conversation. I'd go out the door and within 5 minutes she was anxious about something and ... get herself in a right muddle'

(16KMNN, Male, over 50, ceased caring, not working)

'I have prepared big signs for my dad just to remind him, after his stroke he forgets. Big signs to tell him to turn off the gas cooker, the gas fire ... he's left that on a few times'

(33EFWN, Female, under 50, caring, working)

Safety was also an issue for disabled adults and children with learning disabilities:

'You do have to keep an eye on her ... well we haven't left her with anything she can leave on that's dangerous. There's no gas or anything in there' (21KMWR, Male, over 50, caring, working)

'Roger can't go out very far on how own, because he can't cross roads. He's got no judgement of speeds, distance and if he thinks it's clear then in his mind it's clear, you know, he won't think to look both ways' (20KFNR, Female, under 50, caring, not working)

These demands on carers meant that they often felt that the demands on them were constant:

'There is a sense that we are always on call you know' (21KMWR, Male, over 50, caring, working)

'I never know if I'm going to get a phone call on top of going over normally.... sometimes I've had phone calls in London and I've had to cancel everything and come down.... or whatever and sort it out... I mean they went for a walk in the woods together (older disabled couple) and feel down a bank. They came off the footpath and decided to cut across somewhere else and of course they fell. So I get a phone call in London so I had to drop everything and go down and sort things out'

(26KFWR, Female, under 50, caring, working)

#### 3.2.4 Arranging, monitoring and supplementing services

Another role that has been identified in research is that of monitoring the quality of services and needing to act as an advocate for the cared for person.

'I've had to put myself out for her in the first place ... I got my foot in the door at the Foreland (disabled children's service) when no other child from Canterbury has got in there! .. I had some help but you just can't just sit there and wait for somebody to sort your child out. You've got to get out there' (14KFWR, Female, over 50, ceased caring, working - referring to daughter not husband here)

'She (mother) was sidelined a lot of the time, just sidelined but I would never have allowed her to be sidelined. I stood up and said 'oi, this is my mum and you know you're not giving her the right treatment'. So I managed to secure for her a level of treatment from the health service that it doesn't normally give but had to do that by bashing away, by hammering on doors' (31KMNN, Male, over 50, ceased caring, not working)

In addition to battling for particular services, many carers then feel the need to keep making sure that the services are adequate. One son, for example, noted that he kept an eye on the care provided to his mother in the care home and continued to provide some care himself:

'So now mum's in the home... they're responsible for her 24/7 but I'm never satisfied with the care they give her... I don't think I can ever be satisfied with the care that other people provide. So I like to top it up basically, I go there once a day, at mealtimes to help encourage her to eat... I take food in that she likes'.

(16KMNN, Male, over 50, ceased caring, not working)

Another carer commented:

'I had to use a lot of skills. It's a bit like being a manager of the Rolling Stones a lot of the time. I am responsible for my mother. I'm trying to steer her though a maze of arbitrary decisions to make about her and ill informed decisions in some respects to get the best for her'.

(31KMNN, Male, over 50, ceased caring, not working)

#### 3.2.5 Caring for more than one person

It is not uncommon for carers to be looking after more than one person, this may be both parents or more than one elderly relative and a spouse or they may be part of the sandwich generation caring for children as well as elderly relatives:

'When I had my son...and I was looking after my mother who was sort of dying really. She died in 2001... my father died in 94. That was awful because I was trying to cope with looking after my mother, I was the main carer for her and looking after the baby and my husband being a right whatsit and I had the two girls still at home too. When you look back, you know, you think to yourself how the hell did you ever cope with that?' (14KFWR, Female, over 50, ceased caring, working)

One mother of a severely autistic boy was also caring for her mother in law:

'At one stage I was helping to care for my mother in law who was living across the road and has Alzheimer's .... and then when she went into the home I went up there at least once, twice, sometimes 3 times a week....'
(20KFNR, Female, under 50, caring, not working)

A number of respondents in the research were serial carers in that they had experienced a number of periods of caring for different people across their life course.

#### 3.3 The Impact of Being a Carer

Caring for a relative, particularly intensively over the long term, is widely evidenced as stressful and demanding. Common health related consequences include: depression, musculo-skeletal problems - due to lifting and handling - and chronic exhaustion. Less dramatically, carers, as compared to non carers, tend to experience tiredness and sleep deprivation, isolation, reduced quality of life and social opportunities and, most relevantly to this study, constrained ability to work. Certainly, those carers doing over 20 hours of caring a week – intensive or 'heavy end' carers – are the most likely to be struggling financially and the least likely to be in paid work (Yeandle et al, 2007a). The impact of intensive caring on carers' health, financial situation and ability to work are major issues for the longer term.

#### 3.3.1 Being and Becoming a Carer

The majority of carers in our study had been 'doing caring' for a long time; some had been carers for between 10 and 20 years. Caring became a responsibility for some carers quite quickly and for others it developed over time. One daughter described how her mother deteriorated:

'Well the situation was, she went very quick. She went from being fully supportive and fully looking after herself, apart from me buying her shopping once a week and seeing her twice a week, just to say hello – normal – to be hallucinating, seeing things, not being able to look after herself in a period of 6 weeks!'

(5KMWR, Male, over 50, caring, working)

For carers of people with dementia in particular they often described their becoming a carer as gradual:

'Changes are well gradual ... and you find you're taking on more and more of the function of caring... it's been coming on for years, for 10 years or so I'd say I was more conscious of the caring role. But what happens for older people is the deterioration in their health limits them more and more. So in a way caring is about increasing the amount of work you have to do... rather than switching from being a non-carer to suddenly being a carer' (1KMWS, Male, over 50, caring, working)

Some carers considered that caring was simply a vocation:

'I think you are naturally assumed as a carer or you're not in life... you are either that type of person or you're not' (42KFNS, Female, under 50, caring, not working)

Others felt that the role had been 'thrust upon them':

'Carers find themselves in the caring role. They don't actually volunteer or apply for that role, they are appointed to it. But they don't get any training. They are innocents abroad' (12KMNN, Male, over 50, ceased caring, not working)

And others that it was simply a 'natural' extension of family relationships:

'I think it's a natural instinct. I think maybe because I'm the daughter I see things and I do them and I don't see myself as a carer, I just see myself as a daughter that's doing ... the roles are reversed' (3EFWN, Female, under 50, caring, working)

Of course, in order to identify when you 'become' a carer the person doing the caring has to be prepared to define themselves as a carer in the first place. This is one of the issues that act as a barrier to support being offered to carers. In our study a number of carers certainly felt this way. One daughter for example said:

'I don't view myself as a carer as such. It wasn't until I started reading through about your project that it is a title I have. It's always just been something I've had to do. They're my parents, I have to look after them. I wouldn't ever think, 'my goodness I have rights'.

(33EFWN, Female, under 50, caring, working)

Other carers had been helped to view themselves as carers:

'They (Age Concern) advised me, before you fill in the form (needs assessment) just stop and think that what you are doing **is** caring... and the whole thing is taking over your life in a way that you haven't properly understood. So you stand back and look at it as if you were standing on the other side of the room ... rather than being part of it. That was sound advice! As I went through the form I realised I might have said I'm doing no caring at all and in truth I was doing a lot .... it also prepared me better for the way my role developed ... and (stopped me) getting resentful' (10KFNR, Female, under 50, caring, not working)

How the carer views themselves is likely to impact directly on the services and support they seek.

#### 3.3.2 Social Impact

Isolation is identified widely in research on long term caring and was reinforced by a number of carers in our study. Feeling and being socially isolated for any period of time may subsequently impact upon someone's confidence and ability to get back into work. This may be felt more acutely by men who are less used to periods outside the labour market than many women who may have not worked for periods when their children were young.

'... you tend to lose a lot of friends when you're a carer and you feel very isolated and unless you've got like good neighbours or other relatives you can become a bit of a recluse which is what I am becoming. And I can't really see any other way ... to help that type of problem to be honest'.

(48KMNN, Male, over 50, ceased caring, not working)

'There was me, there was my immediate family who I saw because they lived in the house with us and that was it.... I had very little dealings with the world at large. The only place I got to when I was with my mum at the eye hospital

or went down the chemists to get her pharmaceuticals. Isolation has been the most characteristic thing that I've suffered. Isolation. It's like I've been locked away in jail for 6 years and tortured, mentally tortured... it is a bit like Terry Waite'.

(31KMNN, Male, over 50, ceased caring, not working)

Another common feature of intensive caring is carers feeling trapped and/or restricted in what they are able to do. The needs of the cared for person can severely constrain the carer's capacity to go out:

'She's at that age .... she's 13, when she just doesn't want to be seen out in a wheelchair. But this just limits what you can do, you just don't go too far from home cos her walking capacity is so limited.'
(23KFWR, Female, under 50, caring, working)

'You couldn't leave them. I couldn't leave my mum and dad. The only time I can go out is if someone's there or if I'm just going down to the local shops....
But you couldn't go away for an hour or two hours at a time'
(41EFNR, Female, over 50, caring, not working)

In a similar vein, one carer described her lack of ability to do what she wants as constraining:

'He won't go to the old age place (day care)... If I could just have a day a week free... I could play my music, just do whatever I want to do without thinking oh I'd better not... better keep that down, he's not going to like that. So I just feel quite constrained...'
(25KFWR, Female, over 50, caring, working)

One mother described the complete lack of personal space as very restricting:

'I have to take him (son) everywhere because he can't go anywhere on his own. I do everything. He can't go out on his own ever, he can't be allowed near fires, he needs continual supervision. I can't leave him' (7EFNR, Female, over 50, caring, not working)

At a more profound level a number of carers reported caring as constraining their life choices and as potentially oppressive. One wife considered that her husband's illness had trapped her in her marriage and another that she moulded her life around the need to provide care:

'If it hadn't been for [person's] illness... his Alzheimers. I wouldn't still be here' (4KFWR, Female, over 50, caring, working)

'I am constantly modifying what I am doing in order to be compatible with what her needs are'

(12KMNN, Male, over 50, ceased caring, not working)

'To spend your life, you know, wiping somebody else's bottom so you don't have the freedom to have your life... it's a very oppressive thing to be' (21KMWR, Male, over 50, caring, working)

The many hours of time that caring consumes is a related issue and one that many carers commented upon; for those caring 24/7 it can be likened to shift work:

'I probably spend at least 50 hours on caring for him. I've been sitting here counting the hours'

(19KFNR, Female, under 50, caring, working)

'I was basically there from 8 in the morning until 9 at night and very rarely had any time away'

(37EFNN, Female, under 50, ceased caring, not working)

Our boys have problems during the night, so (husband) does the night shift while I do the day shift. So we work like a timetable' (43EFWR, Female, under 50, caring, not working)

#### 3.3.3 Impact on Health

There is a substantial literature on the impact of carers' health especially in intensive and dementia care contexts. In terms of physical health consequences, lifting and handling the cared for person and managing accidents, poses particular problems:

'It's very difficult to get training for carers on medical things, lifting, etc. This is one of the things that often crops up. Henceforth people hurt their backs. They should be offered the same training as formal carers' (36EFWR, Female, over 50, caring, not working)

Tiredness and sleep deprivation were widely noted by carers in our study, as the following quotes testify:

'During the night ... I would sleep with my door open, I'd sleep with one ear open'

(16KMNN, Male, over 50, ceased caring, not working)

'The doctor insisted I took a second week off because she said I was completely exhausted (with caring) as well as having the infection and she said she even considered putting me in hospital so I must have been really ill and tired'

(39EFWR, Female, over 50, caring, working)

For some carers it was the sleep deprivation that prompted them to seek help from services:

'Anyway I was doing all this stuff and then going to work, working full time and I ended up... I mean I know the symptoms of sleep deprivation and I thought... 'oh this isn't going to continue... we need services to do this stuff instead of me'. So that's what I do, I wait until things are just impossible for me to continue with and then I say, 'right I can't do anymore, someone has to provide some help for me'

(32EFWN, Female, over 50, caring, working)

Research evidence about the impact of caring on mental well being is particularly robust. In our study these carers discussed the affect caring had on both their emotional and mental health:

'You're mental faculties certainly diminish as a carer... One of the side effects of caring is psychological.... If the carer develops mental symptoms then they have to be taken care of' (48KMNN, Male, over 50, ceased caring, not working)

'In terms of the resources... of strength from in here I think that looking after someone with dementia is ... about as draining a thing as you can do. I've never experienced anything like it in my life; nothing in terms of its impact on you. And yet I did have strong resolve but the difficulty emotionally and psychologically that it puts on you...'

(31KMNN, Male, over 50, ceased caring, not working)

One carer spoke for a number of carers when she described the tension between duty to care and resentment about the weight of responsibility. This appeared to be a particular feature of relationships that were of poor quality before caring began:

'People who have children have chosen that path ...accept that they need to look after them. Whereas I never asked for this. I mean my mother when I was a young teenager she was away. She abandoned me and left me looking after the rest of them and didn't have an ounce of maternal instinct in her and yet here I am doing everything for her!

(32EFWN, Female, over 50, caring, working)

The negative emotional impact of being a carer may fall more heavily on men than women as illustrated by the following example:

'I think actually what happened with [name], my husband, having to look after somebody all that time, it's ruined his confidence and he doesn't now feel he can go out and get a job because he's got no value. As a male carer, especially when [name] was younger, there weren't places to go... men didn't go to places with children. So he kept very much to the house on his own, he learnt not to socialise. And I think looking back now, I'd say 'did we make the

right decision?' Should it be that you work part time and give you some sense of value because I think carers lose value'.

(45EFWR, Female, over 50, caring, working)

On the other hand caring did give some people a role and an identity:

'When our disabled son was 6 years old he was handful, so I decided that I wasn't going to work. He (husband) wanted me to work but it was part of the agreement that I wouldn't work... I was quite determined that.... I was going to look after [name], that was going to be my work' (7EFNR, Female, over 50, caring, not working)

A minority of carers also identified 'being abused' which had a profound impact on their health and well being:

'The toilet was the trouble I had with him, he wouldn't sit on the toilet so I used to have to shove him on the toilet, then he'd shove me! That used to get a bit hair raising!'
(14KFWR, Female, over 50, ceased caring, working)

'Just around Christmas time [name] started getting particularly horrible and he would... well one night... well it happened more than once, he started well for want of a better word for it, wanting sex in the middle of the night which I wasn't the slightest bit interested in as you can imagine so he decides to push me out of bed and accuse me of having sex with other men and things like that and .... So I had to lock myself in the other bedroom and ... he was hammering on the door and it was ... awful' (4KFWR, Female, over 50, caring, working)

#### 3.3.4 Working and Caring

Exploring the impact of caring on carers' ability to sustain employment was a key theme of the research overall and is covered in greater detail in Chapter 4. Here we can point to the fact that a number of carers noted the challenges of managing care tasks alongside trying to do paid work:

'I'm not getting very much help myself. Because what happens is the medication that is in the infusion is prescribed by the doctor. It doesn't include the infusion line, the plastic line with the needle and also the sharps bucket. ... had to go and collect a special sharps bin from Altrincham which is 14 miles away ... and I do really have to go to work and not spend my day driving all over the countryside'

(15KMWR, Male, over 50, caring, working)

#### 3.3.5 Financial Impact

The negative financial effects of caring are often considerable. As is clear from earlier in this chapter a number of carers had given up their jobs or reduced their hours to accommodate the demands of caring with the commensurate loss of income. Spending more money on laundry bills due to incontinence and travel costs associated with additional hospital appointments was also relevant.

'I've had very responsible jobs but I'm no longer able to out to do a job because of uncle falling over... you have to be a bit imaginative and think how you can get a source of income'
(25KFWR, Female, over 50, caring, working)

#### 3.4 Summary

Caring, particularly intensive and dementia caring, has a profound impact on the lives and health of carers. It is often a role that relatives take on unknowingly and gradually and for many it involves a complex mixture of time consuming tasks and roles which demand a great deal of physical and emotional labour. Long term caring leaves many carers exhausted, isolated and in poor health. Working carers are required to balance their caring demands with those related to their employment. Some achieve this balance by reducing their hours, shifting their pattern of work or, less commonly, getting regular support from family or services (this is discussed in detail in Chapter 6). Other carers are obliged to give up working altogether. Most carers want to continue working where possible and ideally wish to provide effective care to their relative whilst maintaining employment.

# 4 HOW CARING RESPONSIBILITIES AFFECT PEOPLE'S DECISIONS ABOUT EMPLOYMENT

#### 4.1 Introduction

The aim of this chapter is to profile the experiences of working recounted by the respondents across the study, and to explore in detail their reasons for working or not working and the difficulties they face in combining caring and working. The findings are presented by working status. Where relevant, attention will be drawn to factors such as gender or age of respondent or the nature of their caring situation and how these factors affect decisions about and attitudes towards work.

## 4.2 Nature of employment

Table 4-1: Overview of working and caring status of respondents, by age and gender

	Gender		
Work Status by Age	Women	Mer	
Caring & Working			
Under 50	13	1	
Over 50	7	5	
Caring & Not Working			
Under 50	6	1	
Over 50	7	2	
Ceased Caring & Working			
Under 50	1	0	
Over 50	4	0	
Ceased Caring & Not Working			

Under 50	2	0
Over 50	2	4

Table 4-2: Employer Type

	Gender			
Employer Type	Women	Men	Total	
Self Employed	6	4	10	
Public	9	1	10	
M/L Private	7	1	8	
Small Private	3	0	3	
Not Working	17	7	24	

Table 4-3: Working status by hours spent caring

	Hours Spent Caring per Week		
Work Status	1 to 19	20 to 49	50 +
Caring & Working	3	5	18
Caring & Not Working	1	4	11
Ceased Caring & Working*	1	2	2
Ceased Caring & Not Working*	1	0	7

<sup>\*</sup> Ceased Caring - Hours spent caring prior to change

It should again be emphasised that this was a qualitative study and so we cannot make statistical claims based on the breakdown of figures contained in these tables.

They are included primarily to indicate the coverage of the sample in terms of working status and circumstances of work.

With this caveat in mind, there are nonetheless some significant observations that arise from the tables. First, the number of hours spent caring appeared to have little effect on whether or not the respondent also worked. Further interrogation of the interviews revealed that work status and patterns more often reflected traditional patterns of gender segregation than any particular aspect of caring, such as time or who the cared for person was. Thus the women in the sample who worked were more likely than the men to work part-time.

A second observation was the predominance of self-employment. This was seen across both men and women and was viewed as a way of offering flexible work. The nature, role and importance of flexibility is explored fully in Chapter 5. A couple of carers had 'second jobs' in a self-employed capacity.

'I have a full-time teaching job and then I come home in the evenings and I tutor piano and music basically. And that's sort of during term time obviously. And that's to earn the extra money that really we kind of need now, now that [name of spouse] can't work and so that I feel that I need to keep that going so that's... I've been doing that... Well it's built up quite a lot, hasn't it, since you got ill and we've taken on quite a few more pupils. So I do extra... extra work.'

(51KMWR, Male, under 50, caring, working)

Many of the women who were working or had worked in the past were in 'caring' jobs, such as nursing, personal care, cleaning, health care assistant, special needs teacher.

One respondent, a man based in Scotland, had been able to take advantage of Scottish policy which funds a personal assistant. He became his mother's personal assistant, and his caring became his work.

'So although I actually gave up a full-time job to look after mum, and that was in January 2007, I was actually paid as mum's personal assistant. So really actually mum's gone into the nursing home 3, 4 weeks ago, so my actual paid employment finished at that stage because it was in order to keep mum living at home.'

(46EMNN, Female, under 50, ceased caring, not working)

## 4.3 Role of employment

#### 4.3.1 Interviewees who were caring, working

The predominant reason given for working was related to financial reward. Some respondents expressed this as an essential need ...'to pay the bills', but for others it was to improve quality of life ....'to do some things around the home' or to earn money for other 'treats'.

A frequent theme for those aged over 50 was concern not only about current income but that they also needed to consider the impact on their pensions – in some cases they were continuing to work mainly to compensate for an under-performing pension.

Another common reason for working, and one that was most often mentioned by resident carers was working to escape from demands and stress associated with the caring situation. The desire to escape prevailed even when respondents found no job satisfaction through their work.

'I don't actually want to work. I used to enjoy working and I don't think I do... I don't enjoy work. Whether that's because I've not found what I want to do. I work probably to get out of the house and go... get away, not I don't think about what's going on at home and just a bit of income really.'

(19KFNR, Female, under 50, caring, working - works in care home)

One individual who looked after her husband who was disabled from a stroke and also suffered from Alzheimer's had been advised by her doctor of the psychological benefits of working. Several carers spoke about feeling appreciated in their work, and receiving thanks, both of which were absent in the caring situation.

Frequently more than one reason for working was given. The example below illustrates the position of an older individual who has had to reassess her financial and personal situation since becoming a carer for her husband.

'I suppose firstly, it's financial. And certainly I have just reached the point where shortly I will be getting my old age state pension, but that's the only pension I'll receive, so if we were just to live on pensions and state benefits life wouldn't be all that terrifically rosy. So the financial side of it is still important. But also I feel I've had... a big change has happened since I've kind of become a carer because previously I was probably only working for financial reasons and I was maybe looking forward to... I'd always hoped

maybe we could retire to France or something like that and... which I mean I love France, I feel more at home there than I do here, so I'd always hoped that maybe something like that would happen. But because of the change in the situation now. I'm partly continuing to work also because although it's hard physically, it gives me a break from being a carer, because when I'm at work I have to concentrate on other things and I don't really have time to worry about what's happening at home. And so I suppose that, in the last year or 2, has become a secondary reason for working." (39EFWR, Female, over 50, caring, working)

Another commonly mentioned theme was that of providing structure to daily life and a purpose to life more generally.

> 'Well I think it's very important for people that are in employment as carers to maintain it. I missed the social interaction of other people very badly. I felt like a fish out of water. Suddenly you're stranded and your life completely changes. You know, I'm quite a resourceful person and I have a lot of interests if I was able to pursue them, but you know... I always have this thing oh I've got that, you know, to do, but I think it must be dreadful if you are, you know, in your 30's or 40's and you are forced to give up a job that you've enjoyed to solely care for someone. You know, you've given up your life basically."

(25KFWR, Female, over 50, caring, working)

'I just can't envisage that my working life could be cut short. It's not just that financially I will need to work as long as possible, because I've never had a big income or that, but I just need to be working. I lose the structure and lose the purpose in life and everything if I stopped working. So even the times when I haven't been formally employed I've been doing voluntary work and stuff. So if I did have to give up working here or something like that, or working in the career that I have, I would do voluntary work. I would do anything rather than nothing.'

(32EFWN, Female, over 50, caring, working)

Others articulated in the strongest terms that they were 'not one of these people that can take benefits' (40EFWR, Female, under 50, caring, working)

#### 4.3.2 Respondents who had ceased caring and were working

Those respondents who were working and who had ceased caring gave much the same reasons for working, the only difference was that they tended to emphasise how much they valued support from colleagues and the social aspects of the workplace.

> 'I used to walk in in the morning, I could laugh about it in the morning. You know I'd walk in and someone would say 'what was he like when you got

home' or perhaps there'd been travel in the afternoon, 'did you find him?' and I'd say 'oh yes, I found him up the road here', or that kind of thing.' (14KFWR, Female, over 50, ceased caring, working)

#### 4.3.3 Respondents who were caring and not working

The over-riding issue expressed by this group in relation to work was loss: loss of mental stimulus; loss of financial independence; loss of identity; and even loss of 'prestige'/esteem.

For a couple of women, giving up work had made them feel guilty and, as this quote illustrates, they even feel they needed the cared for person's approval for their decision.

'Before when I'd given up work I felt incredibly, incredibly guilty.'

#### Why?

'Because, I suppose it was my husband's attitude, whereas it was very much... I don't know. I think it was partly my attitude, because I've always been very independent. Also, [name] was very, although he's very understanding, an odd remark like 'oh you're spending my money again', whereas it's not his money, we share everything, you know. We've got a joint bank account and everything. Although it probably wasn't an intentional thing...Whereas this time when I gave up work, it was very much... because I rang him up at work and I explained what the doctor had said and he said 'right that's it'. He, that day, phoned up straight away for the Carers...because I was earning too much at that time to have Carers Allowance. He phoned up straight away and got the Carers Allowance forms sent here and it was sort of like, it was like he gave me permission to be at home.'

(20KFNR, Female, under 50, caring, not working)

Although a minority of respondents in this category were happy not to be working, a more common concern was they now felt they were no longer contributing to society in a wider sense.

'It gives you a sense of yourself, you know, confidence, that you're contributing to society, you know, with your taxes etc. There's this sort of thing about not working – it doesn't sit well with me....'
(36EFWR, Female, over 50, caring, not working)

#### 4.3.4 Respondents who had ceased caring and were not working

This group reported many of the same aspects of work as those who were not working but still caring. In particular, individuals who had ceased caring commented that they missed the social interaction and stimulus associated with work:

'both working with other people and also being part of what I call the working world' (12KMNN, Male, over 50, ceased caring, not working)

Another male in this group mentioned that they missed the sense of dignity they had gained through their work.

## 4.4 Carers who were working: Combining caring and employment

#### 4.4.1 Key characteristics and themes

Despite the importance of work to their lives, analysis of respondents' accounts of combining work and care revealed an often difficult balancing act.

Several respondents said that the needs of the cared for person meant that work had to fit around caring. This was seen in relation to the often intermittent and unpredictable requirements of their caring role, or as this example below illustrates, where the cared for person's needs meant that the entire responsibilities of caring fell to the respondent.

'She wouldn't want someone else in and I think at this point in her illness as well you have to be pretty stable and not kind of bring different things in to the mix, because that could disrupt her.'

(11EFWN, Female, under 50, caring, working - referring to her mother who has Alzheimer's)

'My parents would always be my priority really, quite simply.' (3EFWN, Female, under 50, caring, working)

A key finding was that respondents took the responsibility for combining work and caring on themselves. They felt it was up to them to adapt to the work – and not the other way round. Several accounts highlighted the feeling that they did not expect much (anything) from employers (employer support is explored in detail in Chapter 5).

'I've managed to keep everything going and I try not to let what's happening to me at home infringe on work because, well for two reasons. One is I'm working in a tough, competitive environment, they can't afford to carry dead wood, you know. I need to be able to do my job properly. I can't expect them to, you know, carry me, so that means... I mean luckily I'm good at it, so you know I can do my job OK. But the other thing is I need to keep the worst of what's happening out of work so that I don't even think about it because then I don't get upset at work. So that's why I never discuss anything that's bad at work, because I don't want to get upset.'

(32EFWN, Female, over 50, caring, working)

There was a strong perception, often based on experience that employers would view their caring responsibilities as an unwelcome intrusion.

'Employers don't like it. They're not really interested in what's going on in your personal life. They don't care. You're there to do a job of work and that's... So you can't blame them, they're paying your money.'
(24KFWR, Female, over 50, caring, working)

The result of bearing responsibility, and often hiding their true circumstances from employers was stress, often accompanied by feelings of guilt.

'I hated having to pretend to be a different person and it was really a tough time.'
(39EFWR, Female, over 50, caring, working)

'At [name of previous employer] I really felt like my dirty laundry was getting hung up for everyone to see.... I always felt so guilty, I always felt like there was a burden upon me and I was like 'I'm so, so sorry that this has happened' (33EFWN, Female, under 50, caring, working)

This led to respondents feeling indebted to employers in that they were just grateful that someone would employ them.

An overarching theme was either a self-reliance or reliance on family and friends in order to be able to work. This was seen in relation to being able to work in the first place, where we heard frequent references about only being able to work because of the support received from others, most often family members. In many cases, this has obvious implications for the overall quality of life: For example 'Rachel' cares for her son who has severe epilepsy. Her husband starts work at 5am, finishing at lunchtime to allow her to work until the early evening. They both report frequent disturbed nights because of the nature of their son's disability (for further elaboration see the case study at 8.2).

Other respondents felt very strongly that it was up to them to create their own employment possibilities. The quote below is from a woman who is operating a bed and breakfast business from her own house so that she could care for her uncle and still work.

'Well you have to be a bit imaginative and think of how you can have a source of income...... I've had to give up my career really and I'm doing bed and breakfast that I really don't particularly enjoy but it's a necessity, you know.' (24KFWR, Female, over 50, caring, working)

Another common theme to emerge from the interviews was an anticipation of work ending. It was quite clear that even where respondents enjoyed their jobs and valued them for providing a life outside of caring, if it came to a choice between caring and work, they'd give up work.

'When you look at it, it's quite good and it works out quite well. But there could be a time when it doesn't work out so well, you know, in which case the work would have to come to an end in some way, shape or form.'
(15KMWR, Male, over 50, caring, working)

For those who did not enjoy their work, they would stick at what they did for the sake of the cared for person. Some interviews indicated a concern that if the carer was unhappy or suffering from stress, this would have a negative impact on the cared for person. Others voiced their 'commitment' to work in terms of their commitment to their cared for person. For example, the woman mentioned above who was running a bed and breakfast business fervently wished to honour her commitment to her mum to look after her uncle.

#### 4.4.2 Restrictions on work

It was clearly apparent that respondents felt that their caring responsibilities restricted their working opportunities in several key ways.

Respondents maintained that caring limited the time they could spend at work (and away from the cared for person). We received several mentions from people who wanted to work for longer than their caring circumstances would allow. Caring was also seen as limiting the patterns of work, with part-time and other forms of flexible working, such as being able to work from home, valued highly. Flexible working is explored further in Chapter 5.

A further restriction related to the type of work that can be done – certain work environments were seen as incompatible with caring responsibilities.

'Retailing is a dire situation to have telephone calls at work' (39EFWR, Female, over 50 caring and working)

Several respondents commented that they could not undertake a job that involves travel.

Caring was also seen to restrict career planning and job mobility:

'It is that but even though I can stay in work and I can do those hours I've lost out on promotion prospects a hell of a lot because most of the girls who qualified with me are Sisters and that now but I can't maintain the work record and it costs..... You just cannot get a permanent job because your priority at the end of the day has to be the family and as soon as you take that stance you're penalised for it.'

(52KFWR, Female, under 50, caring, working)

'It restricts the... the sort of the career opportunities that you're going to go for because as you become more and more of a carer then obviously there are certain things that you just won't even consider you won't go for them because you realise that right from the start that they're... they're out. So in a way you kind of frame your career increasingly, including the caring aspect in it. How will the caring fit in amongst it?'

(1KMWS, Male, over 50, caring, working)

As the following quote shows a fear of having to explain their caring circumstances to new employers prevented respondents from exploring other job opportunities.

#### 'So it puts you off thinking about other jobs.'

'It does. Yeah. It does because then you've got to explain everything, that you're a carer, you know, home has to come first in a way and... I don't know how employers would be. Would they not employ me if I needed to take time off with a weeks notice or something?'

(19KFNR, Female, under 50, caring, working)

However, further comments from people in these situations revealed that they would rule themselves out of job possibilities without even speaking to employers.

Aligned to this was a fear that if they had to give up work because of caring responsibilities increased, they would not be able to get back into employment.

# 4.5 Carers who were not working

#### 4.5.1 Key characteristics and themes

Only a minority said they would like to work and definite plans were rare.

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"...if a position came up...." (55EMNN, Male, over 50, caring, not working)
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Not surprisingly the main barrier to work centred around their caring role and commitments. Most often, respondents were worried that they could not commit to regular hours because of their caring responsibilities – especially as these could be unpredictable in nature.

'I would love to be able to work. Currently I don't think it's possible, because what I have to do at home has to take priority and because of how my husband is, he still needs, at the moment, he's still getting used to the idea. Consequently he does use me a bit as an emotional crutch and, you know...I can't really see me being able to say 'right I'm going to work'. Go into work and then getting a phone call that says 'actually can you come home because I've got problems here' as in, if he's in pain or whatever, which he quite often is. Or if he has a tremor and collapses, which has happened before. I can't really commit to a job at this precise moment in time when, you know, he could quite easily knock himself on the head and knock himself out, which has happened.' (10KFNR, Female, under 50, caring, not working)

'You know, if I've got to work on a Monday morning for example and mum's got an appointment with the consultant at the hospital and those kind of appointments are very hard to shift. And some employers, you know, are brilliant, they are flexible but obviously you can understand from their point of view maybe they can't be flexible so I'm aware that when I go back to work there may... there may well be issues.'

(6KFNR, Female, over 50, caring, not working)

This respondent added that she would be prepared to lie to get into a job

'For example I wouldn't say I'm the only person who can look after my mum. You know, I would tell a white lie and say it's not an issue, you know, in order to get the job and then... and then once I've got the job then I can cope with any problems that arise. At the moment I just want to get a foot in the door and get back to work.'

(6KFNR, Female, over 50, caring, not working)

However, she was also concerned that she would face double discrimination in trying to re-enter the job market – being discriminated against on account of her age as well as because she was a carer.

"...on the last few CVs I've sent out I've just started not putting my date of birth on there because, you know..."

(6KFNR, Female, over 50, caring, not working)

Others felt that the cared for person would not want them to work, or in the case of disabled children, would not understand them working.

'Well when I did go into work, and the reason I had to leave was because I actually was so stressed out juggling both at the time, I pulled my muscle. So my doctor actually gave me a sick... I was really ill, but I still was in work. I didn't want to really leave my work because I was really enjoying it and because of the tension of... I mean your carer's role does not stop. All the responsibility I have at the office, that does not come into the house, but my children don't understand, they don't have sense of feelings, they don't understand how a person feels. They've got to be what they are at that time.' (43EFWR, Female, under 50, caring, not working)

Very often the decision whether to work or not was taken as a couple – either husband or wife would give up work to become the principal carer. Financial circumstances and decisions featured prominently here as did emotional and physical stress.

Some alternatives to regular employment were mentioned. For example, one respondent mentioned that she made some money by providing accommodation for overseas students in the summer.

# 4.5.2 Reasons for leaving work

The barriers to working discussed above were frequently based on negative experiences which had caused the respondents to leave work in the first place. We received several accounts of unsympathetic employers who had not made it easy for the carer to take time off or who asked them to work extra hours without realising the stress this might cause. For a few individuals, it was the travel associated with their work which became unsustainable.

Some cited financial reasons for leaving working. One carer described how her job in a fashion retailer at £5 per hour left her no better off than having been in receipt of benefits.

'No. But it was just... Like by the time I'd paid it I had to have a uniform, I had to wear... I think it was all black. I didn't have anything so I had to buy all that. ... it's just ridiculous and Housing Benefit of course that all gets stopped until they re-do it all and everything and I was just working for nothing. Even the Housing Benefit people agreed with me and the Job Centre. It was working for nothing so...'

(17KFNR, Female, over 50, caring, not working)

Because of these reasons, for several, trying to combine work and care simply became too stressful. For some, most often women, the trigger to leave work came in the form of successive caring episodes. Another common exit pathway from work was through illness – respondents took long-term sick leave and then eventually left their job, often more or less completely unnoticed by employers or managers.

'When I found out... or we found out that she had cancer I become depressed quite honestly and I went to see the doctor and she signed me off for 4 to 6 weeks with what she put on the sick note as mental incapacity. It was depression or whatever you like to call it, you know. And subsequently that went when I... other things came along and I resigned from that post. I was Centre Leader for YMCA Training in Margate and that was one way of coping with it and because of their attitudes also so... towards my caring. And thank God that cleared up after that so... It was to do with employer/employee relationships and their attitudes to my caring duties and things like that so...' (27KFNS, Female, over 50, caring, not working)

For several of our respondents aged over 50, it was clear that early retirement had provided a convenient route out of work.

'I'd been for several interviews because I was off work because of the stress with my mum and my dad and things, so I was off kind of long-term sick. And I went in for several interviews with my manager and they very kindly were trying to work round it, you know, trying to reduce my hours and things like that, but at that stage I realised that it wasn't going to be possible because I would have had to get someone in, obviously the times that I wasn't there, because my mum at that stage really wasn't capable of doing any sort of cooking or shopping or things like that. So I spoke to my manager and I said I really don't want to take on the situation, so I'd much rather just go for the early retirement, and which I did.'

(41EFNR, Female, over 50, caring, not working)

# 4.6 Summary

This chapter has provided an overview of respondents' attitudes towards and experiences of work. The focus has been on the difficulties in combining work and care. The overarching finding is that respondents who worked found combining work and care difficult. In the main, they took the responsibility for trying to juggle their responsibilities upon themselves, preferring not to involve employers, perhaps because they had received less than sympathetic treatment in the past. The following chapter explores issues surrounding support in the workplace in more detail.

# 5 THE ROLE OF EMPLOYERS

#### 5.1 Introduction

As was seen in Chapter 4, many respondents who were working did so on a socalled flexible basis, i.e. working on some other basis than a full-time, 9-5 standard employment contract. This chapter explores the nature of patterns and incidences of flexible working in more detail. A key focus is on the utility of flexible working if helping the respondent to combine work and caring. The second part of the chapter examines the support received from employers, managers and colleagues in the workplace.

# 5.2 Flexible working

Many of our respondents worked 'flexibly'. The most common forms of flexible working were part-time working and self-employment. Working from home (which frequently overlapped with self-employment) was also prevalent.

#### 5.2.1 Importance of flexible working

Several respondents emphasised the importance of working part-time to allow them to combine working and caring.

'Eileen' was an example of a carer who had reduced her hours from full-time to 24 hours per week (6 hours a day for 4 days). She was keen to emphasise that her decision was facilitated by both the nature of her work (on an IT project team) and by the supportive culture she worked in. Support received is examined further in section 5.3.

Flexibility was often valued above career and financial priorities, as the following case illustrates:

'Jacqui' was caring for her mother who was in the early stages of dementia. Jacqui's mother lived in a rural part of Scotland, and 'Jacqui' had recently moved to be closer to her. This move entailed a change of job. 'Jacqui' had previously been a lawyer

working in a city. She had worked hard to achieve her career goal, and her employer had wanted to retain her.

'They offered me, part-time, they offered for me trebling my salary, but the job itself was pretty stressful, but it was also pretty fixed. You could never get away with... well it was in [name of city] as well and at that point I was having to be able to go in a lot more often and it would take me the hour and a half to get through to [name of place where her mother lived], so 3 hours a day was not at all...'

(11EFWN, Female, under 50, caring, working)

Her current job in no way used her skills or training and there was no career progression, but it afforded her the flexibility she needed. She was working the equivalent 3 days per week for a charitable organisation. Crucially for her, she could work from home and vary her hours on a day-to-day basis if needed.

As this case shows, being able to vary one's hours can be as important if not more important than reducing the number of hours via part-time work. Several respondents emphasised that working flexibly was not simply a case of fixing up a certain patterns of hours, as their needs changed as caring responsibilities changed (most commonly in response to the deteriorating health of the cared-for person) or because of successive caring responsibilities.

# 5.2.2 Self-employment

Self-employment covered a wide range of occupations: our sample included a self-employed consultant, a journalist, several in the building trade, a bed and breakfast owner, a picture framer and a locum optometrist, among others.

It was clear that for most of these respondents the key advantage of self-employment was that it offered them more control over their pattern of working. However, despite this, it was not viewed as an easy option, as the case of 'Geoff' (47KMWR) clearly illustrates.

'I am self employed. I price work to customers and go and do work so if things like hospital appointments turn up then I don't go to work and if she doesn't feel right I don't go to work. So it's very, very flexible.'

(47KMWR, Male, over 50, caring, working)

However, 'Geoff' also noted that this flexibility came at a price. Firstly, that attending hospital appointments limited the amount of work he could take on and thus the income he could earn. He was also very aware of the responsibility of being his own boss.

'But then there is... With being self employed you've got to find the work, you've got to price it, you've got to do invoices, you've got to do everything. So in some respects it would probably be easier if you were working for someone. But then when you can't go to work it's not so easy to be working for someone and so on balance I would say being self employed is the only thing I could do... really the only way to go.'

(47KMWR, Male, over 50, caring, working)

The resulting stress that 'Geoff' hinted at was portrayed more explicitly by others, notably 'Charles' (12KMNN) who had been a general manager of a property development company in Australia and then moved to Britain to become head of a regional office. His account highlights the stress involved in trying to combine running his own business with caring for his mum. The situation got so bad that he stopped working.

'You know, if we wanted to take a normal work situation, what was my role? My role was the boss, or more like the business owner really, so I could organise, and sometimes from the phone, not even being on site, I could organise the trades as necessary, set things up in advance. One really needs to be there ideally, but what I could do was the carer would come here at 8 o'clock in the morning to get mum up and give her a shower and breakfast, I'd be out the door as she arrived, I'd go and spend an hour on site, get, hopefully the day's or the morning's work organised and come back. And so they'd be off... you know, of course it definitely isn't the most efficient way of doing it.'

(12KMNN, Male, over 50, ceased caring, not working)

'Yes, like, again, I'd have some teenagers, like my girlfriend's daughter would come and sit in with mum for an evening, let's say. She'd do it for a bit of pocket money and I'd take that opportunity to go down to the job site, see what had happened earlier in the day, make my materials list or my, you know, next day's 'to do' list, snag list. Whatever I could do I could do in the evening whilst the 'babysitter' was here and then organise it on the phone or the next morning in that first hour. So, from the point of view, it was very flexible. But I think probably by now you realise it could have been quite stressful!' (12KMNN, Male, over 50, ceased caring, not working)

Another variant of self-employment was freelancing.

'Caring is about having to fit in with events as they happen. You can work around a lot of things but you still need flexibility from the point of view of work which is why for me freelancing from home is ultimately the... the best option because it gives me freedom to make my own arrangements within the... the times that the work has to be done over a period of time but the... my clients aren't concerned about which days I work as long as the work is done within the deadline. But when you work in an office that's different, you have to fit in with... with their arrangements because you can't sort of suddenly turn up and say hi, I'm working today, you know, and they'll accept it. You have to say well next week it's going to be Monday, Tuesday, Wednesday. But mostly they will want you to say it's going to be Monday, Tuesday and Wednesday or whatever every single week.'

(1KMWS, Male, over 50, caring, working)

There was a division between those (most often men) who had always been self-employed and those who became self-employed in order to combine work and caring. The former group was typified by 15KMWR (Male, over 50, caring, working) a builder who declared that self-employment is 'in the blood', or by 26KFWR – a self-employed picture-framer reckoned that similar skills and 'strength of character' were needed to care for relatives as were needed to be self-employed. In contrast, there were a few individuals who were concerned that self-employment did not constitute a 'proper job'. (26KFWR, Female, under 50, caring, working)

#### 5.2.3 Working from home

While many of our self-employed respondents worked from home, other (employed) respondents were able to introduce flexibility into their work by doing some of it at home, often in their own time.

'Yeah. They're quite good. Yeah. If there's extra work to do I can do it at home and I can bring stuff home if I need to they've been... there's a lot of flexibility and support there really.'

(30KFWR, Female, under 50, caring, working)

Having some flexibility in taking work home was viewed as essential by some even when there was already some other form of flexible working in place. The following respondents was on a 50% job-share contract but very much valued being able to work from home.

'A very flexible department who are willing for me to sort of work from home if necessary, carry hours over so I can work from home if necessary. I'm fortunate enough to have a job that allows this. A lot of my work is sort of

computer-based, dealing a lot with sort of excel document spreadsheets and so it is work that I can do at home. So they're very understanding and know that there are times when I have to leave early because I've got appointments and they're very helpful and very flexible and without that it would be virtually impossible for me to work.'

(8KFWR, Female, under 50, ceased caring, working)

Another advantage of working from home was to accommodate the health problems reported by many of the carers.

#### 5.2.4 Time off

One respondent (38EFWN, Female, under 50, caring, working) spoke of her employers 5 day per year 'special request for leave of absence' which helped her along with her line manager's generally supportive approach. However, this was an exception: much more common was the situation whereby respondents used holidays to take both planned and unplanned time off.

A frequent way of introducing flexibility into employment was to use holidays to accommodate caring requirements.

'I suppose it can be flexible. Because I've got regular clients I go to it's sometimes... it's difficult... Well I have to take holiday... If I need to take time off if my husband needs to go to hospital I have to take holiday or... you know, and sometimes they're a bit off if I ask for time off.'

(14KFWR, Female, over 50, ceased caring, working)

Being able to take unpaid leave was not seen as particularly helpful.

'In the past they've been... well I've had various different employers in schools so some have sort of said well, you know, you can have this week off but you will be unpaid. Some have said that and...But then the pressure's there to go back really soon because we can't pay the mortgage, we can't... you know, if you can't eat you can't care for someone either so it's... you know.' (51KMWR, Male, under 50, caring, working)

#### 5.2.5 Term-time working

This was a form of flexible working favoured by respondents with children. Although it freed up the school holidays, it was also seen to limit flexibility in other key respects, as the case of 'Rachel' below demonstrates.

'Basically my hours are set, there's not really any flexibility in them. Because I only work term time – semester time – I don't have holidays. I basically don't have any sort of time-off-in-lieu type way that I can move things.'

(2EFWR, Female, under 50, caring, working)

It was quite clear that any flexibility in 'Rachel's' case was achieved through detailed co-ordination with her husband to ensure their son was cared for.

'For example if my son had a seizure and was in hospital, the way that I try to approach it is if it happens in the morning, then I go to hospital with him, my husband goes straight from work to the hospital and then I go to work, because, although obviously I would rather be with my son, equally it creates a lot of problems for my colleagues. It means other people have to cover, you know, it just creates a whole mammoth sort of thing and I kind of feel, I know people say 'you should be with your son', at the end of the day it just messes everybody else up. It totally screws the schedules, so as long as one of us is with him, you know, that's pretty much how we've done it. Because certainly as well, with my husband's work, initially when my son developed epilepsy, his work just said 'fine, just go' but obviously now because it could be a regular thing, you know, he essentially, no matter how rubbish it makes him feel, if our son's in hospital he has to work because there's only so much kind of time off and sort of sympathy an employer can give you and you just have to face it.'

(2EFWR, Female, under 50, caring, working)

It was clear that this form of flexibility severely affected her work-life balance. She worked Sundays - the only day her husband has off, so the only time they have to be together as a family is Saturday afternoons. She admitted that occasionally she had swapped shifts with her colleague who works on Saturdays, but made it apparent that she did not expect her employer to do anything.

'I suppose informally, the person who works Saturdays and I have occasionally swapped, you know, he's worked a Sunday for me and I've had a weekend off or vice versa and we've kind of done that and it's probably not a very formal arrangement, and it's been good that we've been able to do that at times, that's helped. It's difficult to see how they could be more supportive really, it's just the nature of the job and the kind of out-of-hours element of it that makes it hard to support it.'

(2EFWR, Female, under 50, caring, working)

'Rachel's' case also illustrates the point that respondents frequently took the burden of combining work and care personally and generally expected little from their employers. This theme is explored further in 5.3.

# 5.2.6 Agency work

Our sample contained a couple of respondents, both working in caring jobs, who belonged to an agency or 'bank' of staff which enabled them to control when they worked.

'Claire' was an agency nurse.

'Yes. But I don't have a contract as such because I'm a bank worker, so I don't have a contract, I only work when they need me, or when I'm able to work

#### So, there are advantages in not having an employment contract?

Yes. And I quite like not having a contract, so that when the summer comes I can just say 'I'm not available'.'
(13EFWR, Female, under 50, caring, working)

Another advantage for 'Claire' was that she could work a certain number of hours per year in order to comply with requirements of her profession. However she was also aware of the limitations of working on this basis: because she was not an employee she had no rights to request flexible working.

#### 5.2.7 Informal flexibility

Although flexible work was most often mentioned in terms of hours of work or place of work, there were other, less formal aspects of flexibility which often made a real difference to the respondent's experience of work. As seen in Chapter 4, very often a key caring requirement was being contactable at work. But there was a strong perception, often based on experience, that employers saw this as an unwelcome intrusion.

'Employers don't like it. They're not really interested in what's going on in your personal life. They don't care. You're there to do a job of work and that's... So you can't blame them, they're paying your money.'
(24KFWR, Female, over 50, caring, working)

'Charlotte' had moved from a large bank to a small consultancy company. Her case clearly shows the value of being contactable at work. Her account clearly contrasted her current and previous experiences.

Yes, I was heavily involved with my parents and there was (sic) problems with me being unable to come into work for several days, which they weren't happy about. Which being a big corporation, the silly things, like my [current] boss lets me have my mobile phone on my desk so that I can always be contacted, whereas [name of previous employer] just wouldn't allow that.' (33EFWN, Female, under 50, caring, working)

'I couldn't have the mobile and I felt that the management structure was not sympathetic of my situation at all. I got told a few times that I was exactly the same as everybody else in the office who had children to care for, when of course it's completely different. So my dad had some strokes when I was there, they were not helpful about giving me time off. And I think that really stressed me out and that's when I had such a sore stomach and, in hindsight, I think that that was perhaps brought on, or made more severe, with stress. Perhaps. I mean it was easy for me to just get a doctor's note and stay off and then I could be with my parents, because I just wasn't offered any, I mean no support at all. My parents weren't allowed to phone in the office or, see what I mean? I was sitting all day thinking something might have happened and I don't know, and there was no system in place where... I mean right now, if something were to happen to any one of my parents, I could text my boss at any time, through the night, and I wouldn't have to worry about it.'

(33EFWN, Female, under 50, caring, working)

'Charlotte's' story was echoed by others and illustrates the short-sightedness of employers who discourage contact at work. Previously, her focus on work had been disrupted because she would worry about her parents. Now, with that worry removed, she could get on with her work and consequently be a better employee.

Another advantage of being allowed some flexibility in the use of the phone at work was to allow for outward communication.

'Well basically if there's phone calls to be made I do a lot from my work, you know. My work are quite understanding, you know, and I can maybe type up things, letters, and make phone calls and when I finish work my husband will take me round after work and I'll gather her washing or whatever.' (38EFWN, Female, under 50, caring, working)

# 5.3 Support from employers

#### 5.3.1 Official policy on employing carers

The past and current employment experience of our respondents revealed that very few employers had a formal policy of offering flexible working. The clearest example of a central approach to flexible working came from a large retailer.

'When you get an application from Asda, you've actually got a time grid on the front of the application form that you can specify which hours are actually OK for you working.'

(40EFWR, Female, under 50, caring, working)

The more common scenario was that illustrated by 'Claire' (13EFWR, Female, under 50, caring, working) or 'Rachel' (2EFWR, Female, under 50, caring, working) in Section 5.2, whereby their employers (nursing agency and university respectively) made no special allowances for being a carer – it was simply the nature of the job that meant there was some flexibility in combining working an caring.

#### 5.3.2 Employer support

As was seen in Section 5.2, despite a lack of overall official policy some respondents did receive support from their employers to work flexibility. This support manifested itself in a number of ways, including making adjustments:

'When I was doing FPC qualification it was technically we have to go away to Birmingham for 3 weeks, continuous weeks, and I had actually said to them that's there no way that I could do that and what they eventually did was they actually got a trainer to come to Edinburgh and train me one-to-one. They actually sent somebody here for 3 weeks instead to train me one-to-one.' (45EFWR, Female, over 50, caring, working)

Other employers offered support by holding a job open during a particularly difficult time for a carer:

'I mean they were fantastic because they actually said to me oh do you want to do it and do you want to continue doing it? And I said oh yeah. And it's just a matter of when [name of son] is ill they know I won't be there and I just phone up and they say right that's fine and we'll just find somebody which sometimes can be a nightmare but at other times... I mean that's a nightmare for them but they are very good with me and they've been fantastic to hold my job open for me. So...Because there's not a lot of people that would do that I don't think, especially when it's so unsure about what's going on with me.' (29KFNR, Female, under 50, caring, not working)

This support was most often seen in relation to long-serving employees.

'Yes, they've always been good. They were good when [name of daughter] was ill, because as I say I've been there for about 30 years, 30-odd. More than that, but I was part-time the other time, it didn't count or something. But, no, when [] was very ill and they thought she wouldn't live they gave me, they paid me kind of a little bit of money which kept me going, which was very helpful, so they've been good to me, I've tried to repay it.' (14KFWR, Female, over 50, ceased caring, working)

The experiences shared by the respondents revealed that although a few employers were active in identifying when a carer was struggling and would help them come to some suitable arrangement, a more passive approach where it was up to the carer to approach the employer was much more common. The quotes below illustrate examples of active and passive approaches to employer support.

#### 5.3.2.1 Active management

'But what was happening now is I changed my work time a bit and I spent... I had a longer lunch break. I started a bit earlier and finished a bit later but that meant I could come up here. So [name of wife] day instead of being all day to herself she was now... had 2 sections because up until this time she was still mobile and could get around and... out and about to the shops and that but then that was becoming more difficult for me. No, it was at this time here, sorry, that I started to actually... 2004 I started to work 4 days a week and that was for 2 and a bit years. And then at this stage I needed to come down to 3 days a week but in fact things had got to the stage... because that had gone on a little bit longer than I expected. By the time I needed to come down to 3 days a week [name of wife] really needed me there all of the time so I actually worked from home for those 3 days a week and we'd already decided who was going to take over from me and he just came into that role a little bit more precipitously than he thought he might do but obviously I was on the end of the phone and we'd talk and... So that changeover was a little bit difficult. And then I stopped more or less when I'd expected I would have done, which was February of '07 when my normal retirement age would have been now, October 2008.

# OK. OK, well that's excellent. So it sounds like it was quite a collaborative effort.

It was.'

(12KMNN, Male, over 50, ceased caring, not working)

#### 5.3.2.2 Passive approach

'I had a team leader at the time and I went to her and said, you know, it's just becoming... No, I'd had to approach them before that because I think I was doing the nursing care and still the consultant that wanted my mother being brought into the clinic twice a week and it was only running in the mornings and I was going to have to be coming in and going out. I needed to get some sort of authorisation for that. So I had brought it up and the team leader that I had then, she was someone who was very difficult to get to know as a person, I didn't know what to expect from her, but she was actually very, very sympathetic. And that was about 3 months before I asked for part-time work, because I realised I couldn't continue, I couldn't do enough caring to meet my mother's needs at the time. We had tried to talk my mother into getting the home-helps and the various Council support which she refused. So I thought, well, it's me that has to do it. So then I went and said I'd like to work part-time and here's a working pattern I've worked out, what do you think about it?' (32EFWN, Female, over 50, caring, working)

Other employees received very hostile treatment in aiming to combine work and caring, as a return to 'Rachel's' case shows:

'No. I didn't want to go back full-time. It was looking like I was going to have to go back full-time. I'd applied to work flexibly and it was turned down, and basically there was just no degree of flexibility whatsoever. I was told basically full-time at the exact times or nothing. But obviously I had to go back to pay back my maternity money, which at that point was just not an option. So that was extremely stressful, and really difficult, and then I managed, practically the week before I was due to go back to work full-time to get a part-time position with another department and basically they just kind of let me go without giving any notice, so that...'

(2EFWR, Female, under 50, caring, working)

In some cases, such as that illustrated below, this lack of sympathy and support led to the respondent leaving employment.

'Yes. Dad passed away the end of December, I was on my Christmas holidays of course, Christmas, New Year. I had to decide what we were going to do. My work gave me 3 days compassionate leave and that was it.'

'Just 3 days. Which I felt a bit... I mean the rules that they did, but when I thought about it, I couldn't remember the last time I'd had a day off sick. I mean the whole of 2006 I hadn't had a day, I know for a fact. 2005, I think maybe 1 or 2 odd days, you know. So I went to my doctor anyway and he really signed me off for 2 weeks. He said 'I can't give you any more, but I can certainly sign you off for 2 weeks, I wouldn't worry about that'.

'Well he just put 'stress related to death in family' and that was it. And it gave me a bit of time to think what we were going to do in terms of looking after mum. So I put my notice in at the end of the time, thinking I'd like to see my employer and handed my 4 weeks' notice. And actually they were quite good in the end, they didn't bother making me work any of that time. They said 'that's fine', you know, they understand etc. So that was that.'

(46EMNN, Male, under 50, ceased caring, not working)

#### 5.3.3 Line managers

A supportive line manager was often key in the experience of combining care and employment. In many cases, despite no official policy to support carers, line managers were very supportive of individual cases. For example, despite having no official policy of flexible hours, 38EFWN reported how her line manager was able to assist.

'I mean if I have to, my line manager's not too bad by the fact that I'll maybe cut my lunch hour short the next day or whatever, to make up sort of. We've had to attend meetings as well maybe, concerning mum's care, and I will get, you know, I'll put that in, but they tend to put it in blocks of half days, you know. So I try and maybe just make up the time.'
(38EFWN, Female, under 50, caring, working)

Another carer spoke of how her boss supported her attending her local carers' association.

'I suppose even coming for these meetings for Vocal, for 5 weeks, I wanted to come to these training sessions and obviously they were during the working day and I was just told by my boss 'take the time. If you want to find out what you need to know, I don't have a problem with that, take your time and just go'. I told them enough time in advance what I wanted to do and it was very much like 'just do it'. So they are supportive in that way, they will give me time for like attending Vocal things.'

(45EFWR, Female, over 50, caring, working)

And another account showed how informal support from the line manager continued, despite a set-back in official policy.

'When the discussion was going from part-time to full-time they were fully aware of the situation and with the flexi-time system they said 'yes, take what flexibility you need' and they would try to find ways to help. So very supportive. Then of course just before Christmas we had this thing come out of the blue banning all flexi-time. So there are times when I have to take time off. I keep my own time record. My supervisor hasn't asked me for it, but she can see it any time she wants to, and my conscience tries to... I try to make

up the time as and when I can. So it is a flexi-time situation, but it definitely took a dent when we had that universal email coming round.' (9KFWN, Female, over 50, ceased caring, working)

However, having a sympathetic line manager was not viewed as a suitable substitute for an overall policy in that differing practice across areas of an organisation could cause problems.

'Well you have to ask and it's all at the director's discretion. That's the problem with the University. It's not 'here's a policy' and everyone has to follow it. They have policies and then they say 'ah but we'll just let all these little autonomous autocrats determine everything for themselves' and there are all sorts of things going on here and it's different all over the place.' (32EFWN, Female, over 50, caring, working)

The case of 'Alan', a teacher highlights what can happen when a sympathetic line manager is replaced by one who is less supportive. As 'Alan's' wife explains a lack of consistency of approach was seen to be very unhelpful:

Obviously with his job recently changing, his head [teacher] recently changing, and it's a shame that it seems to me that she's not aware of the policies about flexible working for carers or that carers should be afforded this like emergency time to care for someone who is in crisis because she doesn't appear... well her actions don't support that she understands any of those policies and so I guess it would be nice to think that there was some kind of programme that was making employers aware of that. And we're working in the public sector so especially, you know, even in that sector which is more controllable probably than the private sector in some ways but not even happening there. So it seems very person dependent is our experience. We've had 2 good heads and 2 bad ones, for this purpose, you know.' (Wife of 51KMWR, Male, under 50, caring, working)

Another issue arose when an individual boss might be supportive but then need to be backed up by the employer, or by their representative – HR in this case.

'Yes I took a week off recently because [name of son] had had an operation and I had to do that at fairly short notice because I wasn't aware that I was going to have to take a week or so off work without him going back to nursery or what have you. But the department had absolutely no problem with that. Had to persuade HR that they had no problem with that, but the department were fine! .... I mean there's things like you're supposed to give 2 or 3 weeks for a period of parental leave and then in small print 'unless the department agree otherwise' and HR were saying 'well we've not had our 3 weeks notice' and the department's saying 'no, it's fine'.'

(8KFWR, Female, under 50, ceased caring, working)

In line with 'Alan's' account above, this respondent very clearly articulated the value of having an overall policy that was shared by individual managers.

'I think in order to stay employed I do need to have an employer that will understand and will appreciate the sorts of external pressures I have as well as the internal deadlines as well.'
(8KFWR, Female, under 50, ceased caring, working)

#### 5.3.4 Support from colleagues

Several respondents spoke very warmly about the positive support they received form their colleagues. This support was emotional:

'They're great. They can be very, very supportive. They're always there to listen.'
(40EFWR, Female, under 50, caring, working)

'I suppose there's the emotional support in terms of if I've had a bad day or bad morning, there's always people I can having a moan to, let off a bit of steam with. So I suppose they may not realise it but they do actually give me a degree of emotional support as well.'
(8KFWR, Female, under 50, ceased caring, working)

#### And instrumental:

'My colleagues were as flexible as it was humanly possible to be and yes they were very understanding. ....I was specifically told when I was being interviewed and I was trying to ask a question like could my 3 days a week be bunched into 4 days a week in term times and then could I have weeks off when my son's home? And they said don't ask that question, we'll organise that informally.'

(50KFWN, Female, over 50, ceased caring, working)

However, set against this were frequent mentions of lack of support and understanding from colleagues.

'You just get little comments like that, you know. Sometimes I do know in advance of hospital appointments and things like that and I do give them notice but, you know, anything could come up out of the blue just...'

(19KFNR, Female, under 50, caring, working)

Another, older respondent spoke about how she had been marginalised by her younger colleagues for 'always' talking about her mum.

Given this sort of reaction, it is unsurprising that several respondents chose not to tell their work colleagues about their caring responsibilities.

#### 'So you seem to have very supportive management?

Very supportive.

#### And what about colleagues?

Yes, I would say they're supportive. I mean they don't know of my situation.'

(33EFWN, Female, under 50, caring, working)

'To be honest, I don't really talk an awful lot to my colleagues about... I mean they do know that my son has epilepsy, they do know that. They don't know so much that I have depression because I'd prefer... I think sometimes people view you quite differently and label you. I don't really say too much about that. And on a Sunday I'm a lone worker, so I have nobody to talk to and that didn't bother me when I worked Saturdays and Sundays on my own, but more recently I've found that quite isolating and didn't really enjoy it as much'

(2EFWR, Female, under 50, caring, working)

This latter quote is another from 'Rachel' (see 5.2.5), and emphasises the socially isolated position she was in at work. This lack of colleague support and isolation extended to her line manager who was in a different location and therefore only contactable by phone or email.

This relates to a more general point, that telling colleagues that they were a carer was a big event for many of our respondents. This reflects the point raised in Chapter 4 about carers viewing their caring responsibilities as private and trying not to effect a burden on employers or colleagues.

'Yes. But I don't really discuss it at work at all. I did tell, well not quite the owner, but the semi-owner of the business, at the beginning of the year that [name of husband] had also been diagnosed with Alzheimer's, because I thought I should tell her that there were problems. And she was actually very nice about it. But I said that I really didn't want it to affect, it wouldn't affect my work, and I was just telling her to keep her informed. And I wasn't upset when I was telling her, it was rational, calm, and I said that, you know, I would do my job as usual, but I thought she ought to know. So they do know, but I don't talk about it at work. I mean I might occasionally make a joke, you know, and I do now say more than I did a year ago. A year ago I wouldn't have said anything at all. But I've realised now that I have to, I can't pretend everything's alright anymore, which is what I used to do. So now I will maybe say to the girls, I'll tell the girls for instance that [] doesn't go to the

supermarket any more and that I'm now getting a home delivery from Marks and Spencer's to make my life easier because I've got a lot to do. So I will say things like that, which 12 months ago I probably wouldn't have said.' (39EFWR, Female, over 50, caring, working)

However, keeping caring private and hidden is not necessarily a good strategy. As has already been shown in Chapter 4, this was stressful for the respondent. The following quotes show a rare example where the cared for person - the respondent's son - was visible. The fact that colleagues knew her son meant that colleagues were more supportive.

# 'What about colleagues? What sort of support do you get from them? Is there any difficulty there?

No. Probably as the manager they don't question what I do! And I must admit they're very, you know, '[name of son] comes first' as well because they've all met [].

#### Oh, in what circumstance?

Probably because my husband's brought him in to meet me after work on a Saturday so they've all met [ . They've all met him and a lot of my staff have been there 5 years so they know all about him, not know him, but they know who he is.'

(45EFWR, Female, over 50, caring, working)

#### 5.3.5 Culture of the organisation

Several respondents spoke about working within a supportive culture, where colleagues and managers alike were sympathetic and helpful. For example, 'Eileen' (see 5.2.1) worked in a department which generally supported part-time working whatever the needs for this.

'No, there's lots of people part-time. There was even one guy who's still there, he works half time now, 50%, and it's really because he wants to spend, he's got two young children – he's a couple of years older than me and he's got these very young children – and he just wants to spend more time with them..'

(32EFWN, Female, over 50, caring, working)

'Jill', also highlighted the support she received from her school and wondered if their sympathetic approach might arise from the nature of the job.

'Yeah, and they're also very good if there's illness and... if there's a problem, a hospital appointment for him or anything like that they're very good and supportive for that sort of thing.'

(30KFWR, Female, under 50, caring, working)

'Well I know some other parents have said... you know, who work in a normal 9-5 job and they've had issues coming to appointments for their children, you know, and so... I don't know if that's because of working in a school or something... you know, that they are more understanding of what I have to go to, you know?'

(30KFWR, Female, under 50, caring, working)

#### 5.3.6 Employer trust

A recurring theme was respondents feeling that employers did not trust them. 'Charlotte' (see 5.2.5) had previously worked for a large bank and spoke about the difficulty of taking time off to care for her parents and the lack of trust from her managers and colleagues.

'But I got asked a few times, like 'well if you can prove to us, because you could just be doing anything, couldn't you?' You know what I mean? It was so mis-trusting and they just didn't believe for a second that I was doing what I said I did....'

(33EFWN, Female, under 50, caring, working)

She had since moved to a much smaller organisation who were much more trusting and accommodating. She contrasted her current and previous situations.

'I mean right now, if something were to happen to any one of my parents, I could text my boss at any time, through the night, and I wouldn't have to worry about it. Whereas with [name of previous employer], if I had to take a day off then I would have to phone at 9 and then I had to phone back at 10 and explain to them whether I'd be in and there was an awful lot of rules which got in the way of my responsibilities.'

(33EFWN, Female, under 50, caring, working)

# 5.3.7 Limits to support

Even the most supportive situations was seen to have its limits – in several cases this manifested itself through an ignorance and lack of understanding of the nature of caring responsibilities and the difficulties in being a working carer. For example, although 'Eileen's employers were clearly supportive of part-time working, it became apparent that they did not fully understand the requirements that caring might involve

and the needs for other forms of flexibility. For 'Eileen', the problems came when she tried to take emergency time off to look after her mother.

'You know, the nurse just phoned me at work and I had to go. But it was an emergency, it was completely unplanned and this director says to me 'oh the policy we operate for family leave is that it is to cover for emergencies' and OK he accepts I had one, 'but obviously I hope you don't have more on this particular event. Are you through the period where unexpected issues are going to happen?'

(32EFWN, Female, over 50, caring, working)

'Well one of these things, like family leave. It's a problem in itself because it is OK just for emergencies but you apply for it, or you request it in retrospect. You have an emergency, they phone you up 'we've got an ambulance coming', you get out there, you get over to where she is and you deal with it then. And the next day you come back to the office maybe and then you say 'could I please have family leave for yesterday?' What if they say no? Why should I not... I threatened with my own manager, I said, 'look, next time I'm just going to phone in sick'. It's a bit difficult when you're sitting there at your desk and you get the phone call from the nurse and it can't be 'oh I'm feeling unwell'!

(32EFWN, Female, over 50, caring, working)

Another respondent spoke of how employer sympathy was very much second-place to the needs of the business.

'I'd say it was management. They were more worried about having the centre run effectively and efficiently with a body in there than worrying about me worrying about my caring. And as I remember I phoned them up... I went from work with my wife for her diagnosis and I came back home... well to the job... the place I was working and I was upset rightly and I just phoned them up and I said I need to have time off because I've just found out my wife's got cancer. And I had a deputy there but they were more worried about making sure that they had somebody over her in authority than just letting me go off. They said you can't just go off home now and that, you know? It was a bit heated and a bit upsetting and things like that. But from then down on their attitude to me was... It just became more distant. They said they understood but there was always these management issues behind it making sure that, you know, there was somebody there opening up and dealing with delivering the contract and that sort of thing so... Yeah.'

(35KMNR, Male, over 50, caring, not working)

#### 5.3.8 Disempowered employees

As with other research into employment rights, respondents in our sample were very often unaware of their rights under the law (to request flexible working or to have time off for emergencies). Some had a general awareness of their legal entitlement but

either it did not apply to them (e.g. not enough service to qualify) or did not want to disrupt their employer and/or workplace.

'That what was suggested to me by my counsellor at Vocal today. She said 'what about having an extra half day off a week if they would let you do that?' And my reply to that was, well for a start I wouldn't even dream of asking them at the moment because we've got a lot going on and we're short-staffed and there's a lot of pressure, so it wouldn't be the right time to ask.' (38EFWN, Female, under 50, caring, working)

Even where employers were supportive (as in the case of 'Charlotte' above), respondents frequently felt uncomfortable in asking for more.

'I'm at the bottom of the ladder, you know, I'm an assistant consultant, I'm struggling to get... you know, I'm struggling to get up the ladder and I don't know how comfortable I'd be asking for anything more than what's already given to me. Despite the fact that I may or may not be entitled to whatever. I still, I would feel that it would hold my personal development back.' (33EFWN, Female, under 50, caring, working)

# 5.3.9 Need for a range of sources of support

It was very clear from a number of accounts that employment support for carers was much broader than employers', managers' or colleagues' support. 'Ash' (43EFWR, Female, under 50, caring, not working)had previously been employed as an information advocacy worker, helping other carers who looked after children with special needs. She enjoyed her worked, felt experienced and useful and was supported by colleagues.

'In our [name of place] office there were 4 of us and then there was the manageress and there was an information worker. And they were very good because everybody was a carer except for the 2 of them.'

(43EFWR, Female, under 50, caring, not working)

However, the sheer weight of caring for two children with special needs with only a minimum of other support highlights the fact that employment support for carers needs to be examined from a range of support sources. This is the subject of Chapter 6.

# 5.4 Summary

This chapter has provided a detailed examination of the ways in which employers, managers and colleagues supported carers in the workplace. A patchy picture emerged, one with some positive aspects, but a key finding is that carers are not particularly visible to employers. There was, at times, a lack of understanding or appreciation of the particular requirements and difficulties of combining care and employment. And the predominant approach was ad hoc rather than strategic or informed.

# 6 THE ROLE AND EFFECTIVENESS OF INFORMAL AND FORMAL SOURCES OF SUPPORT FOR CARERS

In this section we report more generally on the role and effectiveness of both formal services and family and friends in supporting carers, and those they care for, to be able to work or seek employment. Inevitably, and as is consistent with wider research, carers perspectives on the role of support reflected the multifaceted nature of being a carer and the interlocking needs of carer and cared for. The section is made up of three sub sections: one focusing on formal support, one on informal support, and one on overarching issues. Whilst the emphasis in this chapter is not on employment directly the broader context of support, or lack of it, is significant for carer's ability to remain in or go back to work.

# 6.1 Support from Formal Agencies

As was made clear in Section 2, over the last decade there has been increasing emphasis on enhancing the role of statutory and voluntary sector agencies in supporting family carers. A particular policy driver is the need to support carers to continue to, or seek, employment opportunities. There is now widespread recognition that in order for carers to be able to work services for their disabled relative need to be accessible, robust and reliable. The predominant formal agencies involved with disabled people and their carers are the NHS, social services departments and the voluntary sector. Evidence in this sub section is thus presented around these three providers and reflects both the effectiveness of services for cared for relatives and carers themselves.

#### 6.1.1 The National Health Service

Mixed views emerged about support from the NHS. Overall there was much less said about the NHS than social services; this reflected the fact that most disabled people and their carers need ongoing support, which is primarily the responsibility of the local authority, as well as the fact that helping carers is traditionally viewed as a social care function rather than that of health.

For some, primary care and most notably the GP, was a source of constancy and support:

'Mum's doctors, her GP especially, has been wonderful'

(41EFNR, Female, over 50, caring, not working)

For others the GP has provided access to, and a link with, a range of services:

'My GP, she's very good. And I see a counsellor at the practice as well. And there's an Admiral Nurse that I'm going to be seeing and Ann the CPN comes around quite frequently and always goes with us when we go to see Dr Smith who is the psychiatrist'

(4KFWR, Female, over 50, caring, working)

As is clear from the last quote, nurses also have a significant role to play. A minority of cared for people received input from nurses; some were specialists in the particular health condition. Although appreciated, carers felt that they were in short supply and tended to focus on specific health care tasks rather than on providing support to either themselves or their relative:

'Well the specialist nurse rings me now and then... but she doesn't really visit, only if I really need help with Richard's medicines, then she'll come along' (26KFWR, Female, under 50, caring, working)

'The Parkinson nurse... she doesn't actually pay visits, only if you ring her for some reason. She's spread from Ashford to Thanet to London. ...'
(15KMWR, Male, over 50, caring, working)

'He had a Community Nurse who comes in at the moment one day a week to site his infusion and they ring up most evenings to check whether he can take it out by himself because the (home) carers aren't allowed to touch it officially' (50KFWN, Female, over 50, ceased caring, working)

In contrast a number of carers with relatives with dementia got specialist input from an Admiral Nurse; these are specially trained nurses whose role it is to provide practical advice and support to dementia carers. In addition to home based one to one input they often run local carers groups. They tended to be highly appreciated:

'We also have an Admiral Nurse...she is brilliant' (18KFNR, Female, over 50, caring, not working)

'... My carers group, that's run by Admiral Nurses. And that been very good, very useful indeed' (12KMNN, Male, over 50, ceased caring, not working)

Discharge of their relative from hospital appeared to challenge the NHS in terms of providing a package of support and medical advice:

'When Jasmine (disabled daughter) came out of hospital I realised I needed a commode and stuff like that for her at home and nobody had sort of said to me where to get it... they sent us back to Dover from a London hospital with nothing and you're on your own with this child and this big bag of medicine. And she can't walk and she can't move ... and you know she's 13 but she's 11 and a half stone so I was lifting her and picking her up and virtually carrying her around' (23KFWR, Female, under 50, caring, working)

A number of carers also commented on waiting lists for primary care based services such as counselling:

'I did apply for a counselling service but the waiting list was 6 months ... and by the time my name came to the top of everything that I'd wanted to speak about at the time has changed so much was just 'what's the point" (37EFNN, Female, under 50, ceased caring, not working)

#### 6.1.2 Social Services and Social Care

Broadly, the social care sector is made up of local authority social services departments and private social care providers such as home carers who may be purchased directly by users or carers or commissioned by social services. Both disabled people and carers are eligible for 'assessments of need' by their local social services departments, to care plans and packages of service provision. Accessing this depends on the level and type of 'eligibility criteria' which tend to be set at a relatively high level i.e. a person has to have a serious level of disability before they are eligible to receive support.

Evidence relating to social care falls primarily into three key areas: respite care; social work and assessment of need; and paying for care.

### 6.1.2.1 Respite Care

Respite care refers to alternative care that provides 'respite' or a break for carers. It most often takes the form of a period in a care home for the disabled relative or a sitting service whereby a paid or voluntary carer comes into the home whilst the carer goes out. Greater availability of reliable respite care, particularly in an emergency, is one of the key provisions outlined in the Carers Strategy<sup>3</sup> mentioned in Chapter 1. Research evidence suggests that respite care tends to be highly valued by carers; it performs a pivotal role in helping carers to live a life 'outside of caring' and, for some, to rest.

Respondents in our study viewed respite as providing an opportunity to manage domestic activities, pursue interests or simply have a break from caring:

'Respite care ... it was really a sitting service and I had carers in for two occasions during the week for about 2.5 hours. This allowed me just to take some time to go out and do things such as going to the dentist and the other session allows me to play in an amateur orchestra every Monday evening' (12KMNN, Male, over 50, ceased caring, not working)

'... and I got to a point when I was just so low and I thought I've just got to do something about this. And I phoned my husband and said I've blanked out 3 weeks in October, I said I'm phoning social services and I'm going to see if I can get respite care, which I've done. He's going to go for 3 weeks to Sampson Court and they are lovely there and I have booked to go to Italy. Because we've not had a holiday since I can't remember ...' (25KFWR, Female, over 50, caring, working)

Some carers needed trained paid or voluntary carers to provide a sitting service:

'The other thing we do get is 4 hours a fortnight respite care. It's kind of like a sitting service. The lady comes, she's trained to deal with epilepsy and she comes in and gives Alan his medicine and plays with him and then puts him to bed and is there whilst he's sleeping'.

(2EFWR, Female, under 50, caring, working)

It was striking how little carers received in terms of respite care and how difficult it could be to access it:

<sup>&</sup>lt;sup>3</sup> HM Government (2008) Carers at the Heart of 21st-Century Families and Communities: A Caring System on Your Side. Stationary Office: London

'She (daughter) went in for two weeks respite. Well maybe it was naïve, I guess I thought originally that we would maybe get respite every weekend or something like that. The social worker came round and said you're entitled to 4 to 6 weeks of respite a year and it has to be in blocks of a week minimum at a time'

(46EMNN, Female, under 50, ceased caring, not working)

'I only get respite because Greg went into crisis. Greg was ill and just went totally like mad... getting up in the middle of the night and eating ... loaves of bread and 6 yoghurts and I couldn't cope any more.' (19KFNR, Female, under 50, caring, working)

Also, if cuts were made to respite provision how difficult that can be for carers, as these parents of two autistic children attested:

'I waited 5 years for the Action Group ... and we could have up to five weeks, the boys would be off to a summer play scheme, meeting other children, making friends. That gave us a bit of a break to recharge our batteries and be ready for them. ...and now because of the funding issue they've cut down to two weeks. So we actually now get seven weeks of summer holidays with the children but two weeks of respite. So it's not really enough'. (44EMWR, Male, under 50, caring, not working)

The role of respite care in facilitating employment was less clear although a small number of carers did comment on its value in this respect:

'Well the support of the carers (sitting service) ... gave me the freedom to get on with my work without the worry of coming home and funding mum in some terrible mess'

(16KFWR, Male, over 50, ceased caring, not working)

'Yes I have a carer comes in and does nights whilst I work' (24KFWR, Female, over 50, caring, working)

For most working carers though however useful respite care is, it was not directly beneficial in helping a carer to work. Before it could be considered useful for working carers there would need to be much more investment in respite provision and it would also need to be far more accessible and flexible:

'The most respite care I've had is 4 weeks. I have to book respite a year ahead if I want to get it in Edinburgh so within the realms of being able to work if I needed emergency respite ...'
(36EFWR, Female, over 50, caring, not working)

#### 6.1.2.2 Paying for Care

Unlike NHS provision, which is free at the point of delivery, care provided or commissioned by social services can be charged for. In addition a minority of carers opt to pay privately for care services, most usually home care or a sitting service.

Charges are paid only by those whose income is above a certain threshold; most only pay for a part of their care package:

'She pays for part of it (care package)... she was assessed financially, she has two pensions which makes her above some sort of limit so she pays' (21KMWR, Male, over 50, caring, working)

".. the only thing we pay for is respite. They paid for the bulk of it (Social work services) which was over £500 and I think the family had to pay £70" (46EMNN, Female, under 50, ceased caring, not working)

'The only thing we currently pay for is if somebody's... a sitting service, people babysit for James so we would have to pay for baby-sitting or for example during the school holidays to look after him during the day so I can go to work'

(8KFWR, Female, under 50, ceased caring, working)

Some social services departments provide vouchers for carers to use to buy in their own care, whilst others use direct payments or welfare benefits to help with service costs:

'We get respite vouchers to be used at the Lothian Autistic Society that produce a list of carers that have worked with children with autism. We've got a carer called Ben who takes them (2 autistic sons) every fortnight because that's all I can pay him... the vouchers (cover) the number of hours he's working with the children, extras we have to pay for... around about £10-£20 depending on what activities they're up to'

(43EFWR, Female, under 50, caring, not working)

'I paid for most of it (sitting service) out of my own pocket. I managed to spread the direct payments out to cover some of it and I made up the rest myself'

(16KMNN, Male, over 50, ceased caring, not working)

'For the Independent Living Fund you are financially assessed and you contribute towards the home care and we contribute towards the respite care. The money from the ILF is to pay for a personal carer to come in' (36EFWR, female, over 50, caring, not working)

The potential to use direct payments to fund care to help carers to work was noted by a few respondents. One parent for example wanted to use them to extend her working day:

'I'm wanting to investigate direct payments and things like that. Because it would be easier for me if I didn't absolutely have to work school hours, because it makes my day very condensed. Literally I'm dropping James off at school, run into work, do as much as I can before I have to turn around and come back and pick up James. Direct payments could be used to pay for one to one support after school, I can them work longer hours and take proper breaks'

(8KFWR, Female, under 50, ceased caring, working)

Some carers paid privately for care services. Although this is expensive it tends to offer choice and flexibility and the carer, and user, can build up a relationship of trust with agency staff:

'So I went to this agency and I got regular carers from there now and they're very good. They're not trained nurses but they're compassionate and have an understanding of the old. They know how to change them and make sure there are no bed sores.... So it works but its expensive' (26KFWR, Female, under 50, caring, working)

'I've found people privately ... via somebody else who was in a very, very similar situation but a few years ahead of me. So these people are working not only for my mother, they're also working for this other chap. I'm getting the people that I think suit mum. Continuity of whose coming in .... I know who's coming in and I've built up a relationship with them. It costs a lot though, the people they came to me from told me they'd spent over £50,000! It's really scary'

(9KFWN, Female, over 50, ceased caring, working)

#### 6.1.2.3 Social Work and Assessments of Need

In law only carers that provide, or intend to provide 'regular and substantial levels of care' for someone for whom the local authority may provide community care services are eligible for an assessment of need (Carers UK, 2001)<sup>4</sup>. Although it was clear from the interviews that carers were not always sure whether they had had a formal needs assessment or not, surprisingly few carers appeared to have asked for, or received, an assessment. As most would qualify for one, this is a concern. Higher numbers of

<sup>&</sup>lt;sup>4</sup> Carers UK (2001) *Policy Briefing: Carers and Disabled Children Act 2000*, Carers UK, London

carers had regular dealings with social workers or care managers whose role was primarily to assess the needs of, and provide services for, the cared for person.

Assessments were felt by carers to be primarily focused on practical support for the user and that after the assessment and care planning period regular input from a social worker ceased. If needs changed this required a new referral:

'Right at the very beginning I said that all the things they were offering like meals on wheels or cleaning or washing I could do myself. I didn't need anybody to come in and pay somebody for what I could do... so (they said) we'll leave it with you, just get in touch if things change. That was the only assessment'

(48KMNN, Male, over 50, ceased caring, not working)

'That's one of the problems with social work, it's not ongoing... there's no ongoing check to see if you are ok. Once they've finished with you they close the case down.... And then when you start again you've got to go through all the rigmarole again'

(48KMNN, Male, over 50, ceased caring, not working)

'I have no social worker or care manager cos he (the user) does not need personal care and the case has been closed down so I've got no one to fight my corner'

(19KFNR, Female, under 50, caring, working)

Some carers had tried hard to get access to a carer's assessment or a care manager:

'I've been trying and trying to get one (an assessment). My cousin lives in Liverpool and she is a social worker and she says I'm entitled to a carer's assessment... I sent e-mails and I had the head of the area of social services for this area and he said I am not entitled to it because what am I doing when my child is at school? .. I have respite then. That's what he said to me. I have got the letter somewhere, it's absolutely disgusting. And my cousin in Liverpool is going off on one but she can't really intervene but they won't give me one. They say it's for people that are looking after elderly people, not for somebody that's at school'.

(16KFWR, Male, over 50, ceased caring, not working)

'I tried but there are too many people wanting a social worker... I did ask for one but was turned down'

(23KFWR, Female, under 50, caring, working)

Others had high praise for their care manager:

'My care manager is fantastic!' (14KFWR, Female, over 50, ceased caring, working)

Where assessments had been done, or were about to be done, they acted as a trigger for services for the cared for person:

...'they did a proper assessment of her mentally, all the rest of it and it was through that that she now has a carer that comes every morning which is great'

(21KMWR, Male, over 50, caring, working)

'It was our disability social worker....we managed to get her after 5 years... once we did get a social worker we had a Section 23 done (assessments of children in need) and then we got respite care and other services' (43EFWR, Female, under 50, caring, not working)

"...I am in the process of getting in touch with the epilepsy support charity social worker for a needs assessment. I want to make sure the transition arrangements between the nursery and the school are in place and the school staff are aware of my son's needs..."

(21KMWR, Male, over 50, caring, working)

There were one or two examples of social workers employing 'creative accounting' to facilitate the carer working whilst also ensuring that the cared for person was appropriately supported:

'Once she (SW) could see that I was determined to carry on working, she then came up with an idea and said 'well there is Carers Allowance but its not a lot of money. But there is another idea'. She obviously went back and discussed it with her colleagues and she said 'Well what we could do is employ you as your mum's personal assistant using the Independent Living Allowance....it enables your mum to stay at home, which is what you want and she wants, then we could set this up'. It was complicated cos my brother had to employ me on my mum's behalf. It got very convoluted but we did it!' (46EMNN, Female, under 50, ceased caring, not working)

Being au fait with the system and knowing who to contact was also regarded as an advantage:

".. a friend of mine is an ex teacher whose wife has got dementia and he gets a lot of help because, you know, he phones up the right people, you know, he gets respite, he gets day care, he wants it so he follows through" (48KMNN, male, over 50, caring, not working)

# 6.1.3 Voluntary Sector

The voluntary sector was universally highly regarded by carers. It tends to be an anchor; it provides much needed advice and information (including financial and benefits), a guide through the care system, and it also directly provides services for

carers such as support groups and emotional and personal support As there were a range of people in different caring situations supporting people with widely different caring needs, this was particularly notable.

Acting as an advocate and advisor was identified by a large number of carers as a key role of voluntary agencies:

'Sheila's been great, she attended meetings with us, she's taken up a role to give us extra back up and advice on everything we need. The problems we've been having with mum's care... she's been a godsend. (She also has) a case worker from Perennial, the Gardeners Benevolence Society, through dad... whose been very, very good as well. Lots of advice and financial advice. Sheila's our guardian angel really' (38EFWN, Female, under 50, caring, working)

Also they were often reliable sources of information:

'The Vocal meetings were looking at what happens after they leave school, what the entitlements were, the benefits ... looking at the care plans written by Social Services once they were actually going to be independent, what happens with employment. It looked at writing trusts and the wills and how we actually make sure that he's safeguarded in the future' (45EFWR, Female, over 50, caring, working)

Voluntary agencies routinely hold carers meetings or run support groups which are highly valued by carers and which often led to the development of friendships:

'Myself I got involved with Vocal, the carers organisation. They were a great help in terms of, you know, they run evening things and good clubs and you get together with other carers and chat things over and that was... that was a support to me personally'.

(46EMNN, Female, under 50, ceased caring, not working)

'[Name of town] Parent Support Forum is made up of a large majority of parents like me who have got children with special needs or who are trying to work and look after them and are juggling things. So when we have a meeting we make sure we have like a half hour networking slot where we can just all talk or moan or whatever we want to do'

(23KFWR, Female, under 50, caring, working)

'We kind of built up a support network from that (the epilepsy support group), several of the mums have got quite friendly and you know, we chat to each other in between times and not just at the meetings ... about issues that surround epilepsy and our children and their differing needs' (2EFWR, Female, under 50, caring, working)

Some groups are run for the carer and the cared for, particularly in the dementia field.

'We go together to the Young Onset Dementia Project which we go to once a fortnight... there's 5 couples that go, one partner has dementia. And we do activities, go for walks... we all cook lunch together and we eat lunch together and we do gardening and things like that. And we've made friends there... even been on a short holiday with the a couple from there' (4KFWR, Female, over 50, caring, working)

Another issue relates to specialist knowledge; most of the voluntary sector agencies have expertise in conditions e.g. dementia, autism, or in caring per se. Some of the more specialised voluntary agencies provide training on how to support the cared for person effectively:

'I'd done some Alzheimer's training... that's helped... it's useful in terms if content but I think actually it was just as useful in terms of talking to other people with similar problems and learning the 'tricks of the trade' (16KFWR, Male, over 50, ceased caring, not working)

'In the past we attended intermittently, my husband and I, a group for parents of children who have epilepsy, organised by the local epilepsy support organisation. And I attended some parenting classes on how to deal with behaviour that could arise from children who had seizures ... which was good as it gave you tools and tips, how to deal with situations when you are totally frazzled, and try and get a wee bit more control ... and a wee bit more understanding about what its like to actually experience a seizure. It was useful ... '

(2EFWR, Female, under 50, caring, working)

Support for the cared for person is also provided via the voluntary sector which carers appreciated and trusted:

'She gets help from Penumbra which helps people with mental health problems.... do workshops on increasing confidence... she thinks she'd like to do counselling for young people who've had similar problems' (36EFWR, Female, over 50, caring, not working)

'The local Autistic Society produces a list of carers that have worked with children with autism in the play scheme. And so we've got a carer called Bill who takes the children every fortnight ... the children like him and they get a chance to go out'

(43EFWR, Female, under 50, caring, not working)

'Vol Care (local voluntary sector agency) provides a girl who comes one day a month to keep mum company; she also did come for a week when I went away with my daughter. I also had one lady come from Crossroads who came every Monday to relieve me...also much earlier on in the piece when mum wasn't so bad I had arranged for a CSV volunteer to be here. .. So I've had good coverage...'

(16KFWR, Male, over 50, ceased caring, not working)

'The Royal National Institute for the Blind has been extremely helpful. Before she went into hospital they were the prime source of setting up the care package for our aunt' (55EMNN, Male, over 50, caring, working)

There are four particular characteristics of voluntary sector organisations which mark it apart from the statutory sector: the local nature of the service; its familiarity and reliability; its accessibility; and its constancy – it is there for the longer term. Carers trusted voluntary sector staff, they built up a relationship with them over time and came to rely on them. For this reason alone carers felt they were understood; the term 'always there when you need them' appeared regularly in the interview data:

'[name of town] District Social Care Group, they're really good. They're really, really good.... they're there when you need someone on the end of the line. You can ring them anytime' (26KFWR, Female, under 50, caring, working)

'If you were to ask me which of all things that were available had the biggest beneficial influence, I'd say it was carers support and in particular Tessa actually. She's brilliant.... Its local and psychologically, I know she is just a phone call away... I can pop in for a coffee and have a shoulder to cry on ...human contact, empathy, sympathy, support'

(16KFWR, Male, over 50, ceased caring, not working)

Voluntary sector provision is not for everyone though. For some carers the expectation that you will 'join in' is uncomfortable, for others sharing the challenges of being a carer simply serves to reinforce how difficult their current situation is or may become:

'... and I went for a while to the local Alzheimer's Society .... All of those were joint meetings, carers and cared for. I didn't eventually find those worked out too well for us. They were heavy on biggish social events which has never been our kind of thing'

(12KMNN, Male, over 50, ceased caring, not working)

'The Parkinson's Society has groups. But we don't really want to go there and sit amongst people and you think 'I might be like that one day'. It's depressing in itself isn't it?'

(14KFWR, Female, over 50, ceased caring, working)

One mother of a disabled child pointed out that as most support groups are populated by women, men tend to feel rather excluded:

'I go to the carers support group ... there aren't many dads there so he (dad) feels uncomfortable when all the ladies talk about their own issues. He feels left out'

(43EFWR, Female, under 50, caring, not working)

Another feature of the voluntary sector is that they are regarded by carers as treating them as experts on the needs of the cared for person which is in sharp contrast to their perceived treatment by statutory agencies:

...'the system didn't help me at all, they saw me as not the person at the centre of attention, my mum was the centre of attention, I was irrelevant. You know, I was an impediment, everybody wanted to get me out of the way so that they could deal with my mum and no one had any interest in asking me about what I thought or anything about it. But I was the one doing the.... I was the one in the driving seat but no-one gave me any credibility for it until the Alzheimer's Society who try to plan care for both of us' (31KMNN, Male, over 50, caring, not working)

### 6.1.4 Support from Family and Friends

Evidence suggests considerable variety in the level and type of support offered to carers by family and friends. The majority of relatives and friends provide practical support, relieve the carer so they can go out to work, or help out in emergencies.

For those who received regular support it was much appreciated and pivotal in enabling the carer to work and/or have any kind of life outside of caring:

'My daughter does a lot actually... she is my main stay. She and her husband, they do a lot for me'.

(41EFNR, Female, over 50, caring, not working)

'If my father wasn't around I wouldn't be able to work, you know' (19KFNR, Female, under 50, caring, working)

'Her sister and my daughter also... a mix... they allow me to work... if I didn't have that I couldn't have worked for the last 2 or 3 years. That's what you need to work, you've got to have that back up from family and friends. Also when mum was really ill my brother came over from France with his wife and helped out'

(5KMWR, Male, over 50, caring, working)

'His mum and dad help with him (husband). His father takes him out. When I go to work he will take him out and take him to the resource centre once a week'

(19KFNR, Female, under 50, caring, working)

Some carers had a network of relatives and/or friends who provided quite a lot of support:

'I am the main carer but my husband really takes his fair share.. and my parents were a great support. They'd take him out places and sit with the girls whilst I had things to do with [name]. Babysit to let my husband and I out... my sister lives nearby and she's very helpful' (13EFWR, Female, under 50, caring, working)

'I do get support... like when my mum had pooed everywhere all over the carpet and the wall and she was sitting in it ... and I'd have to clean it up. My wife would crawl around on her hands and knees and clean it up. Sometimes my daughters also did. So the whole family was involved to a greater or lesser extent'

(31KMNN, male, over 50, caring, not working)

Others had a more informal arrangement with friends of neighbours who would help out at short notice or in an emergency:

'Yes we're lucky in that I don't have close family nearby but when they are available they're pretty good with my children. If there is a hospital appointment people will collect my kids from school.... and give them their tea'

(10KFNR, Female, under 50, caring, not working)

"... everyone in the street is aware of Mark's illness (diabetes and epilepsy)
Topsy (the dog) saved [name] life twice - for some reason she can sense it...
she brought him round a couple of times'
(40EFWR, Female, under 50, caring, working)

Some carers got no support from family or friends at all and were isolated in their caring role:

'We have family who've sort of run away from us... we've never been invited to a wedding at all, my brothers wedding because its too much for them... they don't advertise that we've got children with a disability. In Asian families it's a taboo thing. .. So they kind of sideline us so we are isolated' (43EFWR, Female, under 50, caring, not working)

'... you tend to lose a lot of friends when you're a carer and you feel very isolated and unless you've got like good neighbours or other relatives you can become a bit of a recluse which is what I am becoming. And I can't really see any other way ... to help that type of problem to be honest' (48KMNN, Male, over 50, ceased caring, not working)

Others had a more difficult relationship with their relatives:

'Unfortunately my sister's basically accused my husband and I because of financial matters. She considers herself to be the one who should be dealing

with things. But I've always dealt with mum's financial matters and she's basically accused us of taking money and had us investigated. Which is now in the hands of the public guardians' (38EFWN, Female, under 50, caring, working)

'My ex husband doesn't live far away and he does come although I can't leave them alone together, he just winds [name] up and gets him really upset so I can't leave them alone together for long' (17KFNR, Female, over 50, caring, not working)

### 6.2 Cross Cutting Issues

In addition the issues that relate specifically to particular agencies or types of support a number of cross cutting themes emerged.

### 6.2.1 Support, Information and Advice Located in One Place

Many carers identified the fragmented nature of the 'support system' and the fact that they have to go to a number of different agencies to get information on the range of services and advice they may need. This includes specific services for themselves and the cared for person, information on benefits, the role of the voluntary sector and 'who does what'. What carers wanted was one place they can go to get clear advice on all of these issues:

'One thing I feel, particularly in the dementia field, there are lots of organisations out there but they're not very well integrated together and finding out what you need, what is available and whether it would suit you is a big task for a carer and there's not an easy way through. Getting it all from one place would be great'

(12KMNN, Male, over 50, ceased caring, not working)

One carer suggested that Admiral Nurses could perhaps take this role on as their remit is exclusively to support the carer or that it could be located with one person who worked for the local authority:

'We have an Admiral Nurse now .... she's there to help carers so part of (her job) might be to pull together all the different services and benefits under her umbrella. Or if there was a designated person on the council... social services or local authority for carers that found out about what you could have and not have across all departments'.

(48KMNN, Male, over 50, ceased caring, not working)

A number of carers also identified a role for an agency to help carers get work and engage with normal activities after the end of a period of caring:

'I wonder if there was another department that could organise the return to society after caring ends. You become institutionalised doing caring. You need someone to help you, lead the way back, give somebody like myself an inkling of what's out there socially and work wise, you know what clubs there are and what jobs'

(48KMNN, Male, over 50, ceased caring, not working)

### 6.2.2 Variable Support from Services and Limited Integration

There was evidently considerable variability in what kinds and levels of support carers get across, and even within, the two sample areas. This appeared to be a combination of where you live, different criteria for accessing social care services, how informed you are, how hard you or your advocate are prepared to 'fight for services' and what condition the cared for person suffers from i.e. whether you have an autistic child or a parent with dementia.

Eligibility criteria for social care services appeared to be set at a very high level:

'I've had no support from anywhere and I've been onto Social Services. He's disabled but even though I get the highest rate of Caring Allowance he's not disabled enough for then to put him on the disability team' (17KFNR, Female, over 50, caring, not working)

Although integration is a key aim of recent health and social care policy, it is evident from data already reviewed, that this is difficult to achieve. Part of the explanation may lie in continual service reorganisation:

'Another part of it is to provide a more integrated service... the health and social care. And certainly they do try. But it's just impossible as it was. It's basically because Edinburgh's reorganising, restructuring itself over and over again... it's chaotic'

(32EFWN, Female, over 50, caring, working)

A minority of carers did say that their package of care was integrated:

'They've (SSD) have given me a lot of help with all the aids ... I can't fault social services and the team of physios and I know if I have a problem I can phone them and they will help me with it. They were very good in.... with the mobility, getting him up, showing him how to manage stairs and helping me, you know, to show me what to do, get him out of the bath and all of that ...' (25KFWR, Female, over 50, caring, working)

'We've now got a social worker for [name]... they (home care) go in to do her breakfast Tuesday to Friday and somebody puts her to bed. We do all her meals. She's never been in respite ... but for the past 3 months she's gone to hospital on a Monday to the Templar Day Unit...'
(40EFWR, Female, under 50, caring, working)

A few packages were even set up quickly and in a way that allowed the carer to work:

'With his vascular dementia it deteriorated very quickly, it goes in steps. I was amazed at how quickly they set up a care package because within a week of him being diagnosed I had them round here... carers coming in every night. It felt a bit invasive although it relieved me... they said take the time off, go for a walk or whatever you want. They'd also come in when I was working... also Crossroads and a day centre'

(34KFWN, Female, over 50, ceased caring, working)

# 6.3 Summary

Although it is clear from this chapter that there are a number of specific ways in which services impact on work related considerations, there is a wider sense in which formal support is simply out of step with the lives and concerns of working carers. At present, there are two ways in which services do, or do not, help carers to work: via services for the cared for person, and carers support services. The former tend to act as a substitute for the carer to release them from caring whereas the latter tends to provide emotional and sometimes practical support for the carer. Care packages are rarely set up with any reference to the carer's need to work; the primary focus is the cared for person and their need for support rather than the caring dyad being treated as one 'case' and services being developed to ensure the maintenance of both their lives, including employment. The voluntary sector appears to be more accessible, flexible, to treat carers in a holistic way and offer an ongoing service; it is widely trusted and relied upon by working carers. A higher level of integration between services, earlier intervention to plan for future care needs, and acknowledgement that part of the role of health and social care is to help ensure that the carer can continue to work would go some way to meeting carers needs more effectively.

# 7 THE ROLE OF THE DWP AND JCP IN SUPPORTING CARERS TO REMAIN IN, OR RETURN TO, THE LABOUR MARKET

In this chapter we consider respondents' knowledge and experience of the Department for Work and Pensions (DWP). Through its two executive agencies JCP and Pension, Disability and Carers Service (PDCS) the DWP is responsible for two forms of support to carers: the provision of employment advice and support and the payment of benefits. With respect to employment advice and support there is no dedicated welfare-to-work programme for carers as there has been for other client groups, for example the over 50s, disabled people or lone parents under the New Deal programmes. Carers are not required by law to be available for work or to attend JCP as a condition of receiving Carer's Allowance. The PDCS, which delivers Carer's Allowance, was created in April 2008: it combines the Pension Service and the Disability and Carers Service. Many of our respondents will have first claimed the relevant benefits prior to the formation of the PDCS and in any case the new combined agency in its own words: will be largely invisible to our customers as we continue to operate with both our Pension Service and Disability and Carers Service brands' (PDCS, 2008: 2). A few respondents mentioned the Pension Service but noone directly referred to the PDCS or its predecessor the Disability and Carers Service. The discussion here concentrates on respondents' experience of employment advice and the payment of benefits..

The respondents fell into three broad groups: those with recent knowledge and experience; those with experience in the distant past and those with little or no contact and little knowledge of the DWP and its executive agencies. The first group are the most useful barometer of attitudes towards current JCP practice, whilst those with historic experience are most likely describing systems and policies which no longer exist. Nevertheless, such experiences from the past serve to condition people's attitudes to future possible contact with JCP and the DWP more widely and are interesting from this point of view. The third group despite little direct involvement with DWP are nevertheless worthy of note as they suggest views or received wisdom that may be prevalent in the general population from which future carers will be recruited. The review of evidence will consider respondents' experiences and attitudes in three sections: general views about the location and nature of JCP offices

which have an impact on any of the services which JCP is providing; the specific provision of employment advice and support and thirdly, the payment of benefits.

#### 7.1 JCP Offices

A number of respondents made reference to the fact that there had been closures of JCP offices so that the nearest JCP office was now some way away:

'Particularly when you think about the Job Centre's actually being closed down, so we'd have to go to (name of town). So we'd have to travel to find out.' (20KFNR, Female, under 50, caring, not working).

Although perhaps a relatively minor point it was interesting that a number of people referred to the distance they would have to travel and this may be of particular significance for carers who potentially have to arrange for alternative care for the cared for person whilst they visit JCP. It may also be a disincentive in terms of cost if the individual had to use public transport to access the nearest JCP office.

A significant proportion of those with recent experience of JCP made comments about the environment or atmosphere in the JCP office. The rollout of new style Jobcentre Plus offices was only completed last year so it is likely that some of the respondents here are referring to their experiences prior to the changes. Although Jobcentres do not actually have security guards, they have Customer Care officers who operate as a co-ordinated team with Jobcentre Plus staff in the management of Jobcentre public areas the reference to the presence of security guards was common:

'But the general sort of ambience of the place is...is just...is just not conducive to being made feel welcome. First of all there's like security guards on the door.'

(48KMNN, Male, over 50, ceased caring, not working).

Jobcentres also provide services for people that cannot work because of sickness or disability and people wanting to change jobs as well as out of work jobseekers. Jobcentre Plus staff are equipped to serve people with a variety of circumstances and needs. Nevertheless, a number of respondents also mentioned the other clients and the sense that they themselves were different as carers:

'I've been in once and that was enough....They're not people like me.' (42KFNS, Female, under 50, caring, not working)

Comments of the latter sort in part referred to a sense that as a carer you were in a different position to the unemployed and this needed to be recognised (see further comments below).

There were also a number of observations about the impersonal nature of the experience at JCP, feeling like a number and only being given a short amount of time:

'I've always been treated with a great deal of respect and...and the people have tried to put themselves in my position. But the fact is they have to have a number on their form.'

(25KFWR, Female, over 50, caring, working)

'They didn't seem to volunteer any information. I got the impression it was just you were there for your allotted time and when you're gone it's the next one, you know?'

(48KMNN, Male, over 50, ceased caring, not working).

Other respondents commented upon the open plan nature of the space and the lack of privacy in discussing personal matters.

These concerns about the degree to which JCP offices are welcoming places may not be peculiar to carers but they may amplified by carers' sense that they are not understood or shouldn't be treated like other JCP clients:

'I don't know, I don't think they did enough to try and help you. Well certainly they didn't with me. I might as well have been invisible.'
(49KNFS, Female, over 50, ceased caring, not working).

'Another experience, you know, when I was sitting there with the young chap, he's going through his process and his system and asking questions, much as you have to do. But he said to me when did you take up caring? I said 2003. And he goes well you've been out of work a long time. And I thought didn't I not just say I was a carer? You know, they equate that always as unemployment, not being economically active, you know, as being unemployed, you know? So that's something else that they should look at also, not just see oh you haven't worked since then until now therefore you've been unemployed. And I mentioned I was a carer but they had no sense of what that involved.'

(35KMNR, Male, over 50, caring, not working)

#### 7.2 Provision of employment advice and support

There were mixed responses from those respondents who had recent experience of JCP. Some felt positive: that people at JCP had been helpful but even amongst this

group there was a sense that the help available was limited. A number of respondents felt that their circumstances were understood by those they saw at JCP:

'Actually I must say very nice. I have the same woman....I know other people I've heard other things but I can only say in (name of town) they've only ever been very polite and very nice to me and made it quite clear they're not forcing me to get a job because of my situation, you know, but yet they'd like you to, obviously they would.'

(17KFNR, Female, over 50, caring, not working)

This sense of surprise that the JCP was welcoming or helpful is noteworthy as it suggests that there is a common view abroad amongst those without prior experience of JCP that it may not have much to offer them as carers. This may be unfair to the service but nevertheless it is something that needs to be countered if people are to be encouraged to use its offices. Negative views of recent experience with JCP revolved around a number of different elements; some to do with location and environment as detailed above others concerned the expertise or services available at JCP. It is worth considering these separately.

#### 7.2.1 Expertise about carers

A point made by a number of the respondents was the need for someone in JCP with specific expertise on carers. This took a number of different dimensions from issues of identity as a carer to the need for practical understanding of the challenges that carers face.

'Because I asked whether or not they had somebody, an advisor to deal with people who have been out of work as carers for some time and needed help to get back into the work situation and they said they don't have people to do that specifically, just general, you know, search facilities and advisors....Have somebody specifically trained to help carers get back into the swing of things, either full-time or part-time, either into voluntary work...'

(35KMNR, Male, over 50, caring, not working)

It is worth noting that Jobcentre Plus is working towards fulfilling the commitment in the Government's Carer's Strategy to introduce specialist training for advisers.

#### 7.2.2 The type of work being offered

A number of respondents felt that JCP did not understand or offer the kind of flexible jobs that carers' need:

'And very rarely in job centres will you find part-time work or temporary work. Obviously it's going to be the 30 hours a week stuff.'

(10KNFR, Female, under 50, caring, not working).

Assumptions like these may deter carers from even approaching JCP. There was a suggestion that this might apply to jobs under 16 hours or voluntary activities as well. For JCP a part-time job under 16 hours a week or voluntary activity does not count as 'a job outcome' and hence does not meet the targets that Personal Advisers are working towards. If it is effectively seen as a failure to get someone into a job under 16 hours a week this may act a as significant barrier in providing employment support to carers, especially for those carers who are trying to keep a toehold in the labour market whilst caring, in readiness for a fuller return to work in the future. It is worth noting that one of the roles of the new Care Partnership Manager appointed in each district will be to work with personal advisers to help improve their understanding of the needs of, and opportunities available to people with caring responsibilities. This will include promoting part-time paid employment as a realistic job goal.

Other respondents, those with recent and those without recent experience of JCP felt that it mainly only offered lower level jobs that were not relevant to them:

'I'm used to being a manager and I also find that the staff, generally speaking, haven't got a clue about anything beyond their own level of employment. So unless I want to go to Job Centre Plus and be employed as a civil servant in some, whatever grade they are, it's pretty hopeless. So if you've got anybody who's got any degree, I think, of... especially what I would call 'life experience', which you can't expect these young people to have, I think they undervalue you. I would expect, my anticipation is, that they would undervalue my skills and experience and I'm sure I'd be offered some work, but I'm equally sure that it wouldn't be work that I'd be...' (16KMNN, Male, over 50, ceased caring, not working).

The following respondent had two experiences of JCP a recent encounter over benefits and a past experience of employment advice, which coloured his impression of what JCP today might be able to offer him now as someone who had ceased caring:

'The seeking advice [on benefits] was OK and the unemployment was a bit negative, you know, a bit... you know, how old are you? Oh you're 50 plus, oh well, you know, we might have trouble finding a job for you, it's going to be

low paid manual type of work which was depressing so... But that's not their fault. I mean that's the economy.'

(48KMNN, male, over 50, ceased caring, not working)

The issue of qualifications or experience could also run the other way when someone was willing to take less-skilled work:

'I was too well qualified for anything they had! Not that they had anything to offer in [name of town] anyway. And, quite frankly, if I go back there, I'm going to have to not tell them what I can do, because like I said to you, I'm quite happy to shelf-fill in Asda if I have to, you know, in terms of like 3 or 4 hours a night. But the last time I went for an interview there they said 'well we would want you for an office job and there are no office jobs going.' (10KFNR, Female, under 50, caring, not working)

#### 7.2.3 Forward looking support

The group with the least experience of JCP were, as might be expected those who were currently in employment; when asked if they would think of using JCP for job search or finding out about training opportunities many of these said no. A minority had practically no knowledge of what JCP had to offer, others made the assumption that if they were looking for a job they would use their own resources or networks:

'Well I would look at the...Well I've got the internet so I would...there used to be a Job Centre here but they've closed. I know it's in [name of town] now.' (28KFWR, Female, under 50, caring, self employed).

For a lot of these working carers JCP was simply not on their radar as may be true for many of the general working population without caring responsibilities. The self-employed respondents in particular were likely to refer to using their own contacts to get further work.

A small number of people had experience of trying to get training or being offered training designed to get them back to work but were not necessarily impressed:

'Well, I appreciate that they want to get people back to work, but in some situations it's not possible to go back to work immediately, but there's a kind of long-term prospect that, you know, sure I can't go back to work just now for reasons x, y, z, but I have every intention of going back to full-time employment and I want to get as good a job as I can in the future. I mean the only courses they offered me were a CV workshop and an 'improve your

computer knowledge' workshop. Both of which were things that I could do, you know. It wasn't going to improve my chances of gaining employment either now or at any point in the future.....'
(37EFNN, Female, under 50, ceased caring, not working)

#### 7.2.4 Work-focused interviews

There was a policy change in 2005 under which Work-focused Interviews (WFIs) were no longer mandatory for carers receiving Carers Allowance (the main benefit for those spending at least 35 hours a week caring and who are earning no more than £95 a week). Although they are still required for those on other benefits such as Income Support or Incapacity Benefit (now ESA), which may include some people with caring responsibilities. The majority of respondents had not had or had never heard of WFIs only two had a direct experience as they had to attend as a condition of benefit. Both felt that it was a hoop that they had to jump through but that they were under no pressure to find work:

'But, basically, all they do is ask what you're doing and then they usually say 'oh that's fine', so it's a joke because, well, basically because they're not actually helping you to focus on getting back to work in any way.... it didn't really give me much hope that there was a job that I could have done. Certainly not while I was caring. So I just, I didn't really try any more.' (37EFNN, Female, under 50, ceased caring, not working)

#### 7.2.5 Better off Calculation

For carers who are not currently working but may be considering returning to work JCP can offer a Better off Calculation (BoC), which would assess the monetary benefit of working. The majority of respondents had not had or had never heard of such BoCs. Four respondents had experience of BoCs. Of these two found that they would only be marginally better off and two found that they would be worse off. One of the latter felt slightly affronted by the whole experience as she had not gone back to work for the money:

'But he actually did say to me, he said 'you should have come to me and could have told you. I mean financially you weren't any better off, why did you?' and I didn't go back because of money. I knew we weren't financially better off by £20. It was my self esteem I wanted to do it for.' (43EFWR, Female, under 50, caring, not working)

### 7.3 Benefits

Respondents received information and advice about benefits from a range of sources in addition to the DWP: social services, carers' groups and friends and family were the most common mentioned. Many stressed the difficulty of finding out about the different benefits and the relationships between them:

'Well when you have Carer's Allowance, if you know you can have Carer's Allowance, because what I do is when we have new parents contact us, I send out a pack and I put all that sort of information in there, because we didn't know about it, we didn't know about Disability Living Allowance or anything, nobody told us. But if you get Carer's Allowance, wouldn't that sort of thing, you know, could they not put a leaflet in about that?' 20KFNR, female, under 50, caring, not working)

Some had been helped to sort out their benefit situation by JCP, however as many felt that the benefits were too complicated and that no-one really understood them. Some respondents expressed surprise that their experience of JCP was positive:

'It was fine. To my amazement actually it was fine' (39EFWR. Female, over 50, caring, working)

Others assumed that they would not be eligible for benefits or simply had not managed to get around to sorting it out:

'You know, it's just one of those ironies that when you need the help the most you don't have time to go and get it. And, so I never applied for Carer's Allowance or anything, because I'd hoped that when I saw the carers' support group they would be able to help me out with all the forms, because they're quite complicated and I couldn't... You know, because I was tired, my concentration levels were not as good as they could have been perhaps and it wasn't in the priorities, you know. The priorities were the day-to-day things, get food, get dinner cooked, get the house clean, get my mum up, try and encourage her to take a walk, make sure that she's not spending the whole time in bed. And so it never happened.'

(37EFNN, Female, under 50, ceased caring, not working)

Fifteen respondents were currently, or had recently been, in receipt of Carer's Allowance; some respondents had not claimed Carer's Allowance because of the impact on the cared-for's benefits:

'I can have Carer's Allowance, but then they'd take away mum's something or other and it worked out the same....Yes, I'd looked into it and it's an absolute farce because I'd end up getting pretty much the same amount of money and pay tax on it, whereas if mum got the money she didn't pay tax on it. So it was like 'oh, that's a no-brainer'. The benefit system when it comes to carers is abysmal.'

(16KMNN, Male, over 50, ceased caring, not working)

The main issues that respondents raised about benefits were the general complexity of benefit rules; the value of benefits and the inflexibility of Carer's Allowance with regard to the earnings rule. We will consider these in turn.

#### 7.3.1 Complexity of Benefits

There was a widespread feeling that benefits were too complicated, difficult to find out about and to understand:

'I think they need to have a bit of a more human approach to this, you know, because I'm sure if this is happening with me and I'm not an unintelligent person I dread to think how some other people are coping with things. I think they probably don't even bother to go there with it. I don't think people even realise the things you can claim. I didn't actually realise, you know, until the Deal Carers said to me oh wait a minute you should be getting the carers.'

(25KFWR Female, over 50, caring, self employed)

Another issue of expertise emerged for those respondents who felt that they had been given poor or wrong advice and a few people mentioned a lack of consistency in advice they had been given by DWP staff.

'But generally every time you go in there you get told something different. Even if you speak to the same person 3 months after you've spoken to them before and they tell you something different again.'

(53KFNR, Female, under 50, caring, not working)

Another aspect of complexity, which acted as a disincentive to those currently not working and in receipt of benefit was the prospect of going back to work, being unable to sustain employment and then having to reconstruct the benefit package they had before:

'I think that needs to be looked at, to be more of an incentive, a financial incentive, for people to start working. Because you get one or the other and then if things don't go well, you have to come away from work, then you've got to reapply for these again and that's quite a minefield.' (36EFWR, Female, over 50, caring, not working)

#### 7.3.2 Value of benefits

Ten respondents had household incomes under 10K per annum and only two of these were working. A majority of respondents had incomes under 20K per annum, just under half of these were working. The majority of those with higher incomes were in employment; as demonstrated in other studies many carers are living in relative poverty because of the impact of caring on their ability to work. The value of benefits is therefore of considerable concern to nonworking carers:

'And Carer's Allowance isn't anywhere near enough. £50, they're having a laugh aren't they? Especially for people that look after elderly people and they're with them all the day long.'

(17KFNR, Female, over 50, caring, not working)

However, despite the monetary value of Carer's Allowance it is important for other reasons:

'The people I see who come to me and say can you help me with benefit claims? Which is one of the things that I do because I've done it and tried it. They say the Carer's Allowance it's hardly worth the effort of getting it and if you do almost anything to bring in some money you've got too much to allow them to have it. The one benefit it does have which is not made clear to everybody is that it gives you things like pension contributions and it puts you on a register as existing and doing something which may entitle you to other things.'

(50KFWN, Female, over 50, ceased caring, working)

### 7.3.3 Inflexibility of benefit rules

A number of respondents commented on the conditions for Carer's Allowance, mainly with respect to the earnings limit rule and the problems these caused for sustaining part-time work.

'To keep the hours down, yes. But sometimes that puts you in a difficult position because you might want to work a little bit more, but if you work a little bit more then the benefit is taken away.'
(13EFWR, female under 50, caring, working)

Another respondent pointed out that it was difficult to find work and stay within the earnings rule:

'But my main problem is that, you know, you can only earn £95 a week because of the Carer's Allowance so you can't like work more than... If you're earning say £6 an hour for example you can't really work more than 15 hours. And if you look at the jobs in the paper most of them are like 20-odd hours for part-time work. So there are... What jobs there are there there's very few that I can actually apply to and even the ones that maybe do fall into the category I can apply for sometimes the advert will say must be able to do extra hours during school holidays or something like that but I can't commit to extra hours, not because I don't want to but because of this £95 ceiling. You're not allowed to earn more than £95. £95 used to sound a reasonable amount because I know obviously you can't earn a fantastic salary and then still claim for your Carer's Allowance. I realise that. But, you know, £95 nowadays is nothing, you know, so...

(6KFNR, female, over 50, caring, not working)

A mother of a disabled son made the point that because he was very difficult to leave with anyone else a term only contract would be attractive but this presented problems in terms of benefit rules:

'It's the council tax and the Housing Benefit. If they could get that somehow and let you work and... because I can earn it's £90 I believe before my Carer's Allowance takes... They've just put it up. But the main thing is you can't get anything.... I've got no family actually here so I've got nobody to leave him with. So unless I could be guaranteed a job at term time only and the money has got to also they told me carry through the same all through the year. If I get a job that only pays while I'm working that will muck me all up. She said you'll just have to reapply for Housing Benefit and they'll stop it and it will all have to go through again. It's ridiculous. That's what they told me at the Job Centre. So you can see why people don't bother.'

Some respondents in receipt of a pension felt it was unfair that they could not qualify for Carer's Allowance:

'I would say I think it's wrong that I'm not allowed carer's allowance because I've got a pension. I mean I think I should have something, if it's only £10 a week. But apparently the government's saying that if I have a pension I'm not allowed'

(24KFWR, Female, over 50, caring, working)

The comments made about the benefit rules reinforced the early points about the general complexity of benefits and the difficulty of understanding them.

### 7.4 Summary

There was a spread of knowledge about DWP and its executive agencies amongst the respondents: some having recent contact, others having little or no knowledge of JCP's role. No-one explicitly mentioned the new executive agency PDCS. Either through direct experience or hearsay, there was a widespread feeling that the JCP environment was unwelcoming and this was linked to the sense that carers were not really understood. As a result a majority of respondents had negative views primarily about what was available through JCP.

In relationship to employment support quite a lot of carers self select not to use JCP and do not see it as a relevant source of help to them. This included a number of dimensions: that JCP will only offer low skilled work; that it does not access the part-time and flexible jobs that many carers seek and that it offers nothing on top of what the individual can access through the internet or their own networks or connections.

There was also a sense from some respondents with recent experience of JCP that they received mixed messages for example being told that they won't be much better off in work but somehow feeling that they should work; being expected to work but not offered suitable work; wanting to work but then losing a benefit. This was compounded by the rules for Carer's Allowance, which seemed to frustrate individual's willingness and ability to work part-time.

With respect to advice on benefits there was a high level of discontent over the complexity and inflexibility of benefit rules and a general wish that there was just one place that you could go for advice on this from people who understand the situation you are in.

# **8 CASE HISTORIES**

In this chapter we look at a number of individual case studies, which illustrate the wide range respondents' circumstances. In the rest of the report we are generally concerned to look at a particular aspect of our respondents' experiences: for example the nature of the caring, which they undertake or the support they receive from a specific agency or from their employer. By examining some individual case histories we are able to put the carers' stories back together, and provide a flavour of their lives and situations – in particular the tensions they experience in reconciling work and care or in considering re-entering the labour market. The cases have been chosen as illustrations of different caring scenarios, for example caring and not working, ceased caring and looking for work, caring and working, they do not 'represent' these different situations in the sense of being typical cases but they allow us to consider the real-life dilemmas which a number of our respondents faced.

# 8.1 Balancing work and caring, but for how much longer?

'Chris' is 62 and works full-time as a construction manager for a large building company. He also cares for his wife 'Pat' who is 59 and has front temporal dementia (a form of dementia which tends to affect relatively young adults and is aggressive). At the time of the interview 'Chris' was on sick leave from his job, having been signed off with stress. Prior to this he had been working full-time, 4 days at work and one day working at home per week. His job is very flexible he can work from home and schedule the site visits he has to do around caring. He has worked for the company a long time, enjoys his job and there is considerable goodwill towards him. His company have been very supportive and the team of workers that he manages have been happy to work round the other demands on his time.

'Pat' needs constant attention and cannot be left alone. 'Chris' had in place a package of care, which allowed him to continue working, his sister in law and daughters who live close by help to look after 'Pat', she went to a day centre a couple of times a week and there are close friends who can be called upon at short notice. As 'Chris' said:

'Well what they were doing, you see, they were allowing me to work. Now without that, if I didn't have that, I couldn't have worked for the last 2 or 3 years.'

'Pat's' condition had been worsening but the situation came to a head in the last 6 weeks. She had become very distressed whenever 'Chris' left and was increasingly difficult for other family members to look after: she would cry all the time and could no longer be taken to the day centre. He decided to take time off work to see if her condition improved or if they were at a new point in the trajectory of the illness when he might need to consider giving up work. As soon as 'Chris' was around all the time 'Pat's' emotional state improved. This meant that 'Chris' was in a very difficult dilemma. He was feeling guilty about not being at work and letting his co-workers and the company down but he also felt that he couldn't go back to work because of the effect his absences were having on 'Pat' and the rest of the family.

'Chris' also had some caring responsibilities for his mother whose situation had dramatically changed in the previous 3 months. She was living independently and was fine, he used to do shopping for her once a week and pop in a couple of times to see her, but then she had a stroke and rapidly became unable to look after herself. The family rallied round and eventually they managed to find a residential placement for her. Although, this was working out 'Chris' felt guilty that after his mother had cared for everyone else through her life when she now needed care he wasn't able to give it.

Before the recent events 'Chris' had thought that he might gradually scale down his work, move from 5 to 4 and then to 3 days through to retirement. Now he simply wasn't sure what was going to be possible, whether he would get back to work, which is what he wanted to do, or be forced to take early retirement. On the morning of the interview his GP had signed him off work for another 3 weeks so he was facing some difficult decisions. As to possible sources of help he did not really see what Social Services could offer if the real issue was that his wife couldn't cope with being looked after by someone other than him. His company were not putting any pressure on him but he felt a loyalty to them that meant he did not want to mess them around.

# 8.2 Working and caring: split shifts and split lives

'Rachel' is 31 and works a part-time term only contract as a library assistant for about 17 hours a week. She cares for her son who is four and has epilepsy and some brain damage from earlier seizures. He has considerable care needs and the nature of his disability means that 'Rachel' is on alert throughout the night. 'Rachel' herself has bouts of depression, which she thinks is possibly affected by the general pressure of caring for her son; she has sought counselling support for her depression, but she endeavours to keep her own health issues hidden from her employer.

She took the library job two years ago as it fitted better with caring for her son:

'It took away the need for actually acquiring formal childcare. It meant that my husband and I could care for our son without actually needing nursery or child-minders or anything. So that was really the main reason why I moved.'

She had previously been working for the same organisation but in a higher graded job. 'Rachel' and her husband have found a pattern of working that allows them to split the care for their son:

'Basically, my husband works in the morning and finishes at lunchtime, and I work in the afternoons, therefore he's caring for our son while I'm at work essentially.'

However, this is at the cost of having very little time together as a family or as a couple as 'Rachel' has to work Sundays and her husband works Saturday mornings. At the time of the interview they were getting 4 hours free respite care from a charity every other week, which allowed 'Rachel' and her husband to go out for an evening.

'Rachel' is glad to work as the family needs the money but also it provides 'a bit of life outside the home', though the job is not fulfilling as it is monotonous and does not use the training and skills that 'Rachel' has. 'Rachel' also does voluntary work as a Brownie leader with the Girl Guides and helping to write a newsletter for the National Childbirth Trust.

'Rachel' has applied for better jobs within the same organisation but has not been successful she feels there is little that her current line manager can do to improve her situation as there is little flexibility over hours. 'Rachel' feels that if she does not make a shift then it just falls on someone else, she does have an informal arrangement with someone who works on Saturday and they swap the Sunday for the Saturday if needs be. She has not confided in colleagues and works in isolation from her manager who is located elsewhere in another building. Generally, she feels it is up to her husband and her to manage and only so much can be expected from your employer:

### 8.3 Working but struggling

'Emma' is 33, married, with a 10 year old son and works part-time (eight hours a week) for a private Home Care company. She is the main carer for her husband, 'Terry', who is retired on ill-health grounds following surgery for a brain tumour. He has very poor short term memory and complicated medical needs including incontinence, epilepsy and a complete lack of awareness that he has the condition.

'Emma's' job involves domestic care such as shopping and cleaning for her clients, she does not provide personal care. She took up this job when she was made redundant from a retail job:

'I'm in a bit of a rut. I don't quite know what I want to do but this just fits in...fits in with my husband, fits in with my son at school. You know, it just fits in really and I can choose the hours I work.'

'Emma' feels under a lot of pressure at home and suffers from tiredness, disturbed sleep, being short tempered and irritable. She gains little emotionally from her marriage and carries a heavy weight of responsibility for both 'Terry' and their son. She was on anti-depressants for a while but stopped taking them. She does not enjoy her current job and it is not well paid:

'I don't actually want to work. I used to enjoy working and I don't think I do....Whether that's because I've not found what I want to do. I work probably to get out of the house and go...get away, not that I don't think about what's going on at home and just a bit of income really.'

Part of this stems from the attitude of her employer, which is not sympathetic to her situation. Her mother and father in law help look after her husband, which allows

'Emma' to work but due to the complex nature of her husband's health there are sometimes extra hospital visits that cannot be rescheduled:

'My husband was going to hospital everyday for an ear problem and I booked the Friday off and it was 'why was that? Why have I got to take it off?' And I couldn't take it off unpaid, I had to use up a holiday day and that happens quite a lot if I get an appointment because I have to go to [London hospital] quite a lot....No I don't expect to be paid for taking the time – a day off, you know, but I think, you know, just their rules is that I have to take a holiday day.'

The family are not allocated a permanent care manager from their local authority social services department despite their complex situation and changes to NHS provision may mean that 'Terry' can no longer have access to regular respite care in hospital, a service 'Emma' trusted and relied on. 'Emma' was not aware of the legislation giving the right to request flexible working. When asked what would help her most she replied:

'All I want is respite. That's all I would want is respite really and to be able to go to work because if his father wasn't around I wouldn't be able to work.'

Looking ahead 'Emma' does not know to what extent her husband's condition might worsen and who will help her manage the needs of the family:

'And what the future is I just don't know.'

# 8.4 A life of reconciling care and work

'Mary' is 64, married with two grown up children. She works full-time in a car dealership, where she has been for 30 years. She cares for a severely learning disabled daughter who is in residential care during the week but comes home at weekends. She also has a husband with CJD who went into full-time residential care a little over a year ago. Although he is in a home, she visits him every evening and at weekends:

'I go in every night and I shave him, clean his teeth, do his nails, you know, the sort of things that I can... it's really to help them as much as him. He shouts at me just as he shouts at them sometimes.'

Over the years there have been periods of intense caring for both her daughter and her husband as his condition was worsening. She feels that she has been well supported by social services and always managed to find a package of private and publicly funded care that allowed her to carry on working. When the children were young (she also has a son) she worked part-time for a number of years. Since the age of 7 her daughter has been in many different special residential schools and 'Mary' has been a tireless advocate for her daughter ensuring that she is getting the best placements available.

Her employer has been very accommodating, recognising the pressure she has been under at different times. Although she works a standard pattern week, in practice she is allowed a degree of flexibility:

'Well I vary the hours as I can skip away on a Friday to pick [daughter] up, so basically, my paid hours are 9 to 5.30. I actually work probably about 8 'til 5.20 and then go at half past 3 on a Friday. But basically I think on my contract it probably says 9 to 5.30.'

'Mary' really values her work for: 'Money. And sanity' and gets on well with the people she works with and appreciates their interest and concern for her:

'...but people knew, people cared and that. And they knew [husband], I mean [husband] used to work, I mean that's how we met — he used to work for them years ago, so people there did still know him. But he had done some driving and that, you know, when he wasn't working for them for a while, so they did know him. And, you know, this is what my friend, Angela, she couldn't understand, she said 'the trouble is, I don't know how you cope because he doesn't look any different'.

'Mary' is not sure how much longer she will continue to work, she has thought she might stop her full-time job and work just a couple of nights in the residential home where her husband is but she has not made up her mind yet.

# 8.5 Self- employment as a solution to caring responsibilities

'Sarah' is 48, single and a self-employed private teacher for children with special needs, mostly kids with emotional and behavioural problems. She has a complex range of caring responsibilities; she cares for her mother and father who are in their

80s and have health problems, a family friend of 95 who lives in the next village to her parents and various nieces and nephews who come to stay at her parents' house, She has power of attorney for her parents and the family friend. Her mother has cancer for the third time, her father is waiting for a heart operation and the family friend has a range of mobility and memory problems not untypical for a 95 year-old.

'Sarah' has her own place in London and splits her time between there and her parents' house; her caring responsibilities have built up over the last 20 years:

'I had to spend more time down here so yeah. And because I'm self employed I can do that. So...Yeah, so I change my work patterns according to the needs here. At the moment I go... That's why I do 3 days a week in London and 4 days up here because I don't want to do full-time up here because it's not fair on my mum. Because it's... my dad would want it, she doesn't, and it's like the Queen Bee, you know, you've got to still have... This is her house so I have to have somewhere else which can be my house. Yeah. And you've got to balance it. So at the moment she is still Queen Bee so I do only 4 days here and 3 there. Yeah, because she's... As it occurs we can change it. You see if I had a proper job... or some people call it proper, I couldn't do that. But... yeah, it's important for them.'

Despite the rather hectic schedule 'Sarah' enjoys her work

'What does work mean to me? It's very satisfying. I never had... Yeah, sorry, it's very satisfying, especially working with the kids when you see them responding so it's... I couldn't do an office job or something like that, that would kill me. Having more things to think about doesn't really matter if you get satisfaction out of it.'

'Sarah' is also a trained framer and gilder so can turn her hand to self-employment in this field if necessary and has done so in the past when she needed to live full-time at her parents for a period of time when her mother was very ill and undergoing treatment for an earlier cancer. Asked about the effects of caring on her own health:

'Well I don't know if I can say I feel depressed because you don't have time to feel depressed. You know it's sort of... I go out... It's like at night if I... Like the other night it was an all nighter with [family friend] in the next village and I came back and I just went up and I sat up on the far end of the garden and just looked at the stars. It was a lovely night and I looked at the milky way for about 10 minutes. The dog loved it and it was great, you know, and you just... you just let it go at one end and come in the other sort of.'

When asked if she had thought of giving up work she replied:

'No. I'd go mad. I'd go mad. No, you've got to have... I mean the people who are caring 24 hours a day for their relatives I... I really tip my hat to them because how they do it I don't know. It's as though you're trapped in a prison. If you didn't have some... something else to think about, to run concurrently you can't survive, you really can't survive. You need to have it.'

# 8.6 Not working but would like to work

'Jane' is 41 and married with two children under 12. She is the main carer for her husband who has a progressive disability caused by a rare tumour in his spinal cord. Her husband was retired early on ill health grounds from his well paid professional job. 'Jane' is a qualified accountant and had worked for the Inland Revenue for twenty years, full time and then with reduced hours when she had the children. She is also a fluent French speaker and used to do translation work at the revenue. She had to give up the civil service job three years ago following a car accident in which she sustained a significant back injury. She finally had an operation, which improved her back just at the point at which her husband's condition was diagnosed.

At the time of the interview she was registered as a full-time student; something she was doing to improve her longer term job prospects. In the meanwhile she would love to work, not least for the money as their income has dropped considerably but also as an 'escape' 'from what's going on at home'. She is willing to take almost any work and has considered supermarket till work as she said about working:

'It's not only the money, but you earn your place in society'

She has been to her local Job Centre Plus but felt that they wanted to offer her office work because of her work history but they did not having anything flexible enough. Ironically she felt that the Job Centre Plus had been more helpful to her husband:

'I mean certainly they've been more helpful to my husband in that when he was filling in all his different forms and everything else, they actually said to him 'when you feel up to it, come and see our disability officer and we can probably get you four hours of work, or whatever, a day to fit in with your disability'. They've been more proactive regarding him than they have with me and I'm well....He's more employable!'

'Jane' was undertaking some work, which had originally been voluntary that of helping people complete their tax returns. She also did odd bits of French translation. These used her previous experience and skills. Given 'Jane's' range of competences and willingness to work it seemed likely that with some further support she would be able to find a flexible job. However, her previous experience left her sceptical about the JobCentre Plus's ability to help her.

'Jane' is not eligible for Carer's Allowance because she is a full-time student but felt that the benefits system did not really recognise the situation of people like her. She did not define herself as a carer 'because he is my husband and I suppose it's just become part of life for us" but nevertheless because her husband wasn't fully independent her ability to work is circumscribed. She thought that there should be a Carer's register, which then allowed those registered to get some tax credits for the caring they do.

'Jane' felt that the coming together of her own health problem with that of her husband had made things much more difficult, if she had been working at the time of his diagnosis things might have been different:

'I have to say that if I had been in work when all this was taking place they would have been very flexible. I will say that about the civil service. If I had said to them 'I'm sorry, my husband is really quite sick' a0 they would have given me time off when he was sick, and b) they would have said 'what kind of hours can you work? and I could have turned round to them and said 'well I can only do 16 hours now' and they would have accepted that....if you've already got a job that you've proved yourself in, people are more willing to accept that your life has changed.'

# 8.7 Ceased caring and retraining to regain employment

'John' is 57 and married with two children, he spent seven years caring for his elderly mother who had dementia. She died at the age of 93 last year and he has since been struggling to get back into employment. Prior to giving up work to look after his mother, who he moved into his house so he could care for her, he ran his own consultancy, having worked as a professional in industry before that.

After his mother's death he experienced severe depression and also had a bout of pneumonia, he felt that the experience of looking after her, especially in the later stages of her illness, had depleted his own physical and mental health. In particular, he had felt very unsupported in his role as carer and described the 'mental torture' of having to provide intimate personal care to her. He also felt guilty about his wife and his younger daughter feeling that he wasn't doing a good job of looking after any of them because of the competing demands. Although he felt 'morally bound' to look after his mother, he knew that many of his family and friends thought that he should have put her in a home and as a result did not show him much sympathy.

'But isolation has been the most characteristic thing I've suffered...I've been isolated like being locked away in jail for 6 years and tortured, mentally tortured for 6 years or whatever and now I'm expected to go out into the world as though it hadn't happened and no-one gives me allowances for actually what has happened.'

He had some problems with benefits after his mother died and sought advice from the JobCentre Plus. He was advised to get his doctor to sign him off sick. With regards to getting back to work he had low self confidence:

'I said look I'm 57 nearly, and I am 57 now, and I haven't worked in the job market for x number of years. I've been looking after my mum and I just feel that I can't go out — I haven't got the wherewithal to go out and fight back to get where I am.'

Subsequently an adviser at JobCentre Plus suggested, given his work background, that he might consider being a classroom assistant or teaching in Further Education:

'She helped me a lot. And she said now there is more of a thrust now not to be ageist in the policies and the government policy that people shouldn't be discriminated according to age.'

'John' then decided to start a teacher training course at a local University and was a student at the time of the interview. He was finding it difficult to manage the course and wasn't confident that he would complete it but he valued it:

'It gives me intellectual exercise, social contact, a feeling of value and self worth, a feeling that I'm contributing towards society. A feeling that I'm progressing and developing myself and moving forward and...Life's, you know, pathways. That's what I feel.'

# 8.8 Ceased caring and considering the different options

'Fraser' is 43, single and is currently unemployed having recently ceased full-time caring for his mother, who went into a residential home a month before the interview. He had worked for 18 years as a warehouseman and gave up work in January 2007 to help care for his mother. His mother has had long-term health issues, diagnosed as a schizophrenic and in more recent years suffering from dementia. 'Fraser's' father had been the main carer until his death in December 2006. This change of circumstances led 'Fraser' and his brother to consider different care options for their mother.

'So there was mum, my brother and my father in the house. My father passed away and my brother worked during the day time, so an issue came, you know. We knew mum needed support, couldn't manage on her own any time really. I mean you can maybe nip to the shops for 10 minutes but you couldn't leave her any longer, you see. So we had to decide – was mum going to have to go into care? And at that stage I decided that I would look after mum during the day time, you see, while my brother was at work.'

'Fraser' was relatively dissatisfied with his work, his employer had only given him 3 days compassionate leave following his father's death and he had been signed off by his GP for a further two weeks for 'stress related to death in the family'. He did not explore the possibility of changing his hours of work with his employer and was not aware of legislation giving the right to request flexible working arrangements. A social worker tried to persuade 'Fraser' not to give up work but as 'Fraser' had decided that this was the best solution in terms of providing care for his mother the social worker came up with another idea that he be paid as his mother's personal assistant from her Independent Living Allowance. This funded 22 hours of his time a week; although the time he spent caring for his mother was in excess of this.

At the time of the interview 'Fraser's' mother had been in the care home for 4 weeks and he had arranged a rota with his siblings for visits, so he was going over to her twice a week. 'Fraser' wanted to get back to work:

'I think it gives you a sense of dignity and it gives you an interest in your life. Earns you some income, you would hope.'

He was unsure; however as to what line of work he wanted to do. He didn't want to go back to being a warehouseman or an office job but was wondering about whether to go into care work on the basis of his recent experience as a carer. He had been in touch with JobCentre Plus:

'I went to the office and told them I'm now looking for employment and they said 'well your initial contact is you go through an interview over the phone, and you give your national insurance number and past and present employment etc, any mortgage details and whatever.' So you'll have a 40 minutes, roughly, interview on the phone and then what normally happens is they'll arrange for you to come in to a local Job Centre and you'll have a person to person interview.'

Two weeks later at the time of the interview 'Fraser' had not contacted the Jobcentre Plus further as he was worried about being propelled into a line of work he did not want to do, he wanted a bit of time and space to adjust to the new situation and work out what he really wants to do:

'I'm frightened I'll get pressured into wanting to look at jobs they've looked at. I mean whether they'd give me some time to, you know, I'm sure once you've been in Job Seekers Allowance for 6 months or what, then I'm sure there's a bit of pressure on you, but whether initially....I could hint to them that I'm not sure what I want to do....Well I'm not sure I'd want to go back to what I did for 18 years.'

#### 8.9 Employment not really possible at the moment

'Rani' (34) and 'Tariq' (48) are married with two sons aged 11 and 9. Both sons have autistic disorders and have problems with mobility, communication, concentration, sleeping, with no awareness of physical risk or danger. One son also has asthma. They need care 24 hours a day and cannot be left alone.

Originally from Pakistan, 'Tariq' moved to the UK in the early 1990s, and had worked in retail until two years ago. He stopped working because of the increasing needs of the children. 'Rani' wanted a break from caring and found a job working for a voluntary organisation as an information advocacy worker for parents of children with special needs. She had really enjoyed her work, but had left a few months before the interview as she suffered both mental and physical injuries from trying to combine work and caring.

'....and the reason I had to leave was because I actually was so stressed out juggling both at the time, I pulled a muscle... I didn't want to really leave my work because I was really enjoying it and because of the tension of... I mean your carer's role does not stop. All the responsibility I have at the office, that does not come into the house, but my children don't understand, they don't have sense of feelings, they don't understand how a person feels.'

As well as providing constant care for their sons at home, 'Rani' and 'Tariq' have to cover hospital appointments and cope with the logistical problems involved in each son attending a different specialist school. 'Tariq' suffers health problems in part arising from lack of sleep as he looks after the boys during the night.

With support from their local carers' association, they received an assessment of their support needs from a social work nurse. This resulted in two hours per week of respite care. They consider this inadequate, and are trying to get more help.

They have no support from friends or neighbours, and their families 'keep their distance'. 'Rani' explains that they are isolated from other Asian families because having sons with disabilities does not sit well within a culture of arranged marriages. While 'Rani' derives some support from her local carers' support group and association, 'Tariq' feels excluded from this because he is a man and it is mainly women who attend these events.

'Tariq' thinks he might go back to work, but would only consider self-employment. He admits that it would be difficult to find and sustain a job that would pay as much as they currently receive in benefits. (They currently receive Carer's Allowance, Income Support, Disability Living Allowance, Housing Benefit and Council Tax and Child Tax Credits.) He also feels there is a lack of government support for 'older entrepreneurs'.

'Rani' had attended an interview at her local JCP when she gave up work. The attitude of the staff there was that they would never have recommended that she work as they could see it would not be financially beneficial to her. Her response was that she wanted to work for reasons other than money.

'It was my self esteem I wanted to do it for'

They are both attending IT classes at a further education college in order to gain some computing skills. This was not on advice from JobCentre Plus but in response to a newspaper advertisement they came across by chance. Their main motivation is to be able to help their sons with homework and learning, but also hope the skills will be useful for any future potential employment.

Despite the fact that they have each valued their time working and would like to work again in the future, their current priority is their sons' well-being. They feel that their sons have benefited from them not working and becoming full-time carers.

#### 8.10 Summary

This sample of individual cases illustrates both the diversity of caring experiences and the complexity of the demands that many carers face, particularly those with intensive care demands. None of the cases is 'typical' as there is probably no such thing as a typical caring scenario but there are a number of recurring themes that epitomise the challenges of combining work and caring. Caring is clearly hard work - whether combined with paid employment or not a majority of our carers experienced physical and emotional strain as a result of their roles, and a number had impaired health as a consequence of long-term caring.

The unpredictable nature of the caring situation, both now and in the longer term, is another common feature, and one that has significant implications for sustaining paid employment or getting back into it. Carers have no option but to prioritise the needs of the cared for person, which makes planning to return to work and/or maintaining a regular pattern of work difficult. The complexity of managing their care tasks alongside organising services for the cared for person, attending hospital appointments and often 'supervising' the overall well being of their relative cannot be underestimated. The sense of isolation and 'just getting on with it' is another shared issue although for a minority, friends and family do provide a key source of practical and emotional support. For some carers there is the need to reinvent a life after caring when they have been out of the labour market and perhaps social and public life more generally for some time. Also, for many there are the frustrations of working out benefit entitlements and operating within earnings or hours rules. Overall, however, what is absolutely striking about these case studies, and many of our other respondents, is the extraordinary resilience shown by carers in reconciling competing

demands and pressures and in their determination to provide care for their relative(s) and seek or sustain paid work wherever possible.

### 9 CONCLUSIONS

One of the DWP's aims is to promote work as the most effective route out of poverty for those of working age whilst ensuring the protection of vulnerable groups and those in greatest need. The critical role that work plays in our society should apply to those with caring responsibilities as much as to any other group at risk of falling out of work, yet until recently carers have not been recognised as having any specific rights at work and many continue to lack the support they need to combine working and caring. Unlike other groups such as lone parents, or the young unemployed there have been no specific welfare-to-work policies targeted at supporting carers either in, or back into, employment. A number of factors come together to suggest the demand for informal care will increase. The first is the demographic fact of an ageing population: it is expected that the number of frail elders will increase and with it the demands on families to provide care. In addition Health Service policy (care in the community), advances in medicines (e.g. lower mortality rates for disabled neo-nates), advances in technology (making care at home more feasible) and disabled people's own aspirations regarding their care are all important factors in increasing the demand for informal care. In these contexts the challenge of how to effectively support carers to continue working, and/or facilitate their return to paid work, is considerable.

The aim of the research reported here was to better understand what employment support is needed for carers in order for them to be able to take up and/or remain in work. To this end carers in a range of situations were interviewed: those working and caring; those seeking to get back into employment after a period of caring and those currently not working but who would like to work now or in the future. Specifically the objectives of the research were:

- 1 To investigate how caring responsibilities affect people's decisions about employment
- 2 To begin to fill the evidence gap on the role and effectiveness of existing services for carers
- 3 To assess how DWP and Jobcentre Plus can effectively help claimants with caring responsibilities to return to the labour market
- 4 To provide evidence to enable the DWP to develop its strategy for carers.

This chapter reports the findings of the research by addressing the first three questions and concludes by drawing out the policy implications of the research data for the DWP's strategy for carers.

# 9.1 How caring responsibilities affect peoples decisions about employment

This research, and the report, are primarily concerned with the employment aspects of carer's lives but given that caring intersects with all facets of daily life, it was very important to explore their views of their role and situation through the lens of caring. Caring responsibilities have to be met somehow; the needs of the elderly relative, the disabled child or spouse cannot be ignored so actual or prospective employment has to accommodate care related demands unless suitable substitute care can be found. Caring, particularly intensive and dementia caring, has a profound impact on the lives and health of carers. For the majority the caring role develops gradually as the cared-for person's health deteriorates but for a minority it happens overnight following a car accident or major health event. Most carers, therefore, become a carer unknowingly and gradually and for many it involves a complex mixture of time consuming tasks and roles which demand a great deal of physical and emotional labour. Long term caring leaves many carers exhausted, isolated and in poor health.

Carers do not always define themselves as such; they may simply be the parent, or the husband or the daughter and feel that caring is an intrinsic part of their family role. This means that they may not respond to initiatives directed at 'carers' and may not appear on the 'carers radar' of agencies with an interest in or duty towards carers. Related to this is the finding that many carers are unhappy with being labelled 'unemployed' as they do not see themselves as belonging to this category; for men especially, the term unemployed may serve to diminish the value of the hard work of caring (Arber and Ginn, 1995; Hirsch, 1996). These issues illustrate well the conceptual and practical complexity of 'being' a carer and underscore a point identified by a number carers interviewed for this project: that they felt people did not understand their role or situation. It also helps to explain why 'carers associations' were such trusted sources of advice, information and support because it is in this context that carers felt their needs and situation were genuinely appreciated. These overarching points are important because they provide both a context for, and

influence, how and where a carer starts from in thinking about, and coping with, employment.

This research confirmed many of the findings from previous studies, such as the importance of working for carers in terms of financial benefits and personal satisfaction. Our findings also supported the main restrictions that caring imposes on working – carers were limited in the hours they could work, in how far they could travel to work, and were constrained in terms of job mobility and career planning. Beyond this confirmation, our study has provided a more in-depth understanding of some of the key difficulties in combining working and caring, and highlights gaps in employment support provided and received.

Despite unanimous agreement of the importance of work in our study sample, it was clear that combining working and caring was far from easy. The key themes raised were balancing/juggling, stress, and guilt. Respondents who worked found themselves constantly having to balance their work requirements with the needs of their cared for person. This was viewed as a source of great stress, not least because they tended to regard the responsibility for managing the work/care balance as solely theirs; to offer care to a dependent relative was viewed as a private choice and therefore an individual responsibility to resolve the inherent tensions. This stress was frequently compounded by guilt: people felt guilty that they could not focus entirely on the cared for person; they also felt guilty because they could not focus on their job as much as they might have liked to; and often they felt guilty for not disclosing their caring circumstances to their employers or colleagues but they worried about the stigma that might attach to them if they disclosed their caring situation.

For carers not currently working the desire to work remained in principle but when explored practically they expressed considerable anxiety about how any suitable work could be found. The view that no employer would want to take them on if they knew about their caring responsibilities was common. In addition there were concerns about the impact of going back to work on the health or happiness of the cared-for person and the impact on their own health of having to juggle work and caring. This may illustrate the varied responses that different research strategies may elicit: in surveys carers, people with health issues and lone parents may well give positive responses to the desire to get back to employment; when interviewed in

depth they may retain this in principle motivation but explore in much greater detail the practical barriers to effecting a return to work.

One of the key elements of facilitating effective management of the work/care balance was work related flexibility. The term 'flexible working' covers a very wide range of working practices, and is most often understood as some form of deviation from so-called 'standard' employment, i.e. full-time employment contract, working a standard working day and a standard working year at the employer's place of work.

The circumstances of our respondents reflected all these dimensions of flexible working. Part-time working was common, and other forms time-based flexibility included term-time working and annual hours contracts, flexitime and shift working. A key finding here was that often these forms of flexible working did not afford a great deal of flexibility to the carer. The nature of care giving was often unpredictable, so having, for example, a fixed part-time hours contract was not especially helpful. Although term-time working provided flexibility to carers of children to cover school holidays, this came at a personal cost to the carer who in effect sacrificed any holidays they might have had.

Contract flexibility was seen most often through self-employment, but there were also some agency workers in our sample. Although self-employment was seen to offer a level of control, it too had its limitations; the stress experienced by the carer in being simultaneously responsible for their own business and the cared for person is a key issue. A few respondents had shifted to different types of employment, typically less demanding work in order to accommodate caring responsibilities.

These last points reflect what we have termed more 'informal' flexibility. In many respects this was the most valued of all forms of flexibility. Key here was being contactable at work. This gave the carer peace of mind and they felt that they could be better employees as they could focus more on their job. A vital facet of informal flexibility was employer trust which was highly prized, but more often than not, absent. Some of the carers in the study gained flexibility and trust by working for smaller organisations.

Working carers are required to balance their caring demands with those related to their employment. Some achieve this balance by reducing their hours, shifting their pattern of work or, less commonly, getting regular support from family or services discussed below. Other carers are obliged to give up working altogether.

# 9.2 The role and effectiveness of existing services for carers

Carers obtained support and sought help from a wide range of formal and informal sources: social services, the NHS, voluntary organisations, family and friends, and the DWP through its operating agency the JCP. The formal services with the exception of the JCP agencies do not conceptualise their role as supporting or enabling carers to work. This section focuses upon the roles and effectiveness of existing services other than those of the JCP, which are dealt with in the 9.3; in addition it reviews the evidence about the role of employers in supporting carers.

### 9.2.1 The NHS and Social Services

For most of those interviewed the contact they had with the NHS and Social Services was primarily negotiating services for the cared for person. Care packages were rarely set up with any reference to the carer's need to work; the primary focus was the cared for person and their need for support rather services being provided to ensure the well being of both carer and cared for, including the need to be in paid employment.

Assessments of carer's needs were rare amongst our respondents, despite the fact that many of them would have qualified for such an assessment in law; other respondents were not clear whether they had had an assessment or not, as most of their contact with social workers focused around the needs of the cared for person. What was striking was how little carers get and want. Many of our respondents only wanted a few hours of respite a week, reliable day care, or flexible accessible support at short notice, something agencies appear to find it very difficult to provide.

Many carers complained about the fragmented nature of the 'support system' available to them and the desirability of a single port of call that offers a range of carer focused services including advice on benefits and employment/training. This problem is acknowledged by the House of Commons Work and Pensions Select Committee (HCWPC, 2008b: recommendations 7, 9, 32 and 33).

### 9.2.2 The voluntary sector

The voluntary sector was highly valued by many of the carers we interviewed. It appears to be accessible and, flexible and to treat carers in a holistic way; it also offers an ongoing service throughout the entire caring trajectory and is widely trusted and relied upon by working carers. A number of characteristics of the voluntary sector served to differentiate it from statutory services: the fact that it was locally based, friendly and accessible; it was seen as reliable in providing specialist advice and services and to some extent functioned as a 'one-stop' shop; it was constant, and there for the long-haul. In short, the majority of respondents felt understood and respected by the voluntary sector, which was not how many felt in their dealings with statutory agencies.

### 9.2.3 Employers

In 9.1 the importance of flexibility for working carers was discussed in this section we consider the extent to which our respondents were helped to achieve a balance between working and caring by their employer, including the issue of flexibility.

Despite the importance of flexible working in facilitating work and care, our respondents' accounts revealed a very patchy picture of workplace support. They reported that some employers were wholly unsympathetic to the needs of their employees with caring responsibilities: it was this lack of sympathy that had forced some carers out of their jobs. The experience also damaged their prospects of future employment in that they were afraid they would merely receive the same hostile treatment from the next workplace.

A few respondents reported that employers demonstrated an active approach to supporting employees who were carers. This manifested itself in having an overall policy (rare) or in offering support to accommodate particular activities, e.g. training, or to support specific episodes relating to caring, such as providing time off at short notice. However, the predominant approach was a passive one. Most employers appeared not to have an explicit policy, and it was up to the carer to ask for help if required. Our respondents reported that such employers often demonstrated a complete lack of knowledge or awareness of what the needs of a carer might be. Examples included assuming the needs of a carer would be the same as the needs

of a parent, or failing to understand the fluctuating and often unpredictable nature of caring.

This passive approach was also seen to contribute to the ways in which carers who were no longer working left employment. A common exit-route was via long-term sick leave, whereby the employee slipped away from employment, often completely unnoticed. For older respondents, the route of early retirement was used in a similar way.

Although some respondents praised their colleagues and line managers for providing both emotional and practical support, the more common scenario was one where employees did not tell people about their 'guilty secret' and tried to struggle on as best they could. This contributed to the 'understanding gap' highlighted above.

These findings support studies in other contexts which challenge the contention that providing employees with legislative rights – in this case to request flexible working or to take time off in emergencies – empowers them (see Dwelly and Bennion, 2003; Vickerstaff, Loretto and White, 2008). Many people are not aware of their legal rights and hence are not in a position to invoke them. We found that many of our employed carers were, on the whole, disempowered – they were grateful to employers for giving them a job in the first place and did not want to do anything which would jeopardise their work situation. Thus, our overarching picture is one of a group of largely invisible employees, reluctant to divulge their circumstances to employers for fear of reprisal or being seen to be a weak or less committed employee. There is clearly a need to raise awareness amongst employers of carers and their needs and to enhance understanding of the role of the employer in supporting workers who hold responsibilities for caring.

# 9.3 The role and effectiveness of existing DWP services for carers

Currently, through its two executive agencies the Jobcentre Plus and the Pension, Disability and Carers Service, the DWP has responsibility for two forms of support to carers: the provision of employment support and advice and the payment of benefits. With regard to employment support there is no dedicated programme for carers as there has been for other client groups, such as lone parents or the disabled. There was a wide range of experience of JCP services amongst respondents, varying from people with recent first hand contact to others who had had no interaction with JCP

and knew very little about what they offered. For this latter group the JCP was simply not on their radar as an agency that might provide help.

For others, either through direct experience or hearsay, there was a widespread feeling that the JCP environment was unwelcoming and this was linked to the sense that carers were not really understood; that there were no specialists or experts on caring in the JCP offices. Others felt misunderstood by JCP, for example being labelled as unemployed when they felt they were 'working' full time albeit termed 'caring'. As a result, a majority of respondents had negative views about what was available through JCP.

Other respondents felt that in relation to job search JCP did not have the right kinds of jobs to meet their needs: either because they did not have part-time or flexible jobs suitable to accommodate care related demands or because they were only offered access to jobs that did not reflect their level of experience or previous job status. For these reasons a number of carers self selected not to use JCP.

Amongst some of those with recent experience of DWP, either for job search or benefit purposes there was a feeling of receiving mixed messages; for example that they should consider getting back to work but then discovering that they would not be much better off; wanting to work a very small number of hours but this being something that JCP did not really provide access to. This sense of confusion was further compounded by the rules for Carer's Allowance, which seemed to frustrate individual's willingness and ability to work part-time.

The Pension, Disability and Carers Service had only just come into existence as the respondents were interviewed and no-one mentioned the agency directly or its predecessor the Disability and Carers Service. Many respondents complained about the complexity and inflexibility of benefit rules and wondered whether anyone really understood the system. This finding contributed to the widely noted view that there should be just one place that carers can go for advice on benefits and employment opportunities and that the advice needs to be provided by people who genuinely understand the situations carers are facing.

### 9.4 Policy Implications of the research findings

The focus of this research has been on exploring in greater depth the employment related support needs of carers, both those currently in employment and those looking to return to work now or in the near future. The objective was to provide evidence to enable the DWP to develop its strategy for carers. Since the research began there have been a number of relevant policy developments (see HM Government, 2008:82-99; Employment Task Force, 2008) and a report by the National Audit Office into the DWP's support for Carers (NAO, 2009); and the reports of the Work and Pensions Select Committee (HC Work and Pensions Committee, 2008a, 2008b). In the discussion which follows on policy implications we note where our findings overlap with points made in these other documents.

Removing the barriers to employment for carers requires action on a number of different fronts and by a range of stakeholders. The DWP - as the main governmental policy agent in the field -, most particularly through JCP and PDCS, can play a number of roles in developing appropriate policies and procedures for their delivery. Employers will also have a pivotal role in providing and sustaining employment for carers. The NHS and Social Services, although primarily concerned with the needs of the cared for person, also have a role in supporting carers who wish to stay in, or return to, paid work. Lastly, the voluntary sector, who already do much to support carers on a day to day basis, may also be able to play an enhanced role in supporting working carers. For ease of consideration the policy implications of the research findings are presented around the roles of these different stakeholders.

### 9.4.1 DWP

Carers need greater visibility as they have very specific needs for support in relation to remaining in or retuning to work. Currently some Advisers in JCP do not have specific expertise on the caring or on the employment needs of carers. As a result many carers we interviewed did not have confidence in JCP's ability to provide appropriate advice or help. Our findings therefore confirm the conclusion of others that there is a need for specialist training for JCP advisers who work with carers (Employment Task Force, 2008:9; HCWPC, 2008b: conclusion 4). This would also help to address the problem of consistency in advice and support that a number of respondents referred to.

Flexible patterns of working were found to be critical for those respondents who were already working or considering getting back into work. However, there was the feeling that JCP did not provide access to these kinds of job opportunities. Our findings therefore confirm the conclusions of other work that JCP needs a better system for identifying and flagging up flexible job options especially in jobs that are commensurate with the skills and experiences of those seeking work (Employment Task Force, 2008: 9; NAO, 2009:7; HM Government, 2008:93).

If measures were taken to deliver on the previous two points it might be easier for JCP to market itself as a source of useful help and advice to carers; unfortunately many of those we interviewed assumed that JCP has nothing to offer them. There is a distinctive 'information gap' at present with many carers not knowing about the services that JCP can offer, e.g. Better off Calculation and access to training, and some JCP staff not appreciating what carers actually do. However, before communication can be enhanced there needs to be an overall improvement in the marketing of JCP and PDCS so that carers feel that these are places that can provide them with relevant help and information. The role of the new Care Partnership managers in each District will be critical here.

There was limited experience amongst our respondents of advice on training to help them get back to work, but where this had been offered there had been problems with the content (too basic) or the logistics (how to attend for training and still provide care). In the latter case DWP needs to investigate further whether it is possible to fund replacement care for the period of the carer's training and build on the commitment, which has now been made for those on approved training (see also Employment Task Force, 2008:10; HCWPC, 2008: conclusions 18 and 41).

This research suggested that there is a real need for a liaison between employers and carers: both need to understand the needs of the other, and where a match between job and skills can be accommodated, JCP Advisers could bridge the gap to employment for carers; a number of changes would facilitate this:

 first that JCP Advisers have an understanding of the skills their clients have and how to match them to the jobs employers have available in their area;

- second that JCP has close contact with local employers to get a sense of what is available for flexible work; and
- thirdly, that DWP and JCP take every opportunity to sell the benefits to employers of employing or retaining carers.

This last point is reinforced by the fact that this research suggests that providing employees with legislative rights – in this case to request flexible working or to take time off in emergencies - is not sufficient on its own to guarantee access to either. Some of our carers did not want to risk asking for 'special consideration' fearing that their position would be undermined. Empowering carers to make use of their rights requires a significant campaign of awareness raising amongst employers as well as recognition that carers are often loyal employees (see also HCWPC, 2008b: conclusions 49 and 50).

In terms of welfare benefits this research suggests that there is a need for greater clarity over benefit rules and entitlements and the interaction of different benefits. In addition, if carers with substantial and/or intensive caring responsibilities are to be encouraged to remain in work, consider getting back into work or simply want to keep a toehold in the labour market, the earnings rules for entitlement to Carer's Allowance may need to be reviewed. Financial support for carers is currently under review by Government. (HCWPC, 2008b)

### 9.4.2 Employers

It is important that employers become more aware of carers and their needs, creating a network of sympathetic or care-friendly employers both nationally and locally may be one way of raising the visibility of carers as employees. It was not exceptional for our respondents to keep their caring a secret at work, or at least from their managers. This may be a choice, for example in order to keep a clear line between work and caring and to preserve a space in which the carer can escape their caring role, but for most it was out of fear of the reaction they would get from their employer. Employers need to appreciate that carers who require flexibility are not malingerers and that having access to a phone or the ability to make calls at work may simply allow them to concentrate and get on with their job.

Employers need to have a good sense of which roles within their organisation could be flexible and in what ways. This would enable them to market vacancies as suitable for people with caring responsibilities. It is also important that employers manage more actively those who may be in danger of slipping out of work because of pressures related to caring. Those on long term sick, or with an emerging pattern of absences may be desperately trying to balance the needs of caring and working and modifications to work patterns might enable them to remain in work.

It would also be helpful if employers were more aware of benefits rules, so that some employees with caring responsibilities may not be in a position to vary their hours or take on extra shifts.

### 9.4.3 NHS and Social Services

At present, and not unreasonably, professionals in the NHS and Social Services are primarily focused on the needs of the cared for person and do not necessarily see their role as supporting the carer to remain in or go back to work. However, there clearly are roles for GPs in being alert to the health issues that carers combining work and caring may be experiencing and providing good advice and or referral to occupational health services. Social services need to be more aware of carers' rights to an assessment of their needs and this should be routinely offered and periodically revisited at every opportunity e.g. when a visit to the cared for person is arranged.

It would be helpful for all professionals involved with carers to take a more holistic view of the cared for/ carer for dyad with corresponding and overlapping needs rather than as individuals to be assessed separately. It may also be that these services are the first point of formal contact in an individual's caring history and could provide access to a range of information (HCWPC, 2008b: conclusion 7).

### 9.4.4 Voluntary sector

The voluntary sector is currently respected and trusted by most carers and is a vital source of information and advice as well as physical and emotional support. In many respects it comes close to the 'one stop shop' that many carers noted as a key service in the research. It offers the possibility of joining up the different elements of care and support that the carer has to access. The voluntary organisations that our

respondents had contact with were seen both as experts and supporters; all were regarded as sympathetic. The barriers to involvement with JCP over employment support that many of our respondents expressed might be overcome by locating employment advice and support with third sector organisations that already command the respect and trust of carers.

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### APPENDIX A: FIELDWORK INSTRUMENTS

Information letter - Edinburgh:



### **EMPLOYMENT SUPPORT FOR CARERS**

The research is commissioned by the Department for Work and Pensions and is designed to understand what employment support is needed for carers in order for them to remain in or take up work. In the region of 13 per cent of adults aged between 16 and 64 in full-time employment were caring for a sick, disabled or elderly person. Many of these people (and those working part-time and caring) face pressures managing their work schedules and looking after the person they care for. The research wants to investigate the support they currently receive from their employer, family, social services or the health service and what further support they need. Many carers who are not currently working would like to do so and to combine working with caring responsibilities. The research is keen to understand the support they require to achieve this.

The research will consist of a series of interviews with carers (both current carers and those who have recently ended a spell of caring) who are not currently working but want to do so, as well as those who are working or have recently left the labour market. The interviews will cover the history and nature of the caring that the person does, their employment record and the support they currently receive in their caring role from a variety of sources.

If you are interested in taking part in this research and want to find out more, please contact the lead researcher.



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Gift Receipt:		
The Employment Support Needs of C	arers	
I acknowledge the gift of £25 in recognit project.	tion for participating in this research	
I understand that this gift does not have to be declared for tax purposes, and that it will not affect any benefit entitlements.		
(Name of Person – please print)	(Signature)	
(Name of person making payment)	(Signature)	

### **Cover Letter:**



Dear

I am a researcher at the University of Kent and I would like to invite you to take part in a research study about being a carer and wanting to do paid work, which is being undertaken on behalf of the Department for Work and Pensions. The title of this research is:

### **Employment Support for Carers**

We are keen for you to be part of the research, but before you decide, it is important that you understand what the research is about and what it will involve. Please take time to read the following information carefully and discuss it with friends and relatives if you want to.

### What is the research study about?

People who want to work and also have responsibility for caring for relatives or friends have particular difficulties getting work that will fit in with their caring responsibilities. We want to find out more about the views and experiences of people like you. We particularly want to get a better understanding of what you think can be done to support you to find suitable work, continue in work or return to work. We would like to find out whether there are any particular things about your caring responsibilities and general circumstances that stop you from working or make it difficult for you to work, and what could be done to overcome these difficulties.

### If I want to take part, what do I have to do?

Either myself or another member of our research team will be contacting you to arrange to talk to you, either by visiting you at your home or at another place of your choice. Firstly, we'd like to talk to you about the research some more, give you the chance to ask any questions, and get you to sign a consent form. As well as the sorts of topics mentioned above, we will be asking you questions about your life, your health, and what sort of impact your caring responsibilities have had on your decisions about working and on your financial circumstances. The interview will be recorded with your permission and last about an hour and a half. This recording will be destroyed once the study is finished.

I would like to reassure you that any information collected about you will be strictly confidential, and no one will be able to identify you from your replies. If you are able to take part, you will receive a small gift of £25 in recognition of your time. This gift does not have to be declared for tax purposes, and if you are on benefits, it will not affect any of your benefit entitlements.

### Do I have to take part?

The research is voluntary and it is entirely up to you whether or not to take part. If you decide to take part but change your mind afterwards, you are also free to do so. We will check with you when we speak to you that you are happy to take part.

If you would like some more information about the study or there is anything that is not clear, please do not hesitate to contact myself or the DWP contact

Yours sincerely

Consent form:	
Title of the Project: Employment Support for Carers	
Please initial the boxes on the right, write your name in capitals and sign at the bottom of the page. Thank you.	
I confirm that I have read and understand the information letter about the research and have had the chance to ask questions	
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, and this will not affect me in any way	
3. I give my permission for the interview to be recorded	
(Name of Person – please print) (Signature)	
(Name of person taking consent (Signature)	

## <u>Working</u>

## Interview Schedule: Employment Support for Carers

ID	Code:	

PART A	Background inform	ation about	yourself	
1.	What is your age?			
2.	Are you male □	female □ ?		
3.	What is your marital state	us?		
	never married □	married 🗆	co-habiting	divorced $\square$
	separated	widowed 🗆		
4.	Who lives in your housel	nold with you	1?	
0 0 0 0 0	spouse or partner adult son or daugh child (step/foster) parent or parent-ir grandparent friend other (please spec no one, live alone	ı-law		
5.	What is your ethnic grou	p? tick one b	oox only	
	White British □ Irish □ Any other white backg	round 🗆	Black or Black Brit Caribbean African Any other Black bac	
	Mixed White and Black Carib White and Black Africa White and Asian Any other mixed back Chinese or other eth Chinese	an 🗆 ground 🗆	Asian or Asian Brit Indian Pakistani Bangladeshi Any other Asian bac	
	Any other	□ (plea	ase specify)	

### 6. What is your current employment status?

7.

	Working						
	Full-time  Semi-retired  Fixed-term  Self-employed	Pe	rt-time rmanent nployed				
Types	of fixed-term:		y employe y agency v				
	ng patterns: I that apply)	Compress Standard' Flexitime Fixed Nig Rota Other	y from wee	ours (e.g //back sh ck shifts	g. 9-5; { nifts	3-4)	
	Not working						
	Unemployed		oking for w t looking	ork			
	If not working:		ired health and	/or disab	oility		
	Have you ever worke	d?	Yes		No		
	If yes, when did you s	stop workin	g?				
	Do you undertake vol	untary wor	k? Yes		No		
What is the nature of your employment/ What was your main line of work?							
	Job title						

8a. Wł	8a. What type of organisation are you/did you work for?					
	Medium-size	business (over private employe business (less t	er (betwe	en 50-249 em	ployees)	
8b. Ho	w many hour	s per week are	you/did	d you work fo	r most recently	у?
	Less than 16 16-29 hours 30 or more ho	ours				
8c. W	ould you desc	ribe your emp	loymen	t history as		
	Intermittent di	gular employme ue to caring/par I due to caring/p	enting	g 🗆		
	Please specif	y				
9. Wh	at is your mai	n source of in	come?			
	Employment			Benefits		
	Pension			Savings		
	Other (please	specify				

# 10. We would like to get an idea of which income band your household falls within. Can you tell me approximately how much you get per year?

(Include benefits, salaries, rental income from property, income from children, pensions. Probe for disability and sickness benefits)

	Annual	Monthly
Α	Under £10,000	Under £800
В	£10,000 - £20,000	£800 - £1,600
С	£21,000 - £30,000	£1,700 - £2,500
D	£31,000 - £40,000	£2,600 - £3,300
E	Over £41,000	Over £3,300

	mention all that apply. (nb check current potential benefits)			
	Attendance Allowance Incapacity Benefit Disability Living Allowance Jobseeker's Allowance Income Support Pension Credit Housing Benefit/Council Tax Benefit Tax Credits			
	None of these			
	On the whole, over the last 12 months would you say your health in the whole been good, fairly good, or not good?			
	Good			
	☐ Fairly good ☐ Not good			
	110t good			
illnes: troubl	Oo you have any long-standing physical or mental impairment, s or disability? By 'long-standing' I mean anything that has led you over a period of at least 12 months or that is likely to affect or a period of at least 12 months?			
illnes: troubl	s or disability? By 'long-standing' I mean anything that has led you over a period of at least 12 months or that is likely to affect			
illnes: troubl	s or disability? By 'long-standing' I mean anything that has led you over a period of at least 12 months or that is likely to affect or a period of at least 12 months?			
troubly you for 12c. Eyou h	s or disability? By 'long-standing' I mean anything that has led you over a period of at least 12 months or that is likely to affect or a period of at least 12 months?  Yes			
12c. Eyou h	s or disability? By 'long-standing' I mean anything that has led you over a period of at least 12 months or that is likely to affect or a period of at least 12 months?  Yes No			
troubly you for 12c. E you h	s or disability? By 'long-standing' I mean anything that has led you over a period of at least 12 months or that is likely to affect or a period of at least 12 months?  Yes No			
12c. Eyou h	s or disability? By 'long-standing' I mean anything that has led you over a period of at least 12 months or that is likely to affect or a period of at least 12 months?  Yes No			
12c. Eyou h	s or disability? By 'long-standing' I mean anything that has led you over a period of at least 12 months or that is likely to affect or a period of at least 12 months?  Yes No			
12c. E you h	s or disability? By 'long-standing' I mean anything that has led you over a period of at least 12 months or that is likely to affect or a period of at least 12 months?  Yes No			
12c. E you h Please	s or disability? By 'long-standing' I mean anything that has led you over a period of at least 12 months or that is likely to affect or a period of at least 12 months?  Yes No			
12c. E you h	s or disability? By 'long-standing' I mean anything that has led you over a period of at least 12 months or that is likely to affect or a period of at least 12 months?  Yes No			
12c. Dyou h	s or disability? By 'long-standing' I mean anything that has led you over a period of at least 12 months or that is likely to affect or a period of at least 12 months?  Yes No			

11. Are you receiving any of these benefits in your household? Please

12d. If yes: Does this health problem affect		
	The kind of work that you might do? The amount of work that you might do? How long you might work for? If yes, how many hours can you work?	
12e. Do you	receive care yourself?	
	Yes No	
13a. Has you	r own health been affected by your caring responsibilities?	
	Yes No	
13b. In what	ways? Tick any that apply	
	Feeling tired Feeling depressed Loss of appetite Disturbed sleep General feelings of stress Physical strain (e.g. back ache) Short-tempered/irritable Had to see own GP Other No, none of these	
About Your Carin	g Responsibilities	
	still providing care?	
	Yes	
	No	
14b. If yes, h	now would you describe your caring responsibilities?	
	on-going	
	fluctuates	
	ad hoc	

14c. Do yo	ou share the caring responsibility with other people? Yes No
14d. If yes	, please give a view of the caring responsibility. Are you: the main carer and others provide some help equally responsible for providing the care helping out the main carer
15. How ol	d is the person you care(d) for
16. Is/was	this person male or female?
Male	□ Female □
17. What is	s/was your relationship to this person?
I am/was	looking after my spouse or partner adult son or daughter child (step/foster) parent or parent-in-law grandparent friend or neighbour other (please specify)
18a. Where	e does/did the person you look after live?
□ Witl □ In a □ In s	neir own home  h me in the same household care home/hospital heltered accommodation/housing with extra care er (describe)
	ong does it take you to get to where the person is, if he/she is same household?
Hours/minu	utes
18c. How (	do you get there?
□ Wal □ Car □ Bus	······································

19. What sorts of health problems does/did this person have? Please tick any that apply.				
	mobility (moving around) lifting, carrying and moving objects manual dexterity (using your hands to carry out everyday tasks) continence (bladder and bowel control) communication (speech, hearing or eyesight) memory or ability to concentrate, learn or understand recognising when they are in physical danger physical co-ordination (eg balance) other health problem or disability Please specify			
20. Wł	20. When did you start caring? Approximate year			
	r about how long have you been providing/did you provide ort or care to your relative/friend?			
	<ul> <li>Under a year</li> <li>1-3 yrs</li> <li>3-5 yrs</li> <li>5-10 yrs</li> <li>More than 10 years</li> </ul>			
22. Please tick the nearest amount of time you currently spend/used to spend providing support or care in a typical week.				
	□ 1-19 hours a week □ 20-49 hours a week □ 50+ hours a week			

23. What kinds of a Please tick all thos	ctivities do you/did you regularly help them with? e that apply.
Physical help e.g. w bed	lking, getting up and down stairs, getting in and out of
Personal care e.g. v	ashing, dressing, feeding, using the toilet
Helping with paperw bill, banking	ork or financial matters e.g. filling in forms, dealing with
	e.g. preparing meals, doing his/her shopping, laundry, g, taking to the doctor's/hospital
Keeping him/her cor	npany e.g. visiting, sitting with, reading to
Taking him/her out of friends/relatives	g. taking out for a walk or drive, taking to see
Giving medicines e. dressings	. making sure s/he takes pills, injections, changing
	im/her to make sure s/he is alright/not doing anything gas on unlit, wandering out of doors
Other (please state)	
24. Do/did these ca	re needs
	Fluctuate Remain constant Increase

25. Do/did you, or the person you support, receive any help from the following? Tick those that apply.				
	Yourself	Cared for person		
Relatives				
Friends				
Neighbours				
And what about more formal	sources of help?			
	Yourself	Cared for person		
District/community nurse				
Social worker/care manager				
Home help/care worker				
Meals on wheels				
Respite care (eg in a care hor	me) 🗆			
Sitting service				
Day centre/hospital				
Carers social or support grou				
Other support from carers ago				
Other services				
please specify				
26. Do/did you pay any charges fo	r these services	(not private ones)?		
□ Yes	No			
27. Have you ever been offered or had an assessment of your needs by a care manager/social worker? This would include a dedicated discussion of your needs as a care giver.				

Yes Yes

No

No

Offered

Had

# PART B Interview: Views and Experiences of Working and Support Needs

### Those who are currently working

# 1. How are you managing to care for your relative/friend and work at the same time?

### Prompts:

- What are your main reasons for working? (probe: financial/social)
- What helps you to stay in work? (probe: flexibility; economic, emotional, psychological, social factors)
- Do you think you are better off financially? If you receive Carers Allowance, please tell me about any impact this has on your financial situation.
- What sources of support do you get outside of the workplace that help you stay in work? (probe: respite care, childcare, support groups)
- Have you ever considered giving up work? If so, why? What stopped you?
- What has your working pattern been like since you took on a caring role?
   How has it suited you?
- How do your caring responsibilities fit with your work experiences, especially if the nature of your responsibilities change, fluctuate or are ad hoc?

### 2. What do you think about your current job?

#### Prompts:

- Do you feel you are in a job that matches your skills/qualifications?
- Does it fit with your caring role?
- What about job satisfaction?

### 3. Tell me about the nature of the support that you get from your workplace

#### Prompts:

- · What are the main sources of this support?
- What has been most helpful in allowing you stay in work? (probe: sympathetic/supportive colleagues and management)
- · What sorts of things could be improved?
- Are you aware of flexible working legislation?
- How does your workplace react if you have to take unplanned time off? (eg
  from hospital appointments to crisis with cared for person)

- What if the care needs of the cared for person are unpredictable or fluctuating

   how does your workplace react?
- Do you get any support from elsewhere that helps you to stay in work?

## 4. What further support do you think you need from your employer or other sources, particularly to help you stay in work?

#### Prompts:

- · Where would you go for advice and support?
- What sorts of things would meet your needs better? (probe: help from family and friends, sources of information, childcare, provision of formal care, respite care, financial etc).
- If you needed advice on employment issues (re; return to work/job change/FT-PT options etc) where would you go?
- Have you used the services at Jobcentre Plus to obtain work or get advice?

### If yes ...

- O What was this for? What was your experience?
  - Did they help you in to employment previously/are they currently helping you to find employment?
  - What was/is the nature of the support received?
  - If you are currently receiving support to find work now, do you feel encouraged to find work by JC+/do JC+ seem keen to help you? Please describe the ways they did or didn't help.
  - How effective was the support and advice? Did it meet your needs?
  - Are there things you think Jobcentre Plus could do more of/less of/ differently/ anything in addition to what they already do?
  - Would you like to receive any kind of support described or wanted from JC+ in another place or in a different way? Please describe.
- o Were you offered:
  - A better-off calculation to help you make an informed choice regarding combining caring and entering or increasing hours of work?
  - Advice and/or access to advice about training opportunities? [If yes] did this include a plan of action for you indicating training you need? Have you completed the training? If not, what was the reason? If a provision was provided to offer care services while you attended training, would this make it more likely for you to attend training?
- If you receive Job Seeker's Allowance, as part of discussions with Job Centre Plus advisors regarding your JSA, were your care responsibilities taken into account? If yes, how did the advisor indicate this?

### If no (you haven't used JCP)...

- Might you consider getting advice from Job Centre Plus? If not why
  not? (probe just never thought of it or are there barriers such as
  exposing self as 'in need', concerns about benefits being taken away
  etc, concerns about being forced to work or do they perceive JCP
  negatively but without personal experience)?
- Might you be interested in any of the following services:
  - A better-off calculation to help you make an informed choice regarding combining caring and entering or increasing hours of work?
  - Advice and/or access to advice about training opportunities? If a provision was provided to offer care services while you attended training, would this make it more likely for you to be interested in training?
- If you get Carer's Allowance, or other benefits related to caring, has this influenced how you feel about working?
  - o Do you know about the Carer's Allowance work rules?
  - o Do you know about Working Tax Credit assistance?
  - o Have you ever been asked to attend a work focused interview (WFI)?
  - If so, how did it go (probe: were you comfortable with what was asked, did you feel it was useful and appropriate to your situation, did you feel understood and that your situation was handled appropriately.)
  - Was it useful? (if yes how? If no,why not?).
  - If caring responsibilities, or other circumstances, made it difficult for you to attend the interview, did you ask for it to be deferred to a later date or any other request for accommodation?
  - You are not obliged to take the advice given at the WFI or take any job available (esp. if that job does not fit with your work history or qualifications, or with your caring responsibilities). Knowing this, are you more inclined to attend a WFI or attend one in the future?

(Note to interviewer: If the carer is over 60 or under 18 they will NOT be asked to attend a WFI. Carers do NOT need a work-focused interview if they work at least 16 hours a week and don't get Income Support.)

 Have you received any other help from DWP and its agencies? What was your experience of that help?

### Thank you for your help.

### Non-Working

## **Interview Schedule: Employment Support for Carers**

Coue.	

PART A	Background infor	mation abou	t yourself	
1. W	/hat is your age?			
2. A	re you male □	female □ ?		
3. W	/hat is your marital sta	atus?		
	never married	married 🗆	co-habiting	divorced $\square$
	separated	widowed		
4. W	/ho lives in your hous	ehold with yo	u?	
5. W	spouse or partner adult son or dau child (step/foster parent or parent grandparent friend other (please spono one, live along/hat is your ethnic ground adults and the control of the cont	ghter r) -in-law ecify)		
	White British □ Irish □ Any other white back	kground 🗆	Black or Black Br Caribbean African Any other Black ba	
	Mixed White and Black Car White and Black Afri White and Asian Any other mixed bac	ican 🗆	Asian or Asian Boundian Pakistani Bangladeshi Any other Asian ba	
	Chinese or other en Chinese Any other		ease specify)	

### 6. What is your current employment status?

7.

	Working						
	Full-time  Semi-retired  Fixed-term  Self-employed	Pe	art-time ermanent nployed				
Types	of fixed-term:		ry employe ry agency v				
	g patterns: that apply)	Compress Standard' Flexitime Fixed Nig Rota Other	y from wee	ours (e. //back s ck shifts	g. 9-5; hifts	8-4)	
	Not working						
	Unemployed		oking for w ot looking	ork			
	If not working:		tired health and	/or disa	bility		
	Have you ever worke	d?	Yes		No		
	If yes, when did you s	stop workin	g?				
	Do you undertake vol	untary wor	k? Yes		No		
What is	the nature of your e	mployme	nt/ What v	vas you	ır main	line of	work?
	Job title						

8a. Wł	nat type of org	anisation are	you/did	you work for	?	
	Medium-size	business (over private employe business (less	er (betwe	en 50-249 em	ployees)	
8b. Ho	w many hour	s per week are	you/dic	d you work fo	r most recently	/?
	Less than 16 16-29 hours 30 or more ho	ours				
8c. W	ould you desc	ribe your emp	loyment	t history as		
	Intermittent di	gular employme ue to caring/par I due to caring/p	renting	9 -		
	Please specif	y				
9. Wh	at is your mai	in source of in	come?			
	Employment			Benefits		
	Pension			Savings		
	Other (please	specify				

# 10. We would like to get an idea of which income band your household falls within. Can you tell me approximately how much you get per year?

(Include benefits, salaries, rental income from property, income from children, pensions. Probe for disability and sickness benefits)

	Annual	Monthly
Α	Under £10,000	Under £800
В	£10,000 - £20,000	£800 - £1,600
С	£21,000 - £30,000	£1,700 - £2,500
D	£31,000 - £40,000	£2,600 - £3,300
E	Over £41,000	Over £3,300

menti	mention all that apply. (nb check current potential benefits)				
	Carer's Allowance Attendance Allowance Incapacity Benefit Disability Living Allowance Jobseeker's Allowance Income Support Pension Credit Housing Benefit/Council Tax Benefit Tax Credits Any other state benefit (please state)				
	None of these				
	On the whole, over the last 12 months would you say your health n the whole been good, fairly good, or not good?				
	Good				
	□ Fairly good □ Not good				
illnes troub	Do you have any long-standing physical or mental impairment, s or disability? By 'long-standing' I mean anything that has led you over a period of at least 12 months or that is likely to affect or a period of at least 12 months?				
illnes troub	s or disability? By 'long-standing' I mean anything that has led you over a period of at least 12 months or that is likely to affect or a period of at least 12 months?  Yes				
illnes troub	s or disability? By 'long-standing' I mean anything that has led you over a period of at least 12 months or that is likely to affect or a period of at least 12 months?				
troub you fo	s or disability? By 'long-standing' I mean anything that has led you over a period of at least 12 months or that is likely to affect or a period of at least 12 months?  Yes				
troub you fo 12c. I you h Pleas	s or disability? By 'long-standing' I mean anything that has led you over a period of at least 12 months or that is likely to affect or a period of at least 12 months?  Yes No				
12c. Eyou h	s or disability? By 'long-standing' I mean anything that has led you over a period of at least 12 months or that is likely to affect or a period of at least 12 months?  Yes No				
troub you fo 12c. I you h Pleas	s or disability? By 'long-standing' I mean anything that has led you over a period of at least 12 months or that is likely to affect or a period of at least 12 months?  Yes No				
12c. Eyou h	s or disability? By 'long-standing' I mean anything that has led you over a period of at least 12 months or that is likely to affect or a period of at least 12 months?  Yes No				
12c. E you h Pleas	s or disability? By 'long-standing' I mean anything that has led you over a period of at least 12 months or that is likely to affect or a period of at least 12 months?  Yes No				
12c. Eyou h	s or disability? By 'long-standing' I mean anything that has led you over a period of at least 12 months or that is likely to affect or a period of at least 12 months?  Yes No				
12c. E you h Pleas	s or disability? By 'long-standing' I mean anything that has led you over a period of at least 12 months or that is likely to affect or a period of at least 12 months?  Yes No				
12c. E you h Pleas	s or disability? By 'long-standing' I mean anything that has led you over a period of at least 12 months or that is likely to affect or a period of at least 12 months?  Yes No				

11. Are you receiving any of these benefits in your household? Please

12d. If yes: Does this hea	alth problem affect
	The kind of work that you might do? The amount of work that you might do? How long you might work for? If yes, how many hours can you work?
12e. Do you ı	receive care yourself?
	Yes No
13a. Has you	r own health been affected by your caring responsibilities?
	Yes No
13b. In what	ways? Tick any that apply
	Feeling tired Feeling depressed Loss of appetite Disturbed sleep General feelings of stress Physical strain (e.g. back ache) Short-tempered/irritable Had to see own GP Other No, none of these
About Your Caring	g Responsibilities
<u>₹</u> 8	still providing care?
	Yes No
14b. If yes, h	ow would you describe your caring responsibilities?
	on-going fluctuates

14c. D	o you share □ Yes □ No	tne caring re	sponsibility with other people?
14d. If	the main equally r	carer and oth esponsible fo	of the caring responsibility. Are you: ners provide some help r providing the care arer
15. Ho	w old is the	person you d	are(d) for
16. ls/\	was this pers	on male or f	emale?
Male		Female	
17. Wh	at is/was yo	ur relationsh	ip to this person?
l am/	adult sor child (ste parent or grandpar friend or	or partner or daughter ep/foster) r parent-in-lav rent neighbour	v
18a. W	/here does/d	id the persor	you look after live?
	In a care hor	ne same hous ne/hospital accommodati	ehold on/housing with extra care
18b Ho	ow long does the same ho	it take you usehold?	to get to where the person is, if he/she is
Hours/	minutes		
18c. H	ow do you g	et there?	
	Walk Car Bus Train		

	mobility (moving around) lifting, carrying and moving objects manual dexterity (using your hands to carry out everyday tasks) continence (bladder and bowel control) communication (speech, hearing or eyesight) memory or ability to concentrate, learn or understand recognising when they are in physical danger physical co-ordination (eg balance) other health problem or disability Please specify
20. Wł	nen did you start caring? Approximate year
	r about how long have you been providing/did you provide ort or care to your relative/friend?
	Under a year 1-3 yrs 3-5 yrs 5-10 yrs More than 10 years
	ease tick the nearest amount of time you currently spend/used to providing support or care in a typical week.
	<ul><li>1-19 hours a week</li><li>20-49 hours a week</li><li>50+ hours a week</li></ul>

23. What kinds of activities do you/did you regularly help them with? Please tick all those that apply.
Physical help e.g. walking, getting up and down stairs, getting in and out of bed
Personal care e.g. washing, dressing, feeding, using the toilet
Helping with paperwork or financial matters e.g. filling in forms, dealing with bill, banking
Other practical help e.g. preparing meals, doing his/her shopping, laundry, housework, gardening, taking to the doctor's/hospital
Keeping him/her company e.g. visiting, sitting with, reading to
Taking him/her out e.g. taking out for a walk or drive, taking to see friends/relatives
Giving medicines e.g. making sure s/he takes pills, injections, changing dressings
Keeping an eye on him/her to make sure s/he is alright/not doing anything risky e.g. leaving the gas on unlit, wandering out of doors
Other (please state)
24. Do/did these care needs
☐ Fluctuate ☐ Remain constant ☐ Increase

25. Do/did you, or the person you support	, receive any help from the
following? Tick those that apply.	

	Yourself	Cared for person
Relatives		
Friends		
Neighbours		
3 333 6		
And what about more formal s	sources of help?	
	Yourself	Cared for person
District/community nurse		
Social worker/care manager		
Home help/care worker		
Meals on wheels		
Respite care (eg in a care hor	me)	
Sitting service		
Day centre/hospital		
Carers social or support group	ρ 🗆	
Other support from carers age	ency 🗆	
Other services		
please specify		
26 D-/did and all all all all all all all all all al		
26. Do/did you pay any charges for these services (not private ones)?		
□ Yes	No	
=		
27. Have you ever been offered or had an assessment of your needs by		
a care manager/social worker? This would include a dedicated		
discussion of your needs as a care giver.		
Offered \( \square\) Yes		
	□ No	0

# PART B Interview: Views and Experiences of Working and Support Needs

### Those who are not currently working

#### 1. How do you feel about working?

#### Prompts:

- Would you like to work?
  - If so, why? what do you feel you would get out of working i.e. financially, socially etc? Do you feel you would be better off financially/socially?
  - Explore situation if retired if you retired early was this due to caring demands? Please describe.
- Have you tried to get a job at all?
  - If yes, why? What sort of work were you looking for? What were your experiences of doing this? (probe: qualifications, confidence, job readiness, closeness to the job market, nature of caring responsibilities, potential financial disincentives)
  - If no, why is that? (probe: qualifications, confidence, job readiness, closeness to the job market, nature of caring responsibilities, potential financial disincentives)
- What sort of work do you feel you could do? (probe: types of work, number of hours, flexible working/hours, location, getting to work)
  - Do you think that type of work is available? Why do you think it is not available? (probe: why do you believe this is not the case and are they aware of flexible working legislation)
- If you needed advice on employment issues (re; return to work/job change/FT-PT options etc) where would you go?
- Have you used the services at Jobcentre Plus to obtain work or get advice?

## If yes ...

- O What was this for? What was your experience?
  - Did they help you in to employment previously/are they currently helping you to find employment?
  - What was/is the nature of the support received?
  - If you are currently receiving support to find work now, do you feel encouraged to find work by JC+/do JC+ seem keen to help you? Please describe the ways they did or didn't help.
  - How effective was the support and advice? Did it meet your needs?
  - Are there things you think Jobcentre Plus could do more of/less of/ differently/ anything in addition to what they already do?
  - Would you like to receive any kind of support described or wanted from JC+ in another place or in a different way? Please describe.

- o Were you offered:
  - A better-off calculation to help you make an informed choice regarding combining caring and entering or increasing hours of work?
  - Advice and/or access to advice about training opportunities? [If yes] did this include a plan of action for you indicating training you need? Have you completed the training? If not, what was the reason? If a provision was provided to offer care services while you attended training, would this make it more likely for you to attend training?
- If you receive Job Seeker's Allowance, as part of discussions with Job Centre Plus advisors regarding your JSA, were your care responsibilities taken into account? If yes, how did the advisor indicate this?

### If no (you haven't used JCP)...

- Might you consider getting advice from Job Centre Plus? If not why
  not? (probe just never thought of it or are there barriers such as
  exposing self as 'in need', concerns about benefits being taken away
  etc, concerns about being forced to work or do they perceive JCP
  negatively but without personal experience)?
- · Might you be interested in any of the following services:
  - A better-off calculation to help you make an informed choice regarding combining caring and entering or increasing hours of work?
  - Advice and/or access to advice about training opportunities? If a provision was provided to offer care services while you attended training, would this make it more likely for you to be interested in training?
- If you get Carer's Allowance, or other benefits related to caring, has this influenced how you feel about working?
  - o Do you know about the Carer's Allowance work rules?
  - o Do you know about Working Tax Credit assistance?
  - o Have you ever been asked to attend a work focused interview (WFI)?
  - If so, how did it go (probe: were you comfortable with what was asked, did you feel it was useful and appropriate to your situation, did you feel understood and that your situation was handled appropriately.)
  - Was it useful? (if yes how? If no,why not?).
  - If caring responsibilities, or other circumstances, made it difficult for you to attend the interview, did you ask for it to be deferred to a later date or any other request for accomodation?
  - You are not obliged to take the advice given at the WFI or take any job available (esp. if that job does not fit with your work history or qualifications, or with your caring responsibilities). Knowing this, are you more inclined to attend a WFI or attend one in the future?

(Note to interviewer: If the carer is over 60 or under 18 they will NOT be asked to attend a WFI. Carers do NOT need a work-focused interview if they work at least 16 hours a week and don't get Income Support.)

• Have you received any other help from DWP and its agencies? What was your experience of that help?

### In relation to previous work experience...

### 2. How has your caring role impacted on your experiences of working? Prompts:

- What are your previous experiences of working and caring?
  - What sort of work did you do? (probe: hours, flexibility)
  - What was your working experience like? Tell me about good and bad experiences.
  - How did your caring responsibilities fit with your work experiences, especially if the nature of your responsibilities changed, fluctuated or were ad hoc?
  - What sorts of help did you get from your workplace colleagues, managers etc? (probe: direct support from manager or colleagues, flexible shift patterns/working hours to suit care demands)
- Why did you give up?
  - Did you have to give up work to care for someone? Please tell me about the circumstances.
  - Did the help from your employers/the workplace meet your needs? If not, why was this? Where were the gaps?
  - Did you try and negotiate different arrangements with your employer?
     If yes, what happened? (n.b. Are you aware of the right to request flexible working and did you pursue this option before leaving?)
  - What more could have been done to help you to stay in work by family, friends, or health and social care agencies?

## 3. If you were to consider getting a job, what sorts of things would help you the most?

#### Prompts:

- Out of choice, where would you go for help and support?
- What sorts of things would meet your needs better? (probe: help from friends and relatives, sources of information, childcare, provision of formal care, respite care, financial etc).
- What sort of practical support would you need to help you find a job? (probe: help with application forms, finding out about job vacancies, interview practice, help with confidence building/self esteem and where you would like to go to for that support)
- Have you ever had help or advice from any person or organisations? If so, please describe what this help was and who it was from.
  - o Was it useful?
  - o Did it meet your needs?
  - o Was there a particular reason why you went specifically to them?
- Have you ever gone back to a previous employer or colleague for help or any other reason? If so;
  - o Was it useful?
  - o Did it meet your needs?
  - o What do you think of this idea?

## Thank you for your help.

## **Ceased Caring**

## **Interview Schedule: Employment Support for Carers**

10	<b>O</b> I	
11)	Code:	
	Couc.	

PART A	Background information about yourself					
1.	What is your age?					
2.	Are you male □	female □ ?				
3.	What is your marital state	us?				
	never married □	married	co-habiting	divorced 🗆		
	separated	widowed 🗆				
4.	Who lives in your housel	nold with you	?			
	spouse or partner adult son or daughter child (step/foster) parent or parent-in-law grandparent friend other (please specify) no one, live alone  5. What is your ethnic group? tick one box only					
	<b>White</b> British □		Black or Black Britis Caribbean			
	Irish		African			
	Any other white backg	round 🗆	Any other Black back			
	Mixed White and Black Carib White and Black Africa White and Asian Any other mixed back	an 🗆	Asian or Asian Britis Indian Pakistani Bangladeshi Any other Asian back			
	Chinese or other ethi	nic group				
	Chinese		una annogifu)			
	Any other	_ (plea	ise specify)			

## 6. What is your current employment status?

7.

	Working						
	Full-time  Semi-retired  Fixed-term  Self-employed		time nanent loyed				
Types	of fixed-term:	Temporary a					
	ng patterns: I that apply)	Term-time Job share Hours vary f Compressed Standard' da Flexitime Nig Fixed Night/ Rota Other Please spec	d week aytime he ght/early early/ba	ours (e. /back s ck shifts	g. 9-5; hifts s	8-4)	
	Not working						
	Unemployed		ng for w	ork			
	If not working:	retire ill-he	ed alth and	or disa	bility		
	Have you ever worked	d?	Yes		No		
	If yes, when did you s	stop working?					
	Do you undertake vol	untary work?	Yes		No		
What is the nature of your employment/ What was your main line of work?							
	Job title						

8a. Wh	8a. What type of organisation are you/did you work for?				
8b. Ho	Public organisation  Large private business (over 250 employees)  Medium-size private employer (between 50-249 employees)  Small private business (less than 50 employees)  Self-employed  . How many hours per week are you/did you work for most recently?				
	Less than 16 16-29 hours 30 or more ho	urs			
8c. Wo	ould you desc	ribe your emp	loyment	history as	
	Intermittent du	gular employme ue to caring/par due to caring/p	renting		
	Please specify	/			
9. What is your main source of income?					
	Employment		I	Benefits	
	Pension		;	Savings	
	Other (please specify				

# 10. We would like to get an idea of which income band your household falls within. Can you tell me approximately how much you get per year?

(Include benefits, salaries, rental income from property, income from children, pensions. Probe for disability and sickness benefits)

	Annual	Monthly
Α	Under £10,000	Under £800
В	£10,000 - £20,000	£800 - £1,600
С	£21,000 - £30,000	£1,700 - £2,500
<b>D</b> £31,000 - £40,000		£2,600 - £3,300
E	Over £41,000	Over £3,300

mentio	mention all that apply. (nb check current potential benefits)				
	Carer's Allowance Attendance Allowance Incapacity Benefit Disability Living Allowance Jobseeker's Allowance Income Support Pension Credit Housing Benefit/Council Tax Benefit Tax Credits Any other state benefit (please state)				
	None of these				
	on the whole, over the last 12 months would you say your health in the whole been good, fairly good, or not good?				
	☐ Good ☐ Fairly good				
	□ Not good				
illness troubl	to you have any long-standing physical or mental impairment, s or disability? By 'long-standing' I mean anything that has ed you over a period of at least 12 months or that is likely to affect or a period of at least 12 months?				
	Yes				
	□ No				
12c. Does this/do these health problem(s) or disability(ies) mean that you have substantial difficulties with any of these areas of your life? Please tick any that apply to you					
	mobility (moving around)				
	lifting, carrying and moving objects manual dexterity (using your hands to carry out everyday tasks)				
	continence (bladder and bowel control)				
	communication (speech, hearing or eyesight)				
	memory or ability to concentrate, learn or understand recognising when you are in physical danger				
	your physical co-ordination (eg balance)				
	other health problem or disability Please specify				

11. Are you receiving any of these benefits in your household? Please

12d. If yes: Does this he	12d. If yes: Does this health problem affect				
	The kind of work that you might do? The amount of work that you might do? How long you might work for? If yes, how many hours can you work?				
12e. Do you	receive care yourself?				
<u> </u>	Yes No				
13a. Has yoเ	r own health been affected by your caring responsibilities?				
	Yes No				
13b. In what	ways? Tick any that apply				
	Feeling tired Feeling depressed Loss of appetite Disturbed sleep General feelings of stress Physical strain (e.g. back ache) Short-tempered/irritable Had to see own GP Other No, none of these				
About Your Caring Responsibilities					
	still providing care?				
	Yes No				
14b. If yes, h	now would you describe your caring responsibilities?				
	on-going fluctuates ad hoc				

14c. D	o you share □ Yes		sponsibility with other people?
	□ No		
14d. If	the mai equally	n carer and oth responsible for	f the caring responsibility. Are you: ers provide some help providing the care arer
15. Ho	w old is the	person you c	are(d) for
16. ls/v	was this pe	rson male or fe	emale?
Male		Female	
17. Wh	at is/was y	our relationshi	p to this person?
am/	adult so child (s parent grandpa friend o	or partner on or daughter tep/foster) or parent-in-law arent or neighbour	
18a. W	here does/	did the person	you look after live?
	In a care ho	the same house ome/hospital d accommodation	ehold on/housing with extra care
18b Ho	ow long doe the same h	es it take you to ousehold?	o get to where the person is, if he/she is
Hours/	minutes	-	
18c. H	ow do you	get there?	
	Walk Car Bus Train		

	lifting, carrying and moving objects manual dexterity (using your hands to carry out everyday tasks) continence (bladder and bowel control) communication (speech, hearing or eyesight) memory or ability to concentrate, learn or understand recognising when they are in physical danger physical co-ordination (eg balance)				
20. Wh	nen did	you start caring? Approximate year			
		how long have you been providing/did you provide re to your relative/friend?			
		Under a year 1-3 yrs 3-5 yrs 5-10 yrs More than 10 years			
22. Please tick the nearest amount of time you currently spend/used to spend providing support or care in a typical week.					
		1-19 hours a week 20-49 hours a week 50+ hours a week			

19. What sorts of health problems does/did this person have? Please tick any that apply.

23. What kinds of activities do you/did you regularly help them with? Please tick all those that apply.
Physical help e.g. walking, getting up and down stairs, getting in and out of bed
Personal care e.g. washing, dressing, feeding, using the toilet
Helping with paperwork or financial matters e.g. filling in forms, dealing with bill, banking
Other practical help e.g. preparing meals, doing his/her shopping, laundry, housework, gardening, taking to the doctor's/hospital
Keeping him/her company e.g. visiting, sitting with, reading to
Taking him/her out e.g. taking out for a walk or drive, taking to see friends/relatives
Giving medicines e.g. making sure s/he takes pills, injections, changing dressings
Keeping an eye on him/her to make sure s/he is alright/not doing anything risky e.g. leaving the gas on unlit, wandering out of doors
Other (please state)
24. Do/did these care needs
Fluctuate Remain constant Increase

25. Do/did you,	or the person	you support,	receive any	help from the
following? Tick	those that app	oly.		

		Yourself	Cared for person		
	Relatives				
	Friends				
	Neighbours				
	And what about more formal so	urces of help	)?		
		Yourself	Cared for person		
	District/community nurse				
	Social worker/care manager				
	Home help/care worker				
	Meals on wheels				
	Respite care (eg in a care home	e) 🗆			
	Sitting service				
	Day centre/hospital				
	Carers social or support group				
	Other support from carers agen				
	Other services				
	please specify				
26. Do	oldid you pay any charges for t	hese servic	es (not private ones)?		
	Yes	No			
27. Have you ever been offered or had an assessment of your needs by a care manager/social worker? This would include a dedicated discussion of your needs as a care giver.					
	Offered Yes		No		
	Had  Yes		No		

# PART B Interview: Views and Experiences of Working and Support Needs

### Those who are no longer caring but would like to work

### 1. How do you feel about working?

#### Prompts:

- Would you like to work?
  - If so, why? what do you feel you would get out of working i.e. financially, socially etc? Do you feel you would be better off financially/socially?
  - Explore situation if retired if you retired early was this due to caring demands? Please describe.
- Have you tried to get a job at all?
  - If yes, why? What sort of work were you looking for? What were your experiences of doing this? (probe: qualifications, confidence, job readiness, closeness to the job market, nature of caring responsibilities, potential financial disincentives)
  - If no, why is that? (probe: qualifications, confidence, job readiness, closeness to the job market, nature of caring responsibilities, potential financial disincentives)
- What sort of work do you feel you could do? (probe: types of work, number of hours, flexible working/hours, location, getting to work)
  - Do you think that type of work is available? Why do you think it is not available? (probe: why do you believe this is not the case and are they aware of flexible working legislation)
- If you needed advice on employment issues (re; return to work/job change/FT-PT options etc) where would you go?
- Have you used the services at Jobcentre Plus to obtain work or get advice?

#### If yes ...

- o What was this for? What was your experience?
  - Did they help you in to employment previously/are they currently helping you to find employment?
  - What was/is the nature of the support received?
  - If you are currently receiving support to find work now, do you feel encouraged to find work by JC+/do JC+ seem keen to help you? Please describe the ways they did or didn't help.
  - How effective was the support and advice? Did it meet your needs?
  - Are there things you think Jobcentre Plus could do more of/less of/ differently/ anything in addition to what they already do?
  - Would you like to receive any kind of support described or wanted from JC+ in another place or in a different way? Please describe.

- o Were you offered:
  - A better-off calculation to help you make an informed choice regarding combining caring and entering or increasing hours of work?
  - Advice and/or access to advice about training opportunities? [If yes] did this include a plan of action for you indicating training you need? Have you completed the training? If not, what was the reason? If a provision was provided to offer care services while you attended training, would this make it more likely for you to attend training?
- If you receive Job Seeker's Allowance, as part of discussions with Job Centre Plus advisors regarding your JSA, were your care responsibilities taken into account? If yes, how did the advisor indicate this?

## If no (you haven't used JCP)...

- Might you consider getting advice from Job Centre Plus? If not why
  not? (probe just never thought of it or are there barriers such as
  exposing self as 'in need', concerns about benefits being taken away
  etc, concerns about being forced to work or do they perceive JCP
  negatively but without personal experience)?
- Might you be interested in any of the following services:
  - A better-off calculation to help you make an informed choice regarding combining caring and entering or increasing hours of work?
  - Advice and/or access to advice about training opportunities? If a provision was provided to offer care services while you attended training, would this make it more likely for you to be interested in training?
- If you get Carer's Allowance, or other benefits related to caring, has this influenced how you feel about working?
  - o Do you know about the Carer's Allowance work rules?
  - o Do you know about Working Tax Credit assistance?
  - o Have you ever been asked to attend a work focused interview (WFI)?
  - If so, how did it go (probe: were you comfortable with what was asked, did you feel it was useful and appropriate to your situation, did you feel understood and that your situation was handled appropriately.)
  - Was it useful? (if yes how? If no,why not?).
  - If caring responsibilities, or other circumstances, made it difficult for you to attend the interview, did you ask for it to be deferred to a later date or any other request for accommodation?
  - You are not obliged to take the advice given at the WFI or take any job available (esp. if that job does not fit with your work history or qualifications, or with your caring responsibilities). Knowing this, are you more inclined to attend a WFI or attend one in the future?

(Note to interviewer: If the carer is over 60 or under 18 they will NOT be asked to attend a WFI. Carers do NOT need a work-focused interview if they work at least 16 hours a week and don't get Income Support.)

 Have you received any other help from DWP and its agencies? What was your experience of that help? In relation to previous work experience...

### 2. How has your caring role impacted on your experiences of working? Prompts:

- What are your previous experiences of working and caring?
  - What sort of work did you do? (probe: hours, flexibility)
  - What was your working experience like? Tell me about good and bad experiences.
  - How did your caring responsibilities fit with your work experiences, especially if the nature of your responsibilities changed, fluctuated or were ad hoc?
  - What sorts of help did you get from your workplace colleagues, managers etc? (probe: direct support from manager or colleagues, flexible shift patterns/working hours to suit care demands)
- Why did you give up?
  - Did you have to give up work to care for someone? Please tell me about the circumstances.
  - Did the help from your employers/the workplace meet your needs? If not, why was this? Where were the gaps?
  - Did you try and negotiate different arrangements with your employer?
     If yes, what happened? (n.b. Are you aware of the right to request flexible working and did you pursue this option before leaving?)
  - What more could have been done to help you to stay in work by family, friends, or health and social care agencies?

# 3. If you were to consider getting a job, what sorts of things would help you the most?

## Prompts:

- Out of choice, where would you go for help and support?
- What sorts of things would meet your needs better? (probe: help from friends and relatives, sources of information, childcare, provision of formal care, respite care, financial etc).
- What sort of practical support would you need to help you find a job?
   (probe: help with application forms, finding out about job vacancies, interview practice, help with confidence building/self esteem and where you would like to go to for that support)
- Have you ever had help or advice from any person or organisations? If so, please describe what this help was and who it was from.
  - o Was it useful?
  - o Did it meet your needs?
  - o Was there a particular reason why you went specifically to them?
- Have you ever gone back to a previous employer or colleague for help or any other reason? If so;
  - o Was it useful?
  - o Did it meet your needs?
  - o What do you think of this idea?

## Thank you for your help.

ID	Code:	
	Age:	

## Timeline Grid – Key events in my life

Age	Work history, type of work	Qualifications (NVQs/ Degrees/etc.)	Marriage and Partnerships	Periods of dependent children	History of caring, stages, events	Periods where caring & working combine	Health events	Other significant life events
14-19								
20-29								

Age	Work history, type of work	Qualifications (NVQs/ Degrees/etc.)	Marriage and Partnerships	Periods of dependent children	History of caring, stages, events	Periods where caring & working combine	Health events	Other significant life events
30-39								

40-49								
	Work	Qualifications	Marriage	Periods of	History of	Periods where	Health	Other
Age	history,	(NVQs/	and	dependent children	caring,	caring &	events	significant life events
	lvbe or	Degrees/etc.)	Partnerships	Ciliaren	Stayes,	working		me events
	type of work	Degrees/etc.)	Partnerships	Ciliaren	stages, events	working combine		me events
50-59		Degrees/etc.)	Partnerships	Ciliaren				me events
50-59		Degrees/etc.)	Partnerships	ciniaren				me events
50-59		Degrees/etc.)	Partnerships	ciniaren				me events
50-59		Degrees/etc.)	Partnerships	ciniaren				me events
50-59		Degrees/etc.)	Partnerships	Ciniuren				me events

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## Where to go for information and advice

#### Genera

#### Citizens Advice Bureau

Offers advice on a wide range of subjects from housing and health to debt and consumer issues.

Phone 020 7833 2181

Website www.adviceguide.org.uk

## Directgov

This website offers people guidance about working patterns that would suit them by first taking them through a set of questions about their current job circumstances and their ideal working arrangements.

As well as suggesting suitable flexible working patterns it gives advice on presenting a case to an employer and outlines any rights to flexible working

Website: www.directgov.gov.uk

### **Working Life**

### Age Positive

Promotes the benefits of employing a mixed-age workforce, including older people.

Email agepositive@dwp.gsi.gov.uk

Website www.agepositive.gov.uk

#### Jobcentre Plus

Can help you find the right kind of job: full-time or part-time, temporary or permanent.

Phone 0845 6060 234 (textphone 08456 044 022)

Open weekdays 9am to 6pm, and Saturdays 9am to 1pm

Website www.jobcentreplus.gov.uk

## New Deal 50 plus

A programme for people aged 50 or over who have been out of work and claiming benefits for at least six months.

Phone 08456 062 626 (textphone 08456 060 680)

Website www.jobcentreplus.gov.uk/JCP/Customers/NewDeal/index.html

## Learning opportunities and leisure

#### LearnDirect

Provides online courses, and information about the network of *learndirect* centres.

Phone 0800 100 900

Website www.learndirect-advice.co.uk

#### **UK** online

Their network of centres provide access to computers, internet and email locally.

Phone 0800 77 1234

Email <u>ukonlinecentredata@ufi.com</u>

Website www.ukonlinecentres.com/consumer/

## Money matters

#### The Pension Service

The Pension Service is the part of the Department for Work & Pensions that works out and pays pension entitlements.

Phone 0845 6060 265 (textphone 0845 6060 285)

Open Monday to Friday, 8am to 6pm

Website www.thepensionservice.gov.uk

## Carers Issues

### Carers UK

Carers UK is the voice of carers across the UK. It provides a wide range of advice & information to family carers - those who look after an ill, frail or disabled family member, friend or partner. It also campaigns to end injustice. **Phone** CarersLine on 0808 808 7777

Website www.carersuk.org/

THANK YOU FOR TAKING PART

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## **Section 3: Commentary and Conclusions**

This submission under staff rules contains a total of 33 published items; 22 of which are in Section 1 and 11 of which are in Section 2. Whilst the issues addressed in the two Sections are distinctive and different there are a number of cross cutting themes: age related issues; the role of health and social care services; user and carer involvement; and conceptualisations of ageing, caring and mental health. In addition there are topic areas that bridge the two fields: dementia caring; carers of care home residents with dementia; and the role that caring plays in placing mid life women and older carers at risk of mental ill health. Common approaches to the research is a third shared factor; both fields are characterised by mixed methods and by work that aims to strike a balance between 'pure' social research and applied research that can improve the lives of older people and carers and/or enhance the provision of health and social care. Reviewing and distilling policy messages is a core feature of much of my care related work and the implications of both policy and research for practice and for users is an associated dimension. A capacity to problematise research questions is a growing focus of work in both fields as is an interest in the role that sociological discourse can play in enhancing and deepening understanding of an issue such as early diagnosis of dementia.

My work spans a number of care settings and care pathway stages including primary care, secondary care and care homes. It also speaks to a range of audiences: users and carers, front line care staff (e.g. SCIE e-learning materials), practitioners/clinicians as well as, or alongside in some cases, academic audiences. The two papers on screening are a good example of this (A6 and A7). Additionally the materials are presented in a number of forms - reports for both government departments (e.g. Department of Health, Department for Work and Pensions) and charities (e.g. Mental Health Foundation, Help the Aged), book chapters, academic and practice journals and e-learning. The majority are academic papers (19) or book chapters (6) commensurate with a PhD thesis to allow the presentation of a distinctive body of research.

In terms of key contributions to knowledge and the enhancement of understanding I would lay claim to an impact in three areas:

- Early intervention in dementia care
- Mental health in later life, and
- Older carers

## Early intervention in dementia care

When I began work in this field in 1998/9 almost nothing was published, particularly in the UK, about the nature and impact of early diagnosis of dementia on patients or medical practitioners. This field has moved on considerably since then; early diagnosis and intervention is now one of the gaols of the 2009 *National Dementia Strategy* (Department of Health, 2009) and has been highlighted as pivotal for people with dementia in recent policy related reports and guidance (House of Commons Committee of Public Accounts, 2008; National Institute for Health and Clinical Excellence and Social Care Institute for Excellence, 2007). Whilst my work has played only a part in the paradigm shift towards early intervention, my specific contribution has been: to help develop a scale to assess change in attitude towards early diagnosis amongst GPs; conducting a clinically relevant review of the use, quality and efficacy of screening tools for use in primary care; the incorporation of users/patient perspectives into the development of good practice in diagnosis and management of the early phase of the illness; and identifying the psychosocial benefits of early diagnosis. Additionally, I have been part of projects working with an Asian community

to facilitate understanding about, and access to, early diagnosis and most recently I have incorporated a more critical sociological lens into my work in this field. This important perspective is an emerging challenge to the almost universally positivistic drive for early diagnosis. Extending understanding of how people identify the signs and symptoms of dementia is another, new facet of the early intervention jigsaw, a goal that is being pursued in the 'help seeking' paper (A10) and in a linked research bid.

This body of work has enhanced understanding of early intervention in dementia care, has developed new knowledge and extended the potential of primary care (in particular) to meet user and carer need effectively. I would also argue that this sustained focus on early intervention has played a role in improving the whole dementia care system's capacity to manage and provide for users in the early stages of dementia and their relatives.

### Mental health in later life

My work under this topic head takes two forms: service development for older people with mental illness (primarily dementia) and defining and promoting mental health and well being.

The importance of developing services for people in the early stages of dementia links this area of work with the work on early intervention discussed above. The 'Dementia Advice and Support Service' (R3) was one of the first examples of a service that pro-actively set out to identify and work with people in the early stages of dementia seeking, or having, a diagnosis of dementia. It broke new ground and provided a template for subsequent services development in this arena. The review of the work and roles of Older People's Community Mental Health Teams (R4) was also a first, providing evidence about how 'integration' was interpreted on the ground in teams and in synthesising research and practice related findings about 'what works' in terms of service delivery and meeting need. The development of a tool to assess the extent of a team's integration drawing on national performance indicators in health and social care was of particular value to the Department of Health, service commissioners and the teams' themselves. This report was widely regarded as very useful and has been credited with helping to inform the direction and nature of policy for older people with mental health problems. Examples of this impact are cited in Section 1's summary and overview.

My work focusing on care homes has also helped to foreground the needs of the largely hidden and marginalised population of care home residents. Appreciating the nature and complexity of user need has been an important aspect of this work particularly in relationship to mental illness. The challenges facing the care home sector in meeting need has also been highlighted. The perspective of the user 'living with dementia in the care home' has been largely absent from research on care home life until very recently when researchers have started to (try and) accommodate this experience. Although preliminary, my work capturing evidence from this emerging field of enquiry suggests that the user perspective has much to offer the drive to improve care practice in homes and enhance user quality of life. The incorporation of this work into books used by medical staff and staff in training is a specific contribution that I have made (C1 and C2). My ability to bring a social care lens to a health dominated arena is also a strength.

At a broader more conceptual level my work has also made a contribution to understanding the nature of mental health and ill health, their antecedents and dimensions. Unpacking the links between mental health, well being and quality of life is one such contribution, how it can be promoted another. The role of social inequalities in creating or deepening vulnerability to mental ill health is a third. This work informed the development of the e-learning materials for SCIE as well as being the focus of book chapters and papers. It has challenged the dominance of the 'medical model' of mental illness and extended the range of the lens of analysis used to understand the causes and context of mental ill health. It has also informed approaches to promoting mental well being and identified the importance of taking a life course approach to managing mental distress. This is a powerful element of the paper on older women's mental health (A13) and the chapter on older people with severe and enduring mental illness (C5). The capacity to live 'successfully' with dementia is another challenge to perceived wisdom and one that is explored in a paper that identifies a more complex link between overall well being and having dementia (A12). These intersecting issues have enhanced understanding and extended knowledge of the links between the individual, their personal, economic and social situation, lifelong experiences, and mental health in later life and offered new and different ways to conceptualise 'mental health' and 'successful ageing'.

## Older carers

The 2001 report on older carers (R5) was the first to highlight the significant extent and contribution older people make to family caring. Whilst the receipt of care by older people had long been recognised, the giving of care by elders had not. This prompted a wider interest in older carers and did make a significant contribution to recognition of older carers in policy and by charities that work with carers e.g. Carers UK. My work on late life spouse care and carers of people from black and minority ethnic communities flowed from this original report and fed into the developing policy interest and research around the range of groups under the umbrella of 'older carer'. My work from the other two subject areas also intersects with work in this arena: a focus on women carers and the mental health risks associated with caregiving, dementia carers and carers of people in care homes, drawing on, and developing, knowledge in both fields of enquiry.

At a conceptual level the incorporation of age related issues *inside* the family care debate was a shift in thinking at that time and has broadened analytical understanding of caregiving. The role of lifelong spousal commitment in underpinning the motivation of wives and husbands to care is one example. It has also led to the explicit inclusion of older carers in policy e.g. the *Carers Strategy* (HM Government, 2008) and age and care related initiatives. A push to locate caring within a marriage or as an extension of a long term dyadic relationship is also driven, in part, by mine and others work on older carers.

My work on mid life and working carers is also relevant to the older carers' agenda. Not only are the roots of later life care often located in mid life but also the direction and nature of the care trajectory is influenced by mid life activities and choices. Daughters for example often begin caring for their elderly parents in mid life and continue to provide care post retirement, titrating input as needed. They may be obliged, in the process, to give up work or at least reduce their hours, an issue which is explored in depth in the *Employment Support for Carers* report for the Department for Work and Pensions. If carers do give up work in mid life to care this has a significant impact on their pension status and therefore their income in old age, an issue which is, in turn, addressed in my work on older carers. My membership of the *Standing Commission on Carers* is a key opportunity to actively take this portfolio of work into the policy development and implementation arena.

I have a long standing commitment to dissemination and knowledge transfer. In all three fields I have made strenuous efforts to ensure that research messages are delivered to services and care practice in an accessible manner, that my research and writing has an applied focus where appropriate, and that I involve myself in regional and national reference and advisory groups to communicate with, and learn from, others in the academic, policy and practice arenas.

## These include:

- 2000/2001: Member of the Advisory Group for the 'Forget-me-Not Review of Mental Health Services for Older People (Audit Commission, 2000, 2002)
- 2004-2006: Member of the National Patient's Safety Agency's Mental Health Expert Reference Group
- 2004-2005: Health Development Agency, Reference Group for, 'Promoting Mental
- Health: a review of Public Health Interventions'
- 2004-2006: St. Monica's Trust Advisory Group: 'Balanced Retirement Communities'
   A Case Study of Westbury Fields, Bristol
- 2005-2006: National Institute of Clinical Excellence/Social Care National Institute of Excellence Advisory Group: Care of People with Dementia and their Carers
- 2005-2008: Oversight Group, Care Services Improvement Partnership, South East Region Dementia Collaborative
- 2009-present day: Member of the Reference Group for 'Dementia Choices', a national project run by the Mental Health Foundation
- 2009-present day: Member of the Standing Commission on Carers

Invitations to be a member of these groups are a direct consequence of my research and publication record. I am also a board member of the journal *Quality in Ageing*, and speak at a wide range of national and international conferences.

## Conclusion

The work presented in this thesis constitutes a unified body of research and is accompanied by overarching commentary on the work's aims, results and conclusions. In particular my work has enhanced understanding and extended knowledge of: early intervention in dementia care; mental health in later life; and older carers. It has also contributed to understanding of the role of health and social care services, user and carer perspectives and involvement, and at a broader level, conceptualisations of ageing, caring and mental health. My research is cited at the intersection of social and applied research and at the junction of research and practice. My publications are of doctoral standard and my research work original. That much of the work has practice implications, is produced in partnership with colleagues, and routinely incorporates either the user perspective or is made accessible to users and carers is not only characteristic of work in this field but is also a key strength. I have active plans to continue to build on my research portfolio in both the fields of early intervention in dementia and late life caring. In particular I wish to further develop work in the conceptualisation of late life caregiving, the role and efficacy of services for carers, help seeking in early stage dementia and the promotion of mental health in later life. The material included in my submission provides a distinctive, coherent and extensive body of material upon which to continue to conduct research, publish and develop new knowledge.

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National Institute for Health and Clinical Excellence and Social Care Institute for Excellence (2007) *Guidelines on supporting people with dementia and their carers*, British Psychological Society and the Royal College of Psychiatrists, London

## **Appendix 1: Other Publications**

Mansell, J., Beadle-Brown, J., Cambridge, P., Milne, A., and Whelton, B. (2009) Adult protection: incidence of referrals, nature and risk factors in English local authorities, *Journal of Social Work*, 9(1): 23-38

Healey, F., Oliver, D., Milne, A and Connelly, J. B (2008) The effect of bedrails on falls and injury: a systematic review of clinical studies, *Age and Ageing*, 37: 368-378

Milne, A., Hatzidimitriadou, E and Wiseman, J (2007) Health and Quality of Life amongst Older People in Rural England: Exploring the Impact and Efficacy of Policy, *Journal of Social Policy*, 36(3): 477-495



## **Adult Protection**

Incidence of Referrals, Nature and Risk Factors in Two English Local Authorities

JIM MANSELL, JULIE BEADLE-BROWN, PAUL CAMBRIDGE, ALISOUN MILNE AND BECKIE WHELTON

Tizard Centre, University of Kent, England

#### **Abstract**

- Summary: This study focused on the incidence of adult protection referrals, the people involved as victims, perpetrators and referrers and the type of abuse in two local authorities in the south-east of England.
- Findings: The number of referrals increased over time; those for older people stabilized but those for younger adults were still rising. There was a clear association between location or setting, perpetrator and type of abuse. A referral about someone living in a care home was more likely to identify abuse by multiple staff and institutional abuse or neglect, especially if the individual was an older person with mental health problems. People with learning disabilities were more likely to experience sexual abuse, mainly from other service users or members of their family. Those living in a private home with others, primarily relatives, tended to be at risk of financial, physical or psychological abuse. Older people living alone were particularly vulnerable to financial abuse by family members or, less frequently, home care workers.
- Applications: This study suggests that well-developed adult protection
  procedures identify many more cases than previously estimated. Further
  research is needed to explain the low level of referrals from mental
  health services and variation between territories.

**Keywords** abuse adult protection intellectual disability mental health older people

## Introduction

Increased recognition of the importance and extent of abuse of vulnerable adults in the 1990s has led to attempts in some countries to quantify the amount of abuse occurring and to systematize its recording and how it was dealt with. What were initially largely separate strands of work on abuse of older people

DOI: 10.1177/1468017308098426

(particularly in the family home), of people with learning disabilities (particularly sexual abuse) and of people using mental health services (particularly abuse in therapeutic relationships) were brought together in a new area of policy and practice defined as 'adult protection' (Brown and Stein, 1998). Special arrangements have been created for adult protection in the USA (Goodrich, 1997; Mixson, 1995), Canada (Gordon, 1995), Britain (Association of Directors of Social Services, 1991) and Australia (Kurrle et al., 1997). The Council of Europe has begun to focus on protection of adults and children with disabilities (Council of Europe Committee of Ministers, 2005) and there is now a World Health Organization initiative to develop a global strategy for protection of older people from abuse (World Health Organization, 2002).

The form and operation of these arrangements differs between jurisdictions and necessarily reflects differences in the organization of social work services. In Britain, local authorities, working with other relevant partners such as the police and health services, began to develop arrangements for the recording of incidents of abuse and their management. These arrangements were intended to be coordinated across agencies and to cover all groups of people using services. Studies of these arrangements as they were developed by local authorities identified a number of issues. Brown and Stein (1998) found marked variation in reports of abuse between two English counties: one reported nearly double the number of alerts in a year of the other (26 versus 14 per 100,000 total population). Incidence varied between districts within the counties by a factor of seven (from 15 to 111 per 100,000 total population). In a later study of ten local authorities (Brown and Stein, 2000), covering a total population of 3.6 million, they also found wide variation. In the nine authorities which had working systems, they found an average incidence of 15 reports per 100,000 adult population (i.e. population over 18 years), ranging from two to 28.

Brown and Stein (1998) also found variation between service user groups. The largest group were older people (36% of reports), followed by people with intellectual disabilities (34%), people with mental health problems (16%) and people with physical impairments (14%). They noted that this showed a marked increase in risk of abuse in old age, a disproportionate representation of people with intellectual disabilities and a lower than expected number of mental health service users. In their later study (Brown and Stein, 2000), differences were even more marked, with 51 percent of referrals relating to older people, 32 percent to people with intellectual disabilities, seven percent to people with mental health problems and six percent to people with physical impairments. Differences between service user groups were related to differences between types of abuse. Thus, for example, more reports of financial abuse were made in respect of older people and more reports of sexual abuse were made in respect of people with intellectual disabilities (Brown and Stein, 1998, 2000).

Brown and Stein (1998, 2000) noted that some of the differences between territories, service user groups and types of abuse reflected real differences in risk, depending on the nature of people's vulnerability and circumstances.

However, they also concluded that differences in recording practice were important, reflecting different stages of policy and practice development, the extent to which different organizations played a part and differences in professional cultures and practices.

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Care standards of most recent published

inspection (for residential services only)

services only)

Previous address

Did the abuse take place in a care home?

employed in order to provide comparative information. Only eight months data for 2005 were available. Having checked that there were no significant differences on variables of interest between the first two-thirds and last third of previous years, the number of referrals for 2005 was inflated to give an estimate of referrals for the whole of 2005 in the presentation of incidence data across years.

The majority of data analysis was descriptive; frequency and percentage data are presented. Where comparisons were made between groups (e.g. between client groups, between those from within the authorities and those from out-of-area, etc.), the main analysis used was chi-square because of the nominal level of measurement for most variables. For the few variables where data were ordinal or interval level, Mann-Whitney analysis or independent *T*-tests were used. Multiple and univariate regression was used to explore variations in incidence. One-way ANOVA or Kruskal-Wallis ANOVA were

used for those group comparisons involving more than two groups, depending on whether parametric assumptions were fulfilled. Where very large number of analyses were conducted, only results where p < 0.001 are reported as significant. A more detailed account of the methodology is given in Cambridge et al. (2006).

## Results

#### Incidence of Adult Protection Referrals

Overall 6148 adult protection referrals were recorded on the adult protection database between 1998 and 2005. There was a substantial increase in the rate of referral over time, with the incidence rate for 2005 estimated at 83 per 100,000 total population. Such a crude figure obscures the effect of differences in the age-structure of the population. Table 2 presents these data separately for younger adults and older people as age-specific incidence rates per 10,000 of the population, to allow meaningful comparison. There was a significant difference for each population between districts (younger adults  $\chi^2 = 390.13$ , p < 0.001, d.f. = 12; older people  $\chi^2 = 991.05$ , p < 0.001, d.f. = 12) and across years (younger adults  $\chi^2 = 614.77$ , p < 0.001, d.f. = 7; older people  $\chi^2 = 1035.24$ , p < 0.001, d.f. = 7).

The difference between districts is likely to reflect differences in the age and disability profiles of the local population, the pattern of service provision (such as the number of residential care home places in each district) and differences in adult protection reporting and case management practice. Univariate regression showed that for younger adults, the population predicted number of referrals, though only explaining a small proportion of the variance ( $R^2 = 0.058$ , adjusted  $R^2 = 0.049$ , F = 6.322, p < 0.05). For older people, regression was not significant. Taking only the 2005 data and combining both age groups to obtain sufficient cases, regression of population and number of residential care home places showed that population did not predict referrals about people in care homes in 2005 but the number of care home places did ( $R^2 = 0.244$ , adjusted  $R^2 = 0.210$ , F = 7.115, p < 0.05). Exploratory univariate analysis for each of the age groups revealed that although neither analysis was significant at p < 0.05, the amount of variance explained by the number of care homes was 23 percent for older adults but only 3.8 percent for younger adults.

### People about Whom Adult Protection Referrals are Made

Table 3 illustrates the percentage of adult protection referrals by client group. The group labelled 'older people' includes older people with learning disabilities. There is a separate category for older people with mental health problems. Younger adults with learning disabilities who have mental health problems are included within the learning disability group. 'Other client groups' include people with sensory impairments, physical disabilities, substance misusers and

```
ERROR: timeout
OFFENDING COMMAND: timeout
STACK:
/.notdef
/.notdef
/parenright
/parenleft
/.notdef
/.notdef
/.notdef
/.notdef
/.notdef
/.notdef
/.notdef
/space
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# Adult Protection: Incidence of Referrals, Nature and Risk Factors in Two English Local Authorities

Jim Mansell, Julie Beadle-Brown, Paul Cambridge, Alisoun Milne and Beckie Whelton Journal of Social Work 2009; 9; 23 DOI: 10.1177/1468017308098426

The online version of this article can be found at: http://jsw.sagepub.com/cgi/content/abstract/9/1/23

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### **Adult Protection**

Incidence of Referrals, Nature and Risk Factors in Two English Local Authorities

JIM MANSELL, JULIE BEADLE-BROWN, PAUL CAMBRIDGE, ALISOUN MILNE AND BECKIE WHELTON

Tizard Centre, University of Kent, England

#### **Abstract**

- Summary: This study focused on the incidence of adult protection referrals, the people involved as victims, perpetrators and referrers and the type of abuse in two local authorities in the south-east of England.
- Findings: The number of referrals increased over time; those for older people stabilized but those for younger adults were still rising. There was a clear association between location or setting, perpetrator and type of abuse. A referral about someone living in a care home was more likely to identify abuse by multiple staff and institutional abuse or neglect, especially if the individual was an older person with mental health problems. People with learning disabilities were more likely to experience sexual abuse, mainly from other service users or members of their family. Those living in a private home with others, primarily relatives, tended to be at risk of financial, physical or psychological abuse. Older people living alone were particularly vulnerable to financial abuse by family members or, less frequently, home care workers.
- Applications: This study suggests that well-developed adult protection procedures identify many more cases than previously estimated. Further research is needed to explain the low level of referrals from mental health services and variation between territories.

Keywords abuse adult protection intellectual disability mental health older people

#### Introduction

Increased recognition of the importance and extent of abuse of vulnerable adults in the 1990s has led to attempts in some countries to quantify the amount of abuse occurring and to systematize its recording and how it was dealt with. What were initially largely separate strands of work on abuse of older people

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(particularly in the family home), of people with learning disabilities (particularly sexual abuse) and of people using mental health services (particularly abuse in therapeutic relationships) were brought together in a new area of policy and practice defined as 'adult protection' (Brown and Stein, 1998). Special arrangements have been created for adult protection in the USA (Goodrich, 1997; Mixson, 1995), Canada (Gordon, 1995), Britain (Association of Directors of Social Services, 1991) and Australia (Kurrle et al., 1997). The Council of Europe has begun to focus on protection of adults and children with disabilities (Council of Europe Committee of Ministers, 2005) and there is now a World Health Organization initiative to develop a global strategy for protection of older people from abuse (World Health Organization, 2002).

The form and operation of these arrangements differs between jurisdictions and necessarily reflects differences in the organization of social work services. In Britain, local authorities, working with other relevant partners such as the police and health services, began to develop arrangements for the recording of incidents of abuse and their management. These arrangements were intended to be coordinated across agencies and to cover all groups of people using services. Studies of these arrangements as they were developed by local authorities identified a number of issues. Brown and Stein (1998) found marked variation in reports of abuse between two English counties: one reported nearly double the number of alerts in a year of the other (26 versus 14 per 100,000 total population). Incidence varied between districts within the counties by a factor of seven (from 15 to 111 per 100,000 total population). In a later study of ten local authorities (Brown and Stein, 2000), covering a total population of 3.6 million, they also found wide variation. In the nine authorities which had working systems, they found an average incidence of 15 reports per 100,000 adult population (i.e. population over 18 years), ranging from two to 28.

Brown and Stein (1998) also found variation between service user groups. The largest group were older people (36% of reports), followed by people with intellectual disabilities (34%), people with mental health problems (16%) and people with physical impairments (14%). They noted that this showed a marked increase in risk of abuse in old age, a disproportionate representation of people with intellectual disabilities and a lower than expected number of mental health service users. In their later study (Brown and Stein, 2000), differences were even more marked, with 51 percent of referrals relating to older people, 32 percent to people with intellectual disabilities, seven percent to people with mental health problems and six percent to people with physical impairments. Differences between service user groups were related to differences between types of abuse. Thus, for example, more reports of financial abuse were made in respect of older people and more reports of sexual abuse were made in respect of people with intellectual disabilities (Brown and Stein, 1998, 2000).

Brown and Stein (1998, 2000) noted that some of the differences between territories, service user groups and types of abuse reflected real differences in risk, depending on the nature of people's vulnerability and circumstances.

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#### People about Whom Adult Protection Referrals are Made

Table 3 illustrates the percentage of adult protection referrals by client group. The group labelled 'older people' includes older people with learning disabilities. There is a separate category for older people with mental health problems. Younger adults with learning disabilities who have mental health problems are included within the learning disability group. 'Other client groups' include people with sensory impairments, physical disabilities, substance misusers and

Table 2 Incidence of adult protection referrals

Incidence rate per 10000	1998	1999	2000	2001	2002	2003	2004	2005
Younger adults (age-specif	ic rate)							
District 1	0.88	3.97	2.90	3.01	3.97	5.70	5.45	3.52
District 2	0.14	2.15	3.97	1.31	6.04	6.41	3.60	1.82
District 3	0.00	0.20	1.37	2.92	2.14	3.71	4.09	6.94
District 4	0.35	2.25	3.08	4.92	5.93	8.29	7.21	11.07
District 5	0.18	1.09	2.16	1.26	1.63	2.36	3.44	4.07
District 6	0.24	2.54	2.40	4.43	6.41	7.29	9.50	7.13
District 7	0.00	0.78	0.94	1.26	0.63	0.63	2.04	1.88
District 8	0.95	3.76	4.44	3.15	6.39	9.40	11.85	9.11
District 9	0.29	2.57	4.07	2.22	5.12	6.54	6.92	9.69
District 10	0.15	1.64	6.69	2.37	6.45	6.30	9.16	6.92
District 11	0.00	1.12	5.09	5.36	4.72	5.01	4.82	4.81
District 12	0.17	1.84	1.82	7.89	6.58	2.96	2.61	2.44
County	0.27	2.01	3.29	3.33	4.80	5.49	5.97	5.73
Unitary authority	0.00	0.00	0.07	0.07	2.01	3.93	3.34	9.12
Total	0.22	1.69	2.77	2.80	4.34	5.24	5.55	6.33
Older people (age-specific	rate)							
District 1	2.50	9.20	14.63	29.94	37.87	31.76	31.21	23.01
District 2	0.00	9.43	16.35	7.28	13.79	14.50	36.26	20.45
District 3	0.00	4.92	13.11	12.90	14.29	23.81	14.84	10.47
District 4	3.05	19.90	45.41	16.33	16.67	64.68	40.39	46.10
District 5	0.00	16.39	4.84	22.22	19.05	3.08	18.46	13.43
District 6	0.00	3.77	10.28	41.20	58.18	42.79	44.49	21.43
District 7	0.00	6.49	9.09	7.45	25.65	14.58	16.33	51.78
District 8	2.59	3.65	12.50	21.13	43.08	35.71	52.53	29.10
District 9	0.56	21.55	25.14	15.68	13.37	82.20	21.65	23.72
District 10	0.00	8.60	12.27	20.65	30.80	30.80	28.21	54.80
District 11	0.00	3.23	11.95	7.93	22.16	14.29	13.45	17.24
District 12	0.00	0.67	3.15	1.64	2.80	3.62	5.23	3.90
County	0.71	8.58	15.68	16.81	25.50	31.60	28.66	28.27
Unitary authority	0.00	0.00	0.00	0.00	9.40	10.19	7.95	20.97
Total	0.62	7.54	13.78	14.76	23.53	28.98	26.12	27.68

Table 3 Percentage of adult protection referrals for each client group

Client group	% Referrals				
Older people	48				
Older people with mental health problems	11				
Learning disability	32				
Mental health	3				
Other client group	6				

those classed simply as a 'vulnerable adult'. The difference between client groups in terms of number of referrals in total was significant ( $\chi^2 = 4368.11$ , p < 0.001, d.f. = 4). The majority of referrals were for older people; the lowest number was for people with mental health problems.

The average age of people about whom referrals were raised was 65.7 (range 17–106). Sixty-four percent were female ( $\chi^2 = 422.20, p < 0.001, d.f. = 1$ ); 96 percent were classified as White British.

Identification codes were available for 5162 referrals, relating to 4374 people, of whom 616 (14%) had more than one referral, ranging from two (n = 514) to 10 (n = 1) per individual.

#### **Living Situation**

Almost half (46%) of all adult protection referrals related to people in residential or supported living services, compared to a third (32%) to people living with their family and almost a fifth (17%) to people living alone. There was no association between living situation and district, nor between living situation and year of referral.

Information about the cost of care was available for only 529 cases. For these people the average cost of care in 2006 was £352 per week (range £4 to £3871). There was no significant difference at p < 0.001 in cost of care package by year of referral (p = 0.01) and type of abuse (p = 0.007) but there was a significant difference in cost by client group (Kruskall-Wallis = 61.07, p < 0.001, d.f. = 4), perpetrator (KW = 42.94, p < 0.001, d.f. = 8), location of abuse (KW = 91.61, p < 0.001, d.f. = 6) and whether they lived in a care home, their own or family home or another setting (KW = 96.97, p < 0.001, d.f. 2). Cost was higher for people living in care homes, where the abuse occurred in care homes, for people with learning disabilities and where the perpetrator was a member of staff.

Seven percent of people (n = 433) about whom referrals were raised were recorded on the database as placed by other authorities. The majority of people were placed by London authorities; 79.6 percent of those placed from out-of-area had a learning disability, 53 percent were male and seven percent were from non-white ethnic origins.

Sixty-four residential homes serving people on the adult protection database could be matched to one of the 448 homes for younger adults on the Commission for Social Care Inspection database. In terms of size of services, the homes on the adult protection database had slightly more places (t = -1.982, p < 0.05, d.f. = 450), with a mean number of 12 compared to nine places for homes that did not appear on the adult protection database. There was no significant difference in terms of percentage of care standards met or exceeded. On four of the individual standards, there was a trend for a difference (using Mann-Whitney U test) in the direction of homes serving people represented in the adult protection statistics to have a lower score than those who were not providing for people represented in the adult protection statistics. These were:

risk taking - 'staff enable service users to take responsible risks, ensuring they have good information on which to base decisions, within the context of the service user's individual Plan and of the home's risk assessment and risk management strategies' (Standard 9, z = 2.502, p = 0.012); Protection – 'service users are safeguarded from physical, financial or material, psychological or sexual abuse, neglect, discriminatory abuse or self-harm or inhuman or degrading treatment, through deliberate intent, negligence or ignorance, in accordance with written policy' (Standard 23, z = 1.195, p = 0.028); Staffing – 'staff have clearly defined job descriptions and understand their own and others' roles and responsibilities' (Standard 31, z = 2.711, p = 0.007) and Ethos – 'The management approach of the home creates an open, positive and inclusive atmosphere' (Standard 38, z = 2.101, p = 0.036). There were 45 services on the Commission for Social Care Inspection database for homes for older adults which also appeared on the adult protection database. A comparison of these yielded no significant difference in terms of the size of home, percentage of standards met or exceeded or score on any individual standards.

#### Type of Abuse

Multiple types of abuse were the most common category recorded, representing almost a third of all cases (Table 4). Within this category, the most common combination of abuse types was physical and psychological abuse (19% of multiple type referrals), followed by institutional abuse and neglect (10%), psychological abuse and financial abuse (9%) and neglect and physical abuse (8%). The next most frequently recorded type of abuse was physical abuse, representing almost a quarter of cases. The percentages of different types of abuse recorded in the years 1999 to 2005 had remained relatively stable. For example, physical abuse remained at between a fifth and a quarter of all cases throughout the period in question and financial abuse remained at between 13 and 15 percent. There was a significant association between client group and type of abuse ( $\chi^2 = 827.55$ , p < 0.001, d.f. = 32).

Table 4 Percentage of adult protection referrals by type of abuse

Type of abuse	% Referrals
Neglect	12.6
Financial	14.6
Institutional	0.2
Discriminatory	3.4
Physical	24.0
Psychological	6.5
Sexual	7.6
Other	0.3
Multiple types	30.8

Referrals about older people were more likely to relate to neglect and financial abuse than younger people.

Just over half the referrals related to abuse occurring in residential care, with the next most common location being the person's own home. There was a significant association between district and location of abuse ( $\chi^2 = 449.00, p < 0.001, d.f. = 72$ ). This may be explained by the proportion of each client group served in each district ( $\chi^2 = 764.44, p < 0.001, d.f. = 24$ ). There was a significant association between location and type of abuse ( $\chi^2 = 1089.24, p < 0.001, d.f. = 48$ ). The most frequently occurring types of abuse in residential care settings were physical abuse and neglect. Sexual and physical abuse each accounted for a third of the types of abuse in day support services. The most frequently recorded types of abuse occurring in people's own homes were physical abuse and financial abuse.

#### **Perpetrator Characteristics**

In 12.4 percent of cases there were two or three recorded perpetrators. There was a significant association between multiple perpetrators and type of abuse ( $\chi^2 = 341.51$ , p < 0.001, d.f. = 8). Multiple perpetrators were associated with: institutional abuse, multiple abuse, neglect and discriminatory abuse. The most frequent combinations of types of abuse were: institutional abuse and neglect; institutional abuse, neglect and psychological abuse; and psychological abuse, financial abuse and neglect. There was an association between multiple perpetrators and abuse occurring in care homes ( $\chi^2 = 249.68$ , p < 0.001, d.f. = 1); this is the case for 321 of the 337 cases where multiple perpetrators were recorded. There was also a significant association between multiple perpetrators and client group ( $\chi^2 = 154.85$ , p < 0.001, d.f. = 4) – older people with mental health problems being at particular risk.

Forty percent of referrals recorded the perpetrator as male and 37.5 percent female; the remainder were recorded as both (i.e. more than one person involved with at least one of each gender). There was a significant association between gender of perpetrator and client group ( $\chi^2 = 143.14$ , p < 0.001, d.f. = 8), with abuse by men more likely for those with a learning disability, a mental health problem, and other diagnoses, while older people were more likely to be abused by woman or by multiple perpetrators. There was also a significant association between gender of perpetrator and type of abuse ( $\chi^2 = 708.465$ , p < 0.001, d.f. = 16). Ninety percent of the referrals relating to sexual abuse were perpetrated by men, who were also the major category for physical (57%) and psychological (55%) abuse, while women were the majority category for discriminatory (60%), financial (54%) abuse and for neglect (50%). By far the biggest category for institutional abuse concerned multiple genders, accounting for 91 percent of referrals.

If all staff or managers in residential or domiciliary care are combined then 47 percent of perpetrators were care staff. There was a significant relationship between perpetrator and type of abuse ( $\chi^2 = 1605.51$ , p < 0.001, d.f. = 72). The

majority of perpetrators of sexual abuse (55%) were other service users. The next biggest category for sexual abuse was from a family member or carer (20%). In institutional abuse the largest proportions of perpetrators were care home staff and managers or owners. Half of all referrals relating to financial abuse were perpetrated by family members or carers.

There was a significant association between perpetrator and client group  $(\chi^2 = 607.73, p < 0.001, \text{d.f.} = 36)$ . The majority of referrals for older people with mental health problems related to abuse by residential or domiciliary care staff/managers. In contrast, those with mental health problems, those with other disabilities and older people were more likely to experience abuse from families or carers (51%, 61% and 39%, respectively) but for the latter this was closely followed by residential or domiciliary care staff (31%). Those with learning disabilities were equally likely to experience referrals related to abuse by other services users, residential or day staff/managers and family members or carers (27%, 24% and 23%, respectively).

#### Referrer

A wide range of referrers are represented in the data and in some cases there are two or three different referrers for each case. Fourteen percent of referrers were family carers, 28 percent were managers or staff, 11 percent were care management staff and six percent were classed as 'regulatory staff' such as inspectors of the Commission for Social Care Inspection. In only four percent of cases the referrer was a service user. Other referrers recorded were health professionals, police, probation staff, solicitors, neighbours and members of the public.

There was a significant association between referrer and location of abuse  $(\chi^2=206.56, p<0.001, \text{d.f.}=12)$ , client group  $(\chi^2=299.67, p<0.001, \text{d.f.}=8)$ , perpetrator  $(\chi^2=268.67, p<0.001, \text{d.f.}=18)$  and type of abuse  $(\chi^2=433.52, p<0.001, \text{d.f.}=16)$ . Residential staff/managers were most likely to report abuse that happened in day care settings or public places and in particular were more likely to report sexual abuse and abuse where the perpetrator was another service user, an ex-member of staff or a voluntary worker. Families were most likely to report abuse in cases of neglect or financial abuse and, in particular, if the perpetrator was a home care worker.

#### Discussion

The two local authorities studied in this article serve 1.6m people living in south-east England. This territory has a similar overall age profile to England, includes rural and urban areas, is experiencing population growth and includes both deprived and affluent areas. Although this is a large and diverse population and territory, it is not likely to be representative of other parts of England and caution should therefore be exercised in generalizing the findings of this study.

The number of adult protection referrals increased over the period in which records have been kept. The incidence rate found here is over three times the rate reported for Kent by Brown and Stein (1998). The number of referrals relating to older people appear to have stabilized since 2003 at 26–9 per 10,000 population over 65, whereas the number relating to younger adults (six per 10,000 population 20–65 in 2005) appears to be still rising. The increase over time is likely to reflect the attention given to policy development and implementation rather than an increase in adult abuse per se.

For younger adults, the number of referrals appears to reflect the number of people in the territory, though only a small proportion of the variance is explained. For older people this is not so, but it does appear that the number of adult protection referrals is influenced by the number of care home places in the area. However, the largest source of variation, not directly explored in this study, is likely to be differences in the professional practice of social workers in different locales.

The number of referrals is lower than estimates of the incidence of abuse (e.g. referrals of older people at 0.28% compared with 4.7%; Shugarman et al., 2003). However, this is to be expected given that not all abuse will be detected, recorded and referred. The pattern of referrals does reflect that found in other work. Older people dominate the abuse landscape. Those at greatest risk of abuse appear to be older women, those living in a care home and those who have a long-term illness (probably particularly dementia). Some sub-groups are also at risk of abuse from relatives and carers, especially those who abuse each other and those who are highly dependent on their relatives for help or support. Older people with mental health needs were most likely to be referred for multiple types of abuse. Other older people are more likely to be referred for neglect or financial abuse. People with learning disabilities are much more likely than those in other client groups to have referrals raised about sexual abuse.

A striking finding is the very low representation of people with mental health needs in the adult protection system, presenting a similar picture to that reported by Brown and Stein (1998, 2000). This suggests that *No Secrets* has yet to change this area of practice. It may reflect reluctance by mental health services and practitioners to both recognize adult protection issues when they occur and to respond to them through mainstream adult protection procedures. The status of adult protection work in mental health is more formally differentiated by legal requirements and influenced by the Care Programme Approach (Department of Health, 1996, 1999) which, linked to care management, promotes enhanced casework and worker responsibility. The fluctuating nature of some mental health problems and the nature of their associated vulnerabilities also differentiate adult protection work in mental health, where issues such as capacity to consent and ability to make decisions are often central. It is consequently recognized that generic adult protection policy models as specified by *No Secrets* (Department of Health, 2000) are not ideally suited to

a mental health context, with the consequence that generic adult protection models are seen to offer only limited scope for effective action in mental health (Williams and Keating, 2000).

The extent to which risk factors for adult protection referrals could be studied was limited by the information held on the social services databases. In particular, very little information was held about individual characteristics. For example, it was not possible to know whether individuals with learning disabilities about whom referrals were made had challenging behaviour, itself known to be a risk factor for abuse (Emerson, 2001). Better record linkage and more information about individuals is needed to investigate the personal risk factors for abuse and the interaction between personal characteristics and service patterns.

In general, where people lived appeared to determine the characteristics of abuse. There was a link between location or setting, perpetrator and type of abuse. A referral about someone living in a care home was more likely to identify abuse by multiple members of staff and institutional abuse or neglect, especially if the individual was an older person with mental health problems. People with learning disabilities were more likely to experience sexual abuse, mainly from other service users or members of their family. Those living in a private home with others, primarily relatives, tended to be at risk of financial, physical or psychological abuse. Older people living alone were particularly vulnerable to financial abuse by family members or, to a lesser extent, home care workers.

There was some evidence that lower standards of care in residential homes for younger adults were associated with referrals but there was no evidence for this in respect of older people's homes. The national standards against which care homes are assessed are *minimum* standards (Department of Health, 2001, 2002) and it may be that they are set at too low a level to detect important differences that relate to abuse and adult protection. They have also been shown not to correlate with objective measures of aspects of quality of life in learning disability services (Beadle-Brown et al., 2008) and it may be that their focus on processes does not adequately reflect outcomes experienced by the people they serve.

Differences in the costs of care services provided to people about whom referrals had been made were generally driven by where people lived and/or where the abuse took place. Those living in domestic situations had a lower cost of care package than those in residential homes and where the abuse took place in a care home, the cost of care package was higher than when it occurred in their own home or in multiple locations. Since those in residential homes tended to be those with learning disabilities it is not surprising that those with learning disabilities had a higher cost of care package than older people, and people with mental health problems. It is also not surprising that perpetrator and cost of care package appear to be connected as this is also linked to location of abuse/living situation. Cases where the perpetrator was a member of staff in a

residential services or another service user had a higher cost of care package. Whilst it is likely that this reflects the general pattern of costs across client groups, etc., it is impossible to tell from these data whether higher cost was a reactive response to the adult protection alert or whether it was simply linked to the characteristics of the victims of abuse.

The largest group of people making referral of cases of suspected abuse were staff and managers in services, followed by family carers. Referrers typically reported abuse happening elsewhere. This has implications for the organization of services in that it suggests that services need to be sufficiently open to other people (families, inspectors, members of the public, staff in other services) to increase the probability that abuse is detected. This is consistent with the findings of abuse in long-stay institutions in the past, where closed systems developed deviant norms and practices (Wardhaugh and Wilding, 1993). This is an example of how the vulnerability of 'vulnerable adults' might be a product as much of their circumstances as of their personal characteristics (Platt, 2004).

The implications of these data for social work practice are both strategic and operational. At strategic level, greatly increased incidence compared with early studies has implications for the workload and management of social workers. That abuse occurs in all services and involves many disciplines and agencies requires excellent work in partnership by social work managers, who have lead responsibility for adult protection. In their role as commissioners of services on behalf of their clients, social workers need to attend to the relationship between user and service characteristics and abuse – a relationship only hinted at in this study but one which could become much more important if there was good information gathering and record linkage. At operational level, social workers and care managers will generally be expected to take on significant roles in the adult protection case management process, such as involvement in planning meetings and investigations for their clients. The variation between territories found in this study suggests that differences in social work practice in different places may be an important factor in explaining variation and the implication of this is that the systematization and standardization of social work practice will be important.

Overall, these findings suggest that as adult protection procedures are developed estimates of incidence will stabilize over time, albeit at a much higher level than originally anticipated. If information systems allow for record linkage with databases about people using services and about the quality of the services themselves it will also be possible to routinely identify individual and situational risk factors for abuse. Characteristic patterns of referral are already evident. Further work is required to explain the low level of referrals from mental health services and also to understand the marked variation in referral rates between territories.

#### Acknowledgements

This study was funded by the Nuffield Foundation. The authors would like to thank the two local authorities involved for their assistance with the study.

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Age and Ageing doi:10.1093/ageing/afn112

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# The effect of bedrails on falls and injury: a systematic review of clinical studies

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#### **Abstract**

Background: around one-fourth of all falls in healthcare settings are falls from bed. The role of bedrails in falls prevention is controversial, with a prevailing orthodoxy that bedrails are harmful and ineffective.

Objective: to summarise and critically evaluate evidence on the effect of bedrails on falls and injury

Design: systematic literature review using the principles of QuoRoM guidance.

Setting and Subjects: adult healthcare settings

Review Methods: using the keyword, bedrail, and synonyms, databases were searched from 1980 to June 2007 for direct injury from bedrails or where falls, injury from falls, or any other effects were related to bedrail use.

Results: 472 papers were located; 24 met the criteria. Three bedrail reduction studies identified significant increases in falls or multiple falls, and one found that despite a significant decrease in falls in the discontinue-bedrails group, this group remained significantly more likely to fall than the continue-bedrails group; one case-control study found patients who had their bedrails raised significantly less likely to fall; one retrospective survey identified a significantly lower rate of injury and head injury in falls with bedrails up. Twelve papers described direct injury from bedrails.

Discussion: it is difficult to perform conventional clinical trials of an intervention already embedded in practice, and all included studies had methodological limitations. However, this review concludes that serious direct injury from bedrails is usually related to use of outmoded designs and incorrect assembly rather than being inherent, and bedrails do not appear to increase the risk of falls or injury from falls.

Keywords: accidental fall, injury, restraint, rail, bedrail, cot-side, elderly

#### Introduction

Bedrails are marketed as safety devices to reduce patients' risk of falling from bed. Their use is common internationally, with reported prevalence in hospitals ranging from 8 to 64% [1-5], and in nursing homes from 9 to 71% [6-13]. The commonest reason given by staff for bedrail use is falls prevention [1, 4, 6, 14].

Fall rates of 4–14 per 1,000 bed days have been reported from hospitals [14–24], and around 50% of care home residents fall at least once a year [16, 18, 24]. Such falls are associated with injury, fear of falling, functional impairment, prolonged length of stay, institutionalisation, complaints, litigation and excess costs [15, 22, 25]. Approximately one-fourth of these falls are from bed [4, 14, 18, 19].

The use of restraint is controversial; some papers on bedrails have automatically categorised bedrails as restraint, describing their use as unethical and thereby making any discussion of their effectiveness immaterial. Restraint may be defined as 'the intentional restriction of a person's voluntary movement or behaviour' [16] and therefore bedrails used to stop a patient purposefully leaving their bed may be restraint, but used to prevent an accidental fall from bed, may not be restraint.

Although reviews of the wider literature on institutional falls or restraints [6, 15–19, 26–31] have included bedrails, the tendency is to group them with studies of belt, vest, cuff or chair restraints, and existing reviews specific to bedrails [32, 33] are not systematic or recent. Current practice is thus uninformed by a comprehensive and current critique of the empirical evidence on bedrails, but is strongly influenced by a body of published literature with an overwhelmingly negative emphasis. The three main arguments

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used against bedrails are that their use is morally impermissible; that they are ineffective in preventing falls; or that they are inherently dangerous (either through direct injury, or through increasing the risk of falls and injury). Statements to the effect that bedrails are 'dangerous and possibly unethical'; [34] cause 'humiliation' [35] and constitute 'a type of physical abuse' [36] are commonplace. This complicates the existing clinical challenge staff face in balancing patient safety with the promotion of independence and rehabilitation [5, 13, 29, 37, 38]. Whilst such emotive presentation renders objective analysis of the evidence difficult, it is precisely this challenge that this paper seeks to address.

#### Aims

We aimed to systematically identify and evaluate the empirical evidence for the use or removal of bedrails, and their effect on physical injury or falls, or any other effect, including appraising the capacity of the evidence to support the strong opinions frequently expressed in the literature. We intended the review to provide a resource to inform clinical practice and to identify gaps for future research.

#### **Methods**

#### Overall methodological approach and justification

The methods employed conformed to the principles set out in Quality of Reporting of Meta-analyses guidance [39]. The criteria for inclusion were deliberately broad, including studies of various design type (not restricted to randomised controlled trials) so that studies often cited in the debate over bedrail use could be set out and appraised. Meta-analysis was not attempted, as a recent meta-analysis on falls prevention in institutions identified very few papers where standardised outcome data could be extracted [15].

#### Search strategy and selection criteria

A search was made for articles published between 1 January 1980 and 30 June 2007 using the MeSH terms: restraint, restraint-physical, bedrail, side rail, cot-side, safety rail and protective device. An additional search was made on the websites of patient safety agencies. Full search strategies, including the databases, websites and the full list of studies rejected (with rationale) are available in appendix 1 (see supplementary data on the Journal's website http://www.ageing.oxfordjournals.org).

This review aimed to locate in adult healthcare settings studies of the following:

- The effect of bedrails on falls and injury, including studies of bedrail reduction
- (ii) Direct injury apparently from bedrails
- (iii) Any other effect of bedrail use

We included combined studies of bedrail and non-bedrail restraints only where bedrail data could be separated. Studies were included if, as a minimum, the numbers of falls or injuries were provided. Multi-faceted falls reduction studies including a bedrail component were included only if changes in bedrail use were described.

#### Abstraction of data and outcomes and quality scoring

Trials were grouped by design type [40–42] and assessed independently for quality criteria by three reviewers using a well established quality criteria tool designed for appraising evidence from disparate study designs [43, 44]. Retrospective surveys, case series, and case studies were not individually assessed since their design equates to a null score. Falls rates were standardised from the data presented as falls per 1,000 occupied bed days.

#### Statistical methods

No additional tests of statistical significance were carried out, but tests of statistical significance within original papers or in previously published meta-analysis were abstracted for inclusion.

#### Results

#### Overall characteristics and design of included studies

Of the 472 abstracts retrieved in the initial search, 24 papers [7, 13, 14, 45–65] were identified as meeting the inclusion criteria (Figure 1). Nine studies took place in hospitals [14, 47, 49, 52, 54, 55, 60, 63, 65], nine in nursing homes [7, 13, 45, 46, 48, 50, 57, 58] and six used reports from both settings [53, 56, 59, 61, 62, 64]. Details of quality criteria met by individual studies are presented in appendix 2 (see supplementary data on the Journal's website http://www.ageing.oxfordjournals.org).

### Prospective before-and-after studies of bedrail reduction (Table I)

Five such studies were identified; [7, 45-48] all succeeded in reducing bedrail use. Two studies met eight of a possible total of ten quality criteria [46, 48] two met seven quality criteria [7, 47] and one met five quality criteria [45]. One study described a non-significant decrease in falls [7], two described a significant increase in falls [45, 47], one described a significant increase in multiple fallers [48] and one described a significant decrease in falls rates in the patients who had bilateral bedrails removed, although falls remained significantly less likely to occur in the patients who continued to use bilateral bedrails [46]. Subsets of visually impaired patients [45] and patients with a history of stroke [48] experienced significantly increased rates of falls. One study described an apparently significant reduction in serious injuries [47] but only if minor or suspected head injuries, where nurses checked neurological observations, were defined as serious injuries. None of the studies found any significant changes to overall injuries, fractures or subdural haematoma.

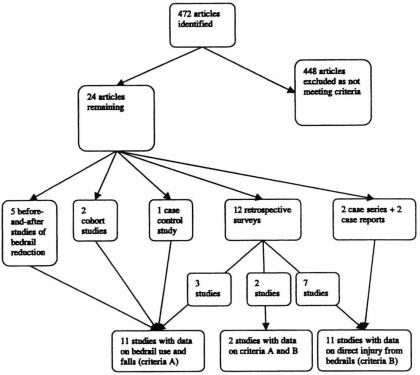


Figure 1. QuoRoM Flow diagram for selection and inclusion of studies.

### Case-control and cohort studies of the relationship between falls and bedrail use

The single case—control study [49] (five quality criteria met) found that having one or more bedrails raised was associated with a significantly reduced risk of falling (Table 2). One retrospective cohort study [13] (five quality criteria met) found that, once adjustments were made for differences in dependency and cognitive impairment, there was no significant difference in falls or injury. A further unadjusted prospective cohort study [50] (four quality criteria met) also found no significanct differences.

#### Retrospective surveys, case series and case reports

Sixteen such studies [14, 51-65] were included. Five described injury rates in falls from bed with and without bedrails [14, 52, 54, 63, 65] but only the multi-hospital study [14] found significant differences, with falls from bed with bedrails raised significantly less likely to result in injuries, particularly head injuries (see Appendix 3 in the supplementary data on the journal's website http://www.ageing.oxfordjournals.org). One retrospective survey of legal claims after falls from bed [60] found that bedrails were raised in only 2.6% of cases. Twelve studies described direct injury from bedrails or injury in falls after bedrail failure, ranging from fatal entrapment to minor injuries [14, 51-53, 55-59, 61, 62, 64]. Four of these [53, 56, 59, 64] drew from the same dataset (Figure 2)

and found that 'half-rails' (an outmoded inverted triangle design) were significantly more likely to be associated with death, full rails with non-fatal injury, and spilt rails with near misses (where a patient was entrapped but released without injury) [56].

#### Discussion

#### What this review adds

This article describes the most comprehensive systematic review and synthesis of published evidence of the effect of bedrails on falls and injury to date and examines the quality and limitations of existing research. By extending its focus beyond RCTs and the few studies where standardised outcomes can be calculated to include observational or quasi-experimental studies, it provides an inclusive analysis which allows users to see the range and the limitations of evidence often used by those advocating strongly against bedrail use. It also offers direction for future research.

### Methodological limitations and interpretation of findings

We did not identify any RCT, so the level of evidence is far less robust than in a Cochrane review or meta-analysis [40]. Even the eight better-designed studies [7, 13, 45-50] met only between four and eight quality criteria out of a maximum of ten. The very nature of bedrail use as a 'low-tech' intervention

Table 1. Prospective before-and-after studies of bedrail reduction

Reference	Study type	Number of quality criteria met [44]	Study population	Intervention	Falls (numbers)	Falls (rate per 1,000 bed days)	Falls rates (statistical significance)	Injured patients (numbers)	Injury (statistical significance)	Other outcomes
Brown, 1997 [45]	Prospective before-and- after study of bedrail reduction	5/10	93 US nursing home residents individually tracked 6 months before/6 months after. Mean age 85.6 years; 80.6% female, 66% highly dependent	Education of staff and bedrail reduction programme. Bedrail reduction achieved but specific level not stated	'Falls in bedrooms at night' pre 16, post 35	Pre 0.94, post 2.07. 1	Increase in falls significant: $(x^2P = 0.008)$ . Increase in falls amongst subset of visually impaired significant: (Zelen Exact $P = 0.01$ ).	Not stated	Not stated	
Capezuti, 2007 [46]	Prospective before-and- after study of bedtail reduction	8/10	251 US nursing home residents individually tracked up to one year before/up to one year after. Mean age 83.6, 77.7% female	Education of staff, selection (non-randomised) <sup>2</sup> by advanced practice nurse of patients to continue or discontinue bedrails, bed alarms, floor mats, low beds. Bedrail reduction achieved: 100% raised bilateral reduced to 48. 6% raised bilateral	'Falls in bedrooms between 2,100 and 06.00' pre 244, post 251. <sup>3</sup>	Continue group pre 1.19, post 0.69. Discontinue group pre 3.78, post 2.04*	Discontinue group significantly more likely to fall than continue group, both pre-intervention ( $p < 0.001$ ) and post-intervention ( $P = 0.01$ ). 46% reduction in discontinue group between pre- and post-intervention, significant when expressed as mean rate of falls per resident per month (Bonferroni adjusted $P = 0.02$ ). 38% reduction in continue group between pre- and post-intervention, not significant when expressed as mean rate of falls per resident per month (Bonferroni adjusted $P = 1.00$ ).	Total injured not stated 'serious injuries'.5: Continue group pre 2, post 1. Discontinue group pre 7, post 4	States not tested due to small numbers	

Hanger, 1999 [47]	Prospective before-and- after study of bedrail reduction	7/10	135 beds (1968 patients) in NZ rehabilitation hospital for older people' 6 months before/6 months after (no demographics provided but unit took around 40% of patients following an acute care admission)	Policy and education to reduce bedrail use, better treatment of delirium, use of toileting programmes, and patients nursed on mattresses on floor. Bedrail reduction achieved: 29.6% bedrails attached reduced to 11.5% bedrails attached	'Falls around the bed,' pre 186, post 232	pre 8.9, post 10.6 <sup>6</sup>	Original paper states increase not significant (unpaired Students <i>t</i> -test, <i>P</i> value not given). Original paper also applies 95% CI to the mean rate of falls around the bed preand post-intervention per 100 admissions ( <i>P</i> = 0.09) and per 10,000 bed days ( <i>P</i> = 0.12) A subsequent meta-analysis found the increase in falls significant (rate ratio 1.16, 95% CI 1.01 – 1.34)	Total injured patients: pre 76, post 78 'minor injuries'. 7 pre 43, post 60 'serious injuries'. 8 pre 33, post 18 including fractures: pre 3, post 3; hip pain: pre 3, post 3; lacerations: pre 0, post 1; neuro obs taken: pre 27, post 11	Overall injury rate and 'minor injury' rate not tested for statistical significance. Stated significant decrease in 'serious injury' (x <sup>2</sup> P = 0.008) but appears actually decreased on occasions neurological observations were recorded (see footnote 8)	Mean length of stay 21.74 days before, 22.31 days after 9
Hoffman, 2003 [7]	Prospective before-and- after study of bedrail reduction	7/10	180 beds (successive residents) in three US dementia care, rehabilitation and hospice care units over one year before/one year after (no demographics provided)	Removal of bedrails, addition of crash mats, hip protectors, body pillows, position alarms, moving bed next to wall. Bedrail reduction achieved: 31.3% raised bilateral 10 18.3% raised bilateral 10	'Falls from bed' pre 142, post 126	pre 2.28, post 2.13	Study states reduction in falls not statistically significant using x² but P value not given. A subsequent meta-analysis confirmed decrease in falls NS (rate ratio 0.93, 95% CI 0.73–1.19)	Injured patients: pre 42, post 35 of which hip fracture: pre 1, post 2	Study states reduction in patients injured NS using x <sup>2</sup> but p value not given.	ued overleaf)

Table I. (Continued)

Reference	Study type	Number of quality criteria met [44]	Study population	Intervention	Falls (numbers)	Falls (rate per 1,000 bed days)	Falls rates (statistical significance)	Injured patients (numbers)	Injury (statistical significance)	Other outcomes
Si, 1999 [48]	Before-and- after study of bedrail reduction	8/10	25 beds (246 residents) in USA rehabilitation units within nursing homes over 1 year before/1 year after. Mean age 83.1, 87% female	Education of staff, advice from advanced practice nurse. Addition of bed alarms, non-slip floors and shoes, transfer rails, exercise. Bedrail reduction achieved: 'virtually all' raised bilateral to 19/130 (14.6%)	Falls within ten feet of the bed pre 19, post 31 <sup>11</sup>	pre 3.68, post 5.42 <sup>12</sup>	No statistical tests on overall falls. States patients significantly more likely to experience multiple (>2) falls post-intervention (RR = 4,95% CI not stated). States patients admitted with stroke significantly more likely to fall post-intervention (RR = 2,95%CI stated as '0.68.5'[sic]) No significant changes in falls pre- and post-intervention in patients admitted with hip fracture	Injured patients: pre 2, post 2 of which subdural haematoma: pre 0, post 1	No statistical tests on injuries	Median length of stay: 42 days before, 40 days after

<sup>&</sup>lt;sup>1</sup> Based on assumption all 93 residents completed 6 month before/6 month after to be included in study.

<sup>&</sup>lt;sup>2</sup> Residents selected for discontinue group had significantly better functional status (P = 0.001) and mobility (P = 0.002) than the continue group, and were significantly more likely to be on antipsychotic drugs (P = 0.04).

<sup>3</sup> Calculated from 9 serious injury falls representing 3.68% of pre-intervention total falls and 4 serious injury falls representing 1.99% of post-intervention total falls.

<sup>&</sup>lt;sup>4</sup> Converted from per resident per month.

<sup>&</sup>lt;sup>5</sup> Serious injury is defined as fractures, dislocated joints, subdural haematoma, lacerations requiring suturing.

<sup>&</sup>lt;sup>6</sup> Converted from per 10,000 bed days.

<sup>&</sup>lt;sup>7</sup> Minor injuries defined as anything not defined as a serious injury.

<sup>8</sup> Serious injury is defined in Table 2 of the original paper as fractures, dislocations, skin lacerations requiring plastic surgery, suturing or grafts, and hip pain without fracture. However, if the text of the paper is read the apparent change in serious injury occurred in an extra category not included in the results tables but defined within the text as minor head injuries where neurological observations were taken. It appears minor bruises and lacerations to the head were counted as minor injuries unless neurological observations were taken, in which case they were counted as serious injuries.

<sup>&</sup>lt;sup>9</sup> Calculated from falls numbers and falls rates per 10,000 days within the paper.

<sup>10</sup> The project encouraged placing beds against the wall, so some of the reduction in bilateral bedrail use occurred where one side of the bed was against the wall and one bedrail was in use on the other side of the bed, rather than in situations where free access was left on one side of the bed. Also implies bedrail use increased in periods when the researchers were not inspecting the unit 'the use of rails was somewhat variable. . . . Rail use tended to decrease. . . immediately after intense feedback and monitoring' Taken from Table 3 in the original paper; using Table 2 in the original paper would give different percentages.

<sup>11</sup> Residents pre-intervention group had significantly less requirement for assistance (P = 0.012) and were significantly more likely to be female (P = 0.003) than the post-intervention group.

<sup>12</sup> Calculated from number of falls, number of admissions, and mean length of stay.

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Table 2. Case-control and cohort studies of the relationship between falls and bedrail use

Number of Differen

Reference	Study type	Number of quality criteria met	Study population	Differences between bedrails/no bedrails patients	Statistical significance (falls)	Findings on injury
Capezuti, 2002 [13]	Retrospective cohort study comparing reported falls for 131 patients with bilateral bedrails with 188 patients with partial or no bedrails, utilising patient characteristic data collected in an earlier body restraint reduction study	5/10	Three nursing homes in the USA over one year in 1990/1991. Mean age 82.8 years, 87% female	Patients given bilateral bedrails significantly less independent and more cognitively impaired (P = 0.0001). Demographic details and 'behavioural symptoms score' not significantly different. Concurrent use of body restraints.	When adjustments were made for the differences between groups, no statistically significant difference in the likelihood of falling (AOR = 1.13 95% CI 0.45-2.03) or recurrent falls (AOR = 1.25 95% CI 0.33-4.67)	Overall injury not stated Bilateral bedrails (n = 130) 2 hip fractures, 1 subdural haematoma. Partial bedrail (n = 188) 2 hip fractures. States serious injuries too few for statistical analysis
Krauss [49]	Case-control study comparing 98 hospital patients who fell with 318 non-fallers matched for length of stay	5/10	Large urban academic hospital in the USA, including general and psychiattic patients (no other overall demographics given)	Not stated	Having one or more bedrails raised was associated with a significantly reduced risk of falling (AOR 0.006 95% CI 0.001 to 0.024).	Not stated
Kron, 2003 [50]	Prospective cohort study of 472 patients' characteristics (including bedrail use) analysed in conjunction with retrospective recording of falls over following 12 months	4/10	Three nursing homes in Germany in 1998/99. Mean age 84 years, 77% female	Not stated	OR of falling with bedrails 0.7 (95% CI 0.5-1.1) OR of multiple falls with bedrails 0.9 (95% CI 0.6-1.5)	Not stated

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already routinely embedded in practice, the high prevalence of frailty and cognitive impairment in potential study populations, and the fact that both bedrail use or removal can be seen as interventions, may make the lack of high-quality evidence inevitable [41, 43, 66]. Additionally, most studies were based on reports from frontline staff, a method limited by incomplete data and under-reporting [14, 19–21]. However, it can be argued that the role of systematic reviews 'is not to let the desire for "best" evidence stand in the way of using the best available evidence.' [43]

The best evidence we located were four of the five before-and-after studies of bedrail reduction which met seven to eight quality criteria [7, 46-48], whilst one beforeand-after study was of lower quality [45]. However, even well designed before-and-after studies can be confounded by concurrent changes in staffing, treatment and patient casemix [48]. Two of these studies [45, 46] tracked individual nursing home residents, whose deteriorating health and mobility over one [45] or two years [46] potentially confounded the findings. Most bedrail reduction studies concurrently introduced additional interventions, including hip protectors, [7] movement alarms, [7, 46, 48] toileting regimes [47] and crash mats [7, 46]. Although unlikely to account for the observed increases in falls from bed in three studies [45, 47, 48] their introduction may have created a 'Hawthorne effect' [42], increasing reporting of falls. One bedrail reduction study [46] found significant baseline differences in mobility, falls history, independence and medication between the patients selected to continue using bedrails and the patients selected for bedrail reduction likely to confound the results. None of these studies showed significant differences in overall injury or fracture rates but were likely to be underpowered to detect these, and the single significant finding that neurological observations were less likely to be recorded after bedrail reduction [47] may be a measure of nurses' beliefs rather than of seriousness of injury. Although overall, the before-and-after studies suggest that unselective reductions in bedrail use may contribute to an increase in patient falls, particularly in patients with stroke or visual impairment, the methodological issues mean this cannot be a firm conclusion.

Three further studies met at least four quality criteria. The single case—control study [49] showed a significantly lower rate of falls in patients with bedrails raised, which needs to be interpreted with caution as only length of stay was controlled for, and other uncontrolled differences between the groups might account for the reduced rate of falling. The two cohort studies [13, 50] found no significant difference in falls rates with or without bedrails, but are likely to be confounded by differences between patients who have or have not been provided with bedrails; [1, 4, 13] even when some differences are adjusted for [13] others will remain.

The design of retrospective surveys, case series, and case studies means they inherently fail to meet quality criteria, but may still provide useful circumstantial information. The five retrospective surveys of falls from bed can only provide information on the likelihood of injury once a fall has occurred, but none supported the current orthodoxy that injury is more likely in falls with bedrails because patients will climb over them and fall from a greater height. Some patients may do so [14, 65] but the largest study found injury, particularly head injury, appeared significantly less likely in falls from bed with bedrails, with most falls from beds with bedrails raised appearing to be feet-first towards the bed end rather than through climbing over bedrails [14]. The study based on legal cases [60] relied on an inherently biased sample but suggests relatives view failure to raise bedrails as negligent. The studies of injury or death from bedrail entrapment or failure describe incidents generally linked to problems with maintenance, assembly or outmoded equipment design rather than to bedrail use itself. Inevitably, these studies cannot provide information on the injuries which might have occurred if the devices had not been used, and few provide data to assess how frequently such injuries occur; one UK study [14] suggests deaths linked to bedrail entrapment in hospitals have been reported at the rate of around one per 20 million admissions, with minor direct injuries from bedrails estimated at 1,250 per 10 million admissions. The US studies [53, 56, 59, 64] suggest an annual average of around 20 deaths through bedrail failure or entrapment across hospital, nursing home and domestic settings.

Our search found no studies describing any effects of raised bedrails other than those on falls and injury described above. Of these, only two included data on any other potential effects of bedrail use and these noted only marginal increases [47] or decreases [48] in length of stay despite substantial decreases in bedrail use. Because a perceived risk of falls is the nurses' main rationale for providing bedrails [1, 4, 5], it is unsurprising to find that patients provided with bedrails are older, less mobile, more cognitively impaired and more likely to be incontinent than patients who are not provided with bedrails [1, 2, 13, 67–69]. Where bedrails have been described as causing incontinence, confusion or reduced mobility [5, 55, 63, 70], this appears to arise from mistaking correlation for causation.

### Why is there a mismatch between the evidence and orthodoxy?

Despite the weak methodological quality of many of the studies, the evidence presented in this review does not support the prevailing orthodoxy that bedrails increase the likelihood of falls and injury, or that bedrails result in an inherent risk of fatal entrapment. So why the current negative view of bedrail use? There appear to be a number of interlocking issues that influence practitioners and policy makers.

Evidence-based practice requires critical appraisal, rather than partial citation. Despite the old dictum that 'absence of evidence is not the same as evidence of absence of effect' [41] commentators have stated that bedrails should not be used to prevent falls from bed on the basis of no significant

#### Entrapment between bedrail bars, or between bedrail bars and the bed frame

Some deaths occurred through head or chest entrapment in poorly designed bedrails, especially wide gaps between vertical bars in bedrails not permitted by current safety standards [87,89] wide gaps between the lowest horizontal bar in bedrails and the bedbase, and triangular gaps in a specific design referred to as a 'half' bedrail. Some deaths occurred where the gap between the top of the bedrail and the head of the bed did not conform to current standards and patient's neck was trapped in the gap. Together these entrapments between or below bedrail bars or between the top of the bedrail and the head of the bed accounted for 36% of deaths and injuries, and an additional 13% of cases involved non-fatal injury from limb entrapment between the rails [56]. These types of fatal entrapments are unlikely to occur if inter-rail and under-rail spaces are less than 12cm whilst gaps between the top of the bedrail and the head of the bed are less than 6cm or more than 25cm [87]

#### Poorly attached or broken bedrails leading to falls from bed

21% of deaths and injuries occurred because bedrails fell off and the patient fell to the floor, either because the bedrail broke, or because the bedrail was not properly attached [56].

#### Entrapment between the mattress and the bedrail

17% of deaths and injuries occurred when the patient became trapped between the side of the mattress and the bedrail [56]. This risk usually occurs when the mattress is not an appropriate size for the bed [87] or with specific types of pressure relieving mattress [59].

#### Entrapment through body restraints caught on bedrails

Some deaths and injuries occurred through body restraints becoming caught on bedrails, leading to suffocation [62]. These deaths would not occur where body restraints are not used.

#### Entrapment in the central gap between split bedrails

Rarely (4% of cases) deaths or injuries occurred when patients slid either head or feet first through the gap between split bedrails, and became stuck halfway [56].

#### Postural asphyxiation through collapsing with neck or chest over bedrails

Very rarely (<1% of cases) deaths occurred when the patient's upper body was 'draped' across the top of the bedrail, compressing their chest or neck [64]. The patients who died in this way appear to have been extremely weak or paralysed. This risk would remain even with correctly maintained and fitted bedrails.

Figure 2. How bedrails can cause death and injury.

findings in inadequately powered arms of studies [7, 35, 36] or because no RCTs have been carried out [34, 71].

Negative opinion may relate to an assumption that patients dislike bedrails. We identified only three studies of patients' views on bedrails: a small study of 17 patients [72] identified one patient distressed by bedrails, whilst in a larger study bedrails were thought acceptable by 89.5% of inpatients surveyed [73, 74], and former patients believed bedrails could be useful, but the term 'cot-side' was demeaning [4]. Additionally, some bedrail reduction studies found patients reluctant to stop using bedrails [7, 48, 75]. Perhaps due to papers that group bedrails with vest, belt, cuff or chair restraint devices, bedrails became 'guilty by association' as the use of these other devices is associated with considerable distress and harm [6, 30, 31, 38].

Further, there can be little doubt that, in the past, routine and inappropriate bedrail use did occur [5, 6, 33, 76]. It may be that challenging the traditional, and often harmful, use of bedrails has resulted in the adoption of an opposing view; if routine bedrail use is 'institutional' and 'bad practice' then not

using bedrails at all represents up-to-date and enlightened practice.

#### Implications for policy, practice, and research

Overall, whilst the evidence base is of limited quantity and quality, it does not support the prevailing orthodoxy that bedrail use should be eliminated or strictly curtailed on the basis of bedrail effect on falls, injury in falls or direct injury, and suggests wholesale bedrail reduction may increase the risk of falls. Practical and ethical considerations mean that bedrails are not usually appropriate for a patient who could be independently mobile without them, or for a patient with capacity who does not want them, nor for a patient with severe confusion who is mobile enough to climb over them. But for patients who request bedrails, or who are incapable of leaving their bed without help, bedrails are unlikely to act as restraint, or restrict independence. For patients without decision-making capacity, staff have a duty of care to act in their best interests [77, 78] underpinned by

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realistic assessment and regular review of the individual risks of bedrail use or non-use [79].

Bedrails should never be a substitute for adequate levels of care and observation [6, 38, 80] or used as a stand-alone method of falls prevention [14, 15, 37]. Crash mats, movement alarms, and ultra-low beds are often suggested as alternatives to bedrails, their effect on reducing injury is unknown [15, 81] whilst we know that recognising and treating delirium, [82, 83] comprehensive geriatric assessment, [84] medication review, [85, 86] or multifaceted falls prevention interventions [15] can reduce falls rates in institutional settings.

Healthcare organisations need to appreciate that fatal bedrail entrapment is neither random nor inevitable but can be prevented by removing outdated equipment, ensuring that all bed, mattress and bedrail combinations are compatible, maintaining equipment, and training staff to fit and use bedrails safely and appropriately [4, 53, 79, 87–89].

Whilst an RCT of bedrail use would present design challenges [90] and for ethical reasons could randomise only individuals without absolute contraindications or indications for bedrail use, the controversy is unlikely to be fully resolved until such a trial is carried out. In addition to effects on falls and injury, any other potential harms or benefits of bedrail use merit investigation, as does the effect of different bedrail designs, partial compared to full bedrails, alternatives to bedrails, and the role of policy or decision tools to support staff in assessing the risks and benefits of bedrail use for individual patients. Given the emotive nature of the bedrail debate, qualitative exploration of the views of patients and staff may also be helpful.

#### Conclusion

Careful evaluation of the empirical evidence on the use and non-use of bedrails does not lend adequate support to the widely held and powerful views that bedrails are inherently harmful. This review suggests that healthcare organisations should not aim for the universal reduction of bedrail use, but focus on eliminating outdated equipment and reducing inappropriate bedrail use on a case-by-case basis.

#### **Conflicts of interest**

None

#### Key points

- Bedrails, used to prevent accidental falls from bed, are not defined as restraints, and most patients find their use acceptable
- No evidence was located that bedrails increase falls from bed or increase fall-related injuries
- Fatalities from bedrail entrapment are not an inherent risk of bedrail use but usually relate to outmoded design, incorrect assembly and incompatible combinations of equipment

 Healthcare organisations and practitioners should be encouraged to reduce inappropriate use of bedrails rather than uncritically push for wholesale and universal reduction in use

#### Supplementary data

Supplementary data for this article are available online at http://ageing.oxfordjournals.org.

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(Due to the large number of references, only 29 are listed below and are represented by bold type throughout the text. The full list can be found in the supplementary data online, on the journal website http://www.ageing.oxfordjournals.org)

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Received 27 September 2007; accepted in revised form 11 April 2008

### Health and Quality of Life Among Older People in Rural England: Exploring the Impact and Efficacy of Policy

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#### **Abstract**

There is increasing evidence that characteristics of place influence health and that the dimensions of rurality interlock with the process of ageing to produce a number of distinctive patterns. For the rising number of older people living in rural England, it is clear that, overall, the countryside promotes the health and wellbeing of the newly retired, fitter cohort who have access to financial and community resources. However, it carries a number of risks for elders who are frail, deprived or isolated; inequalities combine to undermine health and deepen exclusion. The efficacy of policy in taking account of the needs of rural elders is uneven. Analysis of the three most pivotal policy arenas – rurality, ageing and health, and community development – suggests that while some initiatives do promote quality of life, significant limitations remain. Further, the overarching policy response is incoherent and fragmented. Key deficits relate to resource allocation, limited recognition of rural disadvantage, and minimal incorporation of the perspectives of rural elders. That the majority of policy is rurally blind is a fundamental challenge; for rural elders to benefit from policy investment, a systemic shift is required in the mechanisms that steer its development, funding and implementation.

#### Introduction

There is increasing acknowledgement that characteristics of place influence the health and wellbeing of individuals and populations, and that ageing is 'emplaced' within a house, community and wider socioeconomic context (McHugh, 2003). The emerging role of policy in taking account of links between health and place, and in developing responses to the needs that arise from the intersection of age and location, is a parallel trend (Office of the Deputy Prime Minister [ODPM], 2004a). While the impact of urban living on the health and wellbeing of older

people has been recognised by researchers and policy makers, little account has been taken of the influence or significance of rurality (Scharf and Bartlam, 2006). That the rural population of England is ageing, and that older people in rural areas have received little coherent attention, suggests that the time is ripe for exploring the contribution of rurality to their health and quality of life, and to consider the role and efficacy of policy in addressing their needs (Scharf *et al.*, 2002; Wenger, 2001). In exploring these twin issues, we will draw widely on research and policy-related literature. In particular, we refer to a review we conducted for the Countryside Agency in 2002 (Milne *et al.*, 2002).

#### Parameters of the article

In research and policy literature, the terms 'older' and 'rural' are variously interpreted. Literature tends to define 'older' as those above state retirement age; this is mirrored in the article. Until recently, rural remained largely undefined, particularly in policy, although some distinction has been made between 'rural residential/village centre' and 'rural agricultural with isolated dwellings or small hamlets' (Department of Health, 2002). Where relevant, this is reflected in discussion. The article's geographical focus is England, although relevant evidence from other UK sources is included. Policy analysis focuses mainly upon those policy arenas that have particular relevance to the population under review.

Evidence is presented in two parts: a review of the health and quality of life of the older population in rural England, and an analysis of the efficacy and impact of policy; both sections have a number of subsections. The article concludes by identifying directions for future policy development. By way of providing context to the article's main focus, we begin with an introduction to ageing in rural England.

#### Ageing in the English countryside

England is an ageing society. Since the early 1930s, the number of people aged over 65 has more than doubled; today over a fifth of the population is aged over 60, with a particular increase in the cohort aged 80 and over (Department of Health, 2001a; Office for National Statistics, 2002). Over the last 30 years there has been a simultaneous increase in the rural population. Currently, 28.5 per cent of the total population of England – more than fourteen million people – live in rural areas (Countryside Agency, 2005). This repopulation, sometimes termed 'counter-urbanisation', is due to the combined popularity of country living among affluent middle-class professionals and retirees. These are referred to as the dual processes of gentrification and geriatrification (Findlay *et al.*, 1999).

The cumulative impact of these trends has been a significant growth in the older rural population. More than 18 per cent – 2.6 million – of the English rural population is aged 65 and over compared with 15 per cent in urban areas (Department for Work and Pensions, 2005; Lowe, 2003). The percentage is highest

in sparsely populated rural areas such as the South West or the coastline of the East and North (Department of Health, 2002). Overall, a third of England's older population live in the countryside (King, 2000).

#### Differences and distinctions

It is important to recognise that this general pattern masks a number of distinctions. The 'older population' is not a single group; as the cohort ages it becomes more heterogeneous. It incorporates those who have always lived in the countryside and those who are 'incomers'; those aged 60-plus who have just retired and are likely to be active and those aged 75-plus who may be frail; and those dependent on the state pension as well as those with occupational pensions (Department of Health, 2001a).

Similarly, the settlement of retirement migrants to the countryside obscures important regional variations. Growth occurs most markedly in East Anglia, Northamptonshire, Oxfordshire and the South West. This pattern may be explained by the fact that incomers tend to move to areas which, while rural, offer easy access to shops and transport links (Department for Transport, Local Government and the Regions [DTLR] and Department of Trade and Industry [DTI], 2001). A third distinction relates to 'types' of rural community. It is often assumed that rural areas are universally pleasant and secure; in fact, many villages have experienced post-industrial decline as have urban areas, with the same, or worse, concomitant deprivations (Pugh, 2000). This is a particular issue for long-term rural dwellers, many of whom are older, and has a significant impact on quality of life.

What is clear, however, is that the issue of ageing is a dominant and pronounced one in, and for, the English countryside. Despite this, the relationship between rural life and older people's health and quality of life has received no systematic review. It is to this issue that we now turn.

#### Health and quality of life

Health is now widely regarded as a multidimensional and holistic concept incorporating a range of socioeconomic indicators and as an outcome of life course and age-related inequality. It is also closely aligned to concepts of quality of life and wellbeing. In this section we explore the physical and mental health of older people and health determinants, followed by a review of quality of life issues focusing particularly on community and social support. Where useful, we have drawn out distinctions, which reflect the diversity of the population under review.

#### Health

While there is certainly some evidence that rural dwellers live longer and have better health than their urban counterparts, living in a remote area deepens the risk of experiencing poor health; it is also related to decreased life expectancy for disadvantaged elders (Haynes and Gale, 2000). One cause relates to deaths in winter. A recent study showed that 'excess' winter deaths are 25 per cent higher in remote areas (New Policy Institute, 2000). A number of specific health problems also arise from common types of rural employment. Heavy physical labour – such as that associated with farm work – is linked with musculoskeletal problems, respiratory illnesses and accidents (British Medical Association, 2005). Substandard rural housing – which is disproportionately occupied by life-long older residents – also places them at enhanced risk of asthma and damp-related illness (Victor *et al.*, 2002).

Rural living additionally compromise the mental health of particular groups of older people. Elders whose children move away, those who live in remote settings without access to a car, and carers of people with dementia are vulnerable to becoming isolated and lonely (Carers UK, 2004). Further, isolation is one of the known risk factors for developing depression, particularly when combined with physical frailty, reduced mobility and/or widowhood. A number of features of rurality—sparsity, remoteness and few opportunities for socialisation—exacerbate the impact and visibility of these late-life challenges (Countryside Agency, 2003; Help the Aged, 1996). Enhanced levels of depression are implicated in suicide; rates among older men tend to be consistently higher in rural areas (Klaber, 2001).

Considerable stigma appears to be attached to mental illness in a small community. This not only contributes to reluctance to seek help from primary care but also to limited investment in mental health services in rural areas (Institute of Rural Health and General Practitioners Committee of the BMA, 2001). This profile may result in the needs of older people with mental health problems being overlooked and opportunities for early intervention lost (Countryside Agency, 2000b). Health risks are also magnified by travelling distance to services, a process known as 'distance decay' (Countryside Agency, 2002). This has been specifically implicated in poorer outcomes for people with chronic conditions such as diabetes and dementia; it also disproportionately disadvantages older people on low incomes who have limited personal mobility (Haynes and Gale, 2000). The closure of rural branch surgeries is a contributory factor. Access to outpatient care and ambulance response times are also compromised by distance, a process exacerbated by the centralisation of specialist services in urban centres. A rural culture of self-sufficiency may also play a role in discouraging service usage (Age Concern, 1996).

#### **Health determinants**

It is well established that health outcomes are significantly correlated with a number of social inequalities, particularly poverty and poor housing. For most older people, socioeconomic and health status is a reflection of life-long access to resources; old age tends to deepen disadvantage for those who enter this phase of life with little (Rural Development Commission, 2001).

#### Income and poverty

Older people are the largest group experiencing sustained poverty in rural England; this is particularly the case for long-term residents and older widows (Age Concern, 2001; Help the Aged, 2001). Overall, a quarter of rural pensioners (630,000 people) live below the low-income threshold; this proportion rises to a third in remoter districts (Harrop and Palmer, 2002). Around one in ten rely solely on the state retirement pension; only a quarter receives an occupational pension (Department for Environment, Food and Rural Affairs [DEFRA], 2002; Milne *et al.*, 2002). This may, in part, reflect reimbursement patterns common in agriculture – a cash-based system – which leaves people financially vulnerable in later life (Rural Development Commission, 2001).

Despite this profile there is relatively low take up of welfare benefits. A recent study found the proportion of pensioners in receipt of the Minimum Income Guarantee (MIG) to be much lower in rural areas than in urban.<sup>2</sup> Further, only about a tenth were claiming disability-related benefit, such as attendance allowance (Harrop and Palmer, 2002). This pattern raises the issue of self-sufficiency noted above, as well as how effectively disabled pensioners are able to access benefits, and benefits advice, in rural areas. The hidden and dispersed nature of rural poverty also hinders awareness of extent (Scharf and Bartlam, 2006; Shucksmith, 2000).

#### Housing

For many older people the home not only provides security and refuge but represents a place for expressing individuality and independence. The process of gentrification has raised house prices in the countryside, generating problems of affordability for older, longer-term residents (Moseley and Chater, 2000). Furthermore, the proportion of social housing to rent is substantially lower in rural areas than in urban, and much of this accommodation is in poor condition (Shucksmith, 2003). In 2001, the Government's Quality of Life Barometer identified half of rural social housing as 'sub-standard' (ODPM, 2002). As over two fifths is occupied by older people, these combined findings suggest that this group of rural elders is disadvantaged in a most fundamental material and physical way.

#### Community life and social support

In addition to reviewing evidence relating to health and health determinants, it is important to acknowledge the role played by the rural community, particularly its capacity to provide support to older people.

Although the mechanisms between cause and effect are inadequately understood, social engagement appears to be a key component of wellbeing (Le Mesurier, 2003). In particular, the strength of a person's support network has been shown to be directly related to their ability to cope with illness, loss and isolation (Cattan, 2002; Levy et al., 2002; Shucksmith and Murphy, 1999). Evidence suggests that long-term rural elders often know members of their community well – sometimes for several generations – and many feel that they can turn to their neighbours 'in a crisis' (Williams et al., 2001). Informal support does, however, have limitations; while neighbours may be prepared to 'rally round' when an older person becomes acutely ill or requires low level support, this falls away once intensive input is required (Milne et al., 2001). Dementia presents a particular challenge. In-migrants tend not to have the established social links upon which informal support depends; their networks are characterised by the use of formal services or family input 'from a distance' (Buller et al., 2003; Commission for Rural Communities, 2005).

Linked to evidence about social support is the concept of 'community' (ODPM, 2005a). The majority of older people view community life in rural England as socially fulfilling, healthy and secure, a perception supported by the widely noted 'community spirit' (Scharf and Bartlam, 2006). Many older citizens participate in organised activities, such as the church, Women's Institute or Parish Council. They constitute a flexible social resource; a number have work-related skills to offer and wish to remain active (Steering Committee of Better Government for Older People, 2000; Williams and Windebank, 2000). Noted individual benefits of participation include improved morale and self-esteem, and lower levels of loneliness (ODPM, 2006). Belonging to community groups also facilitates enrichment of social networks. Those elders less able to take advantage of these opportunities are those who are housebound by illness or caregiving, dependent on public transport or economically disadvantaged (Commission for Rural Communities, 2005).

Community-based resources are also an important contributor to quality of life. Over the last 30 years there has been a significant decline in a wide range of rural services: in 2000 the majority of rural settlements had no shop selling food (Countryside Agency, 2000a, 2000c). The number of rural post offices is also declining, a trend mirrored by the withdrawal of primary care services noted earlier. Although there has been recent investment in public and community transport schemes, take-up of the concessionary bus scheme by pensioners has decreased (Local Government Association, 2001), yet accessible affordable public transport is a lifeline for dispersed rural communities, especially for older people without a car. A reduction in rural policing is also a concern. A recent survey suggests that, despite relatively low levels of crime in most rural areas, a third of elders report 'fear of crime' as having a negative effect on their quality of life (Cabinet Office, 2001).

The impact of declining community resources is proportionately greater for older people, who tend to be less mobile and rely on local facilities for essential supplies. Given the importance of these services for facilitating social engagement, their loss may also diminish opportunities for impromptu social contact and undermine the social cohesion that binds communities together. It may also place elders with few local links at enhanced risk of social exclusion (Williams *et al.*, 2001).

#### Health and quality of life for older people: implications of rurality

Although there is no single experience of rural living, a number of key themes emerge. Rural life bestows a number of advantages. The relatively low levels of crime and physical decay, the higher levels of social engagement, neighbourliness and the safer, more secure environment, are widely noted as positive dimensions of rurality (Countryside Agency, 2001). These are particularly beneficial to those who have been part of, or are based in, the community for substantial periods of time, the majority of whom are older (Inter-Ministerial Group on Older People, 2000).

Many rural communities offer an ideal environment during the third stage of life when an older person is relatively fit, partnered and able to contribute to village life. Older people with a reasonable income, such as retirement migrants, are not significantly affected by the depletion of local services as they often have a car and can drive to buy food or visit their GP. Even for long-term residents with limited resources, entering old age or becoming widowed in a familiar village may offer comfort, security and access to a trusted network of support.

However, rural life becomes more difficult in the fourth age when physical and mental capacities are more likely to decline, social support structures break down and partners die (Le Mesurier, 2002). Issues such as low population density and dispersed settlement 'impinge on the lives of all rural dwelling elders' and undermine the capacity of informal support to provide help (Windle and Burholt, 2001: 5). Those groups whose needs fall outside of the informal net include older people with mental health problems (particularly dementia), isolated elders with no access to a car and the newly bereaved incomer. The key dimensions of rural life – inclusion, community participation, mutual aid and sparsity – are either not available to these populations or actively undermine their wellbeing. If you are ill, isolated or depressed in a village there are fewer options than in a city and fewer services (Tait and Fuller, 2002). Further, the disadvantages of rural living tend to be experienced in combination: groups of rural elders on the margins of their communities often find that their difficulties are not only more visible but are magnified and deepened.

Thus far we have focused on outlining the key health-related characteristics of older people living in rural England. The focus of the second part of this article

is to explore how far policy meets the needs of this population and how effectively it ameliorates the impact of any disadvantages that contribute to reduced quality of life and poor health.

#### The impact and efficacy of policy

Older people in rural areas are invisible, or at best peripheral, to policy development in England (Milne *et al.*, 2002). This is for a number of reasons. The older population is widely dispersed, encouraging the view that there are few elders living in 'rural areas'. Further, rural England is regarded as universally pleasant and healthy (Pugh, 2000). This stereotypical representation serves to mask the complexity and heterogeneity of rural populations and communities as well as obscure change and disadvantage. That older people in rural England have rarely been the focus of research is an additional deficit: one not shared by the older populations of Wales and Scotland (Shucksmith, 2003; Wenger *et al.*, 1999).

While much is now being done to highlight and address a wide range of rural issues most notably via the rural policy agenda the dominant perspective of the majority of policy remains urban (Scharf *et al.*, 2002; Shucksmith, 2000). Ensuring that all policy accommodates rural issues and takes particular account of rural populations is a recent overarching aim of policy reform (Local Government Association, 2001). The expectation that rural policy will recognise the needs of older people is also on the agenda reflecting, at least in part, their more visible political and social profile (Association of Directors of Social Services/Local Government Association, 2003). The extent to which this cross-fertilisation has been successful is a key component of the following discussion.

In considering the role and efficacy of policy, it is important to acknowledge that the needs of older people are complex and multifaceted; over the last decade there has been a plethora of policy development, and the nature and impact of policy implementation vary widely between areas, communities and across the older population itself (Audit Commission and Better Government for Older People, 2003). For these reasons we have sought to strike a balance between identifying individual policies and exploring policy themes, and between commenting broadly on the overarching impact of policy and its differential effect. The majority focus is national level policy and on those issues which have a particular impact on quality of life and health. Analysis is presented around the three most relevant policy arenas: rural policy; health and ageing; and community development and social capital. While these distinctions help structure analysis, there is inevitable overlap. Discussion begins, appropriately, with a review of rural policy.

# Rural policy

Recent years have witnessed a number of significant rural policy initiatives, most notably the Rural White Paper 'A Fair Deal for Rural England' (DEFRA,

2000) and the 'Rural Strategy' (DEFRA, 2004). Despite definitive emphasis on the twin objectives of social justice and equity, there is little evidence that either policy-making mechanisms or resource allocation systems accommodate the needs of rural populations, including older people, to any greater extent than was previously the case. For example, 'rural proofing' – a tool whereby all new policies are interrogated to ensure they take account of rural issues - has been recently criticised as having minimal impact on policy design and development (Countryside Agency, 2004). There is no evidence, for example, of explicit policy accommodation of the additional costs of providing local rural services, an issue of key importance to older people as the population most acutely affected by their erosion.

There are, however, a number of emerging strategic developments that may yield positive outcomes. A Minister of State for the Environment, Food and Rural Affairs is a member of the recently formed Sub-Committee on Ageing Policy; this offers a pivotal opportunity for the two spheres to interrelate and develop policies in concert (Cabinet Office, 2005). Additionally, a key role of the Commission for Rural Communities is to ensure that all policies reflect the needs of rural populations, including older people. As it is embedded in policy making it is likely to be more effective at achieving this aim than 'rural proofing' (Commission for Rural Communities, 2005). Their impact awaits analysis.

Local level planning-related mechanisms - Local Strategic Partnerships (LSPs) - may also hold promise (ODPM, 2005c). LSPs3 bring together public, voluntary and community agencies in one locality to promote and secure wellbeing, implement policy and develop services (Local Government Association, 2001). Emerging evidence – albeit primarily from urban areas – suggests that LSPs engage effectively with older citizens and incorporate their priorities into Local Area Agreements (LAAs). These set out priorities for a local area and have a particular brief to address deprivation (Cabinet Office, 2001; ODPM, 2006): for example, supporting investment in public transport and local multi-agency 'one-stop centres' offering health care, social opportunities, and information (Performance Management for Local Strategic Partnerships, 2004). The fact that the inclusive 'bottom-up' model of decision making adopted by LSPs characterise existing rural planning mechanisms – such as Parish Councils – and that these often represent the 'voice' of older residents, enhances the likelihood that their views will be accommodated. It is, however, a continuing challenge to include frail older people, particularly those with mobility or communication problems.

#### Rural infrastructure

Failure of the current policy system to accommodate rurality, alongside recognition of widespread service deficits, underpins one of the key aims of rural policy: to develop a sustainable 'rural infrastructure' (DEFRA, 2004).

Older people are primary, and intended, beneficiaries. Specifically, the Rural Services Review<sup>4</sup> defined a set of standards whose objectives are to improve access, quality and range of both universal and specialist services (DEFRA, 2004). Of particular relevance is the ten-year Plan for Transport that aims to improve public transport in 'rural and remote settings'; it explicitly recognises the role this plays in enhancing quality of life for older people (Beecham, 2005). Also, £450 million is being invested to safeguard the future of rural post offices: an initiative partially fuelled by evidence that older people are disadvantaged by their closure (Department of Environment, Transport and the Regions, 2001). Further, an extra £30 million is funding an expansion of rural policing; this may address the concerns older people have about increased levels of crime referred to earlier (ODPM, 2005c). Improvements to rural health provision – a related policy goal – are discussed in the following section.

It is additionally noteworthy that service improvements are underpinned by a policy commitment to partnership; much rural provision is characterised by a sharing of resources and 'organic' links between local agencies. This facilitates a joined-up approach, which is evidenced as particularly effective at meeting older people's needs (Craig and Manthorpe, 2000).

#### Tackling deprivation

Tackling deprivation is another priority for rural policy, one shared with policies tackling exclusion and health inequalities (ODPM, 2005b). Key initiatives include alleviating fuel<sup>5</sup> and income poverty and improving inadequate social housing (DTLR & DTI, 2001). Reducing 'excess winter deaths' – a primary cause of mortality in remote areas – is a particular target (ODPM, 2004a). Encouraging rural pensioners to claim welfare benefits<sup>6</sup> has been the focus of specific campaigns by DEFRA in 2004 and the Commission for Rural Communities<sup>7</sup> in 2005. In its report on rural disadvantage, the Commission noted a need for flexibility in identifying and tackling long-term poverty among older people (Phillipson and Scharf, 2004). The fact that poverty tends to exist at the level of a single household rather than being concentrated in a specific area is a particular challenge (Shucksmith, 2000).

Accommodating the nature and heterogeneity of rural poverty is the focus of related work reviewing the traditionally urban-focused deprivation indices (Swindlehurst, 2005). In the 2004 document 'English Indices of Deprivation', for example, distance from services is calculated on the basis of road distance rather than 'as the crow flies' (ODPM, 2004b). This will help to identify the actual time taken to travel to shops or services and will be of particular benefit to older people, the group most disadvantaged by distance decay. It may also contribute to the argument for a premium for rural services. That 'rural deprivation' is now recognised in a new government index of 'disadvantage' is also positive (Cabinet Office, 2001). Linked to this is DEFRA's introduction of a

more sophisticated definition of 'rural'<sup>8</sup> (DEFRA, 2004). It takes fuller account of the varied characteristics of rural areas and allows 'fine-grained' analysis to help pinpoint populations that have high levels of unmet need (Haynes and Gale, 2000). This encompasses older people whose needs have historically been inadequately recognised.

While rural policy has a key role in defining rural needs, articulating the direction of policy for rural areas and monitoring its impact, addressing rural issues requires a partnership approach. As is clear from the examples already noted, delivery of many of the proposals in the Rural White Paper rests on collaboration with policies and agencies located in other spheres; this is the focus of subsequent sections.

#### Health and ageing

Over the last decade the overarching goals of health policy have shifted from an exclusive focus on those in 'greatest need' to wider public health aims; this has been accompanied by a broadening of the concept of health to incorporate wellbeing and a focus on integrated, graduated responses to need (Wanless, 2002). This trend sits comfortably with the multidimensional needs of older people as well as the interleaving nature of rural life. The expectation that agencies in a rural community will develop a 'balanced portfolio' of service provision mirrors the range of needs older people have: services that promote the wellbeing of that area or population, low-level preventive care and ensuring 'timely and appropriate' access to specialist services for those who are ill or frail (Department of Health, 2001a; ODPM, 2006). An emphasis on 'active ageing' and the promotion of independence are also prominent features of recent health- and age-related policy; aims which also resonate with community development policies (Audit Commission and Better Government for Older People, 2004; Department of Health, 2006).

In parallel, a number of major policy initiatives have been implemented with the aim of reforming care services. An emphasis on close collaboration between health and social care agencies and integrated 'care pathways' are key dimensions of the National Health Service Plan 2000 and the 2001 National Service Framework (Department of Health, 2001a, 2001b). The development of small-scale Joint Care Trusts – integrated models of provision combining health and social services – may hold particular potential for rural areas and those populations whose needs are best met on a localised partnership basis. The Trusts' capacity to work in concert with LSPs may also advantage older people who, as noted above, are often represented in these forums. A related emphasis on equity, addressed via the Department of Health's 'Fair Access to Care' directive, may also have a positive impact; it introduces a requirement that all local authorities adopt national eligibility criteria. This is intended to address current unevenness in service availability, although, as yet, no evidence of its efficacy exists.

A focus on holism is also a relevant feature of age-related policy. The Single Assessment Process, for example – a framework for 'assessing need' – requires workers to take account of the user's physical and social environment as well as their health status (Department of Health, 2001a). While no direct reference is made to rurality in assessment guidance, the inclusion of issues arising from an individual's location suggests greater recognition of the facets of place that may impact on health. The emphasis given to enhancing wellbeing and meeting need *in situ* is also significant as the majority of older people in rural areas wish to remain in their homes and communities (Scharf and Bartlam, 2006).

#### Health and social care services

Despite the fact that the direction of travel for both health- and age-related policy is largely positive, there are a number of competing tensions that influence the nature and pattern of service development. Two issues generate particular concern: the need for locally based services and funding.

As already noted, local services tend to be able to offer the most appropriate type of support to older people. The voluntary sector often makes a pivotal contribution; it tends to be familiar with an area's needs, is networked with other providers and has the flexibility to work with 'the grain' of a community (NCVO Policy Team, 2002). The policy shift towards centralisation—an inevitable product of the drive for cost efficiency—undermines the capacity of agencies to justify small-scale local services, including those provided by the voluntary sector.

Evidence that rural populations are disadvantaged by current resource allocation systems underpins the second concern. In 2001, the Countryside Agency (2000c) confirmed that per capita expenditure for health and social services in England is significantly lower in rural compared with urban areas. This is reflected in service allocation. In 2002, for example, Lowe (2003) evidenced that, of those people aged 65-plus 'in need of support from home care', far fewer received the service in rural than in urban areas. While consideration is given to the additional costs associated with providing services in densely populated inner cities, no equivalent account is taken of those costs arising from sparsity, isolation and physical geography. As the majority users of care services, this urban bias disproportionately disadvantages rural elders, particularly those living in peripheral settings. This inequity is less marked in rural Wales or Scotland where accommodations are made (Asthana et al., 2003).

In the rural policy section, we discussed a number of initiatives that suggest nascent recognition of the dimensions of rurality in wider policy making and the addressing of rural need. That this accommodation has not – as yet – been made within age, or health, related policy is striking. Although 'acceptable levels of service for all' is a core aim of the National Service Framework, there is limited commitment to funding 'universal health and social care provision' in rural areas (Department of Health, 2001a). To paraphrase Wanless (2002), despite

policy commitment to equity and social justice, the overarching challenge is a 'lack of fit' between the aims of productivity such as reduced unit costs and centralised resource allocation and those of ensuring equitable access to highquality local services to rural elders. There remains a persistent myopia: a failure to acknowledge that care in the countryside may not only need to take a different form but may cost more to deliver.

On a more positive note, improving health and social care is a key priority for the Rural White Paper (DEFRA, 2000). Relevant investments include a significant increase in one-stop primary care centres or mobile units. Mobile provision facilitates access for isolated elders, older people with mental health problems and carers; it may also diminish some of the cultural barriers to help seeking and facilitate prevention (Milne et al., 2001). A 'toolkit' specifically designed for rurally based primary care teams has also been developed; it includes consideration of transport issues, deprivation and 'appropriate access' to secondary care (Swindlehurst, 2005). The establishment of NHS Direct also has the potential to offer considerable benefits to elders who live in remote settings (ODPM, 2004b).

#### Community development and social capital

There is widespread recognition that improvements to quality of life for rural residents require greater policy investment in enhancing social capital, enriching communities and facilitating involvement. That these issues have long been viewed as pivotal and positive aspects of rural life magnifies the case for policy efficacy.

As discussed in the first part of this article, developing social capital is particularly important for older people whose lives tend to be embedded in place and who depend, more than other groups, on social interaction to promote wellbeing (Help the Aged, 2004; Shucksmith, 2000). The development of rural infrastructure is complemented by investment in the 'social fabric' of rural communities. The Rural Strategy 2004, for example, supports a programme of investment in community groups and village halls (DEFRA, 2002; Williams et al., 2001). The New Deal for Communities and the Rural White Paper place related emphasis on the importance of harnessing community self-help and have facilitated investment in volunteering opportunities (ODPM, 2002). As the key beneficiaries and providers of informal support and the majority of volunteers, the expansion of such activities is positive for older people and rural communities.

Of linked relevance is the emerging policy emphasis on building 'sustainable and healthy communities', a key focus of which relates to promoting active ageing and inclusion. A Sure Start to Later Life (ODPM, 2006) specifically identifies older people living in rural and coastal areas as being at risk of exclusion, and a number of the new Partnerships for Older People Projects (POPPS) are rurally

located (Department of Health, 2005c; ODPM, 2005c). Shared aims of rural POPPS include: facilitating social opportunities; reaching out to isolated elders; enhancing access to community facilities; and consolidating sparse transport schemes. These resonate with the facets of rurality identified earlier as barriers to participation.

Another strand of community development relates to the involvement of older people in decision making. We have already noted that rural LSPs have the potential to take account of older people's views; recent evidence also suggests that they are involved in developing 'town and village plans', an initiative linked to the Rural Strategy (DEFRA, 2004). Not only does this activity ensure that older people's needs are located at the heart of local planning, but it also provides a bridge into wider activities (Better Government for Older People, 2000). 'Creating Sustainable Communities' goes a step further: it promotes the appointment of older people as 'community leaders' whose role is to identify, articulate and address local needs (ODPM, 2005a). It is anticipated that many rural elders will take up this challenge; this will at least secure a link between those older citizens who are fit and articulate, and policy delivery in rural areas. Those who are frail or disadvantaged may continue to be situated on the periphery.

#### Conclusion

Despite the fact that older people constitute a significant and increasing proportion of the rural population of England, they remain absent from, or at best marginal to, the development and implementation of policy. While some policies recognise the particular nature of rural living, and others address the needs of the older population, none takes account of older people living in rural areas as a discrete group with distinctive, or even recognised, needs. They tend to exist 'off centre': rarely the focus of policy but routinely its recipients.

Although evidence is equivocal and fragmented, a number of policy trends can be discerned which do, or will, enhance the health and quality of life of rural elders. An emphasis on community development, which focuses on building a sustainable service and social infrastructure, is positive, as is an emphasis on promoting inclusion of marginalised populations. Investment in integrated community-led initiatives, which explicitly identify older people as a target population, has considerable potential to facilitate participation and engage with those groups at risk of isolation and exclusion. Recognition of the impact of rural deprivation on community and individual health is an aligned policy goal; the recent push to alleviate poverty and disadvantage is likely to be of direct benefit to a large number of disadvantaged elders. This, in turn, links with the recent extension of health policy to incorporate health inequalities and investing in health improvements for vulnerable populations. Older people at risk of ill health benefit from this wider lens and from approaches that focus on prevention

and integrated flexible responses to meeting need. There is a growing alignment of policy around these overlapping themes, reflecting both the experiences of older people and interlocking more coherently than hitherto with the nature and rhythms of rural life. The expectation that all new policy must be explicitly cognisant of the needs of rural populations – including older people – is also positive.

Promoting health and independence among both fit and frail elders is a related theme of health- and age-related policy: a driver for enhancing access to both universal and specialist services. Rural policy supports this agenda, albeit unevenly, by investing in new services, setting explicit rural service standards and addressing health service deficits. Building on existing rural models of decision making and support is a particular feature of recent policy investment and one that advantages older people. Recognition of the contribution older people make to rural communities, a need for policy to facilitate 'ageing in place' and to develop services that accommodate the context in which an older person lives is also notable.

More critically, the majority of policy, rural policy notwithstanding, is directed by a largely urban agenda. Rural issues are marginal to policy making, and a lack of research evidence has compounded the invisibility of the rural elderly. Overall, 'the needs of the rural elderly remain under-researched and under-addressed in policy' (Buller et al., 2003: 41). Research deficits include exploring the lived experiences of the diverse elderly population living in rural England, the impact of the changing nature of 'rural community life', and the capacity of care services to offer effective support to those who are frail (Buller et al., 2003). While investment in research is important, embedding it into policy making is key to ensuring that the needs of rural elders are coherently considered. This process exists in Wales and Scotland. Evidence from the Bangor Longitudinal Study of Ageing, for example, was fed into the 'Strategy for Older People in Wales' (Wenger et al., 1999). This 'bridge' into the lives and health of rural elders is one that could be usefully duplicated in England. Lack of acknowledgement of the considerable heterogeneity within the population under review and across rural communities compounds the research and policy challenge: an issue that also requires further academic analysis.

Taking account of the needs of older people living in rural areas requires a dual policy response. For policy to be effective, it needs to address deficits in both existing policies and in the policy-making arena. Three key messages emerge: policy needs to be developed with rural elders in the foreground not the background; robust and coherent data should be gathered about their experiences; and account should be taken of how the needs of this population are addressed by policy makers in other parts of the UK. Further, there is a need for the systems and formulae used to allocate resources to take full account of those rural disadvantages, such as isolation and exclusion, that cumulatively impact on

the health and quality of life of older people in rural England. A recent report by the Commission for Rural Communities summarises the overarching policy challenge thus:

The real question for policy makers is the extent to which . . . issues affecting older people in rural areas ... are rural issues requiring a specific rural policy response or whether they are more widespread phenomena or experiences requiring a national policy response which embraces both urban and rural elders equally (Commission for Rural Communities, 2005: 5).

The policy agenda in England needs to 'grasp the nettle' and embed considerations of ageing in a rural context into its development, funding and implementation.

#### Acknowledgment

The authors wish to acknowledge the Countryside Agency who commissioned the report 'Ageing in the Countryside' (Milne et al., 2002).

#### Notes

- 1 At the time the review was written, the Countryside Agency's definition of 'rural' rested on population density alone.
- 2 In 2002, the annual MIG was £5,104 for a single person and £7,790 for a couple.
- 3 LSPs were established under the Local Government Act 2000.
- 4 This was introduced to support the implementation of the Rural Strategy.
- 5 Households that spend more than 10 per cent of their income on fuel to heat their home to an adequate standard.
- 6 Rural pensioners under-claim pension credit, attendance allowance, carers allowance and council tax benefit.
- 7 The Commission for Rural Communities aims to provide independent advice to government and ensure that policies reflect the needs of people living in rural England.
- 8 The new definition consists of two parts: settlement morphology and the wider geographic context in which individual settlements are located.

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- Windle, G. and Burholt, V (2001), Literature Review for the Strategy for Older People in Wales: Transport, Access, Mobility and Rural Living, Bangor: University of Wales.

# Curriculum vitae Alisoun J. Milne BA (Hons), CQSW/Dip. App Soc Studs, MA, PhD

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Fax +44 1227 763674 Date of birth: 26<sup>th</sup> January 1959

Email <u>a.j.milne@kent.ac.uk</u> British nationality

Since 1993 an academic at the University of Kent. Initially - until 1996 - a Research Fellow at the Personal Social Services Research Unit and subsequently a Lecturer and then Senior Lecturer in Social Gerontology at the Tizard Centre. The Centre's programme of work includes teaching, research and consultancy focusing particularly on good practice in community-based services for users and carers.

## Education and professional qualifications

BA Social Studies (2.1) University of Liverpool, 1980 C.Q.S.W/Diploma Applied Social Sciences, Goldsmiths College, London University, 1985 M.A. Social Research (Distinction), University of East London, 1990 PhD (Social Policy), University of Kent, 2010

## **Appointments**

1985-1989	Social Worker, Wandsworth Social Services Department, London
1989-1993	Team Manager, Mental Health Sector, Wandsworth Social Services Department,
	London
1993-1996	Research Fellow, Personal Social Services Research Unit, University of Kent at
	Canterbury
1996-2003	Lecturer in Social Gerontology, Tizard Centre, University of Kent at Canterbury
1999-2002	Nuffield Institute for Health, Leeds University: Visiting Research Fellow
1 (J. 1977)	(Concurrent with Tizard Centre Post)
2003-	Senior Lecturer in Social Gerontology, Tizard Centre, School of Social Policy,
	Sociology and Social Research, University of Kent at Canterbury
2010-	Honorary Research Fellow, Canterbury Christchurch University, Canterbury

## Membership of professional organisations and external bodies

Member of the Higher Education Academy and the General Social Care Council.

Member of the Audit Commission Advisory Group for the Forget-me-Not review of mental health services for older people (1999-2001) and a Health Advisory Service Reviewer within the same speciality (2002-2005).

Co-Chair of the Older People's Care Group Workforce Team, Dementia Sub-Group (2002-04). Member of the National Patient's Safety Agency's Mental Health Expert Reference Group (and member of a Special Sub Group on 'Restraint') (2004-07). A member of the Health Development Agency, Reference Group for, 'Promoting Mental Health (2003-05).

Member of St. Monica's Trust Advisory Group: 'Balanced Retirement Communities' – A Case Study of Westbury Fields, Bristol (2004-2006). Member of the National Institute for Excellence/Social Care Institute for Excellence Advisory Group: Care of People with Dementia and their Carers (2005-06) and member of the Oversight Group: South East Dementia Collaborative (2005-2008). Member of the Age Concern Mental Health in Later Life Inquiry Policy Working Group (2006-07). Member of the Kent Carers Reference Group (2008-) & the Reference Group for the Mental Health Foundation project 'Dementia Choices: people with dementia and personal budgets' (2009-).

City and Guilds Qualification Development - Promoting the Mental Health and Well being of Older People: UK Expert Reference Group Member (2006-08).

Trustee, 'Alzheimer's Society and other Dementias Support Service', Gravesend, Kent (2007-).

Member of the Standing Commission on Carers (2009-)

Member of the British Society of Gerontology Executive Committee (2009-)

## Membership of internal University groups/committees

Faculty representative on the University 'Part Time Strategic Review Committee' (2004-5) and the 'Values Advisory Group' (2005-06).

## **Key achievements**

2001/present day: Raised awareness of, and established a national interest in, *older carers*. Primarily through a Help the Aged funded project which resulted in the report - *The Needs and Roles of Older Carers* (Milne et al, 2001) - but also via a pilot study of former carers in SE Kent Milne et al, 2003), work on gender and caregiving (Milne and Hatzidimitraidou, 2003) and work on dementia carers from black and ethnic minority communities (Seabrooke and Milne, 2004; Milne and Chryssanthopoulou, 2005). At a local level the carers work was taken forward in 2007 by survey based research on 'caring in Kent' (Palmer., Milne., & Hastie, 2008). Work building on barriers to employment amongst carers is also linked and is the subject of a recent project funded by the Department of Work & Pensions (Vickerstaff., Loretto., Milne et al, 2009). It has also played a significant role in my appointment to the Standing Commission on Carers, an independent body of experts tasked with advising the Government on carer related policy development and implementation.

2000/present day: Raised awareness of, and conducted pivotal research into, early diagnosis of dementia amongst GPs (Milne et al, 2000; Milne et al, 2005; Wilkinson and Milne, 2003; Milne at al, 2008). The Audit Commission used a Magnitude Assessment Scale developed in my work (2000) in its national review of mental health services for older people (Audit Commission, 2000, and 2002, Forget-me-not: Mental health services for older people). The research also led to my membership of the Advisory Group for the 'Forget me not' studies, the NICE/SCIE Advisory Group and the SE Dementia Collaborative Oversight Group. It was also a key driver for the establishment of the Mental Health Foundation's 'Dementia Advice and Support Service' (Lingard and Milne, 2004). More recent work on 'dementia screening' is also important and has made a key contribution to raising the national policy and practice profile of early intervention in the diagnosis and management of dementia (Milne et al, 2008; Culverwell et al, 2008). Related work on psychosocial well being and early diagnosis is also relevant (Milne and Peet, 2008) as is more critical analysis of dementia screening as part of the

encroachment of medical surveillance into the lives of healthy older people (Milne, 2010).

2000/04: Via a half time secondment to a national charity, the Mental Health Foundation, I helped establish a range of projects under the umbrella programme of 'Mental Health and Later Life'. These include establishing and evaluating the aforementioned national 'Dementia Advice and Support Service'; obtaining funding for the development of a Certificate in Mental Health Care for Older People (Section 64 grant from the Department of Health); leading the Foundation's contribution to a UK wide 3 year public enquiry entitled 'Mental Health and Older People'; and making significant contributions to a range of publications and conferences. 2002/08: Helped establish a service for older Asians with dementia in NW Kent. The project was underpinned by a research study that evidenced the need for a dedicated service - see Seabrooke and Milne, 2004 - and was also supported by a specific focus on minority elders with dementia by the Mental Health Foundation (Milne, 2002, 2003). This in turn led to a 2007 SE Dementia Collaborative Project on black and minority ethnic elders and early diagnosis of dementia in Dartford & Gravesend (Seabrooke and Milne, 2009).

2003/present day: Contributed to a range of service development projects in the older people's mental health field. This includes: co-writing an integration document on 'Community Mental Health Teams' for the Department of Health (Lingard and Milne, 2004a); contributing to a nationwide Guide, 'Assessing the Mental Health Needs of Older People' (Social Care Institute for Excellence, 2006); and a review of day hospital services for older people with mental health problems for a London based Partnership Trust. These directly influenced service and policy developments in the National Institute for Mental Health and the Care Service Improvement Partnership. Between 2005-2007, the SCIE Guide was built upon by the development of innovative and award winning e-learning materials on older people's mental health (Social Care Institute for Excellence, 2008). More recent work evaluating a Home Treatment Service for Older People with dementia and a multi-component intervention for carers of people with dementia is also part of this body of work (Milne et al, 2010). I have also conducted two relevant recent literature reviews which form the basis of two research projects for the Mental Health Foundation. These are: Psychosocial Well Being in People with Early Diagnosis of Dementia' (Milne & Peet, 2008) and 'Hidden No More: Dementia and Quality of Life Indicators (Warner, Peet & Milne, 2009).

## **Recognition and Dissemination Activities**

The work on early diagnosis of dementia and screening is of national significance and is recognised as such in academic and policy circles. The work on older carers and mental health in later life is also recognised by those outside of the university e.g. the charity sector, practitioners and national bodies with a training and good practice remit such as the Social Care Institute for Excellence. Invitations to speak at conferences and write for journals and books additionally suggest esteem. My recent appointment to the Government body, the Standing Commission on Carers, represents significant recognition of my work on older carers.

A core aspect of all my work is effective dissemination. This partly reflects the practice orientation of the work on early diagnosis of dementia, carers and good practice in services for older people with mental health problems. It also reflects a personal commitment to knowledge transfer and the capacity to write for a practice as well as an academic audience (e.g. Milne et al, 2008 in *International Psychogeriatrics*, and Culverwell et al, 2008 in *Quality in Ageing*).

# University teaching

I have been involved primarily in two courses at the Tizard Centre: setting up, directing and delivering the BA in Health and Social Care Practice at Medway and managing and delivering

teaching on the MA in Management of Community Care. A significant proportion of students are part-time and work in health or social care services. Teaching combines academic study with practical application in the workplace.

Awarded the 1997 and 1998 Tizard Academic Prize for "exceptional teaching for the MA in the Management of Community Care".

# **External Examining**

2005-2009: Examiner for BA Health and Social Care, Brighton University

2009-: Examiner for the MA in Social Work, Canterbury Christchurch University, Kent

## Other teaching related roles

Specialist Assessor in Social Work for the Higher Education Funding Council for England and Wales. Quality Assessment visits to Nene College (February 1994), the University of North East London (March 1994) and the Open University (May-June 1994).

## Selected consultancy

Mental Health Foundation & Alzheimer's Society, 2009: Co managed a literature review entitled 'Hidden No More: Dementia and Quality of Life Indicators' (Warner, Peet & Milne, 2009). This provided the foundation for a larger project on quality of life for people with dementia.

Mental Health Foundation & Alzheimer's Society, 2007/08: Led on a literature review entitled 'Challenges & Resolutions to Psycho-social Well-Being for People in Receipt of a Diagnosis of Dementia' (Milne and Peet, 2008). This provided the foundation for the launching of a campaign in October 2008 focusing on early intervention in dementia care called 'Out of the Shadows'.

Social Care Institute for Excellence, 2005/06: Co-authored a national web based guide entitled 'Assessing the Mental Health Needs of Older People' for the Social Care Institute for Excellence (2006). I also lead the subsequent development of a set of e-learning materials to accompany and support the Guide, 'An Introduction to the Mental Health of Older People' (Social Care Institute for Excellence, 2008).

*Haringey Partnership Trust*, 2004: Evaluation of day hospital services for older people with mental health problems

**Essex Approved Social Work Training**, 2000-2006: Helped to develop a number of modules for ASW training and providing teaching on ageing, mental health in later life and 'policy and the law' in mental health social work

Age Concern, 2000-2002: Led an evaluation of a community development project to reduce social isolation amongst older people in a London Borough - see Falloon, M., and Milne, A (2002) Reducing Social Isolation amongst Older People: Adopting a Community Development Approach, London, Age Concern

Royal College Psychiatrists, 2000: Contributed sections on the Approved Social Workers role and mental health policy and the law to a Guide on dealing with people with substance misuse problems – see Banerjee, et al, (2001) Co-existing Problems of Mental Disorder and Substance Misuse (dual diagnosis): An Information Manual, London: Royal College of Psychiatrists

#### Research supervision and examination

External examiner for a PhD presented in the Department of Social Policy, Hull University: 2005 Internal Examiner for a PhD at the Tizard Centre University of Kent, June 2007 Joint supervision of PhD student in SSPSSR, 2010

### Grants

The Home Treatment Service for People with Dementia in East Kent (PI): audit of the first two years' - Kent & Medway Health & Social Care Partnership Trust 2007/08 & 2008/09, £4,000 and £11,800 respectively

- 'Employment and Caregiving in Kent'- additional analysis of 'Caring in Kent Health & Lifestyle Survey' database, Faculty Small Grant 2008, £1000
- 'Employment Support for Carers', Department for Work and Pensions grant, 2007/08, £98,600 (coapplicant)
- 'Improving Concordance in Older People with Type-2 Diabetes (ICOPE-D)', Research for Patient Benefit grant, 2007/08, (RfPB PB-PG-0906-10182), £77,922 (co-applicant)
- 'Caring in Kent' analysis of carers related data drawn from the '2005 Health & Lifestyle Survey for Kent', 2006/07, Kent County Council, £5000
- 'An analysis of adult protection data from Kent County Council and Medway Council', 2005/06, Nuffield Foundation, £10,000
- 'Community Mental Health Teams for Older People Integration of Services', 2003/4, Department of Health, £15,000
- 'Travel Fellowship', 2005, British Academy, £300
- 'A review of the mental health challenges facing mid life women', 2003, Pennell Trust, £8000
- 'A wide ranging review of the impact and efficacy of policy on the health and well being of older people in rural England', the Countryside Agency, 2002, £15,000
- 'The needs and roles of former carers a pilot project', 2002, University of Kent Faculty grant, £3000
- 'A review and secondary analysis of data older carers', 2000/2001, Help the Aged, £12,300
- 'A cluster of projects: primarily the Dementia Advice and Support Service; the needs of older Asians with dementia and their carers; and user views of receiving a diagnosis of dementia', 2000-2004, The Mental Health Foundation, £104,610
- 'Analysing data and writing up a survey of Later Lifestyles', 1998, Help the Aged, £5,300

#### **Editorial Boards**

Board member of Quality in Ageing

#### Review work

Regular reviewer of papers for Aging and Mental Health and Ageing and Society.

Reviewer of research grant applications for the Big Lottery Fund, the BUPA Foundation and the Research for Patient Benefit, NIHR Programme.

## **Publications**

## **Academic Refereed Papers**

- 1. Milne, A., Palmer, A., Brigden, C., and Konta, E (in press) The Intersection of Work and Care: Evidence from a Local Case Study, *Health and Social Care in the Community*
- 2. Hamilton-West, K., Milne, A., Chenery, A and Tilbrook, C (in press) Help-seeking in Relation to Signs of Dementia: The Role of Illness Representations, *Psychology, Health and Medicine*
- 3. Cambridge, P., Beadle-Brown, J., Mansell, J., Milne, A and Whelton, B. (in press, 2010) The processes and outcomes of adult protection: Referrals in two local authorities, *Journal of Social Work*
- 4. Milne, A (2010) The D word: Reflections on the Relationship between Stigma and Dementia, *Journal of Mental Health*, 19(3), 227-233
- 5. Milne, A (2010) Dementia Screening and Early Diagnosis: the case for and against, *Special Issue of Health, Risk & Society*, 12(1), 65-76
- 6. Seabrooke, V and Milne, A (2009) Facilitating Early Diagnosis of Dementia in an Asian Community: Lessons from a Dementia Collaborative Project, *Quality in Ageing*, 10(4), 29-36
- 7. Milne, A and Dening, T (2009) Editorial, *Quality in Ageing Special Issue: Depression, Suicide and Self-Harm in Older Adults*, 10(2), 2-4
- 8. Dening, T and Milne, A (2009) Depression & Mental Health in Care Homes, *Quality in Ageing Special Issue: Depression, Suicide and Self-Harm in Older Adults*, 10(2), 40-46
- 9. Mansell, J., Beadle-Brown, J., Cambridge, P., Milne, A., and Whelton, B. (2009) Adult protection: incidence of referrals, nature and risk factors in English local authorities, *Journal of Social Work*, 9(1): 23-38
- 10. Culverwell, A., Milne, A., Guss, R & Tuppen, J (2008) Screening for Dementia in Primary Care: How is it measuring up? *Quality in Ageing*, 9(3): 39-44
- 11. Healey, F., Oliver, D., Milne, A and Connelly, J. B (2008) The effect of bedrails on falls and injury: a systematic review of clinical studies, *Age and Ageing*, 37: 368-378
- 12. Livingstone, G., Cooper, C., Woods, J., Milne, A & Katona, C (2008) Successful ageing in adversity the LASER longitudinal study, *Journal of Neurology, Neurosurgery & Psychiatry*, 79: 641-645
- 13. Milne, A., Culverwell., A., Guss., R., Tuppen, J and Whelton, R (2008) Screening for dementia in primary care: a review of the efficacy and quality of tools and measures, *International Psychogeriatrics*, 20(5): 911-926
- 14. Milne, A., Hatzidimitriadou, E and Wiseman, J (2007) Health and Quality of Life amongst Older People in Rural England: Exploring the Impact and Efficacy of Policy, *Journal of Social Policy*, 36(3): 477-495

- Milne A and Chryssanthopoulou, C (2005) Dementia Caregiving in Black and Asian Populations: Reviewing and Refining the Research Agenda, *Journal of Community and Applied Social Psychology*, 15: 319-337
- 16. Hatzidimitriadou, E and Milne, A (2005) Planning Ahead: Meeting the Needs of Older People with Intellectual Disabilities in the UK, *Dementia: The International Journal of Social Research and Practice*, 4(3): 341-359
- 17. Milne, A., Hamilton-West, K., and Hatzidimitriadou, E (2005) GP Attitudes to Early Diagnosis of Dementia: Evidence of Improvement, *Aging and Mental Health*, 9(5): 449-455
- 18. Milne, A., Hatzidimitriadou, E and Chryssanthopoulou, C (2004) Carers of Older Relatives in Long Term Care: Support Needs and Services, *Generations Review, Journal of the British Society of Gerontology*, 14(3): 4-9
- 19. Wilkinson, H. and Milne, A. (2003). Sharing a diagnosis of dementia learning from the patient perspective. *Aging and Mental Health* 7(4): 300-307
- 20. Milne, A., and Hatzidimitriadou, E (2003) Isn't He Wonderful? Exploring the contribution and conceptualisation of older husbands as carers, *Ageing International*, Vol. 28(4), p389-408
- 21. Milne, A and Hatzidimitriadou, E (2002) The Caring in Later Life Report: A Secondary Analysis of the 1995 General Household Survey, *Quality in Ageing*, Vol 3, Issue 3, pp3-15
- 22. Milne, A (2002) Developing a Profile of Older Carers, Generations Review, Journal of the British Society of Gerontology, Vol. 12, No 2, pp 27-30
- 23. Milne, A and Williams, J (2000) Meeting the Mental Health Needs of Older Women: Taking Social Inequality into Account, *Ageing and Society*, Vol. 20, No. 6 pp 699-723
- 24. Milne, A., Woolford, H., Mason, J and Hatzidimitradou, E (2000) The Early Diagnosis of Dementia by GP's: An Exploratory Study of Attitudes, *Aging and Mental Health*, Vol. 4, No 4, pp 292-300
- 25. Milne, A., Evans, S. and Morgan, D. (1999) The Role of Preventive Care: A Case Study of its Purpose and Potential, *Social Work and Social Science Review*, Vol. 8 (1), pp 5-20
- 26. Milne, A (1998) The Early Diagnosis of Dementia by GP's: A Study of Attitudes, *Generations Review, Journal of the British Society of Gerontology*, Vol. 8, No 4. pp. 13-14

## **Editing**

Milne, A, and Dening, T Co edited Special Issue of *Quality in Ageing* (March 09) *Depression, Suicide and Self-Harm in Older Adults, Papers from a Conference* 

## **Published Reports**

1. Warner, J., Milne, A & Peet, J (2010) 'My name is not Dementia': Literature Review, Alzheimer's Society: London

- 2. Vickerstaff, S., Loretto, W., Milne, A., Alden, E., Billings, J and White, P (2009) Employment Support for Carers, Department for Work & Pensions: London
- 3. Milne, A and Peet, J (2008) Challenges & Resolutions to Psycho-social Well-Being for People in Receipt of a Diagnosis of Dementia: A Literature Review, Mental Health Foundation & Alzheimer's Society: London
- 4. Palmer, A., Milne, A and Hastie, C (2008) *Caring in Kent: Profiles and Patterns*, Centre for Health Service Studies, University of Kent, Canterbury
- 5. Lingard, J and Milne, A (2004) Integrating Older People's Mental Health Services: Community Mental Health Teams for Older People, <a href="http://www.nimhe.org.uk/">http://www.nimhe.org.uk/</a>
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