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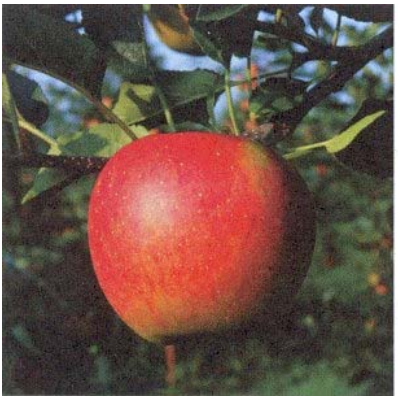
Caring in Kent: Patterns and Profiles, Evidence from the Kent Health and Lifestyle Survey, 2005



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Commissioned by Kent County Council

March 2008

Centre for Health Services Studies

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Commissioned by Richard Spoerry, Kent County Council

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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 co-resident 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' [1]

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[2] [3].

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[4]. The survey included a specific module on carers adapted

[1] Carers UK http://www.carersuk.org/Aboutus accessed 24/12/07
[2] Carers UK (2004) *In Poor Health: the impact of caring on health*, London: Carers UK
[3] Department of Health (2005) *The Carers (Equal Opportunities) Act 2004*, London: Department of Health
[4] 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[5] [6]; this is the most recent GHS to collect detailed data on carers[7] [8]. 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.

[5] Maher J and Green H (2002) *Carers 2000* London: Office of National Statistics, The Stationary Office.
[6] Office of National Statistics (2002) *Census 2001* London: The Stationary Office
[7] 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*"
[8] 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[9]. 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[10].

… 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[11]. 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 [12]. 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[13] [14] [15] [16].

one in six people aged 16 and over is caring for a sick, disabled or elderly person; one in five households contains a carer

[9] Carers UK (2004) *In Poor Health: the impact of caring on health*, London: Carers UK
[10] Office of National Statistics (2002) *General Household Survey 2000* London: HMSO
[11] Office of National Statistics (2002) *General Household Survey 2000* London: HMSO
[12] Office of National Statistics (2002) *Census, 2001* London: The Stationary Office
[13] Office of National Statistics (2002) *General Household Survey 2000* London: HMSO
[14] Wanless (2006) *Securing Good Care for Older People, taking the long term view* London: Kings Fund
[15] Milne, A., Hatzidimitriadou, E., Chryssanthopoulou, C and Owen, T (2001) *Caring in Later Life: Reviewing the role of older carers*, London: Help the Aged
[16] 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[17]

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[19].

[17] ONS http://www.statistics.gov.uk/cci/nugget.asp?id=949 accessed 16/8/07
[18] i.e. deaths in old age
[19] 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[20].

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

[20] Soule, A., Babb, P., Evandrou. M., Balchin, S and Zealey, L (eds) (2005) *Focus on Older People,*London: Office of National Statistics

and over[21]. 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[22] (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[23] 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[24] 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[25] 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[26]

[21] Alzheimers Society (2007) *Dementia UK.* London Alzheimers Society
[22] Department of Health (1990) *The 1990 NHS and Community Care Act* London: HMSO
[23] Department of Health (1995) *Carers (Recognition and Services) Act 1995* London: HMSO
[24] HM Government (1999) *National Carers Strategy* London: HMSO
[25] Department of Health (2001) *The Carers & Disabled Children Act* London: HMSO
[26] 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'[27]. The subsequent Work & Families Act extends the right of working carers to request flexible hours from their employer[28] 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

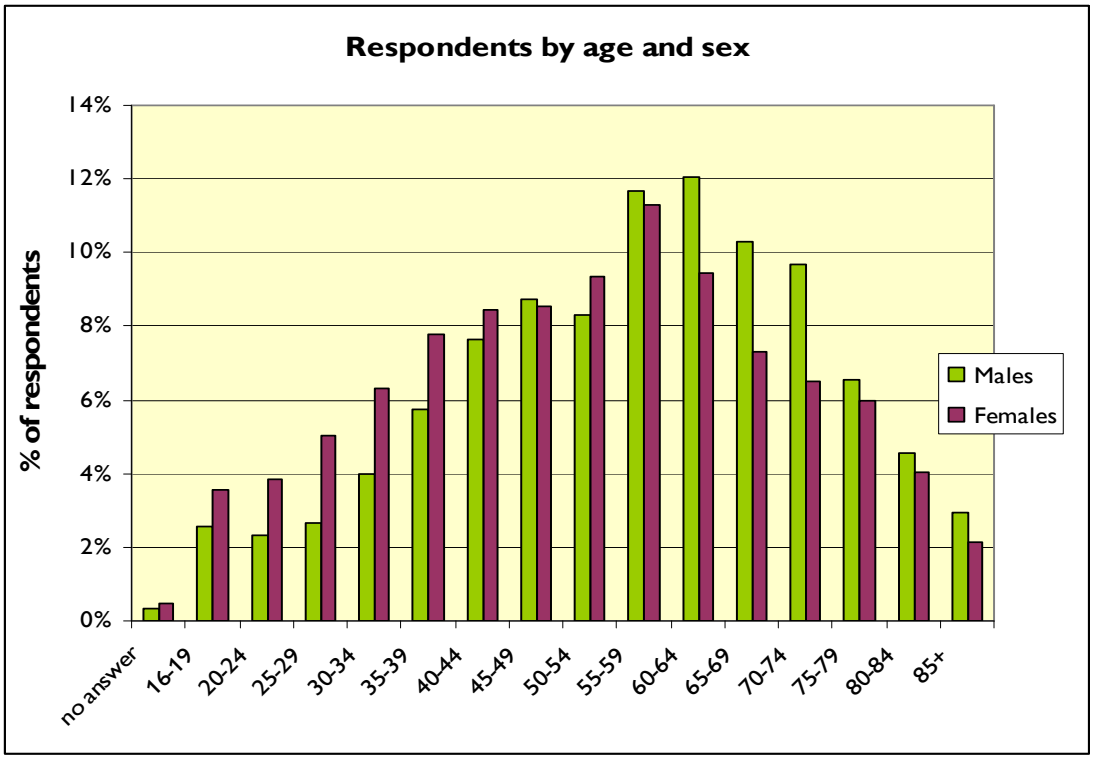
[27] Department of Health (2005) *The Carers (Equal Opportunities) Act 2004*, London: Department of Health
[28] Department of Health (2007) *Work & Families Act 2006*. London: Department of Health

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 1

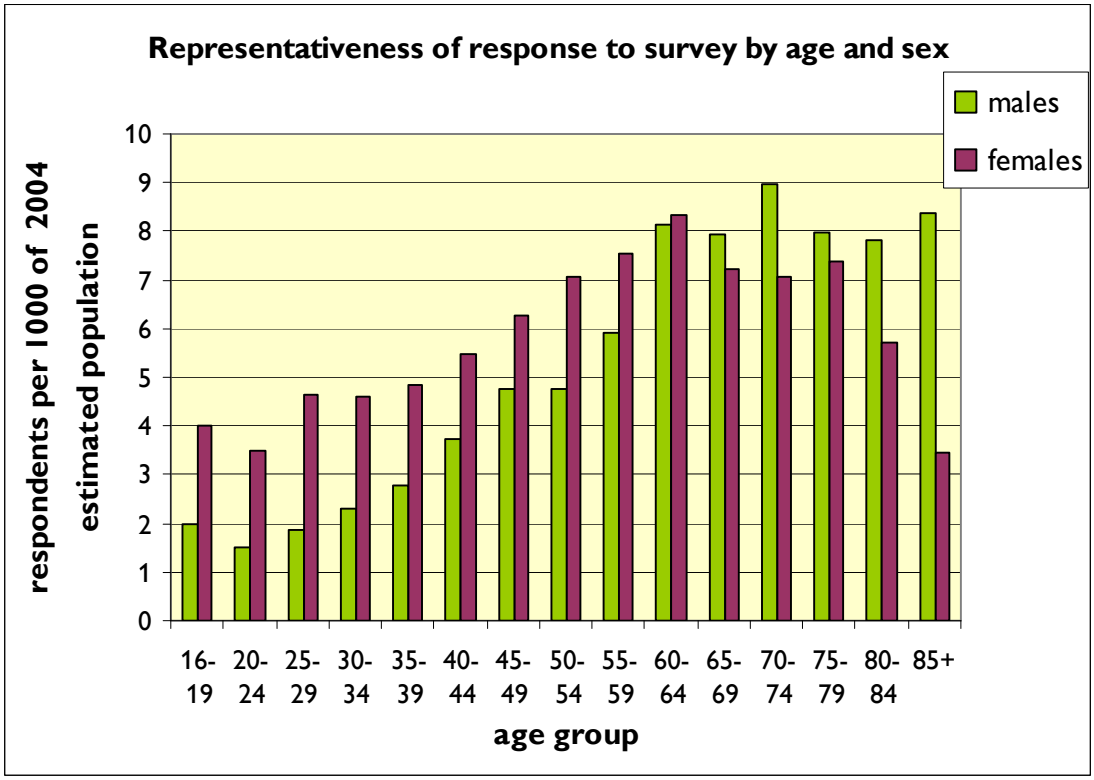


women were better represented up to the age of 64; from this age onwards men were better represented

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

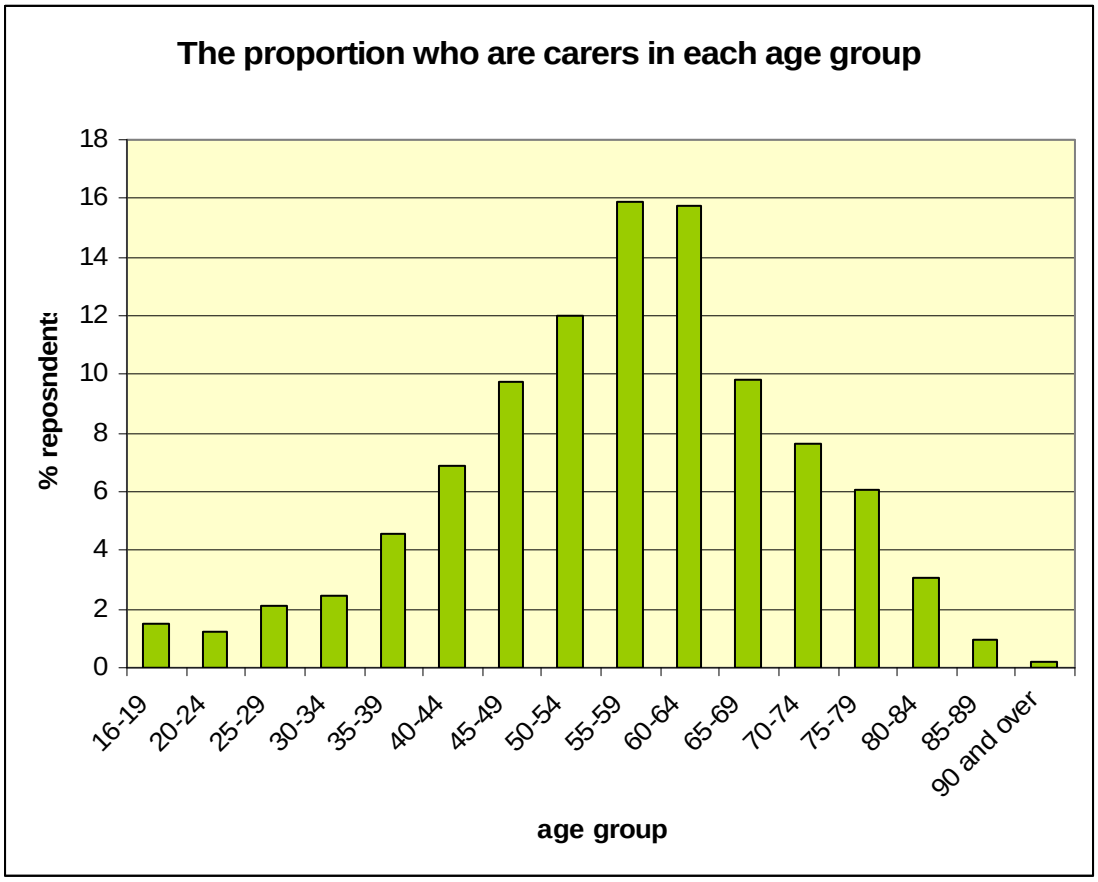
Number & Characteristics of Carers

20% of respondents identified themselves as carers, 40% were men; over half were in the mid-life group

19.7% (N=1142) of the total number of survey respondents (N=5800) identified themselves as carers[29]. 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.

[29] 201 (3.5%) did not reply to the question

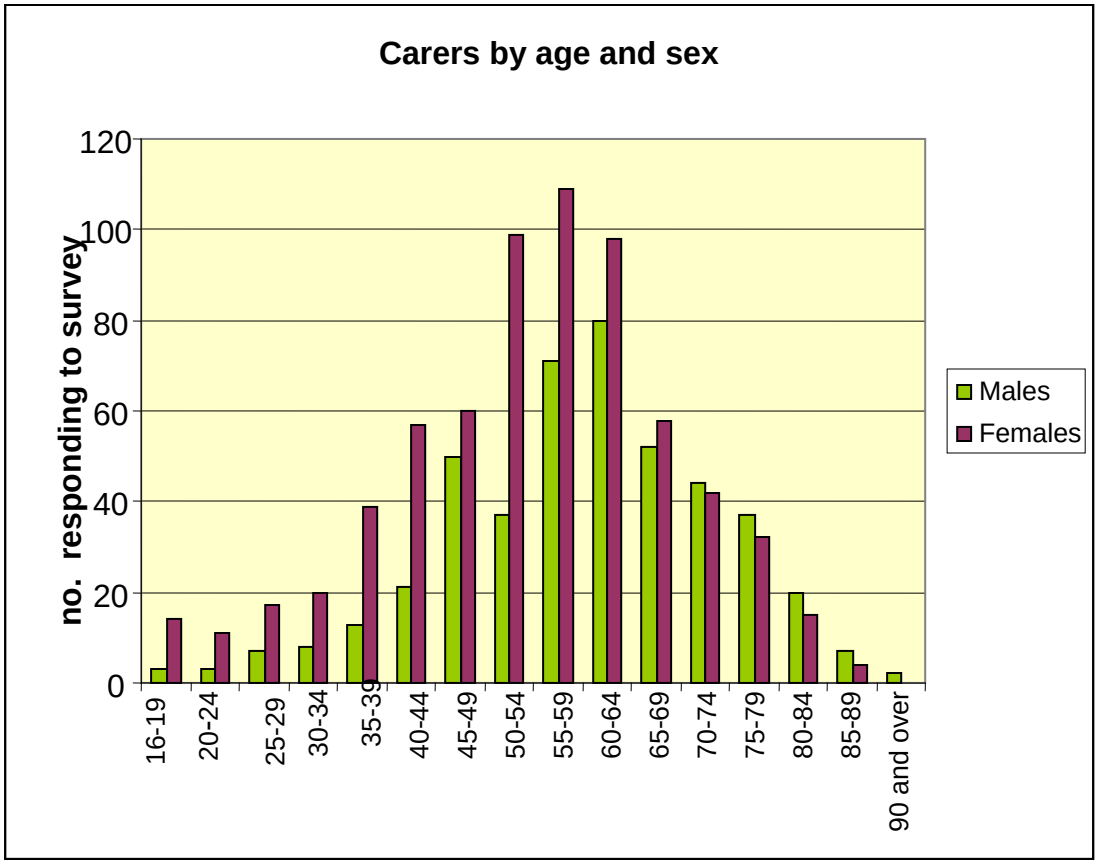
Figure 3



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[30]. 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.

[30] 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.

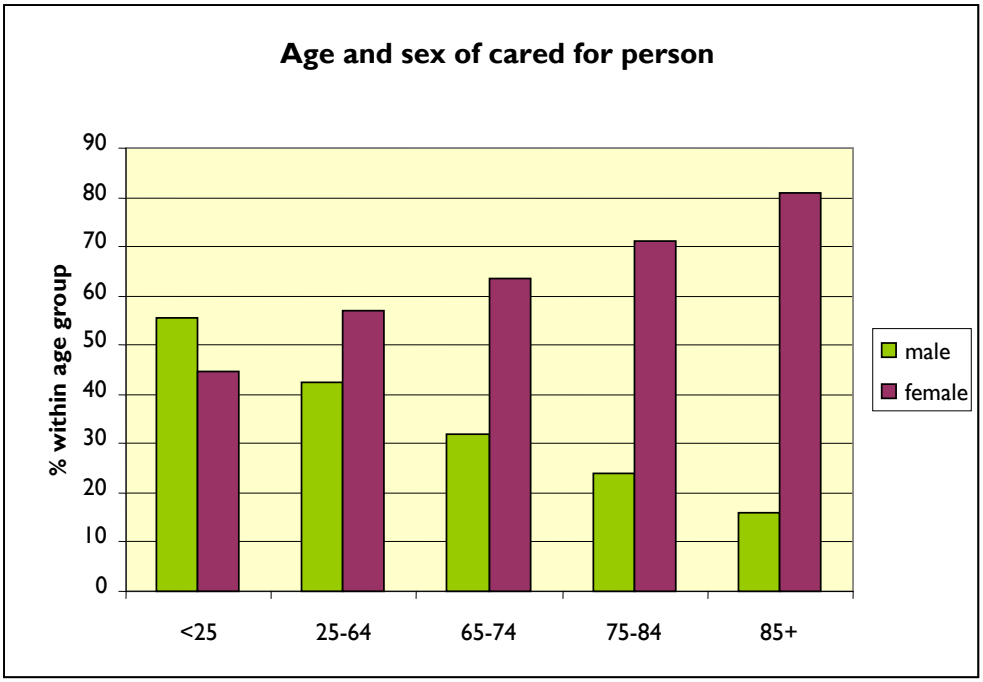
Figure 4



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


Age and sex of cared for person
% within age group
90
80
70
60
50
40
30
20
10
0
<25
25-64
65-74
75-84
85+
male
female

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

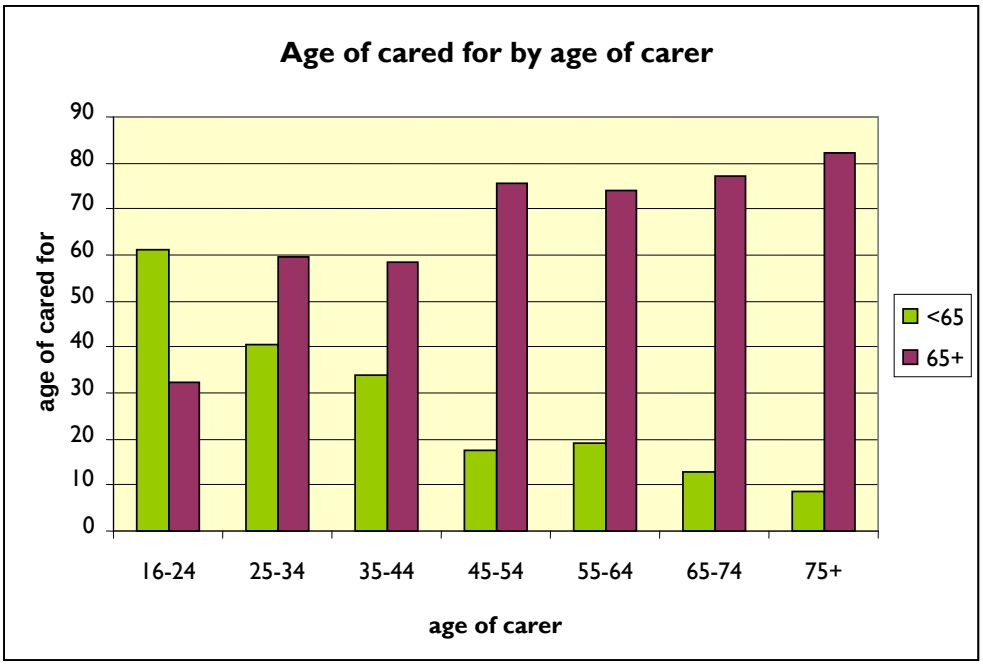


Table 1
For about how long have you been providing support or care to your relative/friend

	Frequency	Percent
no answer	24	2.1
under a year	121	10.6
1 - 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 7

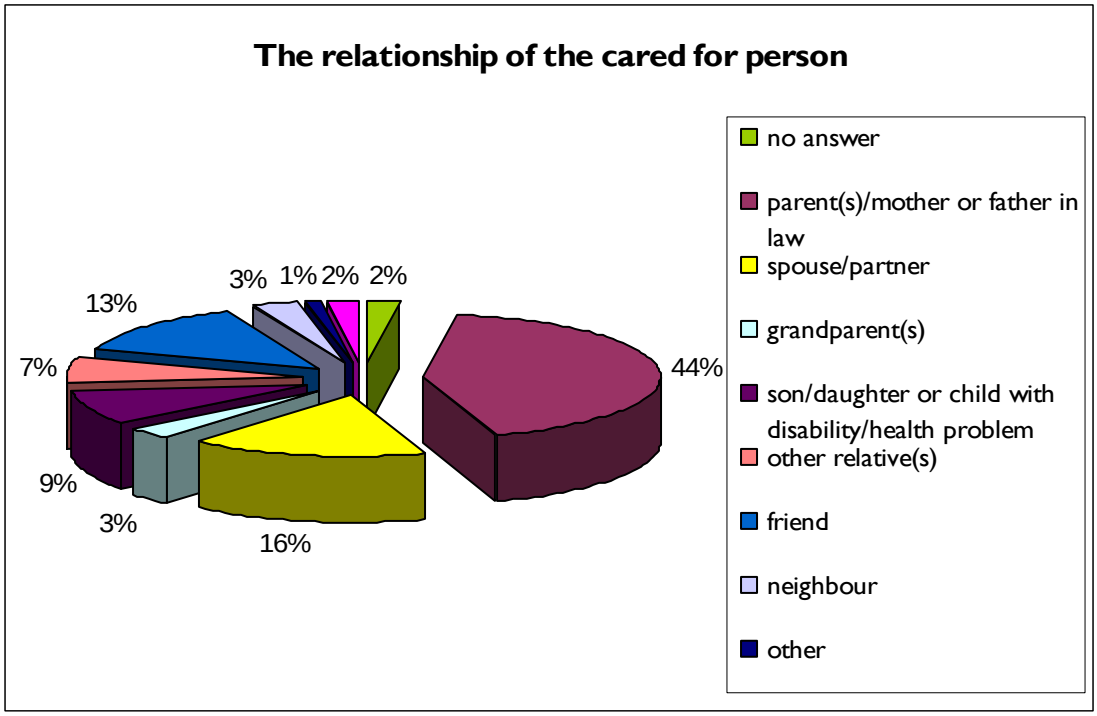
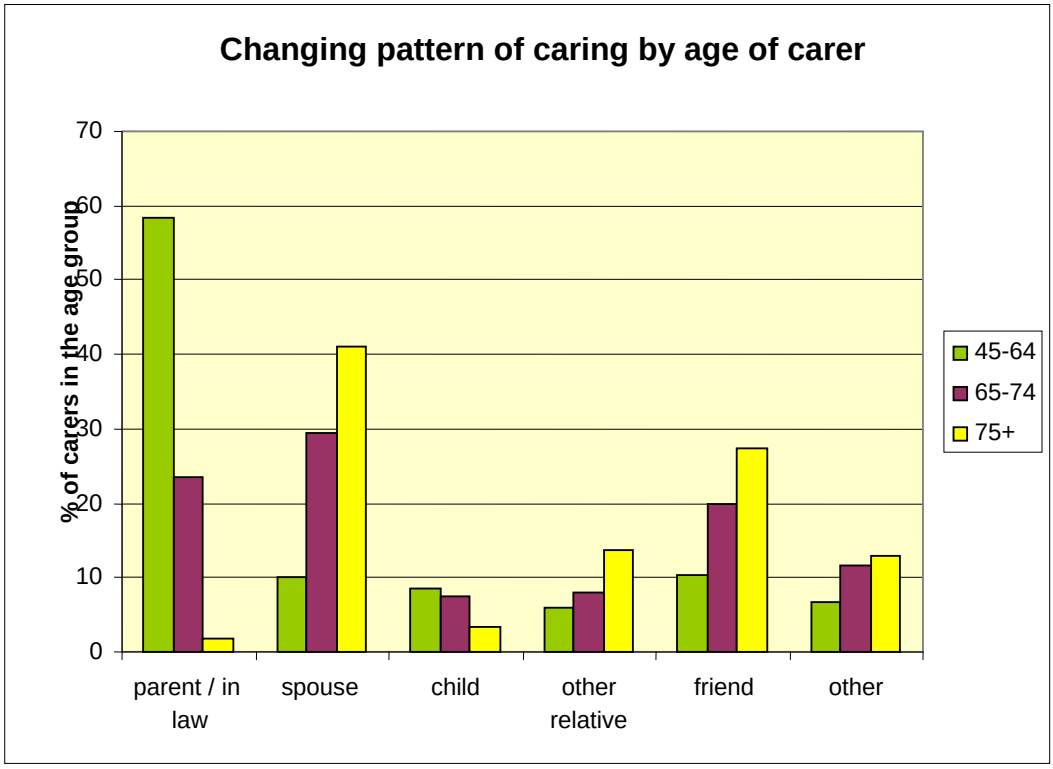


Figure 8



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[31]. Carers providing longer hours of caring were more likely to have the cared for person living with them (Table 2).

[31] This category also subsumes housing with extra care

Table 2

Where does the cared for person live?

Hours of care	1-19 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

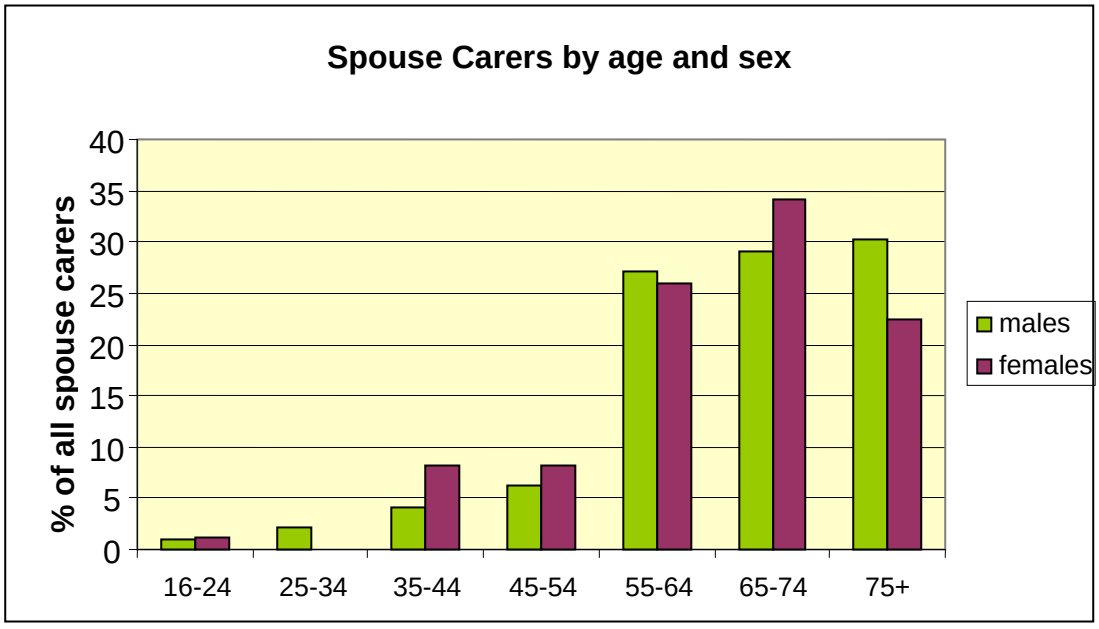
a quarter (27%) were living in their own home

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 1-19 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,
- 11.7% 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 help with walking, 9% with getting up and down stairs, 10% with getting in and out of bed and 19% with giving medicines

Of all those caring:

- 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

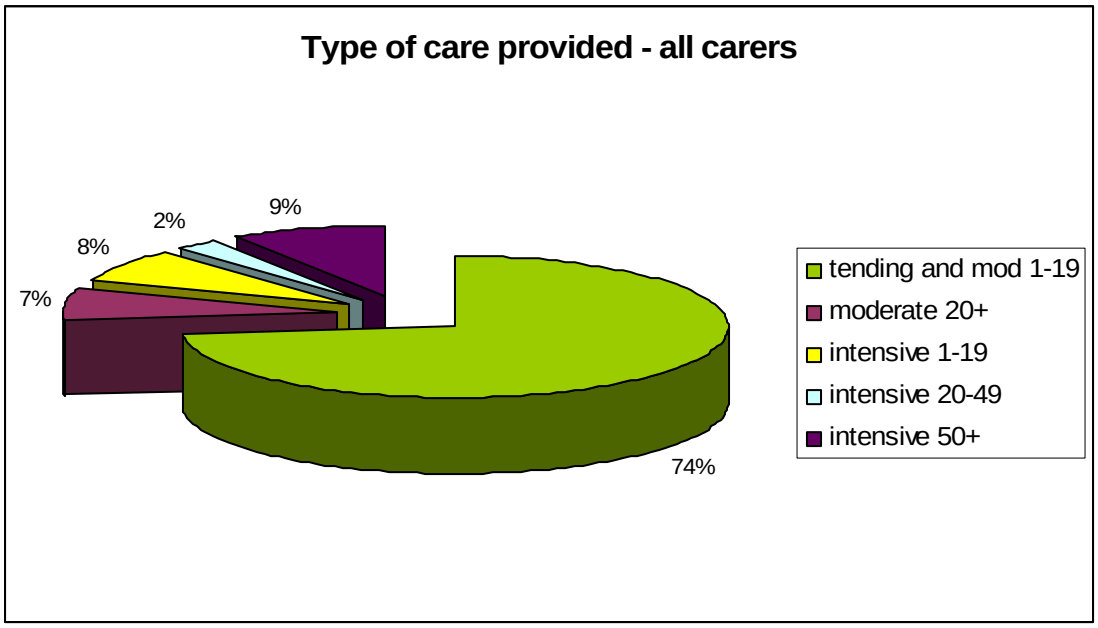
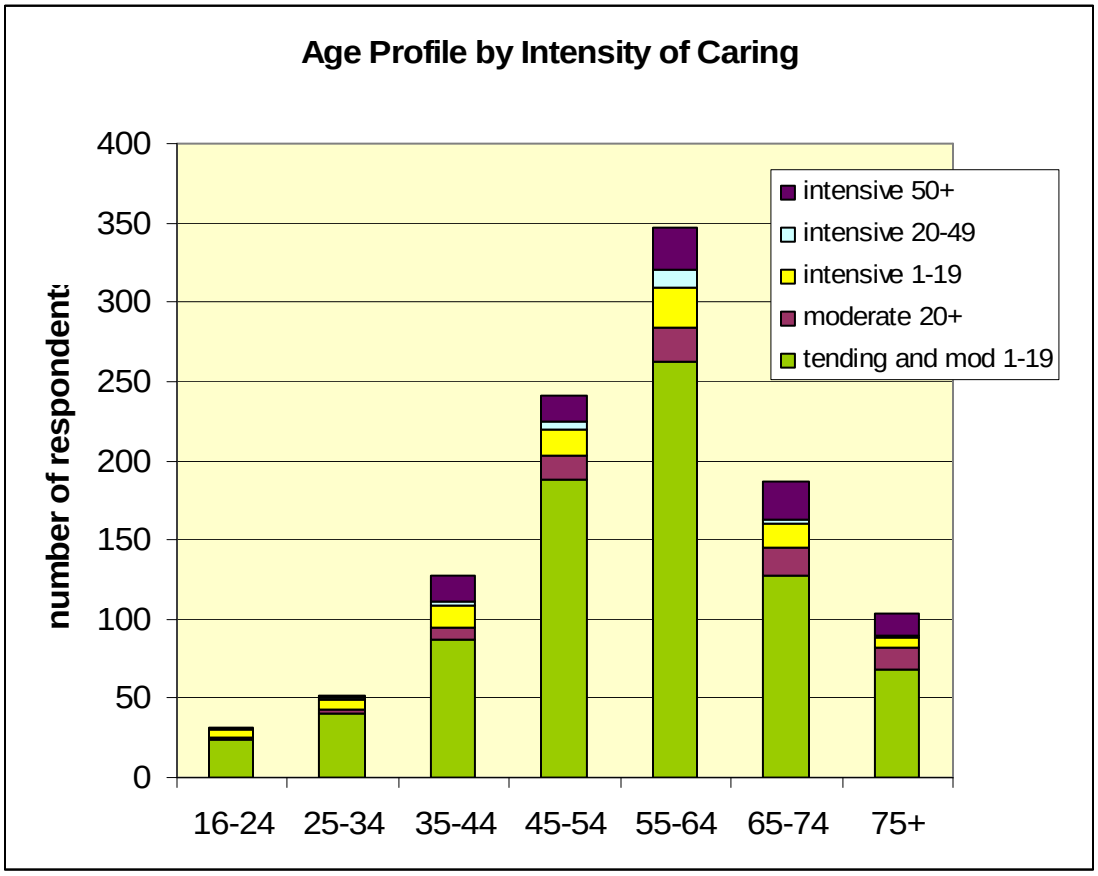


Table 4

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 11



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

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

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

'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'

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

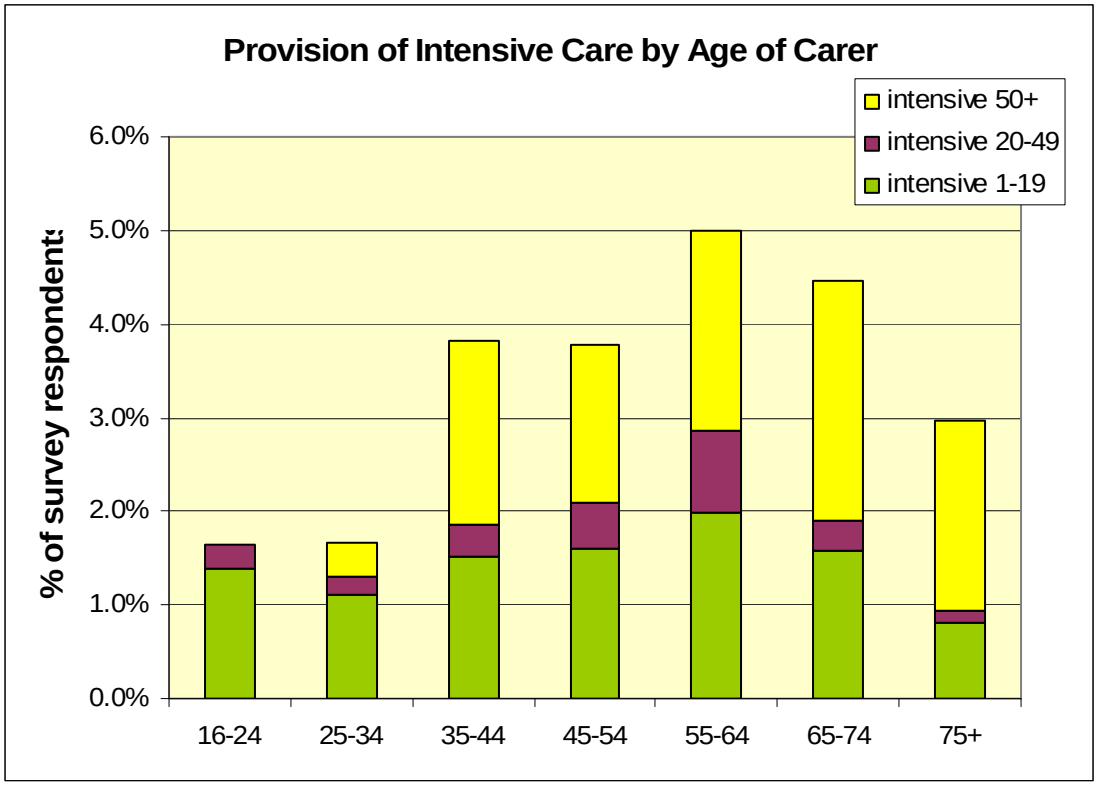
with their carer, and 44.6% were extra-resident. As might be expected carers who were caring intensively for longer hours (50+ hours per week) were more likely to be sharing a household with the person they cared for (84%)

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.

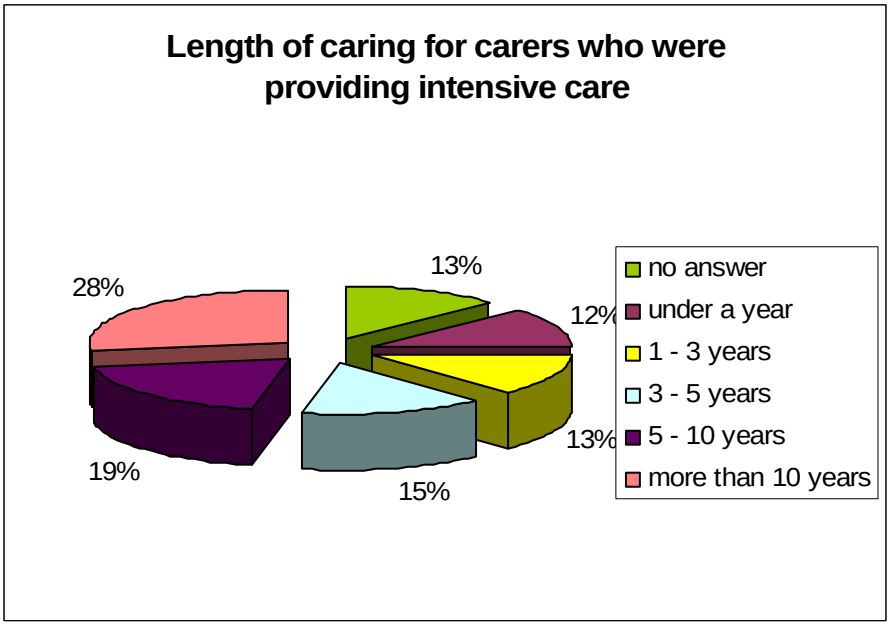
Figure 12



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

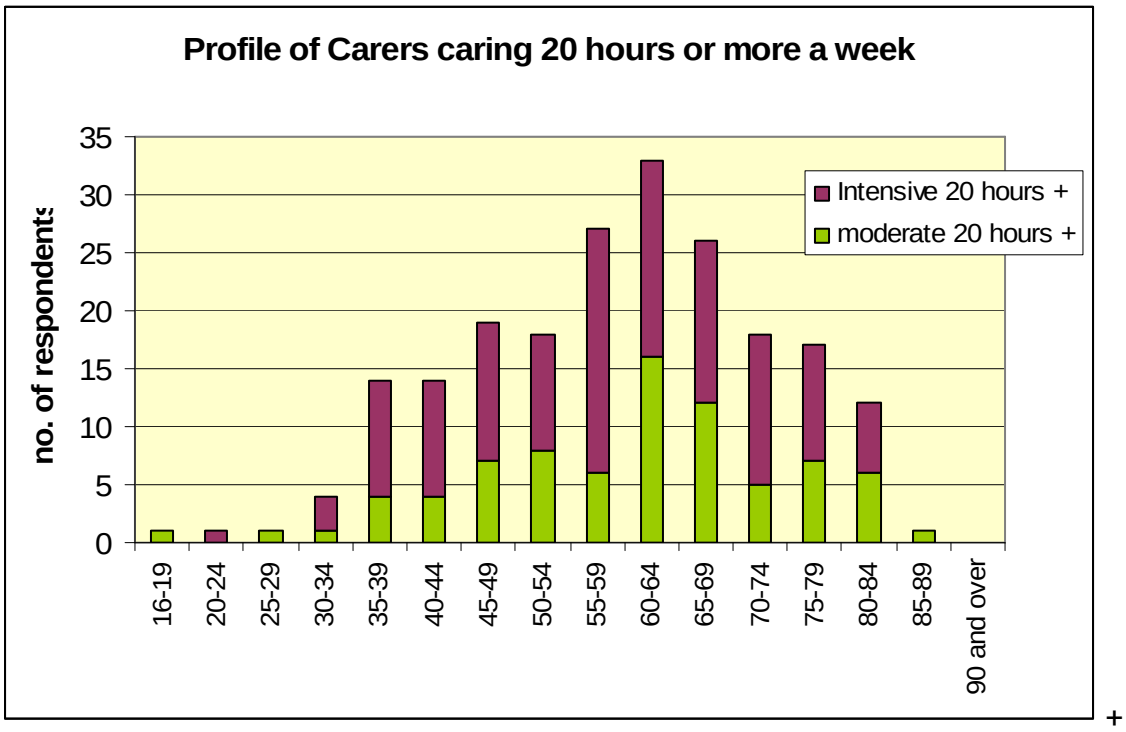
For all carers in the survey, moderate care activities (those that require physical support) were provided by relatively few. 23% of all

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.

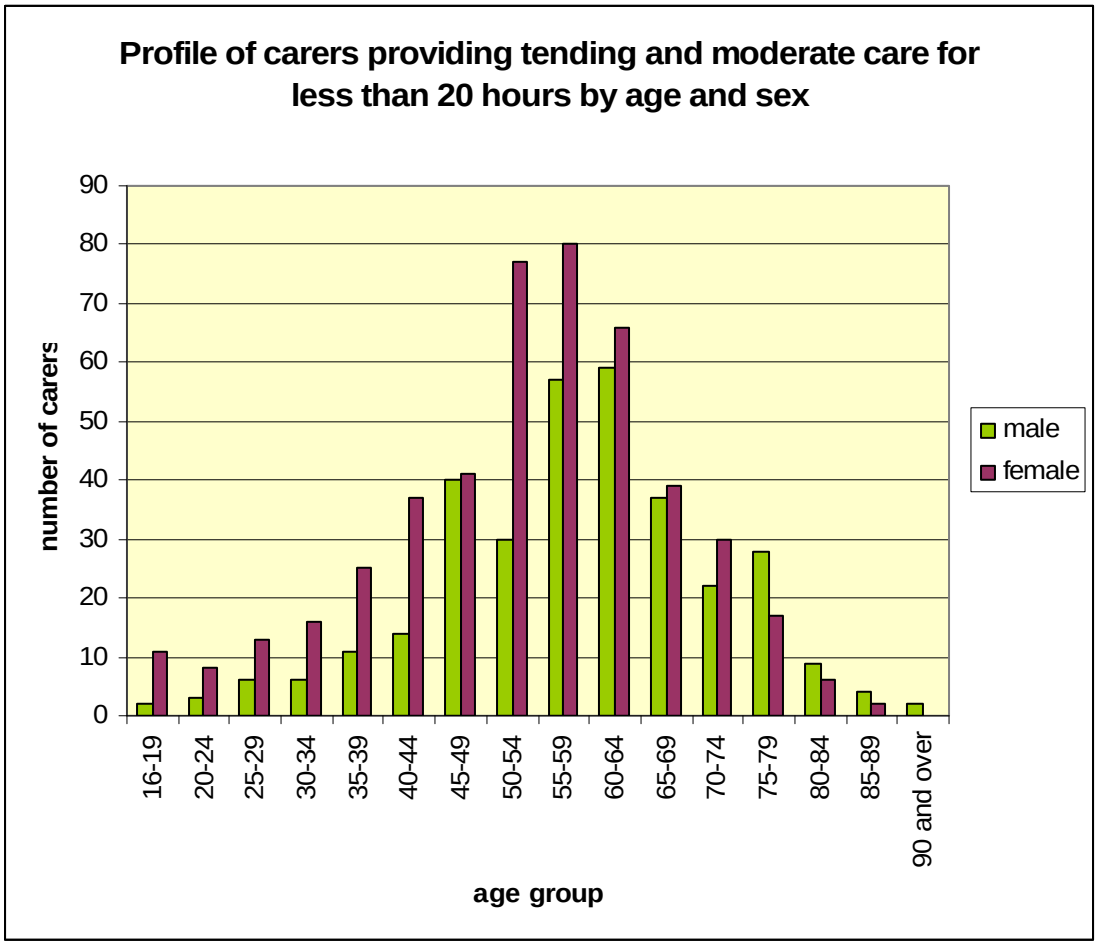
Tending

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[32]. 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.

[32] 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

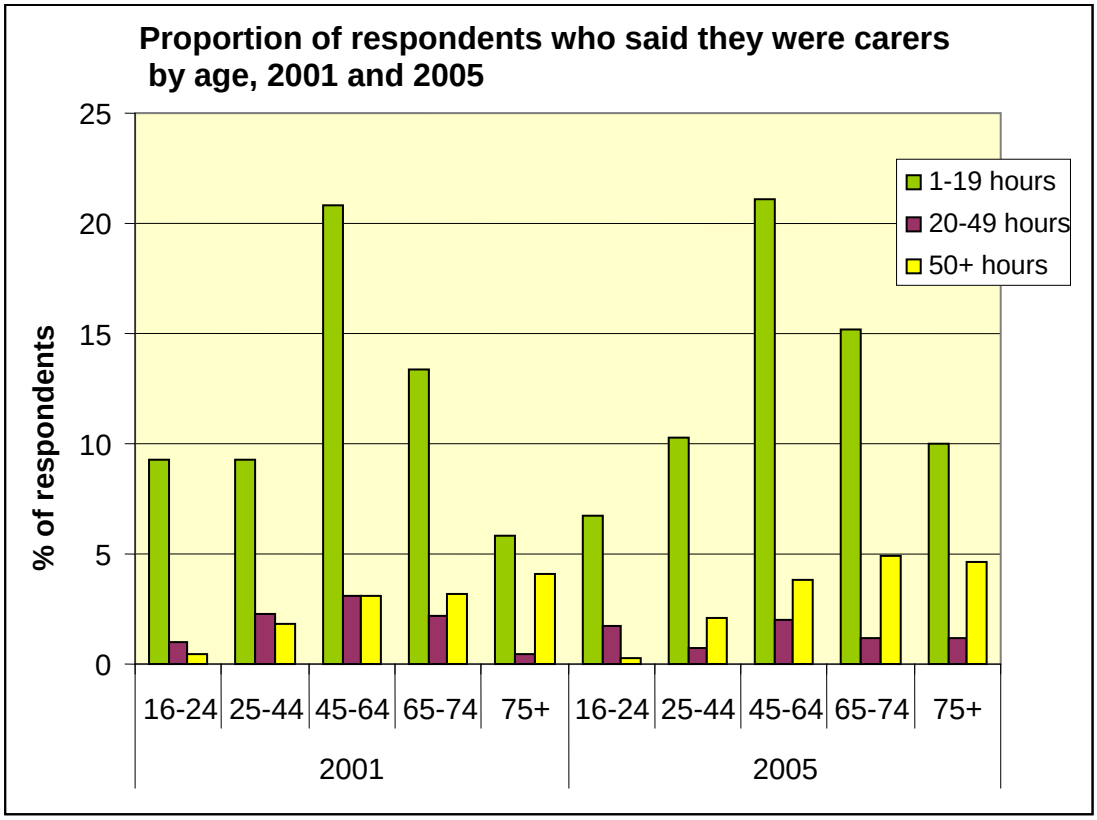
There appears to have been an increase in the amount of caring amongst older people (65 and over) by 2005, both in terms of the proportion who are caring for 1-19 hours and those caring for 50 hours or more a week (Figure 16). In 2001 3.2% of people aged 65-74 were caring for 50 hours or more and in 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 N=3256	Females N=4815	Males N=2355	Females 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%

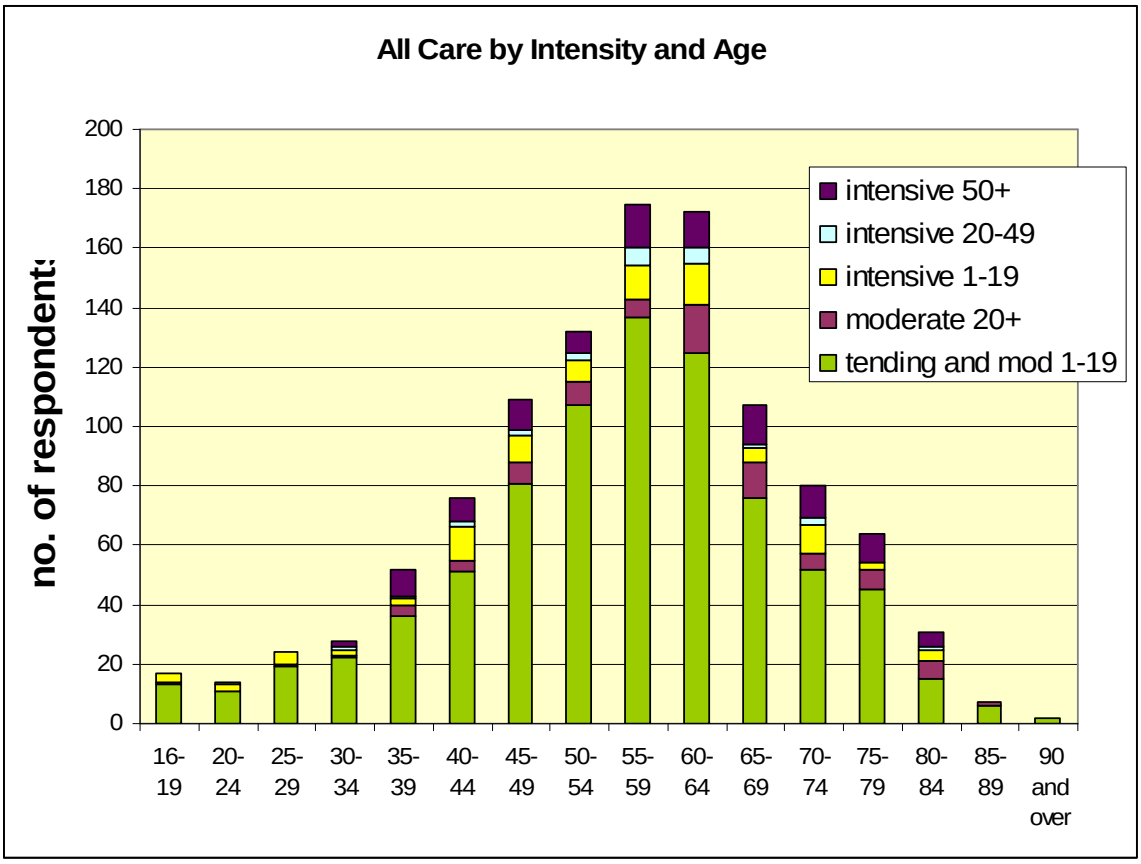
Figure 16



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[33] [34]. 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[35]. What makes the needs of the mid life carer unique is that many are combining paid work, home commitments - which may include supporting children -

[33] 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
[34] Office of National Staistics (2002) *Census, 2001* London: The Stationary Office
[35] 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[36]. For many older workers caring responsibilities emerge resulting in the challenge of 'juggling work and care'[37]. 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.

[36] Census 2001, downloaded from the NOMIS database www.nomisweb.co.uk 20/02/2008

[37] 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

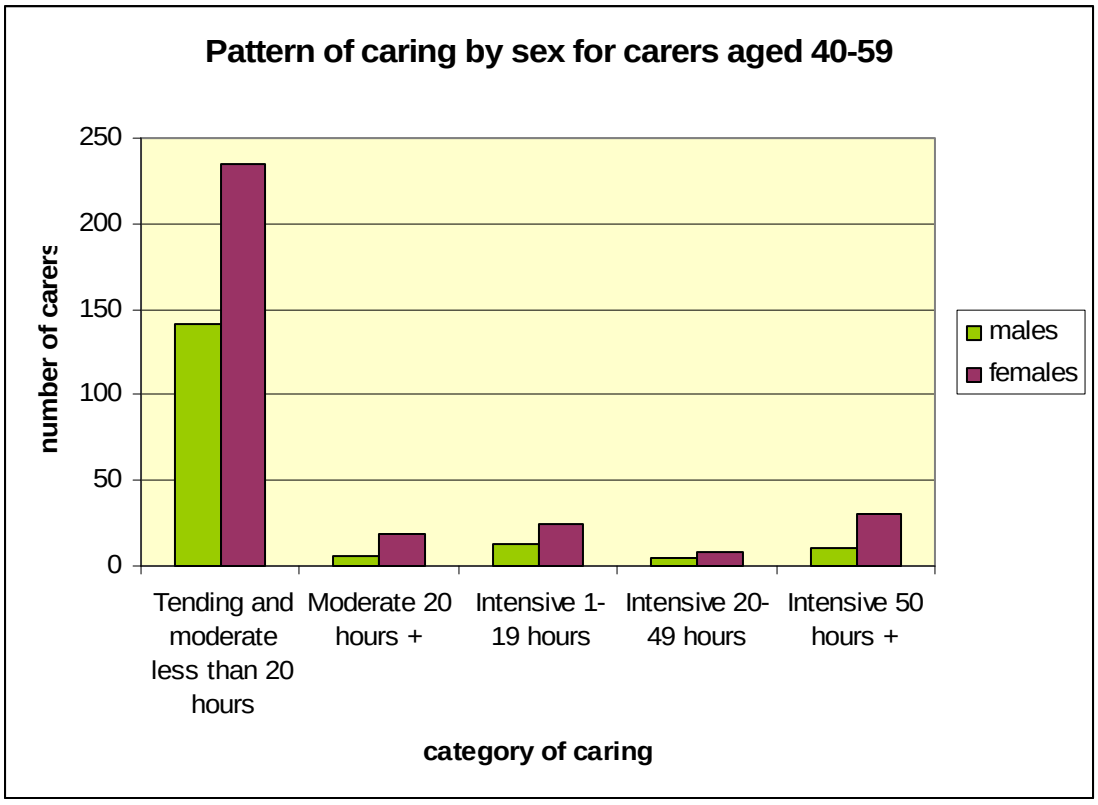


Figure 19a

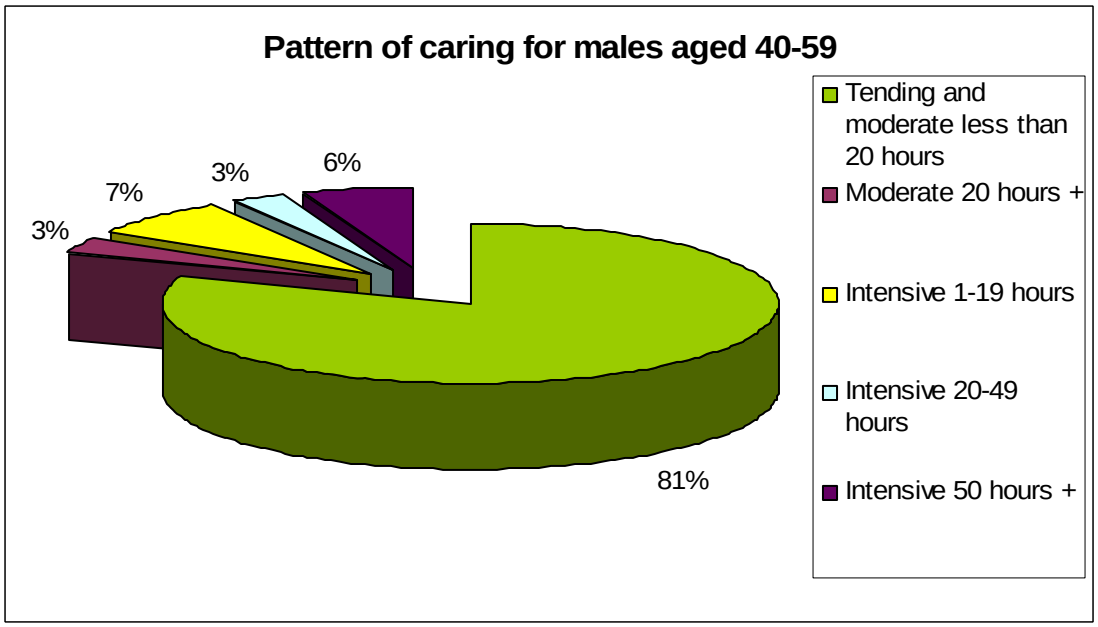
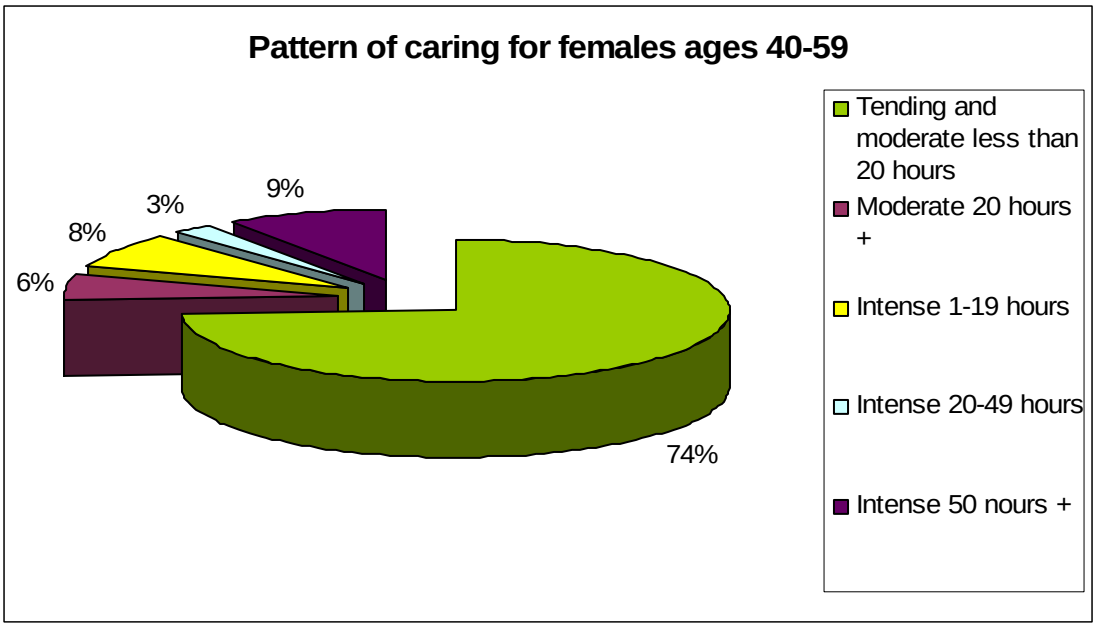


Figure 19b


Pattern of caring for females ages 40-59
9%
3%
8%
6%
74%
Tending and moderate less than 20 hours
Moderate 20 hours +
Intense 1-19 hours
Intense 20-49 hours
Intense 50 nours +

'… caring does get in the way of life…. but its family'

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'.

Two thirds of the cared for were aged 75-84 years and a third were aged 85+

'…other people's looks and words can make caring so much harder'

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.

Betwixt and Between – Carers aged 60-64

3 out of ten people aged 60-64 were caring

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[38]

[38] 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

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[39]. 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.

Older carers are likely to be caring in the context of a long-term relationship

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 ever-greater numbers of older people being cared for by similarly aged or third age carers[40].

Over a third of people will become carers post retirement

Older carers can be distinguished from other groups of carers in a number of key ways.

'it's my duty to look after my husband'

- 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[41].
- Spouse caring constitutes a defining feature of caring in later life; nearly two thirds of the carers of older people with dementia are spouses[42].

[39] Milne, A., Hatzidimitriadou, E., Chryssanthopoulou, C and Owen, T (2001) *Caring in Later Life: Reviewing the role of older carers*, London: Help the Aged
[40] 'third age' is a term for those aged over 60 years.
[41] 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
[42] 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

27% of carers in Kent were aged 65 and over; 20% of these were caring intensively

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.

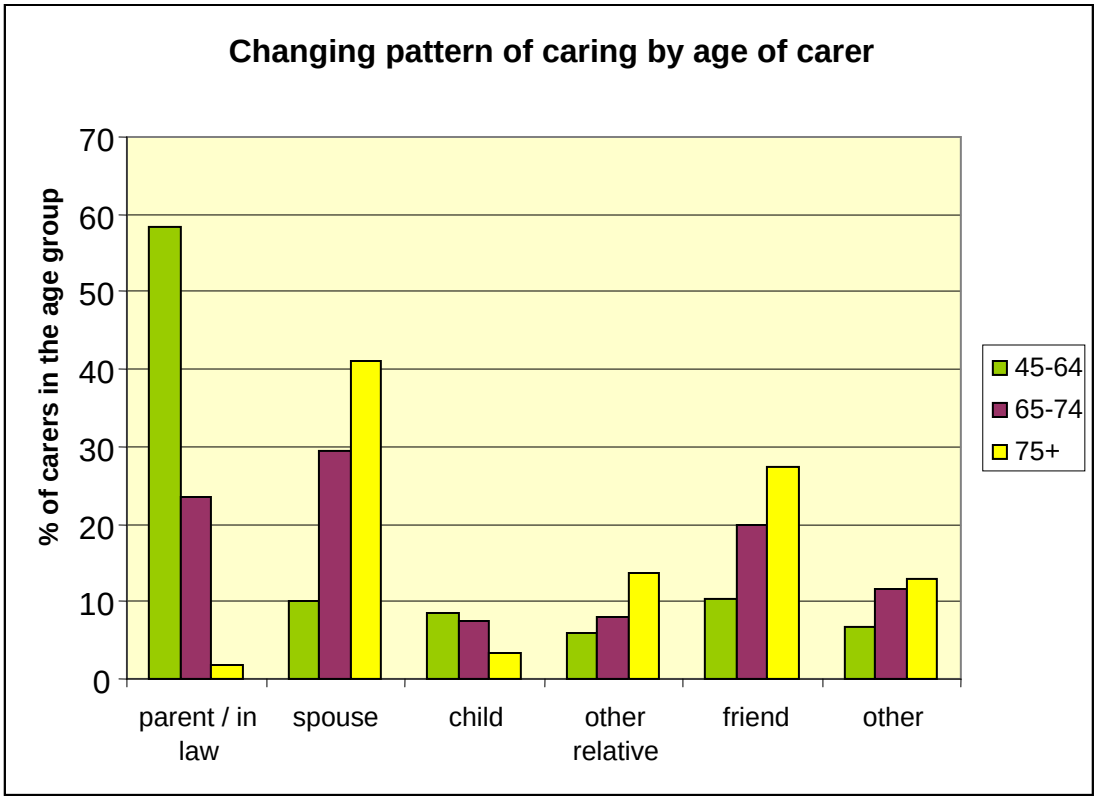
Older carers were most likely to be caring for their spouse (34%), their friend (23%) or their parent / in law (15%)

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 1-3 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

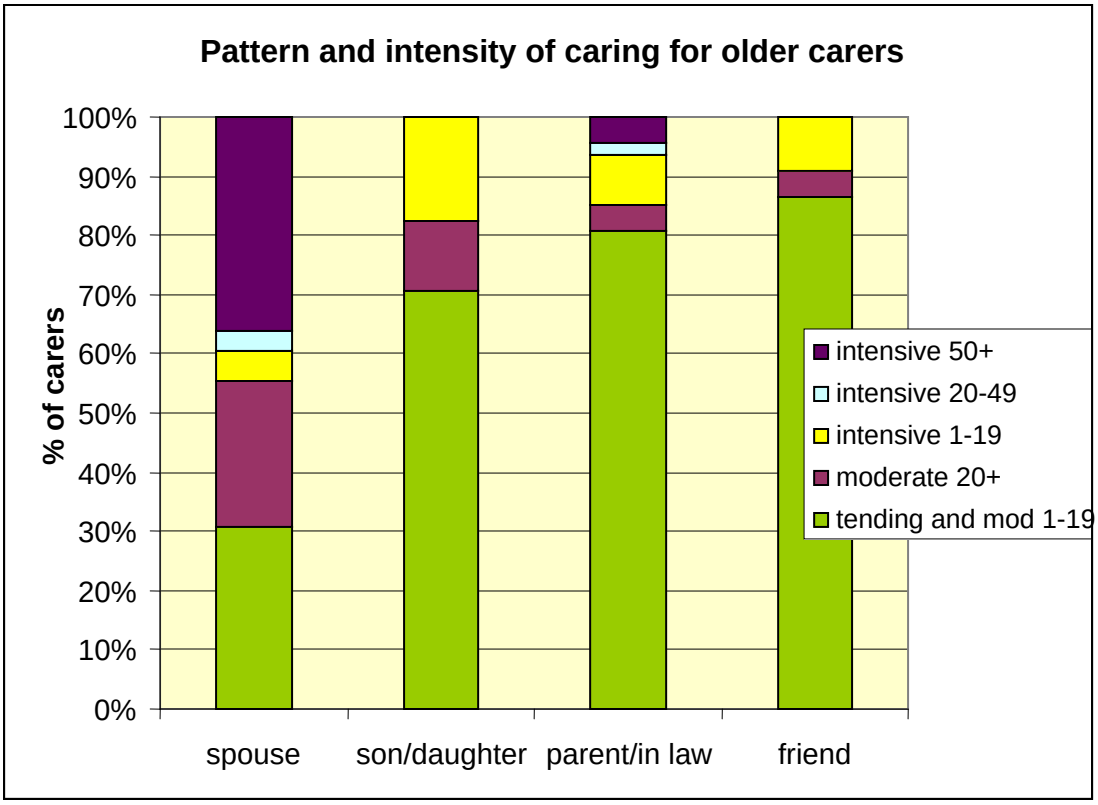


Nearly a quarter of all older carers were providing intensive care; spouses were most likely to be in receipt of intensive care

'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 co-resident. 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

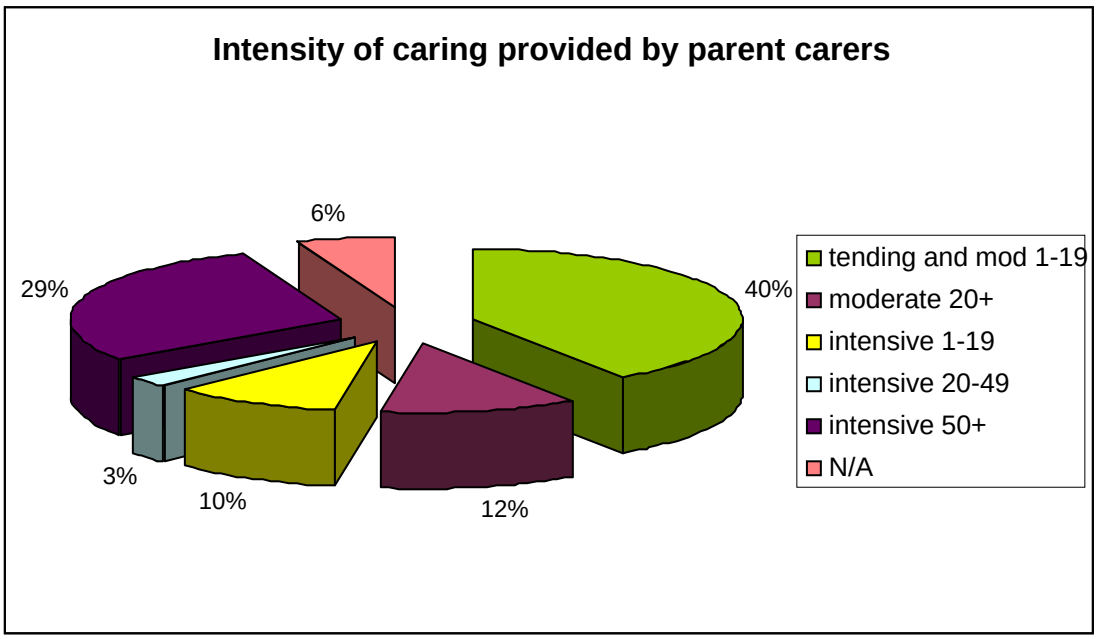
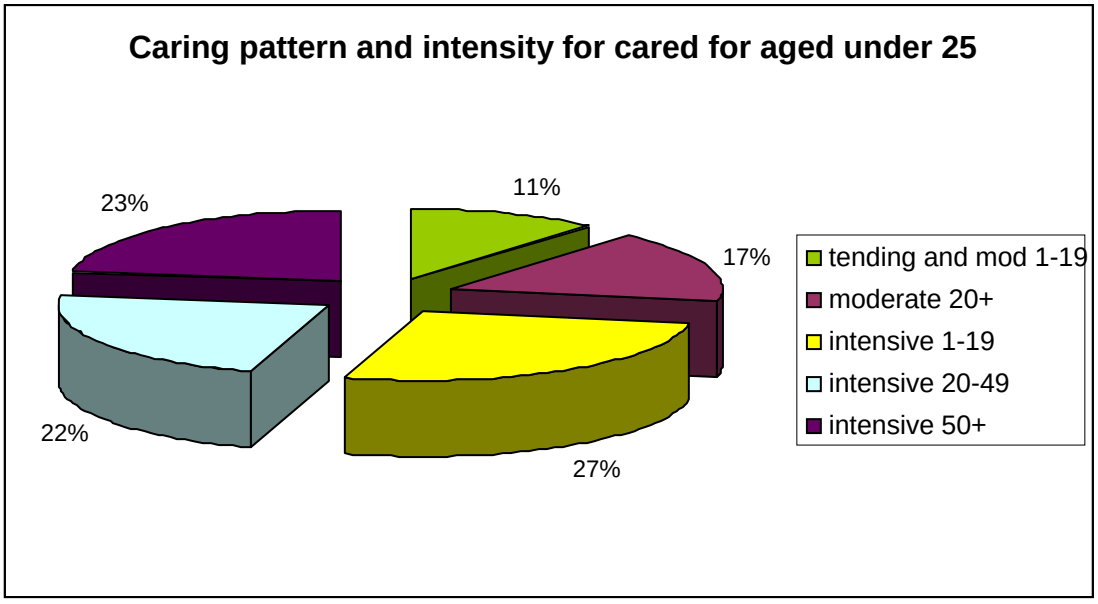


Figure 23



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[43].

Caring & Health

Research evidence suggests there are financial, health, emotional and social consequences related to caring

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[44]. 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.

'I tend to get swamped in the cared for person's needs and medical condition'

'My freedom of movement is severely restricted'

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[45]. 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

[43]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
[44] Milne, A., Hatzidimitriadou, E., Chryssanthopoulou, C and Owen, T (2001) *Caring in Later Life: Reviewing the role of older carers*, London: Help the Aged.
[45]Carers UK. In poor health: the impact of caring on health
http://www.carersuk.org/Policyandpractice/PolicyResources/Research/InPoorHealth.pdf

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[46].

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[47]. 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.

prevalence of mental health problems is 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,[48] 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

[46]Hirst, M (2002) Transitions to Informal Care in Great Britain during the 1990's, *Journal of Epidemiology and Community Health,* 56, 579-87
[47] 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
[48] 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.

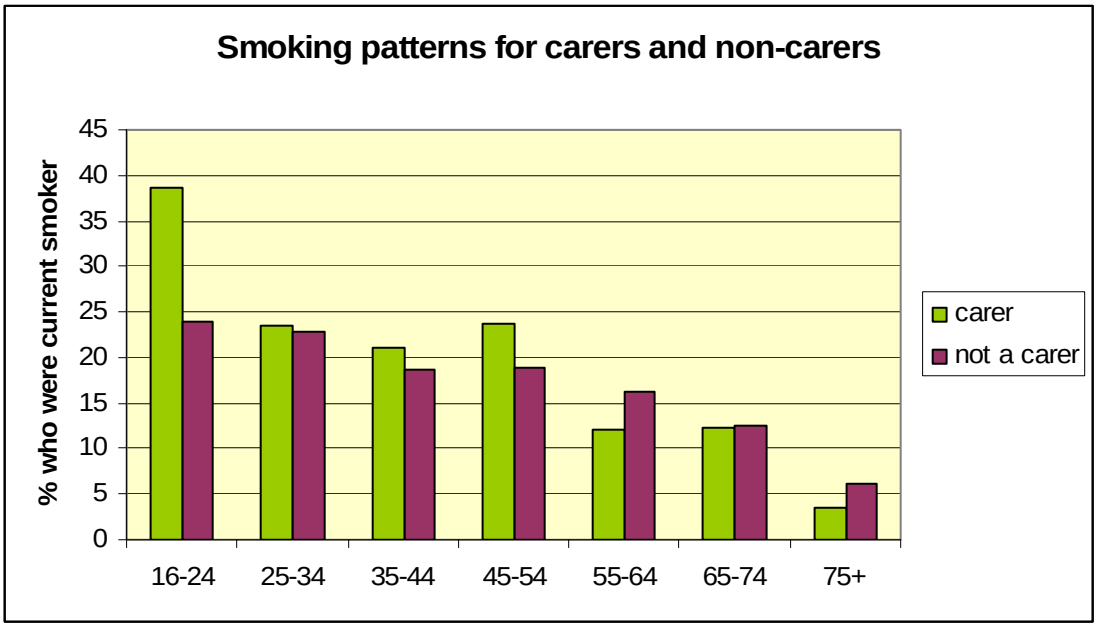
Although few carers (11%) reported their health as worse than it was a year ago, slightly higher proportions of those who were caring intensively were in this situation. 5% of carers who were providing care for 50 or more hours per week reported their health as 'much worse' than it was a year ago compared 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[49].

[49] 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



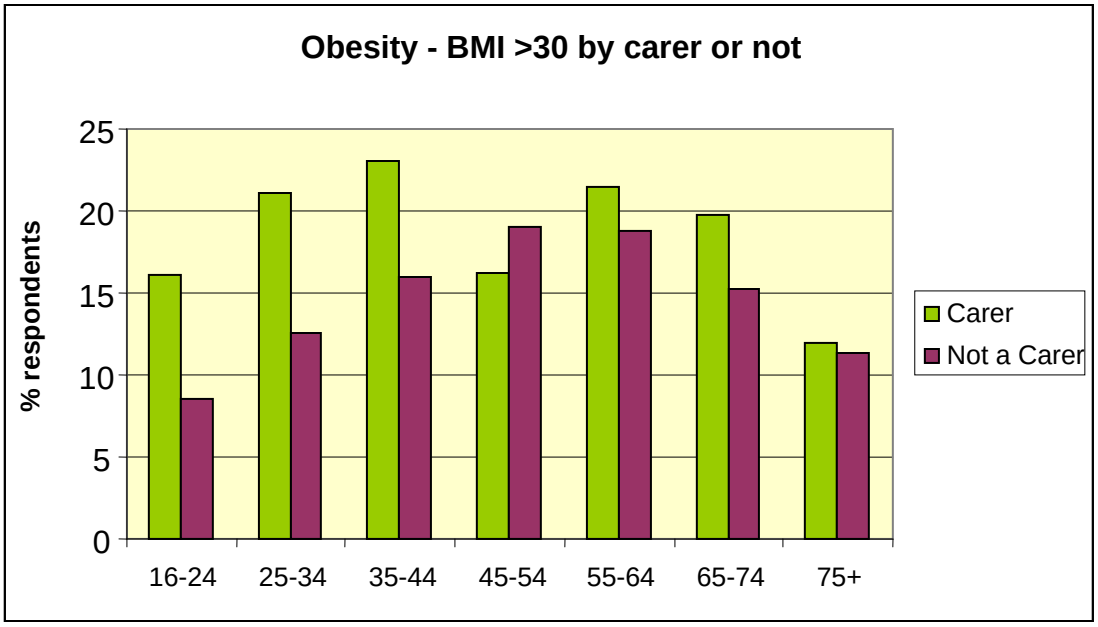
Smoking was more prevalent amongst younger carers than the general population….

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'

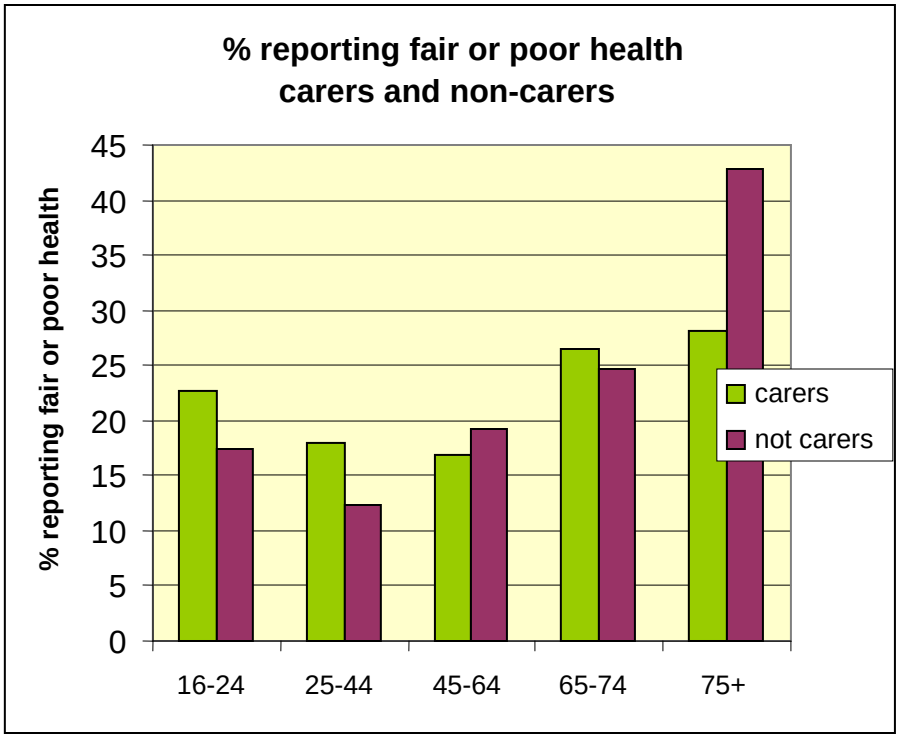
' I get swamped in the cared for person's needs and medical condition'

'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 co-resident 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 by Caring	General Health Status	
	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).

'At times I feel low and depressed … but I soon pull myself together'

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

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

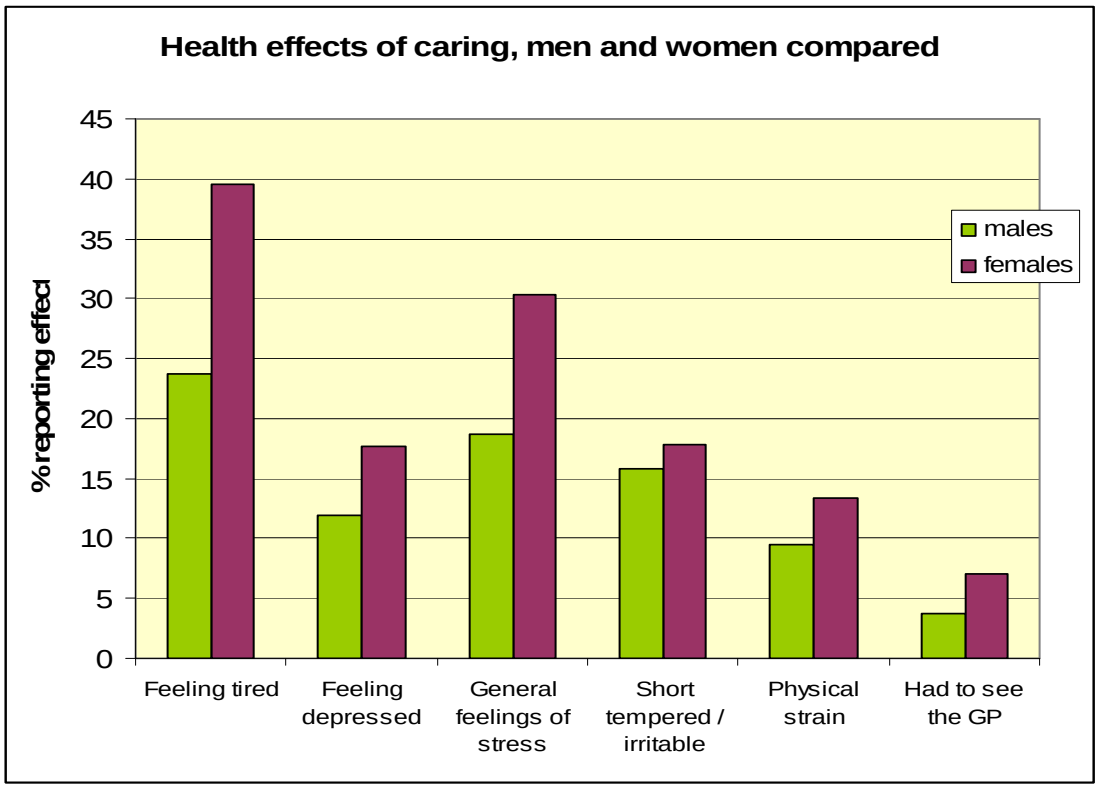
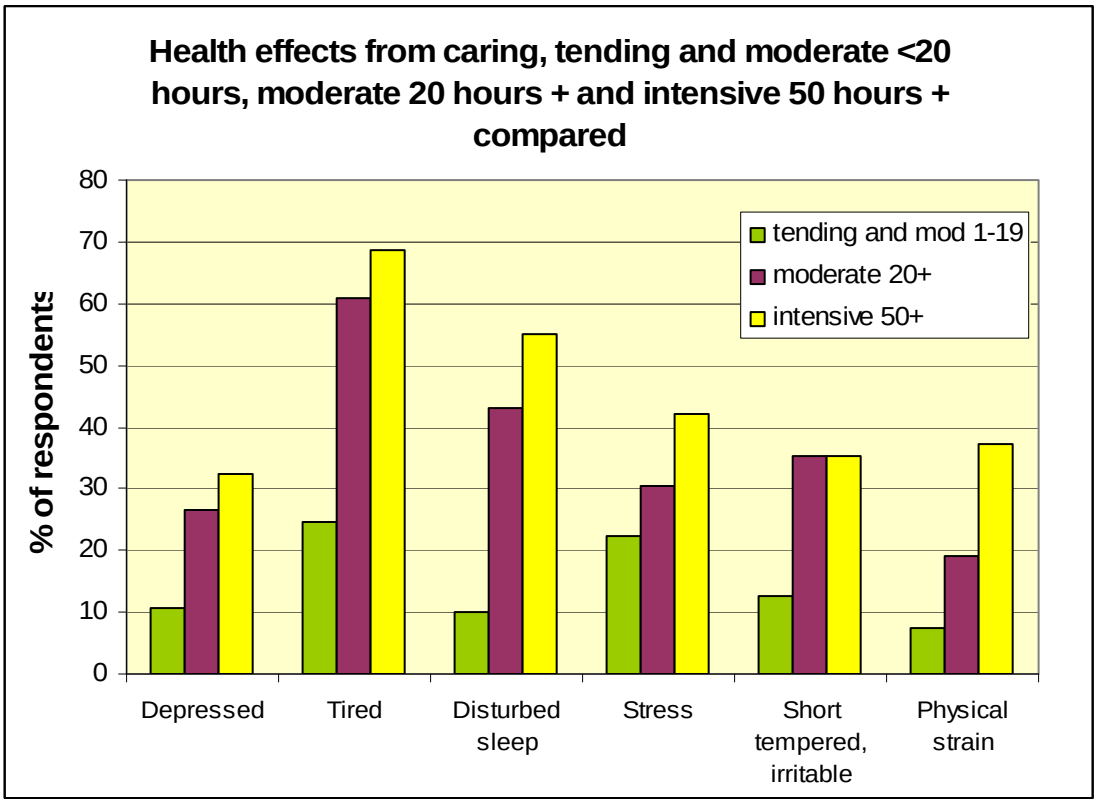
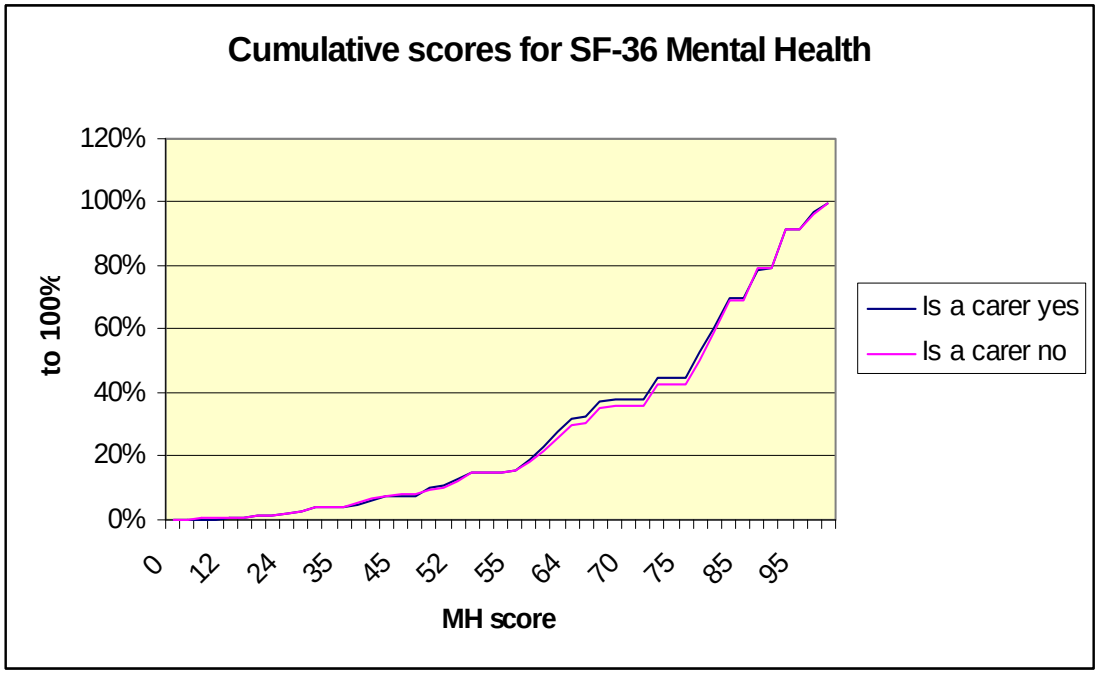

Health effects of caring, men and women compared
% reporting effect
45
40
35
30
25
20
15
10
5
0
males
females
Feeling tired
Feeling depressed
General feelings of stress
Short tempered / irritable
Physical strain
Had to see the GP

Figure 28


Health effects from caring, tending and moderate <20 hours, moderate 20 hours + and intensive 50 hours + compared
% of respondents
80
70
60
50
40
30
20
10
0
tending and mod 1-19
moderate 20+
intensive 50+
Depressed
Tired
Disturbed sleep
Stress
Short tempered, irritable
Physical strain

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[50]. 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: Risk for depression	**Is a carer**	
	Yes (n=1142)	**No (n=4457)**
no answer	.3%	.9%
Major depression	32.3%	27.4%
Dysthymia	.2%	.4%
No risk	67.3%	71.3%

[50] 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[51].

Overall the survey reveals very little difference between levels of deprivation between carers and non carers in Kent

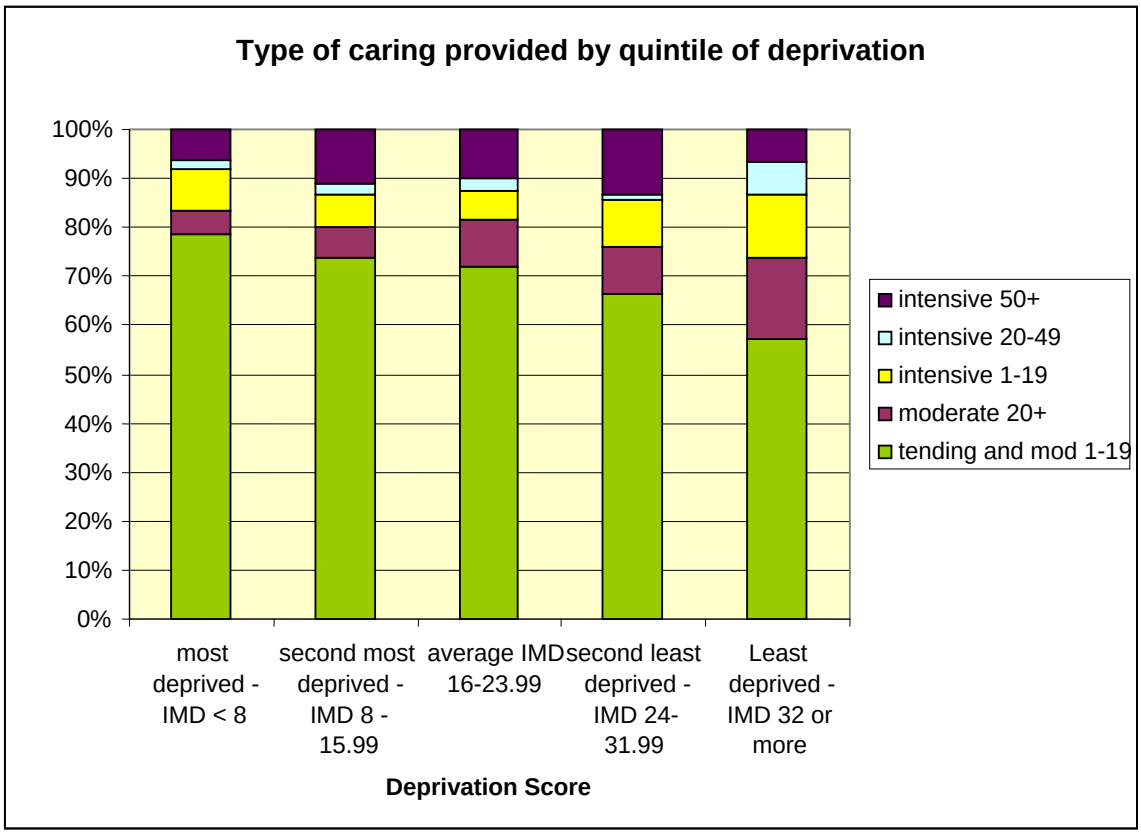
Overall, the Kent survey reveals very little difference between levels of deprivation amongst those providing care and those not (range 18.1% to 20.9%). However, in the more deprived wards the level of care provided appears more likely to have been tending or moderate care of less than 20 hours per week. 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.

[51] Buckner, L and Yeandle, S (2007) *Valuing Carers: calculating the value of unpaid care* London: Carers UK

Figure 30


Type of caring provided by quintile of deprivation
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
most deprived - IMD < 8
second most deprived - IMD 8 - 15.99
average IMD 16-23.99
second least deprived - IMD 24-31.99
Least deprived - IMD 32 or more
Deprivation Score
intensive 50+
intensive 20-49
intensive 1-19
moderate 20+
tending and mod 1-19

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

Housing Type	Is a carer	
	Yes (n=1142)	No (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[52]. 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 (N=546)	**Rural (N=510)**
Tending and moderate 1-19 hours	72.5%	74.9%
Moderate 20+	7.5%	6.7%
All intense	20.0%	18.5%

[52] 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[53]. The 2001 Census found that over 3 million people combine work with caring[54]. 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[55]. In 1996 49% of carers canvassed by Carers UK had given up work to care[56]. Nearly 73% said their earnings had been affected.

In the Kent survey 62.5% of carers aged under 65 were employed or self

[53] 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
[54] Office of National Statistics (2002) *Census, 2001* London: The Stationary Office
[55]Yeandle S and Buckner L (2007) *Carers, Employment and Services: time for a new social contract?* London: Carers UK
[56] 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

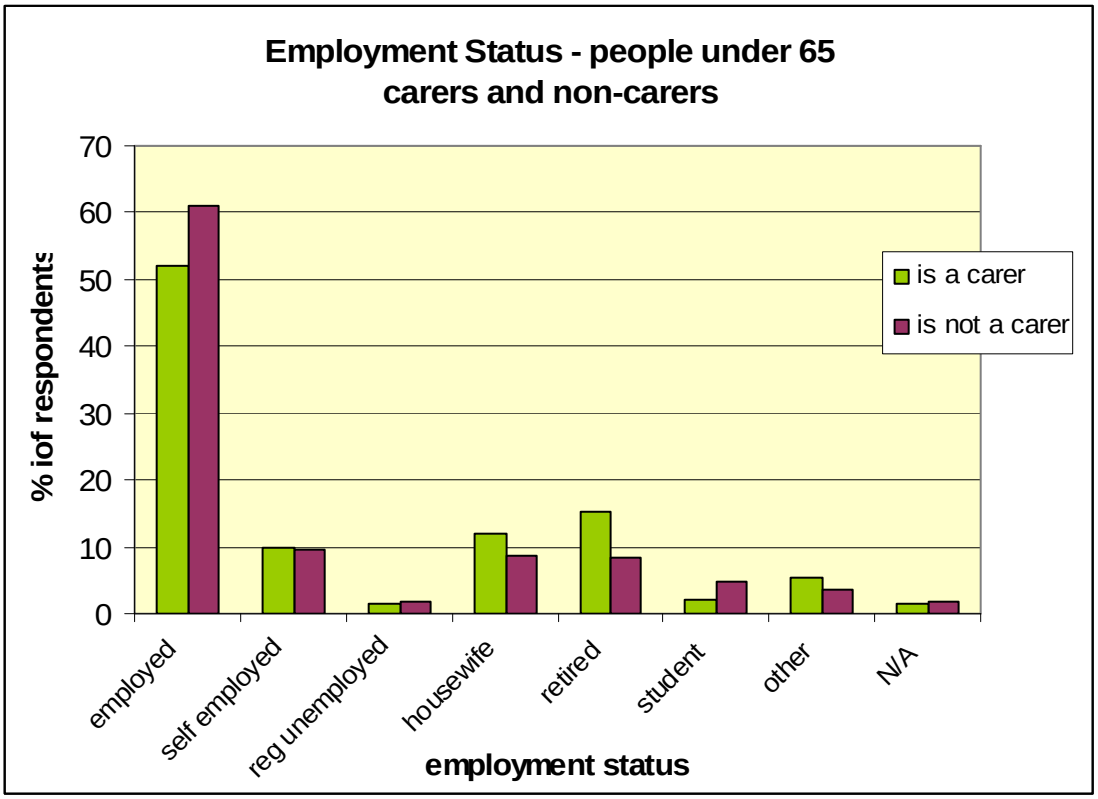
employed. A third (36%) of all carers were retired (with just under a third of these being under the age of 65). A tenth (9.5%) of all carers described themselves as housewives. There was a clear relationship between employment profiles and intensity of caring in the survey. Far more carers who were 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.

A higher number of non carers are employed than carers

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


Employment Status - people under 65
carers and non-carers
70
60
50
40
30
20
10
0
% iof respondents
is a carer
is not a carer
employed
self employed
reg unemployed
housewife
retired
student
other
N/A
employment status

Support from Friends, Family and Services

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[57] [58].

Overall, two thirds of carers were receiving support from family and/or friends

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.

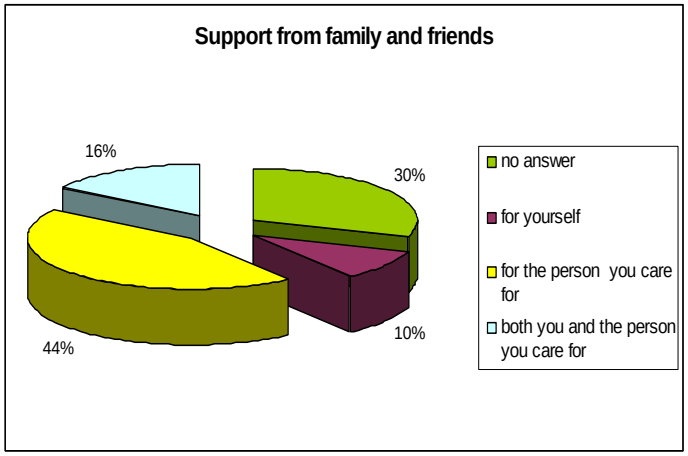
49.3% of households were receiving support for the cared for person… and only 2.7% for the carer alone

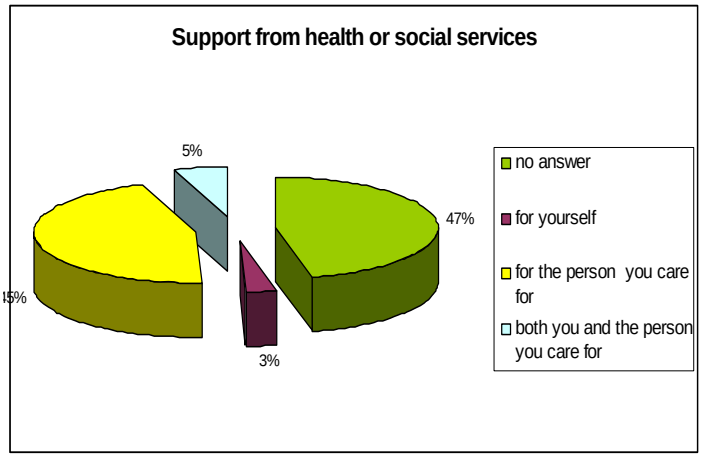
6.7% of carers were receiving no support at all

[57] Milne A, Hatzidimitriadou, E., Chryssanthopoulou, C and Owen, T (2001) *Caring in Later Life: Reviewing the role of older carers*, London: Help the Aged

[58] 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 support from health or social services	Carer/cared for gets support from family/friends/neighbours				Total
	no answer	for carer	for the cared for	for both the carer 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;

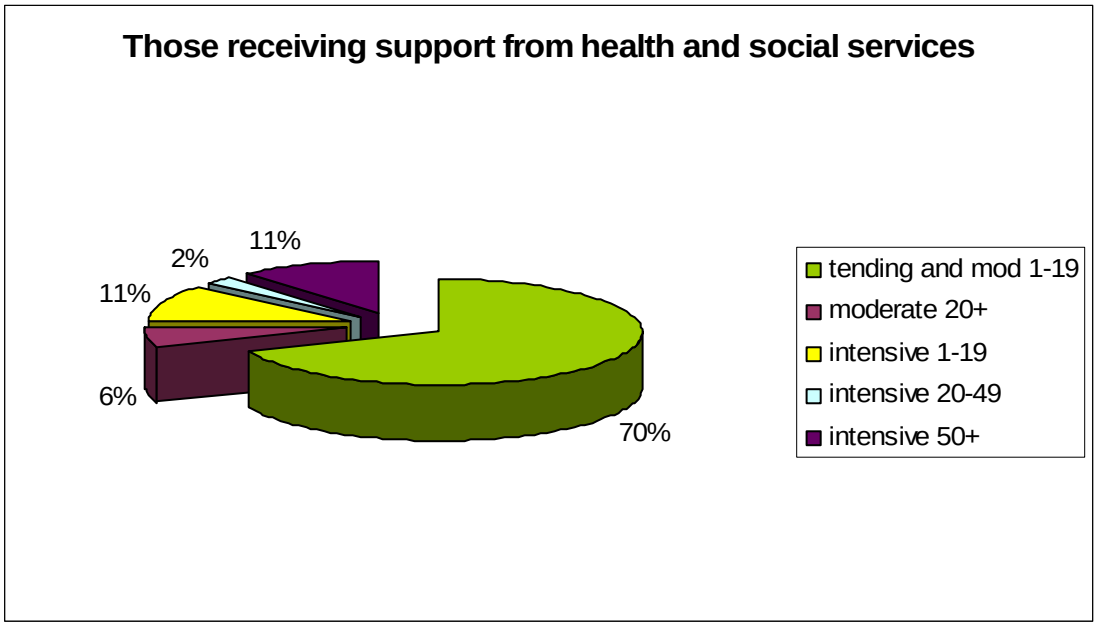
this is the case for only 20% of those sharing a household

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


Those receiving support from health and social services
11%
2%
11%
6%
70%
tending and mod 1-19
moderate 20+
intensive 1-19
intensive 20-49
intensive 50+

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'

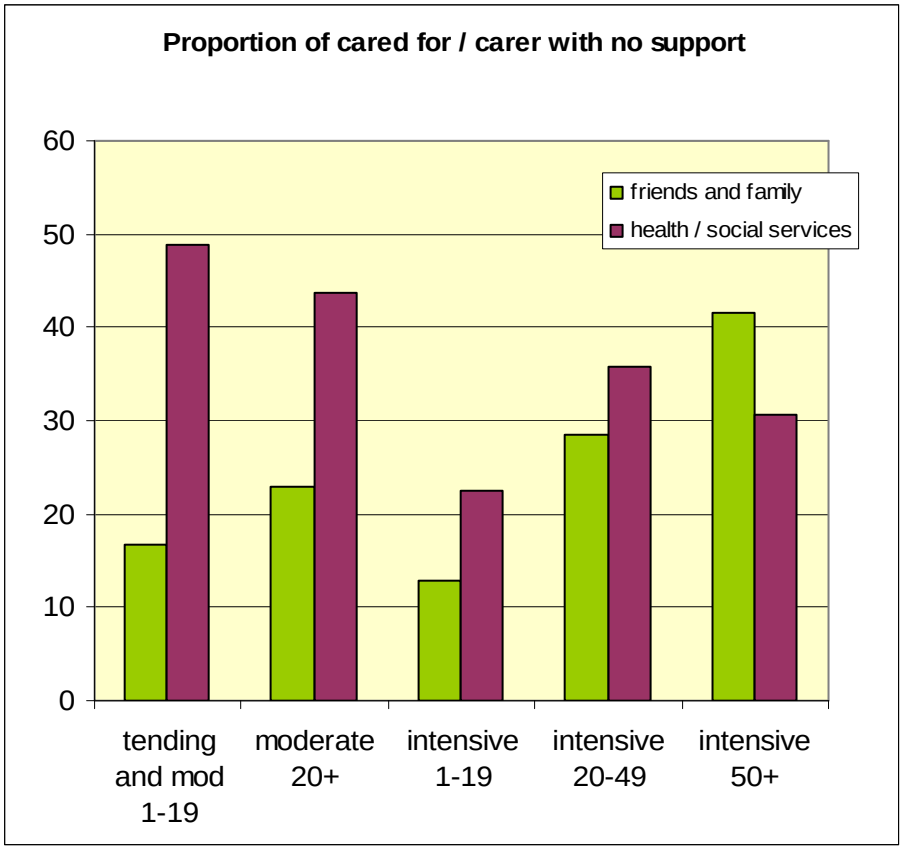
Explanations may lie in three areas. A disabled person living alone may be more likely to be assessed as needing services by social services than one 'buffered' by a carer's support. Secondly, that living alone is considered a 'risk factor' by health and social services in eligibility for service allocation. 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[59]

Those caring on a tending or moderate basis were also more likely to have been receiving support from family and friends

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).

[59] 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


Proportion of cared for / carer with no support
60
50
40
30
20
10
0
friends and family
health / social services
tending and mod 1-19
moderate 20+
intensive 1-19
intensive 20-49
intensive 50+

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[60]. 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.

[60] 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 1 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.

Caring In Kent: Patterns and Profiles

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 co-residency, 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 1-19 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 1-19 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 1-19 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 11.4%	4 9.1%	3 6.8%	3 6.8%
Tending 1-19 hours per week	0 .0%	0 .0%	0 .0%	0 .0%
Tending 20+ hours per week	0 .0%	0 .0%	0 .0%	0 .0%
Moderate Activities 1-19 hours per week	0 .0%	0 .0%	0 .0%	0 .0%
Moderate Activities 20+ hours per week	0 .0%	0 .0%	0 .0%	0 .0%
Intensive Activities 1-19 hours per week	46 53.5%	40 46.5%	34 39.5%	30 34.9%
Intensive Activities 20+ hours per week	15 60.0%	16 64.0%	13 52.0%	6 24.0%
Intensive Activities 50+ hours per week	79 77.5%	74 72.5%	37 36.3%	42 41.2%
All Carers Total	145 12.7%	134 11.7%	87 7.6%	81 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 11.4%	3 6.8%	3 6.8%	6 13.6%
Tending 1-19 hours per week	0 .0%	0 .0%	0 .0%	0 .0%
Tending 20+ hours per week	0 .0%	0 .0%	0 .0%	0 .0%
Moderate Activities 1-19 hours per week	115 72.8%	21 13.3%	7 4.4%	47 29.7%
Moderate Activities 20+ hours per week	43 54.4%	22 27.8%	12 15.2%	48 60.8%
Intensive Activities 1-19 hours per week	35 40.7%	16 18.6%	25 29.1%	32 37.2%
Intensive Activities 20+ hours per week	11 44.0%	6 24.0%	12 48.0%	14 56.0%
Intensive Activities 50+ hours per week	48 47.1%	33 32.4%	55 53.9%	71 69.6%
All Carers Total	257 22.5%	101 8.8%	114 10.0%	218 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	11	8	8	11
	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 1-19 hours per week	255	184	158	79	272	73	134	165	245	321	262	330
	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+ hours per week	33	27	22	32	29	30	27	22	33	22	24	38
	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 Activities 1-19 hours per week	98	76	69	43	100	37	49	52	102	81	105	95
	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 Activities 20+ hours per week	54	54	41	57	54	53	57	42	66	41	52	56
	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 Activities 1-19 hours per week	45	37	36	52	53	40	41	25	42	63	49	61
	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 Activities 20+ hours per week	19	16	17	22	15	17	20	15	21	14	15	19
	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 Activities 50+ hours per week	69	61	56	92	79	90	81	58	86	63	72	85
	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 Total	583	461	407	388	617	349	420	386	606	613	587	695
	51.1%	40.4%	35.6%	34.0%	54.0%	30.6%	36.8%	33.8%	53.1%	53.7%	51.4%	60.9%