

Facts about carers

Who are carers?

Carers provide unpaid care by looking after an ill, older or disabled family member, friend or partner. It could be a few hours a week or round the clock, in your own home or down the motorway.

How many people are carers?

- **6.5 million people in the UK are carers and this number continues to rise.**

The 2011 Census figures for the UK show an 11% rise in the number of carers since the last Census in 2001 - increasing by over 620,000 to 6.5 million in just 10 years.

Number of carers in England, Wales, Scotland and Northern Ireland, 2011

	Number of carers 2001	Number of carers 2011
England	4,877,060	5,430,016
Northern Ireland	185,086	213,980
Scotland	481,579	492,031 ¹
Wales	340,745	370,230
UK Total	5,884,470	6,506,257

- **There will be 9 million carers in the UK by 2037.**

¹ Alternative estimates from the Scottish Household Survey indicate the number of carers in Scotland may be higher, at 657,000.

Carers UK estimates that we will see a 40% rise in the number of carers needed by 2037 – an extra 2.6 million carers, meaning the carer population in the UK will reach 9 million.

Carers are not a static population and each year millions of people take on caring responsibilities whilst caring comes to an end for millions of carers as the person they care for recovers, moves into residential care or passes away.

- **Every year over 2.1 million adults become carers and almost as many people find that their caring responsibilities come to an end.²**

This 'turnover' means that caring will touch the lives of most of the population, as we all need or provide care or support family members caring for loved ones at some point in our lives.

- **3 in 5 people will be carers at some point in their lives.³**

Number of hours of care provided

- **1.4 million people provide over 50 hours of unpaid care per week.**

Almost 4 million of the UK's carers care for 1-19 hours each week. But the numbers caring round the clock, for 50 or more hours or more each week, are rising faster than the general carer population - an increase of 25% in the last ten years compared to an 11% rise in the total number of carers.

However the impact of caring is not just dictated by the number of hours of care provided. If you are working full-time, combining caring with looking after young children, or having to travel long distances to provide care, then even having to provide a few hours of care a week can have a serious impact on your life.

Valuing carers

The vast majority of care in the UK is provided by family and friends, who make up the UK's 6.5 million carers. Social services and the NHS rely on carers' willingness and ability to provide care and without it they would collapse.

- **The care provided unpaid, by the nations' carers is worth an estimated £119bn per year – considerably more than total spending on the NHS.⁴**

² Analysis conducted for Carers UK by Michael Hirst (2014) Transitions into and out of unpaid care

³ Carers UK (2001) It Could Be You – A report on the chances of becoming a carer

Carer demographics

Age

- **One in five people aged 50-64 are carers.**

The majority of carers are of working age and the peak age for caring is 50-64 - over 2 million people in this age bracket are carers.⁵

- **Almost 1.3 million people aged 65 or older are carers.**

The number of carers over the age of 65 is increasing more rapidly than the general carer population. Whilst the total number of carers has risen by 11% since 2001, the number of older carers rose by 35%.

The 2011 Census indicated that almost 178,000 under 18s have caring responsibilities. The vast majority are providing under 20 hours of care a week, however thousands provide even higher levels of care. This is a wide spectrum which means caring will affect these young people in different ways. For example, there is a big difference between a child helping parents to bathe a disabled brother or sister and being the sole support for a lone parent with a severe mental health condition. Broader definitions put the figure of young carers higher, as close to three million children live in households with a disabled family member.⁶

Gender

- **58% of carers are female and 42% are male.⁷**

The Census shows that women are more likely to be carers than men. The percentage of carers who are female rises to 60% for those who are caring for 50 hours or more a week.⁸ Women make up 73% of the people receiving Carer's Allowance for caring 35 hours or more a week.

Caring also tends to affect men and women at different times. Women are much more likely to care in middle age.

⁴ Carers UK and the University of Leeds (2011) Valuing Carers 2011: Calculating the value of carers' support

⁵ Census 2011

⁶ Becker, Deardern, and Aldridge (2001) 'Children's labour of love? Young carers and care work' in 'Hidden Hands: International perspectives on children's work and labour'

⁷ Census 2011

⁸ NHS Information Centre for Health and Social Care (2010) Survey of Carers in Households 2009/10

- **1 in 4 women aged 50-64 have caring responsibilities, compared to 1 in 6 men.⁹**

Women have a 50:50 chance of providing care by the time they are 59; compared with men who have the same chance by the time they are 75 years old. Women are more likely to be sandwich carers (combining eldercare and childcare) are also more likely to give up work in order to care.¹⁰

The imbalance reduces amongst older carers and men are slightly more likely to provide care than women amongst retired people¹¹ – many caring for their partners.

Black, Asian and minority ethnic (BAME) carers

- **The 2011 Census showed that there were just under 600,000 BAME carers in England and Wales.**

2011 data indicates that a smaller proportion of the BAME population provides care than the White British population. However the BAME population is much younger and therefore less likely to have older parents or other relatives needing care. Analysis by University of Leeds has, in the past, suggested that, when age is accounted for, BAME families are more likely to provide care for older or disabled loved ones.¹²

Carers UK's evidence indicates that BAME carers are less likely to be receiving practical and financial support with caring and more likely to miss out on accessing support for longer – often as a result of a lack of advice and information and struggling to access culturally appropriate services.¹³

Disabled carers

Many carers report that caring results in a negative and often lasting impact on their physical and mental health, but as with the rest of the population, many people with existing disabilities or long-term conditions also take on caring responsibilities. The 2011 Census shows that, in England and Wales alone, almost 390,000 carers report being in bad health.

Of respondents to Carers UK's State of Caring 2013 survey, 8% were receiving Disability Living Allowance as a result of their own disability or ill health – reflecting similar Government figures showing that over 40,000 carers in receipt of Carer's Allowance also receive Disability Living Allowance.

Contributions from disabled carers to Carers UK's Caring & Family Finances Inquiry indicated that carers with disabilities are significantly more likely to give up work to care (61% of working age disabled carers compared to 52% of non-disabled working age carers) and were much less

⁹ Census 2011

¹⁰ Carers UK (2000) It Could Be You and Carers UK (2014) Caring & Family Finances Inquiry UK Report

¹¹ Census 2011

¹² Carers UK (2001) Who cares wins, statistical analysis of the Census

¹³ Echoing the findings of Carers UK (2001) Who cares wins, statistical analysis of the Census

likely to be in paid work alongside caring (only 18% were in paid work alongside caring, compared to 33% of carers who were not disabled). Because many working age disabled carers were caring for partners they were also substantially more likely to be on lower incomes or have no-one in their household in paid work - three quarters (74%) of carers receiving Disability Living Allowance were in this situation, compared to 55% of all working age carers.

Carers who have an illness or disability themselves were also significantly more likely to be in debt and much higher levels of debt than other carers – with these carers reporting this resulted from a combination of their own additional disability-related costs and reduced earnings. Almost three quarters (71%) of disabled carers said their financial circumstances were affecting their health.

What kind of care do carers provide?

The amount and type of care that carers provide varies considerably. A carer might provide a few hours of care a week - shopping, collecting medication and taking someone to medical appointments - or they may care around the clock. According to Carers UK's State of Caring 2014 survey:

- 93% said they provide practical help such as preparing meals, doing laundry or shopping.
- 87% provide emotional support, motivation or keeping an eye on someone either in person or by phone.
- 85% said they arranged or co-ordinated care services or medical appointments.
- 83% said they manage paperwork or financial matters for the person they care for.
- 71% of carers provide personal care like help with washing, dressing, eating or using the toilet
- 57% carers were helping the person they care for with their mobility – getting in and out of bed, moving around or getting out of the house.

Who do they care for?

According to an NHS Information Centre survey:

- Most carers (40%) care for their parents or parents-in-law
- Over a quarter (26%) care for their spouse or partner.
- People caring for disabled children under 18 account for 8% of carers and 5% of carers are looking after adult children.
- A further 4% care for their grandparents and 7% care for another relative.
- Whilst the majority care for relatives, one in ten carers (9%) care for a friend or neighbour.

Most carers care for just one person (83%), but 14% care for two people and 3% are caring for at least three people.¹⁴

- 58% of carers look after someone with a physical disability
- 20% look after someone with a sensory impairment
- 13% care for someone with a mental health problem
- 10% care for someone with dementia.

Around half of carers are caring for someone in the same household and half care for someone living elsewhere.¹⁵ This changes across different age groups, whilst younger carers are evenly split, carers aged 45-64 are much more likely to be caring for someone living in another household (typically an older parent) and older carers are much more likely to be living with the person they care for as many care for their partners.

Carers UK's State of Caring Survey 2014 showed that of carers not living with the person they cared for just under a third lived within walking distance and 40 lived within a 30 minute journey of the person they cared for, but a quarter lived over half an hour away. These 'distance carers' are more likely to be providing lower levels of care, but to be combining caring with work and often childcare for young families.

Polling suggests that as many as 2.4 million people are 'sandwich carers' – caring for an older or disabled loved one at the same time as they have young children.¹⁶ This number is growing as the average age for having children rises and care needs amongst older relatives continues to grow. The peak age for these two family responsibilities to coincide is 40-44 for women, and 45-49 for men.

The impact of caring

Financial

Families often face additional costs associated with caring, like care services and assistive equipment; alongside higher living costs as ill health or disability push up household bills like heating and laundry bills and result in additional transport costs and hospital parking charges.

Different carers can face different costs. Carers UK's research indicates that working-age carers of partners and disabled children are most likely to report higher utility bills – reflecting the likelihood of living with the person they cared for. Caring at a distance, often for older parents living in a different part of the country, can result in very high transport costs.

¹⁴ NHS Information Centre for Health and Social Care (2010) Survey of Carers in Households 2009/10

¹⁵ The Health and Social Care Information Centre (2010) Survey of Carers in Households

¹⁶ YouGov Poll April 2012 (2012) YouGov and Engage Mutual Survey - polling a GB representative sample of 1,008 people aged 45-60 who had elderly parents and 500 people aged over 65 who had adult children.

- **Half of working age carers live in a household where no-one is in paid work.¹⁷**

Just as their living costs rise, families also often face a lower income as caring and ill-health or disability reduce their ability to work.

- **Almost 1 in 3 (30%) carers had seen a drop of £20,000 or more a year in their household income as a result of caring.¹⁸**

Carers can claim Carer's Allowance to help with the costs of caring; however, because of the low level of the payment and other entitlement conditions, including an earnings limit, the benefit is ineffective in preventing financial hardship. According to Carers UK's State of Caring Survey 2013:

- **Almost half of carers had cut back on essentials like food (45%) and heating (44%).**

The combination of higher costs and lower incomes can push families into financial crisis and lasting debt - one in ten carers had used up all their savings to pay basic bills and almost half (44%) had ended up in debt.¹⁹

- **53% of carers said their money worries were taking a toll on their health.**

The financial impact of caring is often exacerbated by delays in accessing benefits and other financial support. Caring can come as a shock and families, unprepared for the impact on their work and household bills, often report trying to cope with the costs of caring for months or years before they find help. Caring responsibilities which grow over time can also mean that individuals do not immediately recognise they have become a 'carer' or that support may be available. Too often health and social care services fail to identify carers and guide them to support.

- **42% of carers have missed out on financial support as a result of not getting the right information and advice.²⁰**

Health

- **Carers providing round the clock care are more than twice as likely to be in bad health than non-carers.²¹**

The pressures of caring can take a toll on carers' physical and mental health. 92% said that caring has had a negative impact on their mental health, including stress and depression.²²

¹⁷ Carers UK (2014) Caring & Family Finances Inquiry UK Report

¹⁸ Carers UK (2014) Caring & Family Finances Inquiry UK Report

¹⁹ Carers UK (2014) Caring & Family Finances Inquiry UK Report

²⁰ Carers UK (2013) State of Caring 2013

²¹ Census 2011

²² Carers UK (2013) State of Caring 2013

This impact is often exacerbated by carers being unable to find time for medical check-ups or treatment, with two in five carers saying that they were forced to put off treatment because of their caring responsibilities – unable to trust or find suitable and affordable replacement care.²³ Research by Carers UK includes cases of carers discharging themselves from hospital because of an absence of alternative care for the person they look after.

The GP Patient Survey in 2013 highlighted the impact of caring on carer health – whilst 51% of non-carers had a long-standing health condition this rose to 60% of all carers and 70% of carers caring for 50 or more hours a week. The survey also highlighted higher levels of arthritis, high blood pressure, long-term back problems, diabetes, mobility problems, anxiety and depression amongst carers.

Research by Carers Scotland in 2011 found that almost half of carers with health problems reported that their conditions began after they started caring. Of those whose condition pre-dated their caring role, a quarter said their condition had worsened since becoming a carer.²⁴ Carers attribute this health risk to a lack of support, with 64% citing a lack of practical support and 50% a lack of financial support, as major reasons for their poor health.²⁵

Although most of the carers who were caring for at least 50 hours a week in a Carers UK survey had a GP who knew of their caring responsibilities (84%), of these carers, most (71%) said that their GP didn't do anything differently to accommodate them. Very few had a GP who gave regular carers health checks or did home or telephone appointments.²⁶

Social exclusion and personal relationships

- **75% of carers said it was hard to maintain relationships and social networks because people do not understand the impact that caring has.**²⁷

Carers often report becoming isolated as a result of their caring responsibilities. Carers often attribute this about a lack of understanding about their caring role as well as leaving paid work and being unable to take time off from caring resulting in losing touch with friends, colleagues and family members. 57% of respondents to our State of Caring 2014 survey said they had lost touch with friends – almost half attributed this to a lack of practical support to enable them to socialise.

Research by Contact a Family shows that two thirds of families caring for disabled children reported feeling isolated frequently or all of the time. Again, half of these carers felt that the cause of their isolation was due to a lack of support from statutory services.²⁸

²³ Carers Week (2012) In Sickness and In Health

²⁴ Carers Scotland (2011) Sick, Tired and Caring

²⁵ Carers Week (2012) In Sickness and In Health

²⁶ Carers UK (2011) State of Caring 2011

²⁷ Carers UK (2014) State of Caring 2014

²⁸ Contact a Family (2011) Forgotten Families: the impact of isolation on families with disabled children across the UK

In 2013 our State of Caring survey of heavy-end carers highlighted how many carers care alone, without support – with 37% saying they cared without any support from services or from friends and family, and a further 29% who cared with support from friends and family but none from services. This meant that 4 in 10 carers said they had not had a full day off from caring in over a year and half had not had a holiday away from home in the last five years.

Carers UK research has also shown further worrying evidence of the discrimination and prejudice often faced by families affected by disability, echoing recent reports by MS Society²⁹ and Scope.³⁰ In addition to direct discrimination as a result of the condition of the person needing care, the Equality Act 2010 also recognises that carers can face indirect discrimination as a result of their association with disability. One in eight carers responding to a survey in 2011 felt they and/or the person they cared for had been denied services as a result of their disability or their caring responsibilities, 17% felt they were treated negatively because they received benefits and a shocking 14% had been victims of crime like damage to property or verbal abuse.³¹

- **In 2014, half of carers (49%) said they feel society does not think about them at all.**

Work and caring

- **3 million people combine caring for a loved one with paid work.**

The 2011 Census found that around half of the UK's carers combine work with unpaid caring responsibilities. Over two million carers work full-time and one million part-time. Whilst part-time working is much more common amongst carers than non-carers, carers are also more likely to stop working altogether as they struggle to switch to part-time hours.³²

- **Over 2 million people have given up work at some point to care for loved ones, 3 million have reduced working hours.**³³

The peak age of caring also often coincides with the peak of an individual's career in their 40s-60s. National opinion polling for Carers UK's Caring & Family Finances Inquiry showed that middle-aged people with caring responsibilities were more likely than carers of other ages to have given up work, reduced working hours and see a negative impact on their work, like stress and tiredness. In particular, women aged 45-54 were more than twice as likely as other carers to have reduced working hours as a result of caring responsibilities.

- **70% of carers were over £10,000 worse off as a result of reduced earnings.**³⁴

²⁹ MS Society (2012) Fighting Back - ordinary people battling the everyday effects of MS

³⁰ Scope (2012) Disabled people point to issue of 'benefit scroungers' as discrimination increases
www.scope.org.uk/news/discrimination

³¹ Carers UK (2011) State of Caring Survey 2011

³² OECD (2011) Help Wanted? Providing and Paying for Long-Term Care

³³ Carers UK and YouGov (2013) as part of Caring & Family Finances Inquiry UK Report (2014) Carers UK

³⁴ Carers UK (2014) Caring & Family Finances Inquiry UK Report

Carers report very significant drops in income as a result of reduced working hours - 1 in 3 (30%) had seen a drop of £20,000 a year in their household income as a result of taking on caring responsibilities.

Caring can have a long-term impact on ability to work, as a loss of skills, knowledge, experience and confidence make returning to work when caring ends extremely challenging. Evidence from Carers UK's Caring & Family Finances Inquiry indicated that former carers, who are of working age, remain significantly less likely to be in work than non-carers of working age.³⁵ The loss of earnings, savings and pension contributions can mean carers face long-term financial hardship into retirement.

Caring also affects the type of work which carers are able to take on. Many find local, flexible, often low-skilled and low-paid work which can fit around caring. Evidence from the Carers, Employment and Services research by University of Leeds and Carers UK analysis of the Census showed how carers of both genders, but particularly women, are likely to be in 'elementary occupations' – process plant and machine operative jobs, or sales, customer services or personal services.³⁶ Carers managing to juggle work and care describe having to forgo promotion or miss job opportunities because they cannot increase working hours or move to take up a new position. Almost one in four (23%) say they have changed their working pattern to care and a further third were anxious that caring would impact on their capacity to work in the future.³⁷

- **Half of carers cited problems with accessing suitable care services as a reason they gave up work or reduced working hours.**³⁸

When asked why they have reduced working hours, given up work or find combining the two so stressful, carers are most likely to talk about the practical support from care services they receive. Services which are inflexible and cannot fit with working hours or are unreliable can make work impossible, but carers also describe being unable to find suitable care services to meet the needs of the person needing care, or find they are simply too expensive. This echoes a major research study of working carers in 2007, which found that only a quarter of them felt they had adequate support from formal services to enable them to combine work and care. Furthermore between 40 and 50 per cent of working carers said that a lack of flexibility and sensitivity in the delivery of services is hampering them. The majority of working carers say they need at least one type of formal service which they are not currently receiving.³⁹

Of respondents to Carers UK's State of Caring 2013 survey, 21% said they had given up work because of workplace issues around getting flexible hours or a lack of understanding from their employer. Working carers often struggle to get time off to co-ordinated care services or attend medical appointments, 38% had used their annual leave to care and 22% had been forced to use sick leave.

The impact of caring responsibilities on families' ability to work is a growing economic challenge for employers and the UK economy as well as families.

³⁵ Carers UK (2014) Caring & Family Finances Inquiry UK Report

³⁶ Carers UK (2006) More than a job: working carers: evidence from the 2001 Census

³⁷ Employers for Carers (2011) Caring at a Distance: Bridging the Gap

³⁸ Carers UK (2014) Caring & Family Finances Inquiry UK Report

³⁹ Carers UK (2007) Carers, services and employment report series

- **Around one in nine workers in the UK has caring responsibilities.**⁴⁰
- **Estimates from Age UK showed a cost of £5.3 billion a year to the economy in lost earnings and tax revenue and additional benefit payments.**⁴¹

Findings of research by the Employers for Carers business forum into the impact of caring on their workforces, particularly sandwich caring and distance caring⁴² have highlighted how the loss of key and experienced employees results in expensive recruitment and retraining costs as well as a loss of expertise and knowledge.⁴³ 9 in 10 employers surveyed about the impact of dementia caring on their staff said these caring responsibilities were affecting their workforce - putting pressure on employees, causing physical and mental health problems and leading to declined productivity, as well as the loss of valuable staff members.

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Carers UK is a charity led by carers, for carers - our mission is to make life better for carers.

We give expert advice, information and support

- **We connect carers** so no-one has to care alone
 - **We campaign together** for lasting change
 - **We innovate** to find new ways to reach and support carers
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⁴⁰ Census 2011

⁴¹ Age UK (2012) Care crisis wipes over £5.3 billion from the economy

⁴² Employers for Carers and Carers UK (2012) Sandwich caring (2013) Distance Caring

⁴³ Employers for Carers (2011) Caring at a Distance: Bridging the Gap