

State of Caring 2018



About the research

A total of 7,397 carers and former carers responded to Carers UK's annual State of Caring survey between March and May 2018.

Only responses from the 6,828 people currently providing care who completed the survey are included in this report as it is designed to provide a snapshot of caring in 2018. However, Carers UK will be using the responses of former carers in other pieces of work throughout the year.

Compared to the carer population as a whole, respondents to this survey were more likely to be female and caring for a high number of hours every week.

Of respondents to the State of Caring Survey 2018 who are currently caring:

- 75% live in England, 8% live in Northern Ireland, 9% live in Scotland, and 8% live in Wales.
- 78% identify as female and 20% identify as male.
- 24% consider themselves to have a disability.
- 1% are aged 0-24, 4% are aged 25-34, 12% are aged 35-44, 30% are aged 45-54, 33% are aged 55-64, 15% are aged 65-74 and 5% are aged 75 and over. As fewer 1% of carers currently providing care who are under 18 took part in the survey, we have not explored results specifically for this group in the report.
- 3% are lesbian, gay or bisexual.
- 12% also have childcare responsibilities for a non-disabled child under 18.
- 38% are in paid work (49% full-time and 51% part-time).
- 33% have been caring 15 years or more, 15% for between 10-14 years, 24% for 5-9 years, 25% for 1-4 years and just 3% have been caring for less than one year.
- 47% care for 90 or more hours every week, while 16% care for 50-89 hours, 24% for 20-49 hours and 5% care for 1-19 hours a week.
- Most (75%) care for one person, 19% care for two people, 4% for three people and 2% care for four or more people.

As not all respondents completed every questions in the survey, a number of the figures given in this report, including those presented in this Appendix, are based upon responses from fewer than 6'828 carers. This, together with the sample sizes of different groups, should be taken into consideration when reading the results.

State of Caring 2018

Carers UK carries out an annual survey of carers to understand the state of caring in the UK each year.

This year a total of 7,397 people shared their experience of what it's like to be a carer. This is the largest State of Caring survey carried out by Carers UK to date.

This report considers the responses from the 6,828 people currently providing care who completed the survey to provide a snapshot of caring in 2018.



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Context: the state of caring in 2018



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As we mark the 70th anniversary of our National Health Service, the shape and sustainability of our health and care system are understandably in the spotlight. Too often missing from this debate is the role family and friends play. It is frequently forgotten or, perhaps worse, taken for granted that the majority of care provided doesn't come from the NHS or from care homes. It comes in the form of unpaid care which relatives, friends and neighbours provide, estimated to be worth £132 billion a year.¹ As the future funding and service models needed in the health and social care system are debated, the support that unpaid carers need to provide care without putting their own lives on hold must be at the heart of these debates.

A far greater role for the NHS itself in identifying and supporting carers must be high up on its agenda. Healthcare staff are in a unique position to identify those who are in a caring role and direct them to support. As this research shows, this is a key priority for carers along with having the right information and equipment to enable them to care well and enabling them to get regular breaks from caring. The recently

published Carers Action Plan sets out plans to develop quality standards for carer friendly GP practices in England and build on positive initiatives such as Carer Passports in hospitals and the work of John's Campaign. These initiatives are improving understanding of the needs of carers in some areas and among hospital staff in particular but an overarching duty across the NHS to identify and support carers has the potential to embed consistent and systematic identification of carers.

Rather than being given the financial and practical support to care, evidence from our 2017 survey showed that many carers are finding breaks increasingly hard to access, 4 in 10 (40%) of unpaid carers said they had not had a break in over one year, whilst one in four (25%) had not received a single day away from caring in five years. The latest data from NHS Digital on Adult Social Care Spending in England, covering 2016-2017 showed the number of carers getting support or being assessed from local authorities has dropped by 5% since last year with spending on carers dropping by 6%. Spending on the respite services that give carers a much needed break from their caring has also decreased.

¹ Carers UK, University of Sheffield, University of Leeds (2015) Valuing Carers 2015 - the rising value of carers' support

Along with many other organisations, Carers UK has consistently called for an urgent increase in short term funding for social care alongside the planned wider reforms. In this year's survey carers are reporting again that charges for essential care services like a day centre or visits from a care worker are increasing or that already inadequate care packages for those they support are being reduced with carers expected to fill the gaps.

Continuing rises in the costs of living, coupled for many with year on year freezes on means tested benefits means that for those struggling the most, making ends meet is getting more difficult. A welcome change from the Scottish Government means that carers in Scotland who receive Carer's Allowance will see an increase in the amount they get as it rises to the same level as Jobseeker's Allowance. Carers UK continues to press for at least the equivalent rise for the rest of the UK with equivalent increases to carer premia to ensure that those on the lowest incomes benefit.

For those combining work and care, seeking work alongside caring or looking at returning to paid work after a period away for caring, there continues to be many challenges. Both employers and politicians are increasingly realising the need to support working carers. Carers UK's employers forum, Employers for Carers and the Carer Positive scheme for Scottish employers continue to grow. An inquiry, which Carers

UK provided extensive written and oral evidence to and the subsequent report from the cross-party group of MPs that scrutinises the Work and Pensions Department made a number of important recommendations about the benefits system, back to work support and new workplace rights for carers. Carers UK is arguing for a right to paid care leave of at least 5-10 days.

In its most recent ADASS Budget Survey around a quarter of Adult Social Services Directors said that cuts that have been made to services have made the quality of life of carers worse and around 1 in 5 expect this to be the case for the next year. The views of those working in social care are echoed by carers themselves who report concerns for the future. Only 1 in 10 carers (10%) responding to this year's survey said that they felt confident that the support they receive and rely upon will continue.

As we debate the kind of skills, people, technology and funding we will need for our future health and care system, it is imperative we put in place what the families and friends caring every day across the UK need to enable and support carers to care without putting their own lives on hold. The weight of evidence and experience provided by the thousands of carers responding to this survey sets out clear priorities for action which national governments, the NHS and employers must now take forward.



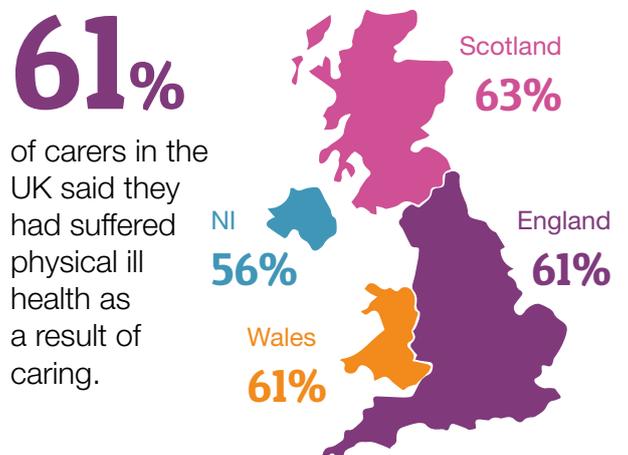
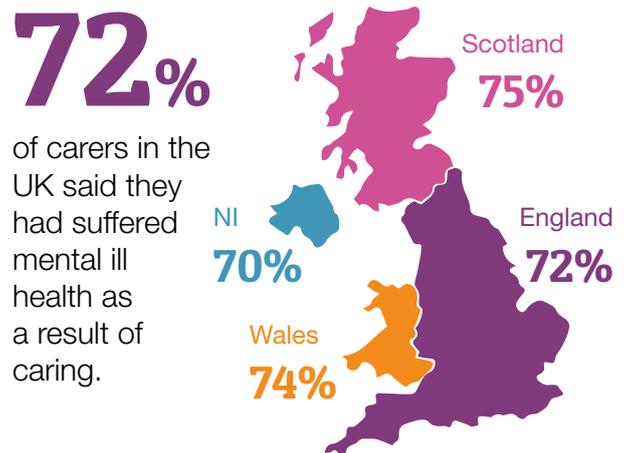
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The impact of caring on health and wellbeing



The support provided by the UK's unpaid carers is worth an estimated £132 billion per year – more than the NHS's annual budget in England.¹ Yet the cost of caring on individuals is often high, taking a toll on carers' emotional and physical health. The NHS and social care sector relies on family and friends, but we regularly hear carers say that they feel little attention is paid to them in terms of being identified, valued and supported.

This year, the Carers Week research report highlighted the impact of caring on people's health and wellbeing.² Almost three quarters (72%) of respondents to the State of Caring 2018 survey who are currently providing care said they had suffered mental ill health such as stress or depression as a result of caring, while well over half (61%) said their physical health had worsened as a result of caring.



I am 79 and I wonder how much longer I will have the physical stamina to cope.



¹ Carers UK, University of Sheffield, University of Leeds (2015) Valuing Carers 2015 - the rising value of carers' support

² Carers Week (2018) Supporting Carers to be Healthy and Connected.

Just over 1 in 10 (12%) said their health was no different as a result of caring and only 4% said their mental health had not been affected.

People caring for a disabled child (81%), 'sandwich carers' – those that have childcare responsibilities for a non-disabled child under 18 (80%), and carers struggling to make ends meet financially (80%) were most likely to say their mental health and wellbeing had suffered as a result of providing care.

People providing palliative or end of life care were most likely to report a negative impact of caring on their physical health, with over 7 in 10 (72%) of this group stating this. They were followed by carers struggling to make ends meet (69%) and 'round the clock carers' – those providing 50 hours or more of care per week (66%).



I don't think about my own health because my priority is my husband, my job, my family, then me.



I am worn out physically and mentally drained.



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The NHS at 70

This year, the National Health Service is turning 70 years old. We asked carers to choose their top priorities for what the NHS should be doing for carers over its next 70 years.



Overall, carers were most likely to prioritise the following:

- Routinely identifying and supporting carers
- Giving carers the right information, training and equipment at the right time to be able to care well and safely, and
- Ensuring that carers get proper breaks

These priorities were closely followed by wanting the NHS to do better at recognising and valuing the knowledge that carers have, treating them as partners in care. For carers providing palliative or end of life care, those caring for more than 5 years and for carers over the age of 65 being valued and treated as a partner in care was a top three priority.

The need for the NHS to routinely identify and support carers was the top priority for carers in every nation except Scotland where legislation and measures are already in place to ensure carers are identified.

What carers want from the NHS



Provide better support for carers' physical and mental health'.



Provide more in-home support and allow carers time out away from caring situations in order to restore their batteries.



I would like to see a more integrated approach: social care and health care providers should work together to support carers and the cared for.



Recognise our contribution and value us.



Accept equal responsibility for patients and their care after hospital stays, rather than putting all the responsibility on the carer.



Understand and respect carers' expertise.



Practical support with caring

Practical support from health and care services is essential for carers, helping them to manage their caring responsibilities and to maintain their health and wellbeing.

We asked carers what type of support they receive or buy. The most common support that carers reported was equipment in the home of the person they care for, such as hoists, grab rails or easy-grip handles on taps which almost half (48%) of respondents said they receive or buy. Other leading practical support that carers reported receiving or buying included:

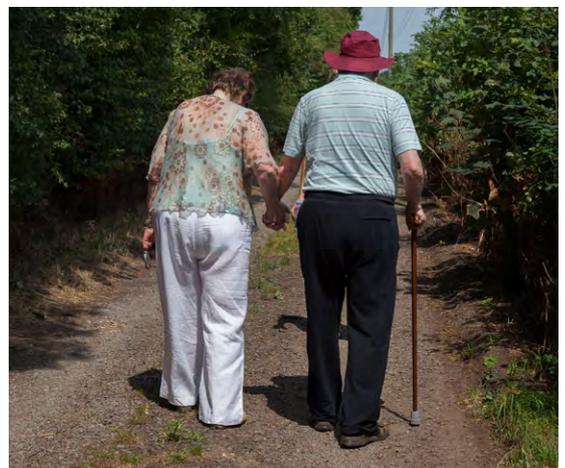
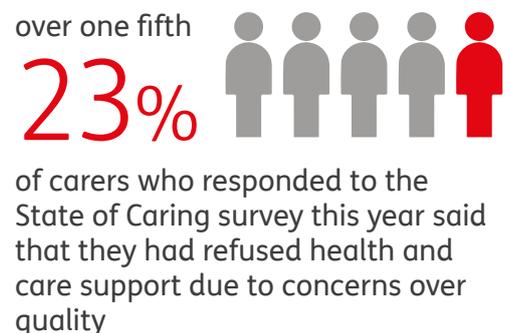
- Help from family and friends (31%);
- Technology like alarms, sensors or remote monitoring (27%);
- Practical support from care workers coming in to help (26%); and
- A motability vehicle (21%).

Despite a number of carers buying or receiving this practical support, however, these figures also reveal the large numbers of carers who are missing out on help. Indeed, as many as 1 in 5 carers (20%) said they receive or buy no support to manage their caring responsibilities. People providing care for a disabled child were the most likely to report that they get no support, with almost 3 in 10 (29%) stating this. There was little difference in the percentage of carers not receiving or buying support across the four nations.

We know that breaks are vital for carers to be able to deal with the physical and emotional strain of providing care and to support them to be able to continue in their roles. Yet carers often report not being able to take even a short break and the significant impact that this has upon them. Disappointingly, only 16% of carers responding to the survey said that they receive or buy a break for themselves from caring.

Carers over the age of 75 were most likely to report that they receive or buy a break from caring (22%), followed by carers over 65 (20%) and round the clock carers (19%). Carers in paid work were the least likely to report this, with only 12% saying they receive or buy breaks for themselves. Across the nations, carers in Northern Ireland were least likely to receive or buy breaks from caring, also with just 12% reporting this.

We know that in some instances carers refuse health and care support because of concerns over quality. Disappointingly, over one fifth of carers (23%) who responded to the State of Caring survey this year said that they had refused support because of this. This was reported most strongly by those caring for someone at the end of life, over a third (37%) of whom stated they had refused support because of concerns over quality.



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Costs, cuts and closures

We asked carers about cuts or changes to the care or support services that they or the person they care for had experienced in the last 12 months. Shockingly, 1 in 7 carers reported they or those they support received less care or support services during the previous year due to a reduction in the amount of support from social services, a service closing without being replaced or an increase in costs.



There was little difference between the four nations in the percentage of those whose care and support had been reduced by social services, though carers in England were the least likely to report that the care and support that they receive had increased.

We asked carers to tell us more about changes to support services that they had experienced and the impact of this upon their lives.

Carers who had experienced increases in the care they receive or buy told us about the positive impact this has had – helping them to feel more supported, removing some of the physical and emotional strain of caring, or providing them with a well needed break from caring to catch up on sleep, have some time to themselves or to see family and friends.

In contrast, many carers spoke about service reductions that had caused hardship for them and the person they care for, often resulting in poor health outcomes and a decline in their sense of wellbeing. For a number of carers, these changes had caused them fear regarding the future and uncertainty about how they might cope with their caring responsibilities going forward.



I've become much more isolated and depressed.



The respite centre is closing in August. There are no other facilities in our area which are suitable so we will lose our respite. This will have a huge impact as I am a single parent and need some time to recharge and relax without having to worry about my sons welfare.



Mum has started going twice a week to a day centre. This has had a huge impact on my mental health and gives me some time to myself when I don't need to constantly think for two people.



We feel trapped and unsupported.



Once your child starts school you lose [services] that were part of your life and a support network for myself as well as my child. Now I have no one for support, it has a massive impact on carers mentally and emotionally when they suddenly stop. No one prepares you for that!



Experiences of Carer's Assessment



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A Carer's Assessment provides an important opportunity for carers to get access to information, help and support from their local authority.

Encouragingly, the majority of carers who responded to the survey (66%) said they had received a Carer's Assessment in the last 12 months. However, over one fifth (21%) said they had not received an assessment during this time and a further 13% were not sure if they had received an assessment or not.

There was little variation in these figures between different groups of carers, whilst across the four nations, carers in England were most likely to have received an assessment in the last 12 months (see below).

Comments from carers highlighted a number of examples where carers had found their assessment a thorough and helpful exercise. However, comments also revealed confusion about the Carer's Assessment, what it is, who is meant to carry it out, and whether people had received one or not. A number of carers said that their Carer's Assessment had been completed at the same time as the assessment of the cared for person and that their needs had not been considered independently or addressed directly. Others commented that they hadn't heard of a Carer's Assessment.



The assessment was quite thorough. But what it lacked was the possibility of hands-on support for the carers, especially in time of crisis.



I received funding for a local gym which has been a lifesaver for me.



I asked for a Carer's Assessment and they said they would do a joint one, but they only cared about and asked about my daughter.



Carer's Assessments in England

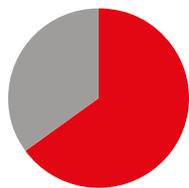


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The majority
of carers in
England

67%

said they had received a Carer's
Assessment in the last 12 months



As different legislation on Carer's Assessments exists in each of the nations, here we consider responses from England only. Results for Northern Ireland, Scotland and Wales will be published in separate reports by each nation.

Three years after their introduction the Care Act and Children and Families Act should be making it easier for carers in England to get an assessment that looks at the impact of their caring role on all aspects of their life and which considers what support they and their family need. It should also be making it clearer for carers to find out about what is available to support them locally and whether they are entitled to local authority funded help.

Encouragingly, the majority of carers in England responding to the survey (67%) said they had received a Carer's Assessment in the last 12 months, with over 8 in 10 of these carers (82%) saying they had waited less than six months for their assessment and 18% saying they had waited longer than six months. This is a slight improvement from what carers reported in the State of Caring survey 2016, when 65% said they had received an assessment in the last 12 months, with 78% saying they had waited less than six months and 22% saying they had waited longer than six months.¹

1 in 5 respondents (20%) said they did not receive an assessment in the last 12 months, however, with 63% of these carers stating that they have been waiting for longer than 6 months. This suggests that opportunities to offer carers the support that they need to perform their caring roles are being missed.

Round the clock carers were those most likely to have received a Carer's Assessment in the last 12 months, whilst sandwich carers were the least likely to have had an assessment during this time. People providing care to a disabled child were most likely to have waited six months or more or to have been waiting longer than six months for an assessment.

Disappointingly, almost a quarter (24%) of those providing palliative or end of life care reported having waited longer than six months before receiving their assessment or that they have been waiting longer than six months and have still not received one. This figure shows no improvement on last year and remains unacceptably high despite the vital importance of receiving a timely assessment for this group.

We asked carers in England **who had received an assessment** in the last 12 months to what extent they felt that a range of issues had been adequately considered during the process. Carers reported that the suitability of their housing for continuing their caring role was the issue most likely to have been thoroughly considered in the assessment and reflected in the support they received, with 44% of respondents stating this. Carers' ability and willingness to provide care

and what needs to be put in place for the person they support in case of an emergency were the other issues most likely to have been considered thoroughly and reflected in the support carers received. This still means that under half of carers (43%) said their ability and willingness to provide care was thoroughly considered and reflected in the support they receive, and that only 38% felt that support in case of an emergency was properly considered. There was little difference in the issues carers felt were most thoroughly addressed in their assessments across different groups of carers.

Support carers need to juggle care with work or to return to work, and the support carers need to juggle care with training or education were the most likely issues for carers to say had **not** been considered properly considered in their assessment, with 42% of respondents stating this. The need to have regular breaks from caring was also reported to be one of the most likely issues to **not** have been properly considered in the assessment, with 33% of respondents reporting this.

Under half of carers

43%



said their ability and willingness to provide care was thoroughly considered and reflected in the support they receive

¹ Carers UK (2016) State of Caring survey 2016

Support from technology

We asked carers whether they were aware of any technology that can support them with care and caring. Across the UK, almost two fifths of carers (39%) said that they were aware of this kind of technology. Half (51%) of respondents, meanwhile, said that they or the person they care for uses technology to support their caring and/or care.

People providing palliative or end of life care were most likely to report being aware of technology that can support them with care or caring and were also most likely to report that they are using technology to support them or the person they care for, with almost two thirds of carers in this group (61%) stating this.

Sandwich carers and those providing care to a disabled child were least likely to report being aware of technology that could support them with their care or caring, with almost a third of carers in these groups stating this (34% and 31% respectively). They were also the carers least likely to say that they were already using technology to support them or the person they care for, with 48% of sandwich carers and 49% of carers providing support to a disabled child saying this.

Across the UK, carers in Northern Ireland were least likely to be aware of any technology that can support them with care and caring (28%) or to say that they or the person they care for uses technology to support their caring and/or care (40%). Carers in Scotland were the most likely to be aware of technology that can



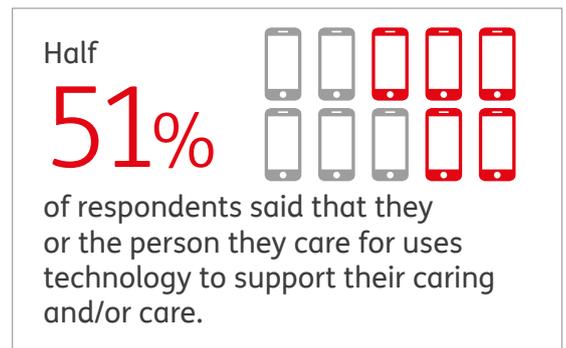
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support them with care and caring, which two fifths reported (41%), whilst carers in England were the most likely to report that they were using technology to support them or the person they care for, with over half of carers saying this (53%).

Across all groups of carers, using the internet as a source of information was the most commonly used form of technology with the over three quarters (81%) of carers reporting this. Using the internet as a form of communication or online support was also reported by almost two fifths of carers (39%).

Other more popular forms of technology that carers said they use included remote health care such as online GP appointments, repeat prescriptions, online video consultations, and online mental health services (30%); and remote monitoring and alerts such as motion sensors, fall detectors, personal alarm and GPS (26%).

There was little difference in the ordering of these priorities across different groups of carers, although palliative carers were more likely to report that they use remote health care which 45% said helped support them, and remote monitoring and alerts which two fifths (40%) said they used.



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Costs of Caring

Carers face high levels of poverty. Research by the New Policy Institute found that 2.1 million informal carers are in poverty in the UK. The poverty rate among carers is 22%, though this varies considerably by age, care intensity and relationship to the recipient.¹ Despite the huge contribution that carers make to our society, Carer's Allowance remains the lowest benefit of its kind, at just £64.60 a week for a minimum of 35 hours (2018/19 rates). We regularly hear from carers and their families who are facing difficulties making ends meet and who are struggling to afford their basic living costs alongside the additional costs that are associated with caring.

Over a third of carers (37%) responding to our survey described their financial situation as 'struggling to make ends meet', while a further 20% said they are in or have been in debt as a result of caring. Under half of carers (48%) said that they could afford their bills without struggling. For those who care for 50 hours or more per week, almost 2 in 5 carers (29%) said they were struggling to make ends meet, nearly a quarter (23%) said they are in or have been in debt as a result of caring, and 45% said they could afford their bills without struggling.

Carers of working age (18-64) who live in a household in which no one works were most likely to report struggling to make ends meet financially, with just under half (49%) of people in this group reporting this. People caring for a disabled child, sandwich carers and those providing palliative or end of life care were also more likely than other groups to describe themselves as struggling to make ends meet, with over 2 in 5 of all these carers stating this (46%, 45% and 43% respectively). Those providing care to a disabled child and sandwich carers were also the most likely to report having been in or being in debt as a result of caring. Older carers, in contrast, were by far the most likely to report being able to afford their bills, with 7 out of 10 carers (70%) over 65 stating this and 77% of those over 75, compared to an average of 43% for carers of working age.



© Peter Alvey Photographer



I am now financially dependent, wholly, on my husband, which makes me extremely anxious.



We are caught in a Catch 22 situation. I want to work but would lose £500 by working. This month I have less than £150 to feed 3 of us. I'm in despair.



I spend my time terrified about benefits and benefit cuts and how we will live if things get any worse for us.



¹ New Policy Institute (2016) Informal care and poverty in the UK.

Little difference in the financial situation of carers was found across the four nations.

For those carers struggling to make ends meet, cutting back on luxuries was the most common way they said they cope, with 8 out of 10 of carers in this group reporting this. Cutting back on hobbies and leisure activities and cutting back on seeing friends and family is also common among this group, with 75% and 61% saying that they do this, respectively.

Most worryingly, almost half of carers struggling to make ends meet (47%) said they cut back on essentials such as food and heating to cope. Going without these essentials is likely to have a detrimental impact on a carer's health, whilst cutting back on hobbies, leisure activities, and seeing family and friends can have a significant effect upon a person's wellbeing. More should be done to ensure carers have an adequate income to support themselves and to ensure that providing care does not jeopardise people's health and wellbeing.



© Olivia Hemingway



I am not in debt but have been using my savings to supplement Carer's Allowance.

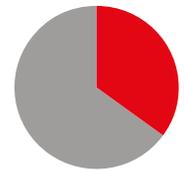


What worries me is that I am supporting myself out of the money I have put aside to provide for my care further down the line.



Over a third
of carers

37%



described their financial situation as
'struggling to make ends meet'

Of those struggling
to make ends meet

47%



said they cut back on essentials
such as food and heating to cope

Juggling work and care



Carers' financial situations are often negatively affected by the impact of caring on their ability to participate in paid work. Across the UK, 2.3 million adults report having given up work to care at some point in their lives and almost 3 million have reduced their working hours.¹ Many carers face a lack of understanding from colleagues and managers. Working carers need a mixture of support, ranging from understanding and flexibility at work to reliable, affordable care services that give them peace of mind that the person they support is being well looked after.

Almost 1 in 4 of the carers who responded to our survey (38%) reported being in paid work. This figure rises to 45% when only people between the ages of 18-65 are considered. Nearly half of all carers who reported being in paid work (49%), including those over 65, are employed or self-employed full-time, and as many as 32% of these full-time workers are juggling work with providing 50 hours or more of care per week.

¹ YouGov and Carers UK (2013).

Sandwich carers were more likely to report being in paid work compared to other groups, while women who responded to the survey were significantly more likely to be juggling their caring responsibilities with paid work than male carers, with 40% of women reporting that they were employed or self-employed full-time or part-time, compared to 27% of men.

Overall, over one third of carers (35%) reported that they had given up work to provide care, with a further 16% saying that they had reduced their hours of work in order to support the person they care for. Two in 10 carers (20%) said they had taken a less qualified job or turned down a promotion as a result of their caring responsibilities or that they had retired early in order to provide care. Sixteen percent said that they work the same hours as they did before they started caring but that their job has been negatively affected by it as a result of tiredness, lateness, or the impact of stress.

Only 4% of carers responding to our survey said that caring has had no impact upon their capacity to work.

Overall, carers struggling to make ends meet, round the clock carers and those caring for a disabled child under 18 were the most likely to report having given up work to care, with almost half of carers in these

groups reporting this (49%, 47% and 46% respectively). Sandwich carers, those providing care for a disabled child and people providing palliative or end of life care were the most likely to report having reduced their working hours to care, with over 2 in 10 of these groups (21%) stating this.

There was little difference between female and male carers in regard to the impact that providing care was reported to have had upon their employment. Overall, 38% of men and 36% of women said they had given up work to provide care. Women were more likely to have reduced their hours to care and to report that their work had been negatively affected as a result of their caring responsibilities, but men were more likely to report having retired early to provide care.

Overall, over one third of carers

35%



reported that they had given up work to provide care, with a further 16% saying that they had reduced their hours of work in order to support the person they care for



I've had to give up my career. My husband works full-time to support the family



I've had to leave my current job, due to the distance it is away from my Mum. I hope however to get a job that is closer



Expectations of the future

We asked carers about their expectations for the future in terms of the practical support they receive with caring, their health and wellbeing and their ability to provide care, and their quality of life.

In terms of practical support with caring, as many as 1 in 4 carers (25%) said they are worried that the support they currently buy or receive might be reduced, while almost two thirds of carers said that they do not know what might happen with the support they currently buy or receive (65%). Only 1 in 10 carers (10%) said that they felt confident that the support they receive and rely upon will continue.

Those providing care to a disabled child were least confident that the support they currently receive would continue, with just 3% stating this, while 31% said they worried their support might be reduced. Carers who reported struggling to make ends meet financially and sandwich carers were similarly uncertain about the support they would receive in the future, with only 5% and 6% of these groups saying they felt confident about it, respectively.

When we asked carers about their expectations for their own health in the future, troublingly, the majority (58%) said that they expect their physical health to get worse in the next two years. Only 3% said they thought their health and wellbeing would improve. Carers' expectations for their mental health and wellbeing were similarly discouraging, with over half of carers (57%) saying they expect their mental health to get worse in the next two years and only 4% saying they expect it to improve.

Those struggling financially to make ends meet, older carers and those providing round the clock care were also more likely than other groups to say they expect their physical health to get worse, with between 63% and 66% of these groups reporting this. Carers who said they were struggling financially to make ends meet were the most likely group to expect their mental health to get worse in the next two years (65%).

We asked carers about how they thought their mental and physical health would affect their ability to provide care in the future. Almost half of carers responding to the survey (43%) said they expect that they will be able

to provide less or no care in the future because of poor current or future physical health, while over one third (35%) of carers said they expect that they will be able to provide less or no care in the future because of poor current or future mental health.

Only half of respondents (52%) said that they didn't think their physical health would affect their ability to provide care in the future. Sixty per cent (60%) said they didn't think their mental health would affect their ability to provide care in the future.

half of carers

50%



said they expected their quality of life to get worse in the next 12 months.

Two fifths of carers

42%



said they thought it would stay the same.

Only

8%



said they expected it to get better.

Only 1 in 10 carers

10%



said that they felt confident that the support they receive and rely upon will continue.

Across the UK, carers in Scotland were most likely to expect to be able to provide less or no care in the future because of poor physical and mental health.

In terms of their quality of life in the future, disappointingly, half of carers (50%) said they expected their quality of life to get worse in the next 12 months. Two fifths of carers (42%) said they thought it would stay the same. Only 8% said they expected it to get better.



I will have to carry on as a carer, regardless of my mental or physical health. The thought of being unable to cope frightens me.



I constantly worry about the future.



With the right support, my physical health and well being would improve and I would be able to care for many years.



My biggest worry is government changes to benefits, and not knowing what the future holds and whether everything we have now will be taken away.



I hope I can cope as long as my husband needs me.



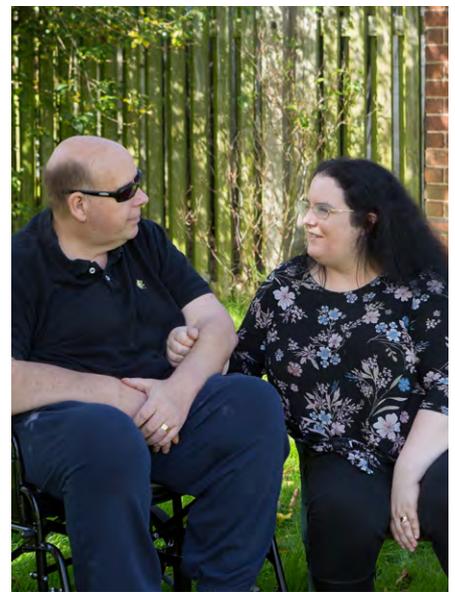
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Recommendations

The care provided by the UK's 6.5 million cannot be taken for granted. National governments must take the lead in coordinating action across national and local government, the NHS and employers. Carers will judge the strength of government commitments by concrete actions.

Ensure that carers and our families do not suffer financial hardship as a result of caring

- Carer's Allowance, just £64.60 on 2018/9 rates, must be raised across the rest of the UK to at least the level of Job Seeker's Allowance, as has been done in Scotland, with equivalent increases to carer premia to ensure that those on the lowest incomes benefit. In the longer term, financial support for carers must be increased significantly.
- The earnings threshold for Carer's Allowance needs to rise year on year in line with the National Living Wage pegged at least to the equivalent of 16 hours a week so carers don't have to choose between Carer's Allowance and keeping in touch with the workplace. A taper should also be introduced.
- To auto-enrol carers in a second pension – a Carer's Pension that recognises the value of unpaid work and ensures that we do not suffer financial hardship later in life.



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Deliver a National Health Service that recognises, values and supports carers

- A new duty on the NHS to put in place policies to identify carers and promote our health and wellbeing. Ensure that all staff are trained to know about carers and how to support us.
- Increase identification and support through primary care.
- Ensure carers are better prepared for caring and can get support early to look after our own health and wellbeing with easily available advice and information for carers to help us plan, prepare and provide care.



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Put in place enough funding so that older people and people with disabilities are able to access the quality and affordable care they need and that we are able to have a life alongside our caring roles.

- An urgent and significant increase in funding for care services is needed now or the role of families and friends caring will become increasingly unsustainable as carers are pushed to breaking point by a lack of support.
- Consideration of new funding models for social care and the priorities for future NHS spending must have carers' contribution, both financial and practical, at their heart and deliver a sustainably funded health and care system that is fairer for families.



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Give us a break: Provide funding and choice of quality services to enable carers to take the breaks we need:

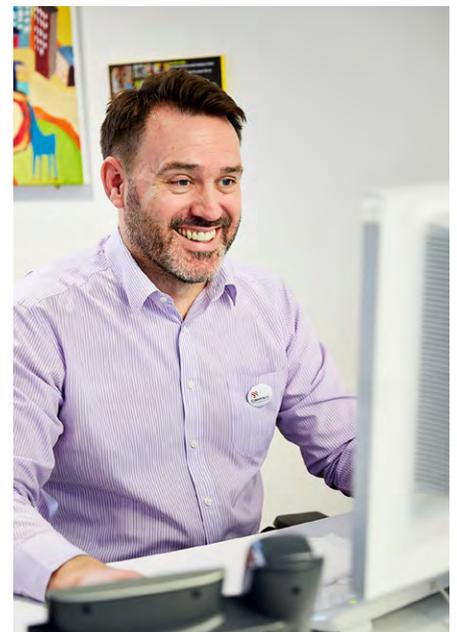
- Increase and ringfence funding for carers' breaks making it transparent so carers know what we are entitled to, and ensure greater consistency in what is available. A choice of appropriate and good quality care must be available or carers cannot get the breaks we need for our own health and wellbeing.



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Ensure carers are able to juggle work and care, if we wish to, with support to return to work alongside or after caring:

- Create a new right to paid time off work to care of at least 5-10 days.
- Put in place tailored support for carers looking to return to work, including recognising the skills carers have developed through our caring role.
- Work with employers to include carers in health and wellbeing support at work.
- Recognise that good quality and affordable care services are an essential part of enabling carers to remain in or return to work alongside caring.



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Carers UK
20 Great Dover Street
London SE1 4LX

T 020 7378 4999

E info@carersuk.org

carersuk.org



@carersuk



/carersuk

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