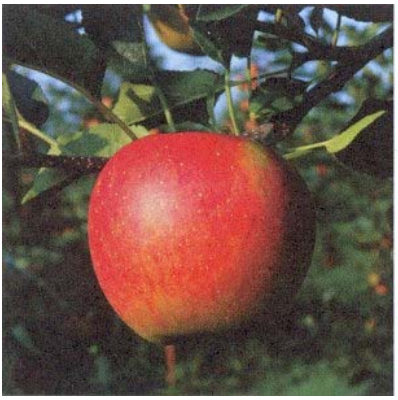
CHSS
University of Kent
Centre for Health Services Studies

Caring in Kent: Summary Report
Evidence from the Kent Health and Lifestyle Survey, 2005



Ann Palmer, Health and Social Survey Unit, CHSS
Alisoun Milne, Tizard Centre
Charlotte Hastie, Health and Social Survey Unit, CHSS

Commissioned by Kent County Council

April 2008

Centre for Health Services Studies

CHSS is one of three research units of the University of Kent's School of Social Policy, Sociology and Social Research and contributed to the school's recent Research Assessment Exercise 6* rating. This puts the school in the top three in the UK. CHSS is an applied research unit where research is informed by and ultimately influences practice.

The Centre is directed by Professor Andy Alaszewski and draws together a wide range of research and disciplinary expertise, including health and social policy, medical sociology, public health and epidemiology, geriatric medicine, primary care, physiotherapy, statistical and information analysis. CHSS supports research in the NHS in Kent and Surrey and has a programme of national and international health services research. CHSS undertakes research in a wide range of health and health care topics.

Researchers in the Centre attract funding of nearly £l million per year from a diverse range of funders including the ESRC, MRC, Department of Health, NHS Health Trusts and the European Commission.

The Health and Social Survey Unit is part of the Centre for Health Services Studies

Established during the late Eighties and early Nineties, when it undertook “Apple a day” health and lifestyle surveys throughout Great Britain, CHSS has established a reputation for quick and efficient health and social surveys. The unit provides support for all stages of constructing surveys and is a cost-effective solution for Managers, Professionals and Researchers in Health and Social Care.

For further details about the work of the Centre or for more copies of the report please contact:

Peta Hampshire
Administrator
Centre for Health Services Studies
George Allen Wing
University of Kent
Canterbury
Kent CT2 7NF

Tel: 01227 824057
E-mail: P.R.Hampshire@kent.ac.uk
Fax: 01227 827868
www.kent.ac.uk/chss/

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

Ann Palmer, Health and Social Survey Unit, CHSS
Alisoun Milne, Tizard Centre
Charlotte Hastie, Health and Social Survey Unit, CHSS

Commissioned by Richard Spoerry, Kent County Council

The Tizard Centre (www.kent.ac.uk/tizard/) is located within the top-rated School of Sociology, Social Policy and Social Research at the University of Kent. It is one of the leading academic groups in the UK working in learning disability and community care

Funding and Acknowledgements
Acknowledgements are due to many people for their support and advice. These include the residents of Kent who responded, the Kent Public Health Network, the Public Health Information team at Kent & Medway Strategic Health Authority, and Richard Spoerry and Debbie Smith at Kent County Council

University of Kent | Tizard Centre

T: +44 (0)1227 827373
F: +44 (0)1227 763674
E: tizard-info@kent.ac.uk
www.kent.ac.uk/tizard

Kent County Council

Contents

	Page
Introduction	2
National Context	2
Kent Health and Lifestyle Survey	4
The Profile of Carers in Kent	5
The Nature of Caring: Types and Levels	7
Particular Groups of Carers	12
Caring and Health	15
Deprivation, Poverty and Caring	16
Employment and Caring	17
Support from Friends, Family and Services	17
Neighbourhood Involvement and Local Support	19
Discussion and Conclusions	20

Introduction

The 2005 'Kent Health and Lifestyle Survey' conducted by the Centre for Health Services Studies and commissioned by Kent County Council, contained a specific module on carers adapted from the national General Household Survey, 2000. This short summary report summarizes the findings from the main report on the carers module: *Caring in Kent: Patterns and Profiles.* The report offers a review of the epidemiology, characteristics and needs of family carers in Kent drawing on analysis of data from the survey. It 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.

National Context

'Carers provide unpaid care by looking after an ill, frail or disabled family member, friend or partner. People from all walks of life and backgrounds are carers - over 3 in 5 people in the UK will become carers at some time in their lives. Caring can be a rewarding experience, yet many face isolation, poverty and ill-health. Carers give so much to society yet as a consequence of caring, they experience ill health, poverty and discrimination'

Recent years have seen a growing recognition of the important role that carers play in maintaining vulnerable adults in the community. This is due in part to the increasing proportion of older people in the population who require support from relatives, as well as the development of community care and related policies which emphasise the positive role of the family as the mainstay of care provision for dependent adults.

The 2000 General Household Survey reveals that across the UK 16% of the population - 6 million people - provide unpaid care. 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.

In addition to a growth in the total number of carers, longitudinal data suggests that since the 1980's 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. There is a growing proportion of older carers, more carers have sole responsibility for care and there is an increase in the number of carers who live with the person they support. Further, the people receiving care tend to be significantly older and frailer are more likely to have a mental impairment, primarily dementia.

One of the primary causes of an increase in the need for family care is the ageing profile of the UK population. The population aged 65 and over increased from 13% to 16% between 1971 and 2005 & the number of people aged 85 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.

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.

Despite medical and social advances and the fact that many older people report being in 'good health', morbidity statistics reveal that diseases are more common in later life and also that the prevalence of chronic disease and disability increases with age. 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.

Many older people suffer multiple chronic conditions; the number of chronic conditions increases with age. 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% have no chronic conditions. For those aged 65 -74 the commonest conditions are: arthritis (50%), forgetfulness (34%), back pain (33%), poor vision (32%), indigestion (29%) and breathless on exertion (28%).

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 and over. The number of people with dementia in the UK is predicted to rise from its current figure of 700,000 to 940,000 by 2021 and 1.7 million by 2051.

Since the 1990 NHS and Community Care Act's concern with 'providing practical support for carers', carers have become an increasingly important policy priority. Significant policies include: the Carers (Recognition and Services) Act 1995, the 2001 Carers & Disabled Children Act which introduced a right for carers to receive an assessment of need and the 2004 Carers (Equal Opportunities) Act which extended carers' rights to access social care services, direct payments, and health care support. The 2007 Work & Families Act *extends* the right of working carers to request flexible hours from their employer. Also important is the 1999 'National Carers Strategy' and the upcoming 'New Deal for Carers' which will be launched later in 2008.

Kent Health and Lifestyle Survey 2005

The Kent 2005 Health and Lifestyle Survey was a postal survey of 23,000 people across Kent. The sampling frame was the GP registration list from the Kent Primary Care Agency. A one in fifty sample of those aged 16 or over was obtained electronically.

The people in the derived sample were sent a postal questionnaire together with the information sheet and a stamp addressed envelope for return. Non-responders were sent a reminder at three weeks; further contact was made with non-responders at six weeks and again at three months. The survey results were analysed using SPSS.

5800 people in Kent responded to the survey; 5714 gave both age and sex. The population of Kent was estimated to have been 1,077,421 in 2004. Survey respondents were older, increasing steadily in numbers to age 60-69 and then falling off again. Women were better represented up to the age of 59; from this age onwards the opposite was true. The survey is also more representative of married, separated or divorced and widowed people than of single people. More older people were married than younger; more women were widowed.

The Profile of Carers in Kent

19.7% (N=1142) of the total number of survey respondents (N=5800) identified themselves as carers[1] [2]. 3% of carers were aged 16-24, 16% were 25-44, 53% were 45-64, 18% were 65-74 and 10% were aged 75 and over. 70% of carers aged 75 and over cared for relatives in the same age group. Over half of carers were thus in the group aged 45-64. 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 as it is a popular retirement area.

As is the case nationally 40% of carers were male and 59% female (1% unknown). With increasing age male carers predominated; this reflects the fact that amongst men older spouse carers are the largest group. 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. It is well documented that the vast majority (71%) of care recipients are aged 65 and over; in Kent the percentage total was 72%.

Overall two thirds (66%) of the cared for were female and a quarter (26%) were male. The vast majority (91.5%) were caring for one person. In the older groups women predominated with 71% of those aged 75-84 being female and 25% male; in the group aged 85 and over, women constituted 81% and men only 16%. 25% of carers in the survey had been caring for 5-10 years and 17% for ten years or more. Only one in ten carers had been caring for less than one year.

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, 7% were 'other relatives', 16.5% were friends or neighbours and 3% were grandparents.

Young carers were more likely to be caring for a parent/in law whereas caring for a spouse increased with age for 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.

[1] 201 (3.5%) did not reply to the question
[2] 201 (3.5%) did not reply to the question

In terms of the type of health problem 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. An additional fifth (21.5%) had another 'unspecified health problem'.

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.

Although carers can 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.

This profile dovetails with the other distinguishing feature of caring, the type of relationship the carer has with the cared for person. 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.

In this survey 86% of spouses were living with their carer. For disabled sons and daughters, the picture was mixed. Over half (58%) 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 were women (19%). This is likely to reflect the fact that there was a higher proportion of older men being cared for by younger wives; there may also have been more widower men living with their daughter or son than widowed women.

78% of cared for parents/in law were extra resident with only 10% being co-resident; another 10% 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.

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.

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.
Of all those being caring:

- 22.5% provided 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 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

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.

In the Kent Survey overall:

- 73.4% of carers were providing *tending and moderate levels of care for less than 20 hours per week*
- 7.25% 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.*

The level of caring is more likely to be intensive with increasing age; men were more likely to be providing tending or moderate care activities and a greater proportion of women were involved in intensive care for longer periods.

In terms of type of condition, in the survey half (51%) of those being cared for who had a learning disability, a quarter (25%) of people who had dementia (13%) and a fifth (20%) of people with a

physical health problem were receiving intensive care.

Of those providing intensive care:

- Over half (54%) were helping with getting in and out of bed,
- Three quarters (77.5%) were helping to wash,
- Nearly three quarters (72.5%) were helping with dressing,
- A third (36%) with feeding and
- Two fifths (41%) with using the toilet

Two thirds of all carers who were providing intensive levels of care were female and a third male. 20% were aged 35-44; 22% were 45-54, 26% were 55-64, 20% were 65-74 and a 10% were aged 75 years and over. 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%)

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. Intensive care for 20+ hours per week is more likely to be provided by those aged 55-64 than other age groups.

One third (32%) of people providing intensive care for 50 or more hours a week said they had been caring for over 10 years and the same number for between 5 and 10 years. Overall, two thirds of people providing intensive care for 50 or more hours per week said they had been caring for over 5 years.

Of those providing moderate levels of care:

- 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+ hours of care per week were giving medicines. The proportion of people providing moderate care was: 2.5% of those aged 25-34, 27.8% of those aged 55-64, 21.5% of 65-74 year olds and 17.7% of the cohort aged 75 and over.

Most people (70.5%) providing moderate care for 20 hours or more were caring for someone living with them. A fifth (21.5%) of those in receipt of moderate care for 20 hours or more were living in their own home, a small number (2.5%) were living in a care home or housing with extra care. Only 35% of those caring for a spouse and 42% for a child were tending or providing moderate care for less than 20 hours.

In terms of the type of health condition of the cared for person receiving moderate care (20 hours or more a week): 72.2% had a physical disability, 13.9% were suffering from dementia, 12.7% had 'another mental health problem' and 8.9% from 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. 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. As might be expected slightly more of the moderate carers were providing support on an extra resident basis; more intensive carers were providing care on a co resident basis.

The majority of intensive care recipients were 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.

Providing low levels of instrumental or physical care - tending - for less than 20 hours per week was the majority care pattern evidenced in the survey; this was the case for 73% of all carers in the Kent survey. Two fifths (41%) of this group were male, and three fifths female (59%).

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 levels of care support tasks such as doing the shopping or taking the person to the doctor's.

Half (48.5%) of those care recipients with dementia, over half (53%) of those people with a physical health problem or disability (53%) and a third (35.5%) of people with a learning disability, were tending. Many of those (64.9%) with a physical health problem were older people.

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 received tending. Three quarters (77.5%) of 'other relatives' and friends (78%) and 100% of neighbours were also in receipt of tending.

Although tending is 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.

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.

Has there been any change in the pattern of caring in Kent since 2001?

It has been possible to compare some of the carer related findings from the 2005 survey with data from the previous 2001 'Health & Lifestyle Survey. It asked the same question about caring:
'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? Do not count anything you do as part of your paid employment.'

In 2001 16.4% of respondents living in Kent said they were carers; this compares with 19.7% in 2005; however the 2001 survey carried an enhanced sample of older people.

In 2001, 10.8% of those aged 16-24 were carers, rising to 27.0% for the group aged 45-64 and 10.4% of those aged 75 years and over. In 2005, 8.7% of those aged 16-24 said they were caring, rising to 25.1% for those aged 45-64 and 16.9% aged 75 and over.

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 and an increase in the number of carers aged over 65. In both surveys and for all ages the proportion of women who were caring was greater than men.

In 2001 11.6% of Kent carers reported they were providing support to friends or family for 1-19 hours, 1.8% for 20-49 hours and 3.1% for 50 hours or more a week. By 2005 comparison figures had become 15.1%, 1.4%, and 3.4%. The burden of additional hours has primarily been borne by older carers. The numbers of hours spent caring has increased for all ages from 45 years.

Particular Groups of Carers

Analysis of the 2005 survey data has been explored for a number of specific groups of carers: mid life carers, 'betwixt and between', older carers and parent carers.

Mid life carers (aged 40-59) constitute the largest group of carers in the UK. They are at the forefront of recent policy developments. What makes the needs of the mid life carer unique is that many are combining paid work, home commitments - which may include supporting children - and care for an elderly relative.

43.5% of all carers in the Kent survey aged 40-59; were proportionately more in the 'older' cohorts of 50-54 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. 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%) are divorced or separated, 5% were single

and 3% were widowed.

Amongst mid life carers:

- Two thirds (64%) of the cared for were aged 75 and over; 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'.

Three fifths (61%) of mid life carers were supporting their parents/in law, a tenth (10%) supported a disabled son or daughter, a tenth (9%) a friend, 6.5% a spouse and 5% 'other relatives'. Parents/in law were receiving the highest level of care from mid life carers.

The survey identified a group of carers who were defined as 'betwixt and between' – those aged 60-64 years, older than mid life carers and not yet old. They constituted 15.8% (N=172) of the total proportion of carers in the Kent 2005 survey; about equal proportions were male (49.5%) and female (45%).

Three quarters (74%) of the cared for were aged 65 years or over. The majority of care provided was tending (73%); only a tenth (10%) were 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. Only a quarter (26%) of these carers were co-resident.

Although the number of carers declines with age, 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. We define this group as older carers. 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 can be distinguished from other groups of carers in a number of key ways.

- Care-giving is more likely to take place within the context of a long-term - often life long - relationship,
- Dementia is more likely to be present
- There is an increased risk of carers having health problems of their own.

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.

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.

Over a third (33.8%) of care recipients were a spouse/partner, a fifth (22.6%) were supporting friends, a sixth (15.3%) were parents/in law, a third (33.8%) were spouses/partners, 6.1% were sons/daughters, a tenth (10.2%) 'other relatives' and a fifth (22.6%) were friends. Whilst carers aged under 65 were most likely to be caring for a parent/in law, older carers were more likely to be caring for a spouse.

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.

Nearly a quarter (22.0%) of older carers were providing intensive care of 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/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'.

Overall 9% (N = 101) of all Kent carers were parent carers. Most were aged over 45 years with a quarter (28%) aged 55-64 years and a fifth (14%) 65-74 years. Over three quarters (78%) were mothers; three fifths (59%) of disabled sons/daughters were co resident.

Whilst 40% of parents were providing tending and moderate care for less than 20 hours a week, 41.4% were providing intensive care, 28.7% for 50 hours or more a week. Younger carers (who were parents) were more likely to be providing intensive care. Conversely nearly half (49.2%) of parent carers aged 45 and over were providing tending & moderate care for 1-19 hours per week. 52% of the cared for were aged under 25.

The majority of parent carers (59%) were supporting a son or daughter with a learning disability. Long term care of a child with a learning disability is widely evidenced as being highly stressful and demanding.

Caring and Health

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.

50.1% of carers in the Kent survey reported that caring had adversely affected their health. This was the case for equal numbers of men and women. The negative impact of caring was particularly marked for those providing intensive care. 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. More older carers also report adverse affects.

In terms of specific health conditions, of those carers who said their health has 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.

Nearly a tenth of intensive carers reported 'other' effects of caregiving; these included marital break up, bruises and scratches from pinching by the cared for person, reduced independence and limited opportunity to pursue leisure interests. One carer spoke for many when they complained that their 'freedom of movement is severely restricted'. More positively, one or two carers reported that the family 'pulls together' to help them provide care. Another commented that they were aware 'that others are in a far worse situation'.

Deprivation, Poverty & Caring

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.

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 50 or more hours per week). Further, carers are more likely than non carers to be owner occupiers (78.5% compared to 75.1%) particularly if they were providing lower levels of care. In terms of geography, there were few differences between East Kent & West Kent.

The key benefits received by carers in the Kent survey relate 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.

Employment & Caring

Caring has significant implications for employment, particularly for those under retirement age. The 2001 Census found that over 3 million people combine work with caring in the UK; this is approximately 1 in 8 workers.

In the Kent survey 62.5% of carers aged under 65 were employed or self 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. Far higher numbers of carers who were providing low levels of care were employed. Of those carers who were working over two thirds (68%) were providing tending.

A higher number of non carers (51.5%) were employed or self-employed than carers (47.1%) including all ages. In terms of type of employment a higher proportion of moderate and intensive carers are in 'lower supervisory/technical occupations' or 'semi-routine/routine' occupations than non carers. These findings resonate with national trends.

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.

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. 6.7% of carers appear not to have been receiving support from either friends and family or health and social services.

40% of people with care related needs who were living in their own home were getting support from services; this is 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%). Two fifths of co resident households received 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.

70% of all support from services appears to have been allocated to those in the lowest level care group whereas only a sixth (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.

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, living alone is routinely considered to be 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.

That such a low proportion of carers were receiving 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.

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 was 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 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'. 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

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 were involved in a local organisation and 21.8% with voluntary work. Comparison figures for the general population were 43.9% and 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 and a sixth (15%) felt they could not; this compared with 62.8% 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 as female, carers saw their neighbours every day (36% vs. 17%). The 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.

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. 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 main report on 'Caring in Kent' and this summary document, draw on the Kent wide 2005 survey of health and lifestyles, and offer a comprehensive picture of caring in Kent. 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.

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 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'.

Overall, caring reduces the likelihood of employment among carers, 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. Two thirds of carer households were receiving support from family and/or friends and slightly fewer from health or social services. 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.

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.