

Caring into later life

The growing pressure on older carers





Contents

Introduction	04
Key facts	05
How many older carers are there?	06
Dave's story	07
Older carers demographics	08
Barbara's story	11
The support older carers provide	12
Health and wellbeing	16
NHS and social care	20
Conclusion	24
Recommendations	25
Appendix	26
Authors	27

“

Although I am retired, and I do not work, I have to do everything in the home – washing, cleaning, preparing meals, shopping, looking after my wife... it is very hard work. I am fortunate that in spite of having suffered a heart attack, which destroyed half the muscles in my heart, I can still manage to cope.

” - *Male carer in his early eighties*

“

As a carer over 65 I feel forgotten.

” - *Female carer*

Introduction

There are 1.2 million people in England¹ aged 65 and over who are providing unpaid care to a disabled, seriously ill or older relative or friend.

Many of these carers are also juggling this with childcare responsibilities, sometimes from a distance if their loved one does not live close by, and a rising State Pension age means they are often also working into later life. Many older carers are managing their own health problems and disabilities as well, and perhaps have care and support needs themselves.

As our population ages and people live for longer with long-term health conditions, family members will find themselves under increasing pressure to provide more support, for longer. By 2050 it is projected that the world's population of people aged 85 and over will increase more than fivefold, Europe will have the oldest population in the world, and in the UK 11 million

people alive today will live to be 100.^{2/3} Demand for care will rise dramatically in line with this trend and we will see the number of older carers rise to over 1.8 million by 2030.⁴

Older carers contribute billions to the UK economy with the unpaid care they provide, but caring into older age without enough support can have a big impact on their own health, wellbeing, and ability to have lives of their own outside their caring role. With many carers retiring early or finding it difficult to return to work after taking time out to care, it also affects their ability to have fuller working lives and ensure that they can provide for themselves and their families financially in later life.



¹ See Appendix (p26) for a note on the geographical scope of this report

² Department for Work and Pensions (2011) Number of Future Centenarians by Age Group

³ Carers UK, Employers for Carers and HM Government (2013) Supporting Working Carers: The Benefits to Families, Business and the Economy

⁴ Source: Projecting Older People Population Information System (POPPI) which uses Office for National Statistics (ONS) population projections. The ONS national population projections (NPPs) are based on the latest available population estimates and a set of demographic assumptions about future fertility, mortality and migration based on analysis of trends and expert advice. More information about this is available on their website: ons.gov.uk

“

I have no life of my own – people expect me to be the carer forever. Which I probably will be because the person I care for is my brother, and he is entitled to a life as well.

” - *Male carer in his late sixties*

If carers are to have healthy and fulfilling lives in older age, more must be done to ensure that there is adequate support in place from health and care services both for older carers and for the people they care for. The commitment in the NHS Five Year Forward View to better support and identify carers, especially those aged 85 and over, is crucial and builds on the progress made by NHS England’s Commitment to Carers.

This report brings together and analyses evidence from national data sources and older carers themselves to set out some of the key facts about this growing and diverse group and look at what steps must be taken to better support older carers.⁵

“

There is little understanding of the devastating impact that caring for one’s closest dear one has on people like me.

” - *Female carer in her late seventies*

“

I had to give up my full time job, which I enjoyed, to care full-time for my husband.

” - *Female carer in her late sixties*

Key facts

There are **1.2 million carers aged 65 and over** in England

The number of **carers aged 85 and over grew by 128%** in just ten years

Nearly **3 in 5 (59%) carers aged 85 and over are male**

Nearly half (45%) of carers aged 75 and over are **looking after someone who has dementia**

Over half (55%) of carers aged 85 and over **provide 50 or more hours of care a week**

6 in 10 (60%) older carers who provide 50 or more hours of care a week say their health is not good, rising to 72% of carers aged 85 and over

Nearly half (48%) of carers aged 85 or over who are providing 20 or more hours of care a week say that they **feel anxious or depressed**

The number of older carers **offered a service following a carer’s assessment has decreased by 4% in seven years**, and for carers aged 75 and over this number has fallen by 9%

⁵ See appendix for a full list of data sources

How many older carers are there?

The number of older carers is growing at a staggering rate. There are nearly 1.2 million carers aged 65 and over in England – an increase of 35% in just ten years, compared to an 11% rise in the number of all carers, and a 4% rise in the number of carers aged 25-64 in the same time period.⁶

The fastest growing group is carers aged 85 and over, whose numbers have more than doubled, growing by a huge 128% in ten years to over 87,000.

Age Range	No. of older carers 2001	No. of older carers 2011	% increase
Aged 65 – 74	582,287	725, 251	25%
Aged 75 – 84	261,240	377,923	45%
Aged 85 and over	38,291	87,346	128%
Total	881,818	1,190,520	35%

Source: Census 2001 and Census 2011

These numbers will continue to grow, with estimates suggesting the number of older carers in England is set to increase to over 1.8 million by 2030. More than 200,000 of these carers will be aged 85 and over.⁷

Increases in life expectancy are currently outstripping increases in ‘healthy life expectancy’⁸ which means that as people live for longer they are also likely to need care and support for a bigger proportion of their lives. For boys born between 2008 and 2010, healthy life expectancy is 63.5 years compared with a life expectancy of 78.1 years, so they are expected to be in poor health for 14.6% of their lives.⁹ For girls, healthy life expectancy is 65.7 years compared with a life expectancy of 82.1, so although women are expected to live longer they are also expected to live a fifth (20%) of their lives in poor health.¹⁰ By 2032,

1.1 million older people in England will need care from their families – an increase of 60%.¹¹

Changing family structures may also have an impact on how care is provided in the future and by whom. In a review of the evidence on family structures and care, the Centre for Policy on Ageing (on behalf of Age UK) found that family size is getting smaller and the care of older people by their children and their children’s spouses is likely to decline. At the same time, gains in life expectancy for men mean there are a falling number of widows and there are more spouses and partners who are available to provide care.¹² This suggests that the shift towards caring in later life will continue as more care is provided to people in older age by other older people, often their spouse or partner.

⁶ Census 2011

⁷ Source: Projecting Older People Population Information (POPPI) which uses Office for National Statistics (ONS) population projections

⁸ Life spent in good or very good health (the amount of time that a person is expected to live free from significant health issues)

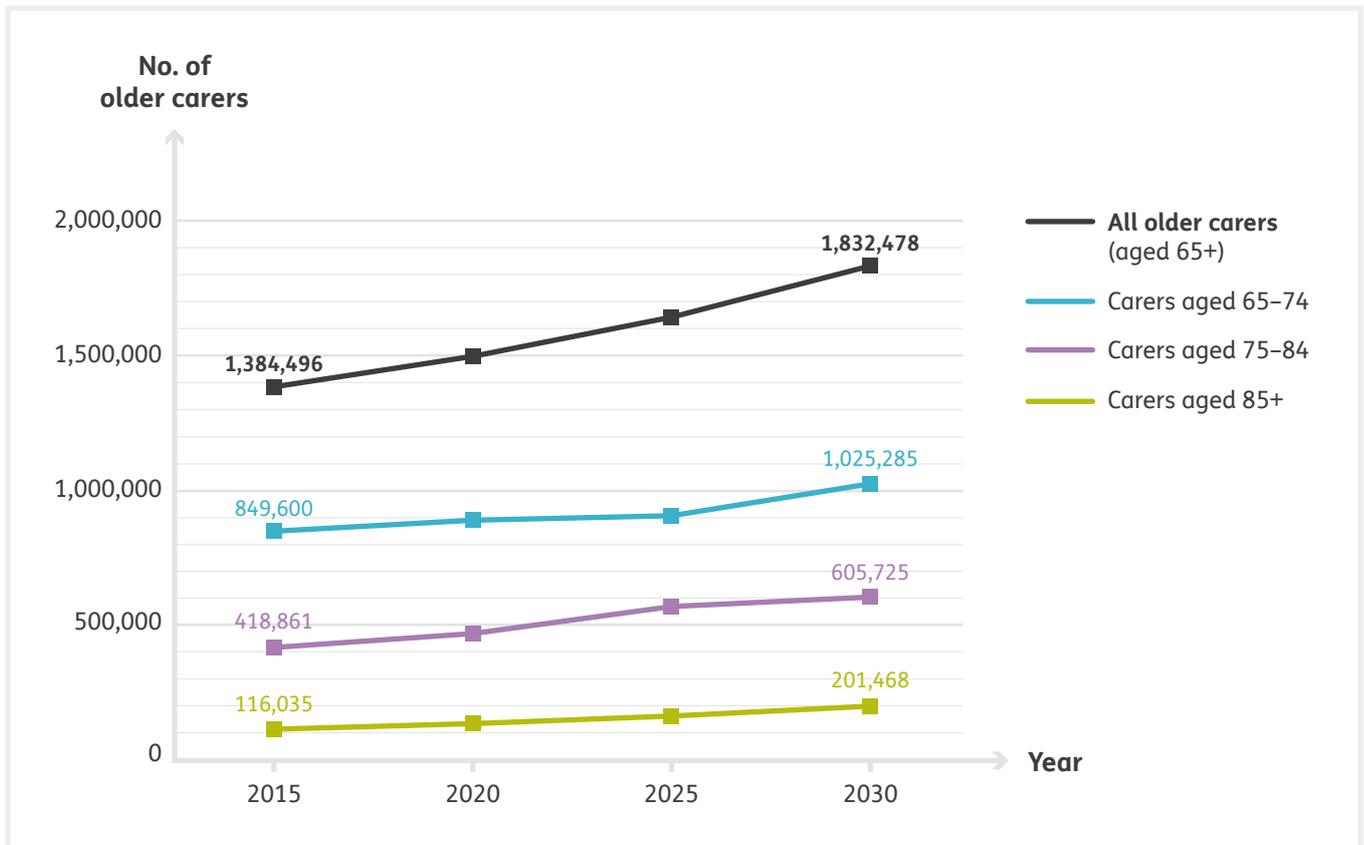
⁹ ONS, referenced by ILC-UK (2014) Mapping Demographic Change: A factpack of statistics from the International Longevity Centre-UK

¹⁰ ONS, referenced by ILC-UK (2014) Mapping Demographic Change: A factpack of statistics from the International Longevity Centre-UK

¹¹ Pickard L (2013) ‘A growing care gap? The supply of unpaid care for older people by their adult children in England to 2032’, Ageing and Society FirstView: 1–28

¹² Centre for Policy on Ageing on behalf of Age UK (2014) Review: Changing family structures and their impact on the care of older people

Projected growth in number of older carers



Source: POPPI

Dave's Story

Dave, 90, is a former tram driver and shop assistant. He has been caring for his wife Ethel for the last 20 years.

Ethel has poor eyesight and limited mobility which means she can't walk by herself without a stick and needs lots of help with day-to-day tasks.

Dave says: "I help Ethel with everything – we don't get any help with practical tasks. She'll ask me to read things or tell her what colour something is. She can't see the gas numbers on the cooker or the cycles on the washing machine. She can't bend down to pick things up and struggles to get up, but then so do I if I sit down for half an hour. I know my limitations.

"We like to be independent and between us we manage to get by. We just accept this as the way it is. You just get on with it don't you?"

"We like to get out every day in the car, whether it's popping to the shops or the library. We need to get out and talk to other people and we've got our interests.

"We're together 24 hours a day. I never leave Ethel by herself. We've been married for 68 years and we know what the other one is thinking about any topic – we can practically read each other's thoughts."



Images: Chris Steele-Perkins

Older carer demographics

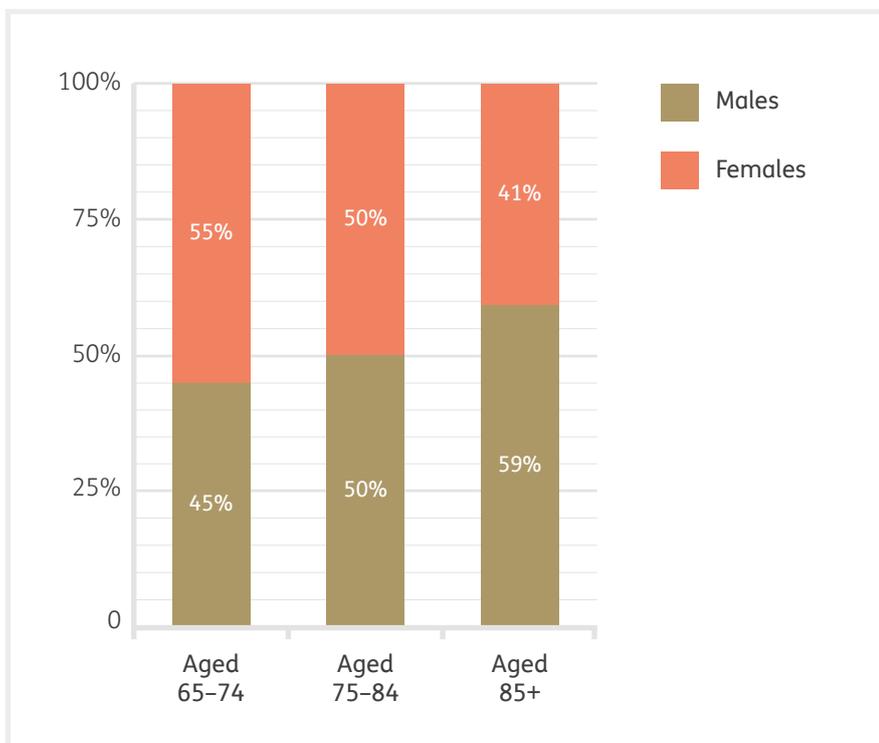
Carers over the age of 65 are more likely to be female (52% are female and 48% are male).

However, this balance shifts as carers get older; 59% of carers aged 85 and over are male. This is in sharp contrast to the carer population as a whole: 58% of all carers are female and 42% are male.¹³

The tipping point when the number of male carers begins to outweigh the number of female carers is in the late seventies or early eighties. However, because women have a longer life expectancy than men, this means that men in the 75-84 age group are more likely to be in a caring role than women of the same age.

This may be because male carers are more likely to be looking after a spouse or partner than female carers,¹⁴ and this type of caring becomes more common in later life.¹⁵ Although women have longer life expectancies, they also often face disability and illness in later life and are likely to need care and support.¹⁶

Gender of older carers



Source: Census 2011

“
I am finding it more and more difficult to care as well as I would like, mostly due to my age.
- Male carer in his early seventies”

¹³ Census 2011

¹⁴ See p15

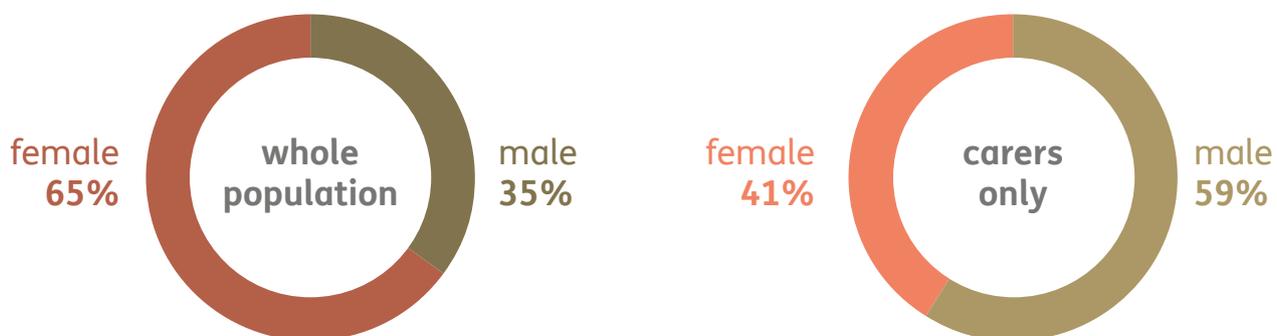
¹⁵ See p15

¹⁶ World Health Organisation (2003) Gender, Health and Ageing, available at: who.int/gender/documents/en/Gender_Ageing.pdf

Gender split of people aged 65–69

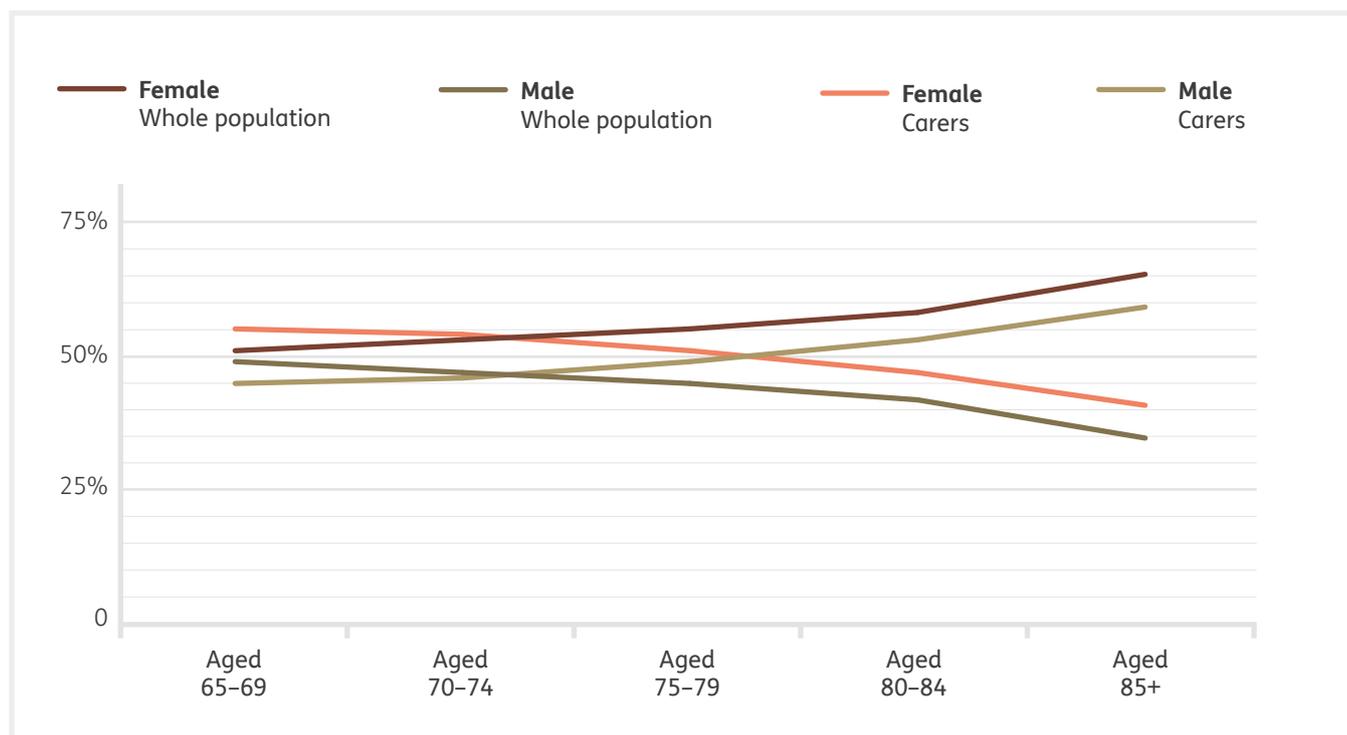


Gender split of people aged 85 and over



Source: Census 2011

Gender split of older carers compared to all older people'

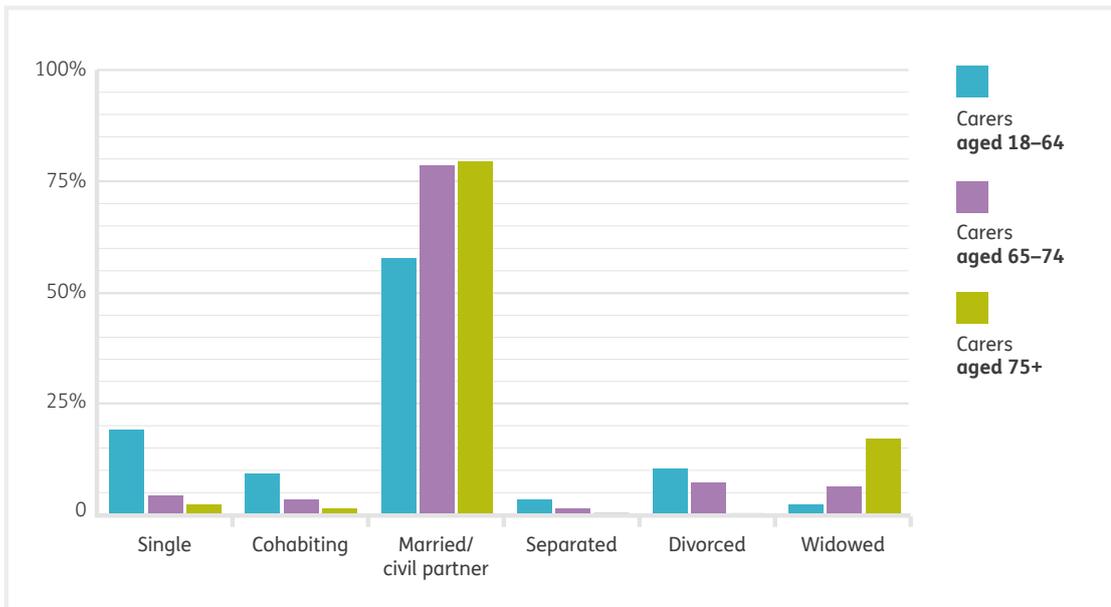


Source: Census 2011

Older carers responding to Carers UK's State of Caring Survey 2014 were more likely to be married, in a civil partnership or widowed than 'working age' carers, and less likely to be single, separated or divorced.

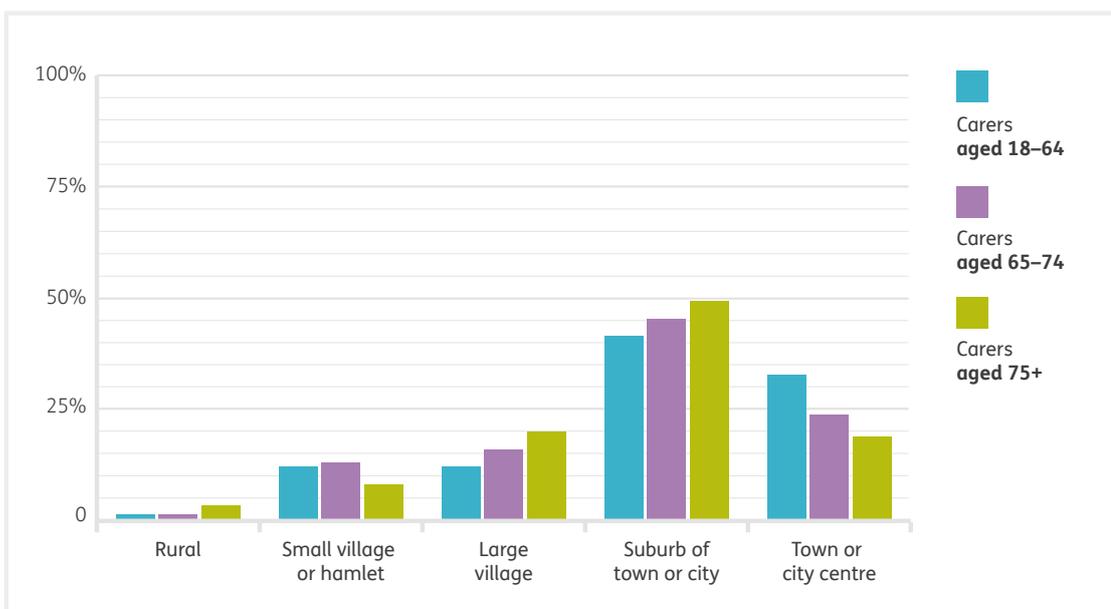
Older carers are also less likely to live in a rural area or in a town or city centre, and more likely to live in a large village or suburb.

Carers' marital status



Source: Carers UK (2014) State of Caring Survey

Where carers live



Source: Carers UK (2014) State of Caring Survey

Barbara's story

Barbara, a single mum, has cared for her profoundly autistic son Howard all his life. Howard is now 61 and has always lived at home with Barbara.



Although Howard is more independent now than when he was growing up, he has a number of health conditions which need managing in addition to autism, including chronic asthma, heart problems, learning difficulties and diabetes. Barbara has to monitor what medication he is taking and stay on top of the housework, including cooking, cleaning and general maintenance.

Barbara, 88, has herself been diagnosed with Asperger syndrome, a form of autism. She also has severe arthritis and has undergone a hip replacement which makes life more difficult.

Barbara says: "We don't have any help at all. We cope, although I am less mobile these days. Howie needs less care than he did growing up. He goes to a class run by a charity one day a week which teaches him how to live independently, but I still need to keep an eye on him. He once took too many tablets.

"When I look back at everything I don't know how I've managed. I just have. Doctors told me Howard was a 'write-off' when he was a child – to put him in an institution and forget about him. He couldn't speak until he was ten and needed more care than an ordinary child. But I tried to get him interested in things. He became hooked on computers some years ago and graduated from university in computer science. Some write-off."

As well as caring for Howard, Barbara also cared for her parents at the end of their lives while juggling a full-time job as a social worker before she retired. Barbara's mum, who had severe arthritis and stomach cancer, and her dad, who suffered from dementia and epilepsy, lived with Barbara in her home for 17 years. Barbara did everything for them, including personal care, and didn't get any help with meeting their care needs. They both died within a month of each other when Barbara was 76.

"It's difficult to explain what caring for Howard is like. It's so different from caring for Mum and Dad. When looking after them I was left with spinal injuries and such through lifting, and had problems caused by interrupted sleep and exhaustion. Howie is ambulant and used to public transport – he is a transport enthusiast. But caring for him I have to follow the rules – his autism rules. I have to remember to follow the right 'script'.

"Howard and I lead a happy life. But I worry what will happen to him when I die. We have our own home and Howard would want to remain here. There must be many carers in similar circumstances throughout the world who lay awake at night wondering what will happen when they are gone. Howard loves his home and is happy here; it would break his heart to be moved."

The support older carers provide

As carers get older, they are more likely to provide more hours of care: a third (32%) of carers aged 65 to 74 are providing 50 or more hours of unpaid care a week, compared to 55% of carers age 85 and over – despite these carers being more likely to be in bad health themselves.¹⁷

This may be because the person they are looking after is also getting older and is more in need of help and support, but these additional support needs are not being met by social care services.

This is supported by Age UK's findings which show that there are 900,000 older people between 65 and 89 who have unmet needs for social care. Nearly a third (31%) of older people who have difficulty in carrying out some essential activities of daily life do not receive any formal help, meaning that: half of those who struggle to wash do not receive any help; 1 in 3 of those who find it difficult to go to the toilet do not receive any help; and over two thirds of those who find it hard to eat on their own do not receive any help.¹⁸

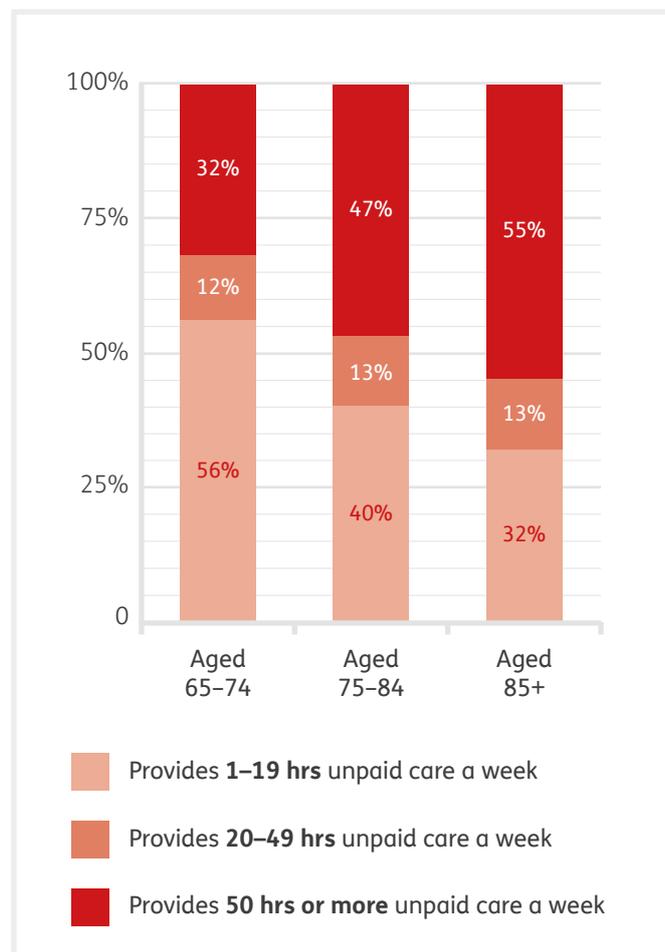
The Personal Social Services Survey of Adult Carers in England found that over a third of older carers have been caring for 10 years or more, with a fifth caring for 20 or more years, showing that many older people have been in a caring role for a significant part of their lives. However, this may underestimate the number of older carers who are new to caring, as only carers of social care users were surveyed.¹⁹

“

I am an only child with a 97-year-old mum who is tenaciously holding on to what independence remains to her despite severe mobility problems, very poor sight and hearing difficulties. I do not feel comfortable if I am more than a few minutes travelling time away from her, 'just in case'.

” - Female carer in her late sixties

Hours of unpaid care by older carers



Source: Census 2011

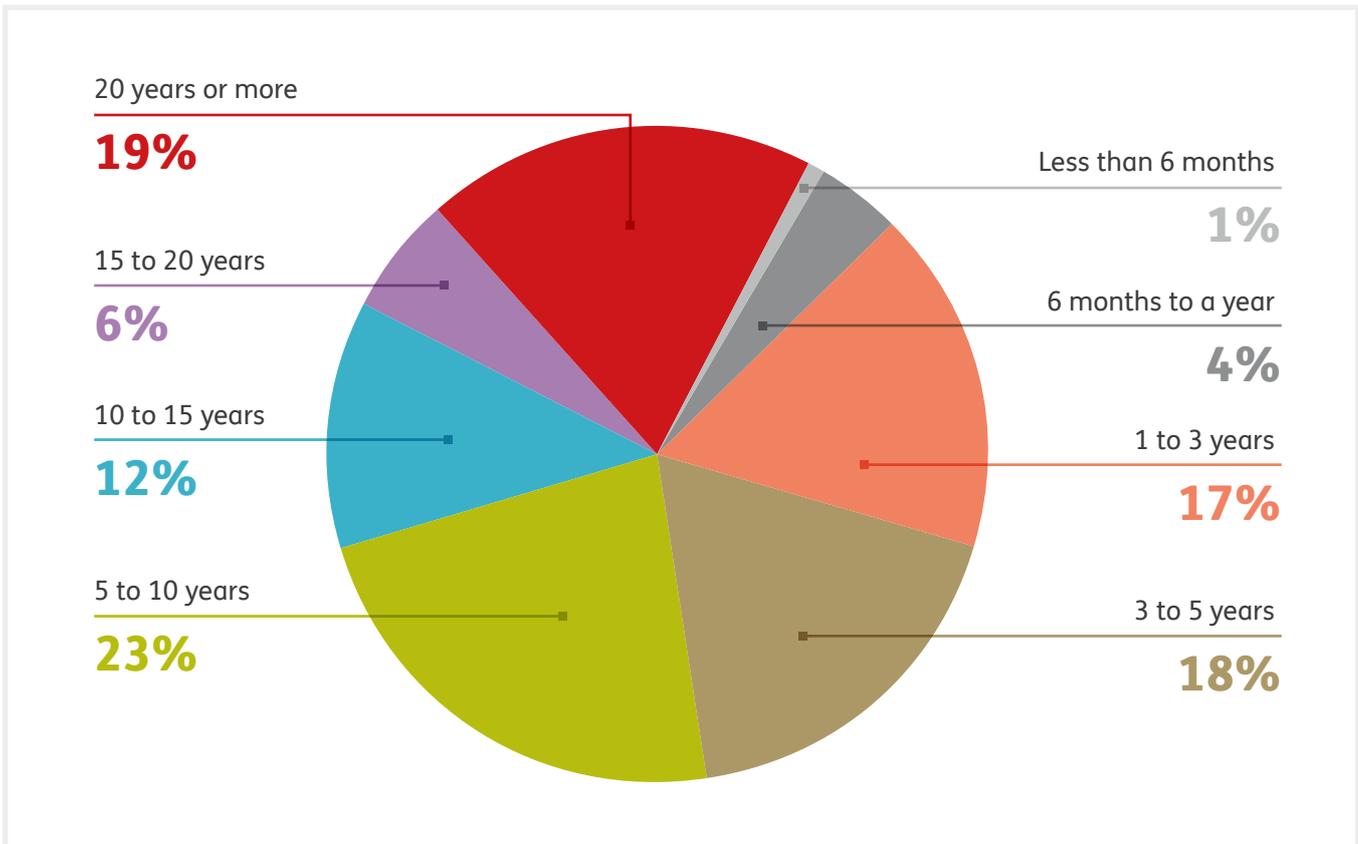
¹⁷ Census 2011

¹⁸ Age UK (2015) Social care spending falls by £1.1 billion (available at: ageuk.org.uk/latest-news/social-care-spending-falls-by-billion)

¹⁹ This means the survey may not fully reflect the experiences of those who are new to caring so have not yet sought or received help from social care services, whose caring role is more short-term, or whose loved one has needs which do not meet the eligibility criteria for receiving state-funded social care support.



How long have older carers been caring?



Source: Personal Social Services Survey of Adult Carers in England 2012-13

The vast majority of older carers (84%) are looking after someone who is also older (aged 65 or over).²⁰ Carers UK's State of Caring Survey 2014 found that, unsurprisingly, as carers become older they are less likely to be looking after a parent and much more likely to be caring for a partner. In fact, 8 in 10 (81%) carers aged 75 or over said that they were looking after a spouse or partner.²¹ Older male carers are 14% more likely to be caring for a partner than older female carers. Older female carers are twice as likely as older male carers to be looking after a parent or a son or daughter.

The age of the people that older carers are looking after is reflected in the types of conditions and disabilities that they have, with dementia and needs that arise from being older (such as mobility problems) being more common among the people older carers look after compared to carers aged 18-64. Nearly half (45%) of carers aged 75 and over are caring for someone with dementia, which is more common than any other condition in this age group. Many carers in this situation struggle to cope with the impact that dementia can have on the person they love, including the confusion, anger, cognitive decline and challenging and distressing behaviours that it can cause.

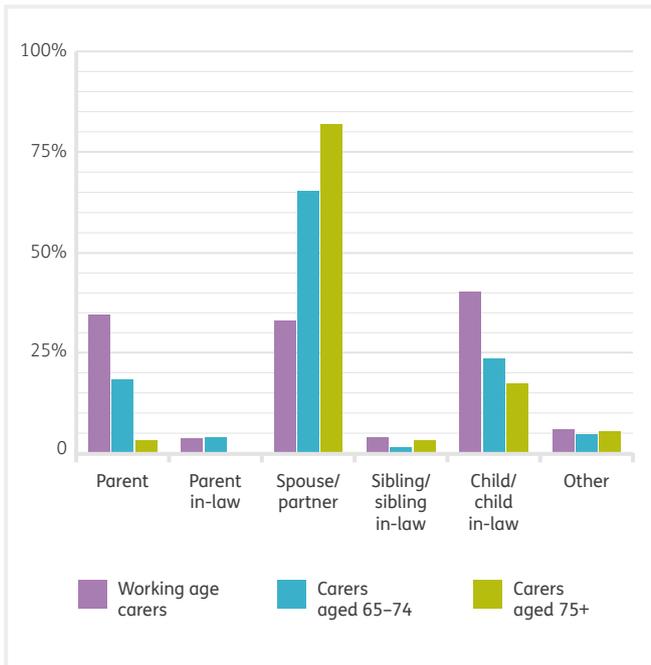
“
Caring can be such a lonely existence... There is so much people don't understand. I think people tend to think that when someone has dementia they only lose their memory, but the impact is much, much greater. You really lose a person. When you grow older one of the huge joys is to share memories. We can no longer do this. We can no longer share the joys of our grandchildren.

- Caryl, 74, cares for her husband who has dementia ”

²⁰ Personal Social Services Survey of Adult Carers in England 2012-13

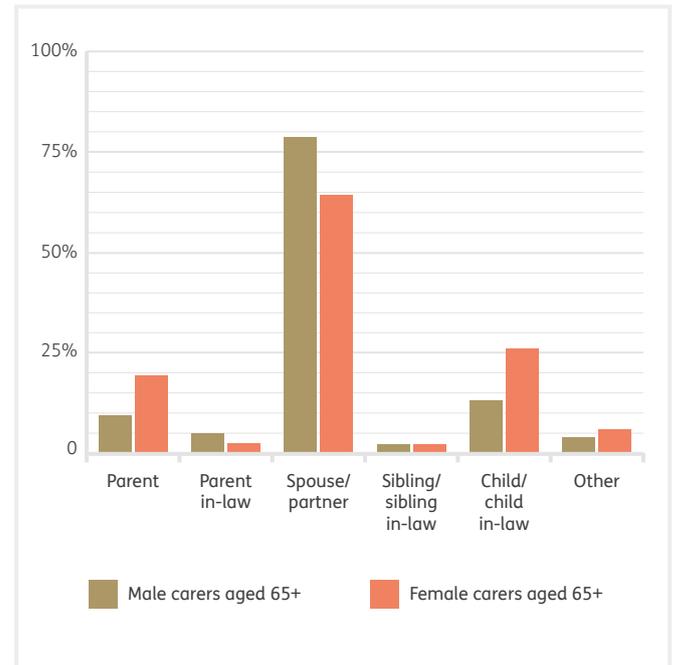
²¹ State of Caring Survey 2014

Who carers are caring for by age group



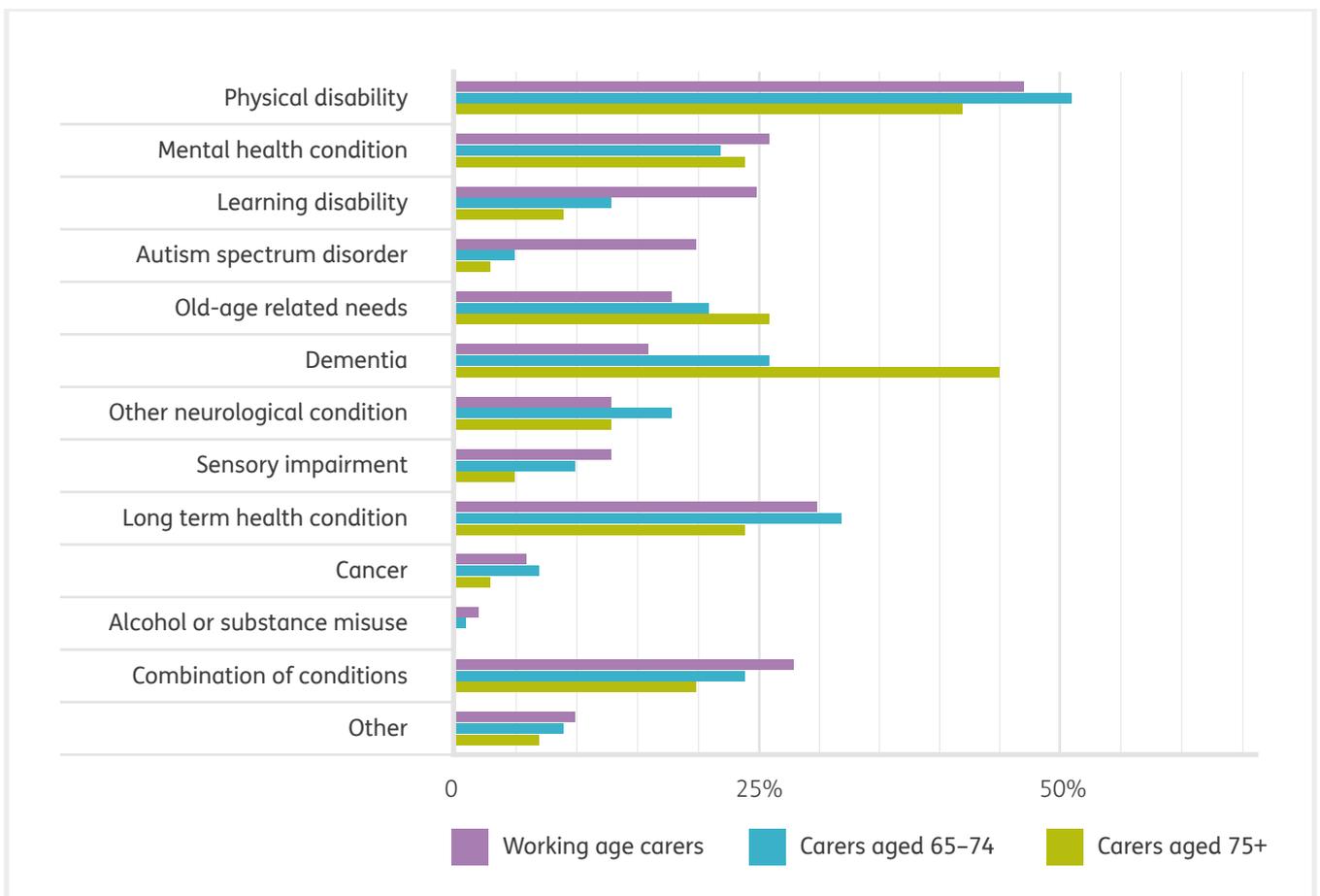
Source: State of Caring Survey 2014

Who carers are caring for by gender



Source: State of Caring Survey 2014

Condition or disability or person being cared for



Source: State of Caring Survey 2014

Health and wellbeing

Older carers who provide lower levels of care (1 to 19 hours a week) report being in better health than non-carers of the same age.

This could be because they are less likely to be living on their own, and research suggests that health outcomes are often better for married people²² and people with stronger social relationships.²³ It may also be that people in relatively good health are more likely to take on caring responsibilities for a family member or friend.

However, this pattern reverses for older carers providing 20 or more hours of unpaid care a week, suggesting that the impact of providing a lot of care takes its toll on older people and outweighs the possible health benefits of not living alone. Research by Carers UK has shown that carers do experience isolation or loneliness and find that caring responsibilities can have a negative impact on their relationships,²⁴ and carers aged 75 to 84 are more likely than older non-carers to report their health is 'not good' (fair, bad or very bad).²⁵

If we look only at the proportion reporting that their health is 'bad' (bad or very bad) then carers aged 85 and over who are providing 20 or more hours of care a week are less likely to report being in bad health than non-carers. This may be because people who are aged 85 or over and also have considerable health problems are unlikely to be able to provide such a high level of care, and may actually need a lot of support themselves.

“

I have a complex chronic health care problem, but caring has to go on each day no matter how I feel.

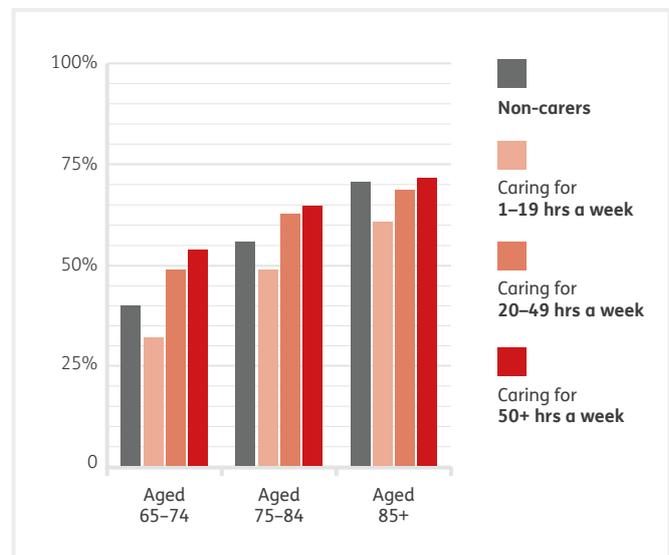
” - Male carer in his late sixties

“

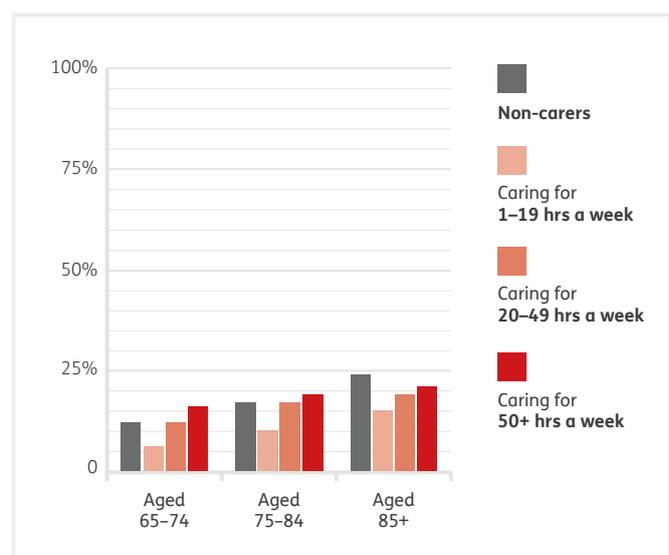
I have put on weight, I can't get to the swimming pool, and my finances are diminishing by the month. I now have asthma.

” - Female carer in her early seventies

Percentage of people in 'not good' health



Percentage of people in 'bad' health



²² Kiecolt-Glaser, J. K. and Newton, T. L. (2001) 'Marriage and health: His and hers' Psychological Bulletin, 127(4), pp472-503

²³ Holt-Lunstad, J., Smith, T. B. and Bradley Layton, J. (2010) 'Social Relationships and Mortality Risk: A Meta-analytic Review' PLoS Med, 7(7)

²⁴ Carers UK (2015) *Alone and caring: Isolation, loneliness and the impact of caring on relationships*

²⁵ Census 2011



Older carers are also more likely than older non-carers to report feeling anxious or depressed, especially if they are providing a lot of care. Nearly half (48%) of carers aged 85 or over who are providing 20 or more hours of care a week say that they feel anxious or depressed, showing that much more must be done to ensure they have the help and support they need. Carers looking after someone with dementia – 45% of those aged 75 and over²⁶ – may also face particular challenges; research has shown that people caring for someone with dementia describe feeling emotions including guilt, confusion, resentment, helplessness, grief, sadness and fear, and they have also stressed their need for support to deal with the emotional aspects of caring.²⁷

Older carers are also more likely than older non-carers to suffer from long-term back problems^{28/29} and from pain or discomfort.^{30/31} Lifting the person they are caring for and helping them dress or move around can all place a strain on carers' backs, and may be especially difficult for older carers if they are not in good health themselves.

“ I am often too depressed to socialise as I have nothing to talk about and it is very lonely because people don't understand.

” - Carer in their late sixties

“ Most of the time I do maintain relationships and social activities, even if electronically rather than face to face. But there are times when I am completely stuck and I can so well understand how carers just slip into sadness and depression.

” - Female carer in her early seventies

“ I have reasonable health, but am very stressed with constantly caring for someone with dementia, and the relentlessness of the situation.

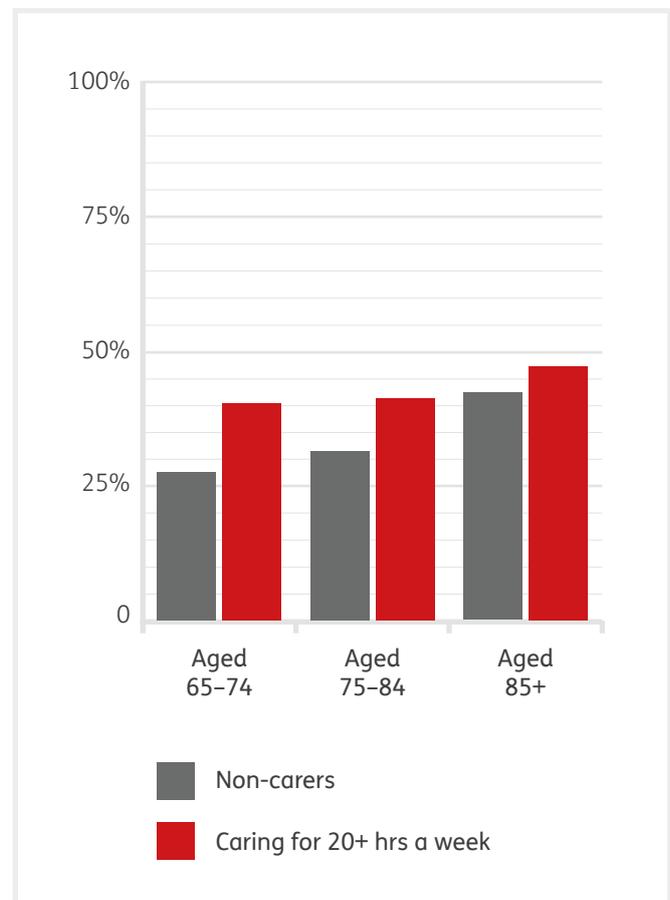
” - Female carer in her late sixties

“

I became socially isolated, largely housebound and developed a mild form of agoraphobia after years of not getting out of the house much.

” - Female carer in her late sixties

Percentage of people who feel anxious or depressed



²⁶ Carers UK (2014) State of Caring Survey

²⁷ Callaby et al. (2012) and Cascioli et al. (2008), referenced in Newbrunner, L., Chamberlain, R., Borthwick, R., Baxter, M. and Glendinning, C. (2013) A Road Less Rocky – Supporting Carers of People with Dementia, published by Carers Trust, p.20

²⁸ Slight, moderate, severe or extreme

²⁹ 15% of older carers (aged 65+) and 18% of older carers caring for 20 or more hours a week report long-term back problems, compared with 14% of older non-carers (GP Patient Survey)

³⁰ 72% of older carers (aged 65+) and 76% of older carers caring for 20 or more hours a week report feeling pain or discomfort, compared with 69% of older non-carers (GP Patient Survey)

“

I have no friends now, so no-one to talk to who's unbiased. It's a very lonely place to be.

” - Female carer in her late sixties

“

I used to be a get-up-and-go person, watched my weight and went to beauty therapists for nails and hair doing but now I feel like an old woman and dread getting up in the morning to the same old routine.

” - Female carer in her early seventies

“

Although 'retired' I was still active as a scientist before I had to become a full-time carer and find it very difficult to keep some scientific studies going since I have so little time that is not taken up with caring, housekeeping or sleep.

” - Male carer in his early seventies

Quality of life

A quarter of carers (24%) responding to the Personal Social Services Survey of Adult Carers in England report that they are able to spend their time as they want, doing things that they value or enjoy. However, 6 in 10 (61%) say that they do not have time to do enough of the things they enjoy and 1 in 7 (15%) don't do anything they value or enjoy with their time. As this survey reflects the experiences of older carers of people who use social care services, it is possible that quality of life is lower for those who are unable to access any social care support, for example because it is too expensive, poor quality or there are no suitable services available.



Image: Chris Steele-Perkins

NHS and social care

Support from social care services

Carers' assessments are carried out by local authorities to identify carers' needs: to look at how being a carer affects them, how much they can realistically do while maintaining a life of their own, and any help that they need. A carer's assessment is a vital gateway to help and support for many carers.

Last year, in 2013/14, 197,000 older carers were offered a carer's assessment and 175,000 took it up. This is a 4% increase on the number of older carers who had an assessment in 2006/7. However, this lags far behind the 35% growth in the number of older carers (in ten years, rather than seven), suggesting that older carers were less likely to have a carer's assessment in 2013/14 than they were several years ago.

The number of older carers aged 75 and over who had a carer's assessment has not increased at all, despite the rapid growth in the number of carers in this age group.

This highlights how important new rights for carers under the Care Act 2014 will be. The Care Act, in force from April 2015, will entitle all carers to a carer's assessment if they appear to have needs. It is crucial that sufficient funding is put in place to deliver these new rights for carers and reverse the fall in the proportion of older carers receiving a carer's assessment. The NHS Five Year Forward View also sets out an important vision for identifying and better supporting carers, with a focus on carers aged 85 and over, and for health and social care to work together on this.

Age Range	No. of older carers who had an assessment 2006/07	No. of older carers who had an assessment 2013/14	% increase
Aged 65 – 74	65,470	72,285	10%
Aged 75 and over	103,080	102,730	0%
Total	168,550	175,015	4%

Source: HSCIC RAP data



Image: Chris Steele-Perkins

In 2013/14, 167,000 older carers were offered a service or information and advice following an assessment, an 11% increase on 2006/7. However, the number of older carers offered a service following a carer's assessment, rather than information and advice only, has actually decreased by 4% in this time and for carers aged 75 and over this number has decreased by a worrying 9%.

Over a quarter (27%) of older carers say that they have found it fairly or very difficult to find information and advice about support services or benefits.³¹ However, as a survey of carers who are already in touch with their local authority and whose loved one has social care support, this is likely to significantly underestimate the number of older carers who have struggled to find the information and advice they need.

³¹ Personal Social Services Survey of Adult Carers in England 2012-13

“

I would love some respite but my husband with dementia refuses to attend a day care centre or allow strangers to stay.

” - Female carer in her late seventies

“

I have to continue working to help pay for services and meet the extra costs incurred by looking after my wife who has multiple disabilities. I am 77 years old.

” - Male carer

“

People think that everyone who needs social care support gets it... they don't! Care workers are often underpaid and unqualified, though some are excellent and really understand what they are doing.

” - Female carer in her late sixties

“

The council are cutting our domestic help from two hours to one hour, meaning I now have to do all the caring and most of the cleaning myself. They are talking about [cutting respite care as well]. So much for care in the community.

” - Male carer in his late seventies

What support are older carers entitled to?

Practical support

Carers' assessments are a way of identifying someone's needs as a carer. They look at a carer's role, how much it affects them, how much they can realistically do while still being able to have a life outside of caring, and any help they need.

From April 2015, new rights in the Care Act 2014 and Children and Families Act 2014 will make it clear for the first time that carers are entitled to an assessment regardless of the amount of care they provide. The Care Act also means that those caring for adults have a right to support with their caring role if their support needs meet the national minimum eligibility threshold.

The council could provide this support by arranging services for the carer or the person they look after (such as help from care workers in the home or respite care), by providing a 'direct payment' so that they can buy support directly, or by offering carers any other kind of help that will meet the carer's needs (such as gym membership or a leisure class).

Even if carers do not meet the eligibility criteria, there may still be help available designed to prevent them from developing a need for support, and the council will have a duty to provide carers with advice and information.

The person who is being cared for should be offered an assessment of their needs for care and support. If their needs meet national eligibility criteria then they might be offered practical support (such as help from care workers or technology that can help them to live more independently) or a direct payment to buy support themselves. The council may charge them for services, depending on their income and capital.

For more information see:

carersuk.org/help-and-advice/practical-support

Financial support

The main benefit for carers is Carer's Allowance which, at £62.10 a week, is the lowest benefit of its kind. However, many older carers cannot be paid Carer's Allowance at all because it is considered to be 'overlapping' with their State Pension (essentially, both are seen to be a payment in lieu of work so they cannot receive both). Many older carers feel this ignores the contribution they make as a carer, and fails to recognise the extra costs they face as a result of caring.

If receiving an overlapping benefit is the only reason why a carer cannot be paid Carer's Allowance, they can still apply for the 'underlying entitlement' to Carer's Allowance which could increase benefits they receive because they are on a low income (such as Pension Credit, Housing Benefit and Council Tax Reduction), or may mean they become entitled to means-tested benefits for the first time.

The person they are looking after may also receive support to help with the extra costs of illness or disability. Depending on their age this could be Attendance Allowance, Personal Independence Payment or Disability Living Allowance.

The benefits system can be complicated so it's important that people get expert advice about what support they are entitled to. For more information contact the Carers UK Adviceline (see p.23) or see: carersuk.org/help-and-advice/financial-support

Experiences of social care services

Of older carers with experience of social care services, 46% report that these experiences have been positive (15% excellent and 31% good) while 38% say that their experiences were mixed or fair.³² 1 in 7 (15%) have had only negative experiences of social care services, including 5% who say that services have been terrible, suggesting that more must be done to ensure that older carers and their families consistently receive good quality care that they can rely on.

Experiences of health care services

44% of older carers responding to Carers UK's 2014 survey report good experiences of NHS services, while 14% say that their experiences have been terrible and 41% have had fair or mixed experiences of the NHS. A quarter (26%) of older carers who have been to hospital with the person they look after feel that their role and expertise as a carer is recognised and valued, while 17% feel their role and expertise was ignored.

4 in 10 older carers who have used health and social care services have experienced difficulties with the way these work together.



³² Carers UK (2014) State of Caring Survey 2014

“

Some home care workers are excellent, but they are not well paid and have very difficult working conditions.

” - *Male carer in his late sixties*

“

I found social services very confusing to deal with, with different departments and different people. I eventually learnt to make careful notes of who I spoke to and what they said.

” - *Female carer in her late sixties*

“

I am on duty 24/7 because I cannot trust the agency support that is on offer. I need to be wakeful at night to make sure my husband is safe and help him turn, or get in and out of bed to the bathroom.

” - *Carer in their late seventies*

Where can older carers go for advice and support?

Advicelines

The Carers UK Adviceline is open 5 days a week to provide expert advice on any aspect of caring. There is also a listening service for carers to talk through their situation with a trained volunteer who understands what they are going through.

Open Monday to Friday, 10am to 4pm
(listening service Mondays and Tuesdays only)

T 0808 808 7777

E advice@carersuk.org

The Age UK Advice line is a free national line that is open 365 days a year and takes in excess of 250,000 calls annually.

T 0800 169 6565

Online

The Carers UK online forum is a place where carers can share what's on their mind, day and night, with people who understand and can support them through the ups and downs of caring.

carersuk.org/forum

Guides and factsheets about older age, caring, practical and financial support, health and wellbeing are available at:

ageuk.org.uk/publications and carersuk.org/help-and-advice



Face to face advice and support

There is a national network of local Age UKs which provide help to older people in their local area, including face-to-face information and advice.

To find a local Age UK visit:

ageuk.org.uk/no-one/we-provide-advice

Find out what support is available for carers locally at:

carersuk.org/help-and-advice/get-support/local-support

Conclusion

Older carers are an extremely diverse group. The needs of a man in his nineties who is struggling to care for his wife and manage his own health problems are very different to the needs of a woman in her mid-sixties who is supporting an older parent and trying to juggle work alongside looking after grandchildren.

This report looks at some of these differences, highlighting the varying health and support needs of male and female carers at different stages in later life. Solutions must be found to better identify and support these different groups, and particularly those carers aged 85 and over identified as a priority in the NHS Five Year Forward View who are more likely than other carers to be caring around the clock, to be suffering anxiety and depression and to be in poor physical health themselves.

As the number of carers continues to grow rapidly over the coming years, and the balance shifts towards caring in later life, there is a clear imperative to take urgent action to improve support for older carers, ensuring they have the help they need to care safely and well and to live a healthy and fulfilling life in older age.

“

Whilst the profile of carers has been raised in recent years it is far from understood by many people who are not carers what the role can entail.

” - *Female carer in her late sixties*

Recommendations

- 1.** Government must ensure a sufficient and sustainable settlement for health and social care to make sure older carers get the practical support they urgently need and reverse the downward trend in older carers being offered support services
- 2.** Government should introduce a duty on NHS services to identify and support carers, reinforcing the commitment in the NHS Five Year Forward View
- 3.** NHS England needs to fulfil the ambitions set out in the Commitment to Carers to review progress towards the relevant NHS Outcomes Framework indicators and NHS Mandate objectives on a regular basis
- 4.** Government, local authorities and other local sources of advice need to work together using new duties in the Care Act to develop advice and information that is tailored and accessible for older carers, including carers who cannot access electronic resources
- 5.** Local authorities must take steps to ensure they are identifying and engaging with older carers in their area, and developing or stimulating the development of services to meet their needs
- 6.** Further research, including qualitative research, is needed to better understand the views and experiences of different groups of older carers and help to plan for the rapid changes in the older carer population, including carers aged 85 and over, older BAME carers, and older male carers
- 7.** Plans for integrated support for older carers need to be clearly set out in Joint Health and Wellbeing Strategies and Better Care Fund plans and supported by good evidence and guidance on the value of integrated support for older carers, recognising that better supported older carers will reduce pressure on the NHS
- 8.** Older carers should be fully involved in co-producing and commissioning support services, including in the development of Joint Health and Wellbeing Strategies and Better Care Fund plans.
- 9.** Good quality, reliable and affordable care services should be recognised as essential in order to support carers who wish to continue working and should therefore be embedded in local employment and economic growth strategies. Government and local authorities should take steps to improve support for former carers who want to return to work
- 10.** Government should review how the contribution of older carers can be better recognised in the social security system
- 11.** The Government should use the Family Test to ‘carer-proof’ all future social security, NHS, social care and employment legislation and policy to ensure it does not negatively affect families’ ability to care
- 12.** National and local government need to include measures in their strategies to address older carers’ emotional health and wellbeing, including to reduce older carers’ isolation and loneliness

Appendix

Definition

‘Older carers’ refers here to people aged 65 or older who are providing unpaid care to a relative or friend. However, where possible the data is broken down into ten-year age groups.

Data sources

This report draws together and analyses data from the following sources:

- Carers UK’s State of Caring Survey 2014
- Census 2001 and Census 2011, Office for National Statistics (ONS)
- Projecting Older People Population Information (POPPI), which uses Office for National Statistics (ONS) population projections and prevalence rates from existing published sources
- National Adult Social Care Intelligence Service (NASCIS) Referrals, Assessments and Packages of Care (RAP) data
- GP Patient Survey (run by Ipsos MORI on behalf of NHS England)
- Health & Social Care Information Centre (HSCIC) Personal Social Services Survey of Adult Carers in England

Quotes from older carers are drawn from Carers UK’s State of Caring Survey 2014 of over 5,000 carers, specifically from the responses of 625 older carers living in England.

Scope

This report limits its scope to older carers in England due to the focus here on health and social care, which are devolved matters, and on the implications of the Care Act 2014 and the NHS Five Year Forward View.

Authors



Carers UK

Carers UK is here to make life better for the 6.5 million people in the UK who are supporting a loved one who is older, disabled or seriously ill.

Carers UK is the only national membership charity for carers, giving expert advice, information and support, connecting carers so no one has to care alone, campaigning for lasting change and innovating to find new ways to reach carers.

Carers UK
20 Great Dover Street, London SE1 4LX
T 020 7378 4999
E info@carersuk.org
carersuk.org

 [@carersuk](https://twitter.com/carersuk)  [/carersuk](https://www.facebook.com/carersuk)



Age UK

Age UK is the country's largest charity dedicated to helping everyone make the most of later life.

Age UK provides a wide range of services and its information and advice reaches 5 million people each year. The Age UK network comprises around 170 local Age UKs reaching most of England. Our family also includes Age Cymru, Age NI and Age Scotland.

Age UK
Tavis House, 1-6 Tavistock Square,
London WC1H 9NA
T 0800 169 80 80
ageuk.org.uk

 [@age_uk](https://twitter.com/age_uk)  [/ageuk](https://www.facebook.com/ageuk)

E4071 © Carers UK April 2015

Carers UK is a charity registered in England and Wales (246329) and in Scotland (SC039307)
and a company limited by guarantee registered in England and Wales (864097).

Registered office: 20 Great Dover Street, London, SE1 4LX.