

State of Caring

A snapshot of unpaid care in the UK



2019

State of Caring 2019

Each year, Carers UK carries out a survey of carers to understand the state of caring in the UK.

Over **8,000** carers and former carers shared their experience of what it's like to be a carer.

This report provides a snapshot of caring in 2019 by only including the responses from the **7,525** people who are currently providing care.

This is the **largest** State of Caring survey carried out by Carers UK to date.

About the research

Carers UK carried out an online survey between March and May 2019. A total of 8,069 carers and former carers responded to the survey – we have only included responses from the 7,525 people who are currently providing care in this report.

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 survey:

- 73% live in England, 10% live in Scotland, 9% live in Northern Ireland, and 8% live in Wales.
- 81% identify as female and 18% identify as male.
- 24% consider themselves to have a disability.
- 1% are aged 0–24, 4% are aged 25–34, 13% are aged 35–44, 30% are aged 45–54, 32% are aged 55–64, 14% are aged 65–74, and 5% are aged 75 and over.
- 3% identified as lesbian, gay or bisexual.
- 5% described their ethnicity as black or minority ethnic.

- 20% also have childcare responsibilities for a non-disabled child under 18.
- 39% are in paid work. Of those, 47% work full-time and 53% part-time.
- 31% have been caring for 15 years or more, 15% for between 10–14 years, 24% for 5–9 years, 26% for 1–4 years, and just 4% have been caring for less than one year.
- 46% care for 90 or more hours every week, while 17% care for 50–89 hours, 23% care for 20–49 hours, and 13% care for 1–19 hours a week.
- Most (74%) care for one person, 20% care for two people, 5% 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 7,525 carers. This, together with the sample sizes of different groups, should be taken into consideration when reading the results.

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Context: The state of caring in 2019



Recent polling published by Carers UK has suggested there could now be as many as 8.8 million adult carers in the UK¹, compared to 6.3 million adult carers recorded in the 2011 Census. The number of people aged 65 years or over who are caring has grown from 1.4 million to potentially over 2 million. This is a 43% increase from 2011 to 2019. Improving support for carers whether it's practical or financial must be at the heart of how we address our ageing population.

There have been a number of positive developments for carers in the last year. These include measures to support carers in the NHS Long Term Plan and Cross-Government Carers Action Plan in England, an increase to carers' benefits in Scotland and greater awareness of caring as an issue, and an increased focus on personalisation across the UK. But even with these developments, carers and the people they care for still face economic and societal pressures. Many services in the UK have reached crisis point, with unpaid carers facing the consequences of local cuts to budgets and delayed funding solutions in some of the nations. Recent research from the Health Foundation shows the spending gap between England and other nations widening with public spending on

care for older and disabled people is much higher in Scotland and Wales than England². In particular, the two year delay in publishing the Green Paper on Social Care in England is of deep concern. The results of this year's survey show clearly why system-wide reform is needed to ensure carers are properly supported and able to have a good quality of life alongside their caring responsibilities.

Carers' support is valued at £132 billion a year³, but this comes with high personal costs. Many carers are suffering from loneliness and social isolation, need support to help them stay in work, and are facing their own health problems as a result of their caring role. This is in addition to the financial cost of caring; with 39% of this year's respondents saying that they are struggling to make ends meet, and over two thirds reporting that they regularly use their own income or savings to pay for care or support services, equipment or products for the person they care for.

A higher state pension age means that people are working for longer and are more likely to be working alongside caring. Increasing numbers of employers are recognising

¹ Carers UK (2019) Juggling work and unpaid care, Yougov polling www.carersuk.org/images/News_and_campaigns/Juggling_work_and_unpaid_care_report_final_0119_WEB.pdf

² Health Foundation blog (2019) The real cost of a fair adult social care system.

³ Carers UK (2015) Valuing carers – based on 2015 carer projection

the importance of supporting carers in their workforce to continue working, so they can retain talented staff rather than incurring the costs of recruiting and retraining new employees. But with workplace support still very varied across the country, nearly half a million people have had to give up work over the past two years as a result of caring. This equates to around 600 people every day⁴.

Caring is still often thought of as being part and parcel of women's lives and within families women are still most likely to be providing care and most likely to be providing more hours of care. Women make up the majority (58%), of carers and 20% of women aged 45 to 54 are providing unpaid care to someone with a disability or illness, or who is older⁵. Providing support for carers, especially those looking to stay in, or return to, paid work, is essential if women are to be able to participate fully in the economy and live a life free from poverty in older age.

When asked how they expect their quality of life to change over the next year, 11% of carers said they expected it to get better, 45% expected it to get worse, and 44% expected it to stay the same. This shows that

there is much to be done to increase support for carers and that many carers have serious concerns about the future. Two thirds of carers told us that they have focussed on the care needs of the person they care for, rather than their own needs, and over half (53%) of those who have yet to retire are unable to save for their retirement. This brings to light the reality of the impact of caring on carers' ability to plan for their future retirement and their own care needs. Action must be taken to support them.

The UK Government has previously committed to valuing, recognising and supporting carers⁶, but if this is truly to become a reality then carers' voices, opinions and experiences must be heard, listened to and acted on. It is of paramount importance that even in the current challenging political context, the next Prime Minister focuses on supporting carers and ensuring a sustainable future for our health and social care system.

This report contains a snapshot of what caring is like in 2019, capturing the impact that caring has on carers' lives and evidencing the policy recommendations that would improve this.



⁴ Carers UK (2019) Juggling work and unpaid care, Yougov polling

⁵ Census 2011

⁶ www.parliament.uk/written-questions-answers-statements/written-statement/Commons/2018-06-05/HCW5732

Financial pressure

Many carers face very difficult financial situations due to their caring responsibilities, despite the valuable contribution they make to society. Carers often find their own income affected by caring (for example because of having to give up work or reduce their hours to care), and this can be compounded if their partner or another family member has also had to leave work due to their illness or disability.

When asked how they would describe their financial situation, almost 2 in 5 (39%) carers say that they are struggling to make ends meet. This is a slight increase from 2018 when 37% said that they were in that situation, showing that even more carers are facing financial hardship.

Carers who have been caring for 15 years or more and those who care for more than 35 hours a week are more likely to say that they are struggling to make ends meet, with 41% and 43% saying that respectively. Over half of carers who are receiving Carer's Allowance (53%) are also struggling to make ends meet.



Almost 2 in 5

39%



carers say that they are struggling to make ends meet

Over half

53%



of carers who are receiving Carer's Allowance are struggling to make ends meet



I have had to use my pension pot to be able to afford to live so I could give up work to care for Mum. I will shortly have to sell my house to continue to be able to afford everything.



I manage to pay the bills but we never have holidays and very limited social lives. I constantly cut back to make sure we live within our means.



I am using all my savings. At some point I will be in debt as unable to work and care.





Just under half of all carers (46%) say that they can afford their bills without struggling financially, but 21% are or have been in debt as a result of caring, 8% cannot afford utility bills and 4% cannot afford their rent/mortgage payments.

Carers who are struggling financially often have to make difficult decisions and cut back on spending. Of those carers who are struggling to make ends meet, 44% are relying on their savings and 36% are using credit cards. A third of carers who are struggling financially (33%) are using their bank account overdraft, 15% are falling into arrears with utility bills, and 9% are falling into arrears with their housing costs ie rent or mortgage payments.

Many carers find that cutting back on household spending is an essential part of balancing their budget. Whilst 81% have cut back on luxuries, 47% of carers have also had to cut back on essentials like food and heating.

Over three quarters of carers who are struggling financially (77%) have had to cut back on hobbies and leisure activities and 64% have cut back on seeing family and friends. 14% have even had to cut back on the support services which help with caring. 6% of carers who are struggling to make ends meet have said that they have used food banks and 3% have used pay day loans.



I cannot always afford to feed myself properly as I need to ensure my mum and children are fed.



I can afford things, but buying wipes, bed pads etc is an added expense on an already tight budget.



I feel it is unfair that we do not get help with council tax as my mother lives with us, due to us having our own savings. We adapted our home to enable my mother to live with us, but yet we do not get any help. I am saving the government and health care a lot of money by how well I care for my mother.



Had to sell my house to pay debts and now renting. The debts arose because of the physical and emotional exhaustion and financial cost of caring.



I am bankrupting my future to pay for the present.



Practical support with caring

Carers make a huge contribution to the lives of those they care for and to our wider society. Despite this, too many are going without the support they need and all too often they are going without any support at all. This year's survey found that one in five carers (21%) neither buy or receive support with caring. Whilst these figures in this section are largely similar to last year, there is still a large level of unmet need, with many carers struggling without any support at all.

Carers were asked what type of practical support they receive or buy. The most popular type of support was equipment in the home of the person they care for (like hoists, grab rails or easy-grip handles on taps) with 48% receiving or buying this.

Carers also reported receiving or buying the following types of support:

- help from family or friends 31%
- technology (eg alarms, sensors or remote monitoring to help with caring) 26%
- practical support from care workers coming in to help 26%
- a Motability vehicle 21%
- a break from caring 15%
- use of a day centre for older/disabled people 11%
- help with other household chores (eg shopping or cleaning) 11%
- help managing or co-ordinating care 4%



Shockingly, over two thirds of carers

68% 

said they regularly use their own income or savings to pay for care or support services, equipment or products for the person they care for

Of those struggling to make ends meet

78% 

regularly use their own income or savings to pay for care or support services, equipment or products for the person they care for

90% 

of carers don't know what might happen to the practical support they receive in the future or worry that it might be reduced



In this year's survey we asked carers about spending their own money on support. Shockingly, over two thirds of carers (68%) regularly use their own income or savings to pay for care or support services, equipment or products for the person they care for. This is even higher for carers who are over the age of 65 (70%), for those struggling to make ends meet (78%), and for people who care for more than 50 hours a week (73%).

When asked how they feel about the practical support they may receive in the future, only 1 in 10 (10%) carers say that they are confident that the support they currently receive will continue in the future. A quarter of carers (24%) worry that the support might be reduced and two thirds (66%) don't know what might happen.

Carers were asked if they or the person they care for get a cash sum from their local authority, health body or Health and Social Care Trust (in Northern Ireland) to pay for care and support services directly eg a direct payment or personal budget. Almost 7 in 10 (69%) carers don't receive a cash sum for either themselves or the person they care for. However, for 4% of respondents they receive a cash sum for them as the carer, and for 4% the cared for person receives a cash payment. For 22% of respondents both the carer and cared for person receive a cash sum.

Technology

Carers responding to the survey were asked if either they or the person/people they care for use any technology to support care and caring. 4 in 5 carers (79%) reported using one or more types of technology. Surprisingly, this number was slightly lower (77%) for distance carers who do not live in the same home as the person they care for.

Using a more inclusive definition of technology in this year's questions meant a considerable increase in the number of people using technology compared with 2018 when 51% of carers reported using it to support them to care.

Across the nations, carers in Northern Ireland were less likely to use technology with only 65% using any type to support their caring. This compares to 75% in Wales and 79% in Scotland.

Of those carers who use technology, the internet was the most popular type with 88% using it as a source of information and 44% using it as a form of communication or online support.

Remote health care such as online GP appointments, repeat prescriptions, online video consultations, or online mental health services was another popular way to use technology with 27% of carers saying they use this.

79%



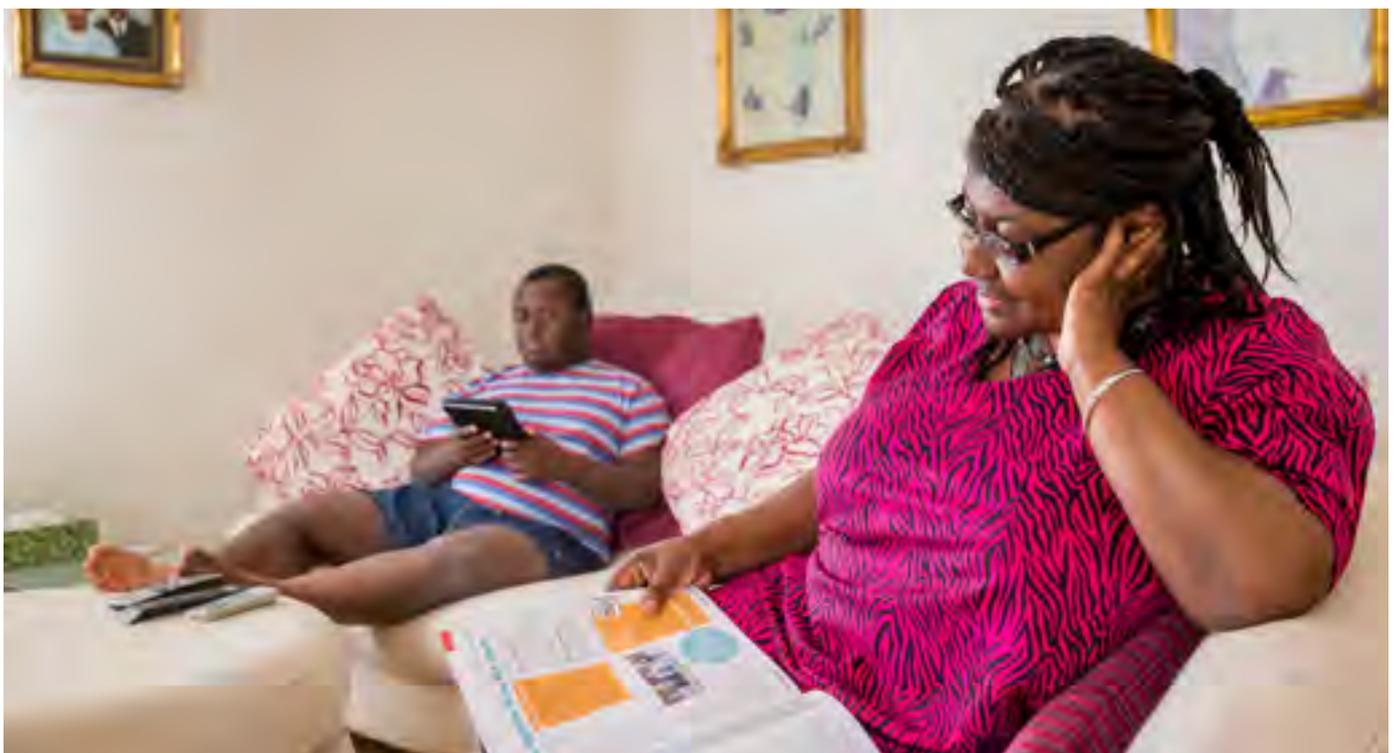
4 in 5 carers reported using one or more types of technology

19% of carers who use technology said that they used remote monitoring and alerts such as motion sensors, fall detectors, personal alarm, or GPS trackers, whilst 12% use medication management tools such as medication dispensers or medication reminders.

8% of carers are using environmental monitoring such as heating and lighting control, door video systems, or smart appliances. 13% of those who use technology use vital signs monitoring such as blood pressure monitor, blood glucose monitor, and heart rate monitors.

4% of carers are using apps, including those which help with pain management, mood management and care co-ordination.

These figures show that there are still significant opportunities to increase the numbers of carers who use technology to help them in their caring role.



Carer's Assessments in England



27%

of carers in England reported that they had an assessment or a review of their assessment in the last 12 months



In England, the Care Act 2014 gives all adults caring for another adult(s) the right to an assessment from their local authority, whilst the Children and Families Act 2014 gives a similar right to parents of disabled children. These assessments look at the impact of carers' caring role on all aspects of their life and what support they and their families need as a result.

27% of carers in England reported that they had an assessment, or a review of their assessment, in the last 12 months. In 2016, when we last asked this question in this way, 31% of carers had received an assessment. Carers who are providing palliative care and those looking after someone with a mental health condition were slightly more likely to have had an assessment with 31% of each group respectively saying this happened in the last year whereas only 17% of parent carers had an assessment or review in the last 12 months. 30% of older carers (aged 65 or over) had received an assessment or review in the last 12 months.

Out of all carers who received an assessment in the last year, 80% waited less than six months for this assessment but 20% waited longer than six months.

As different legislation concerning Carer's Assessments exists in each of the four nations of the UK, here we consider responses from England only. Results for Northern Ireland, Scotland and Wales will be published in separate reports by each nation. Carers Wales will also be publishing their Track the Act report looking at the implementation of the Social Services and Well Being Act (Wales) 2014.



I had to request it and it seemed more of a trial for the social worker to organise it, as if I was wasting her time; it did not feel as if I was at the centre of the request. More about the admin for her to complete, rather than the content or help I received.



They did it with my mum present and so I wasn't able to speak freely – when I read back what they'd written it bore no resemblance to what I'd said – it was a box ticking exercise.



Although the assessment took place in reasonable time, no-one bothered to pass on the results to me until I raised the issue and it arrived at least 12 months later but just referred me to my local Carers Support organisation, whom I had told the assessor I was already in contact with.





The assessment meeting began by the lady saying up front “don’t get too excited, there is nothing much we can do or provide”.



Excellent care assessment but still feel as though I am alone in the caring role.



The assessment was carried out by our local carers support charity very thoroughly and expertly and with great understanding and sensitivity. However, my six eligible needs have been completely unmet by the LA due to being self-funding.



Experiences of assessments

The majority of carers in England who had been assessed / reassessed in the last year felt that their needs were not given sufficient consideration. Of all the support aspects looked at in assessments, carers were most likely to say that the suitability of housing was thoroughly considered, but only 40% of carers reported that. Even fewer carers said that other aspects of their needs had been thoroughly considered:

- carers' ability and willingness to provide care was only thoroughly considered and reflected in support in 37% of assessments;
- only 30% of carers felt that their need for support to look after their own physical and mental health alongside caring had been thoroughly considered;
- only one quarter (26%) said their need to have regular breaks from caring was considered.

Only 18% of parent carers who are looking after a disabled child under the age of 18 felt that their need to take a break was properly considered in their assessment or support, and only 12% felt their need to juggle work and care or return to work was properly considered.

The experiences that carers have shared suggest that implementation of the Care Act and Children and Families Act is varied across England and they are not realising the benefits that were intended by the legislation. Even for those carers who had a positive experience of the assessment itself, often there is not support available locally following on from it to relieve any of the issues they have raised.



When I received my copy of the assessment it totally played down the amount of care I have to give. For example I do all my mother's shopping and cook all her meals but it said I assisted her in these activities, as if she had capability.



40% 

of carers said that the suitability of their home for continuing their caring role was taken into consideration in their carer's assessment

Only one quarter of carers

26% 

said their need to have regular breaks from caring was sufficiently considered in their carer's assessment

Only

30% 

of carers felt that their need for support to look after their own physical and mental health alongside caring had been thoroughly considered



Time was spent on this assessment but at no time was forward planning even taken into consideration. I'm 66; just how much longer I can go on for is not being taken into account.



Costs, cuts and closures

When asked about changes in care and support services over the last year, 32% of carers reported that they had experienced a change in the amount of services that they receive. Of these carers who experienced a change, for 26% this was because the amount of care or support arranged by social services was reduced, whilst for 10% of respondents the care or support service was closed with no replacement offered. 6% of respondents reduced the amount of care or support received because the cost increased, and 5% reduced the amount of care or support received because the personal budget no longer covers it.

However, 24% of respondents who experienced a change in the amount of care or support arranged by social services saw an increase because the need for support increased, and for 4% of carers there was an increase even though the needs stayed the same.

Of all carers responding to the survey, 1 in 8 carers (12%) reported that 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. This is slightly lower than last year when 1 in 7 carers reported the same. However, we have asked this question every year and have seen constant reductions in support over time.

Numbers of carers reporting a reduction in support was higher for those who are struggling to make ends meet – 1 in 6 (17%) reported less support due to a reduction in the amount of support from social services. For the devolved nations, carers in Scotland were most likely to report a reduction due to cuts in social services, with 14% reporting this compared to 9% in Wales, 11% in Northern Ireland and 12% in England.

53% of those experiencing a reduction in support are caring for over 90 hours a week and 42% have been caring for 15 years or more. It is deeply concerning that there has been a reduction in support for these people when there is strong evidence to suggest that these carers are more likely to suffer from poor health themselves.

For the second year in a row, carers in England were least likely to report that the care and support that they receive had increased – 7% of all respondents from England reported this compared with 10% from both Scotland and Wales, and 11% from Northern Ireland.



I paid for someone to give me a half day a month break, so that I could get my hair cut, go to the dentist, have my smear test and mammogram and other things. Unfortunately because of the increase in rent and cost of living I can't afford to pay anyone so now I just have to manage somehow.



1 in 8 carers

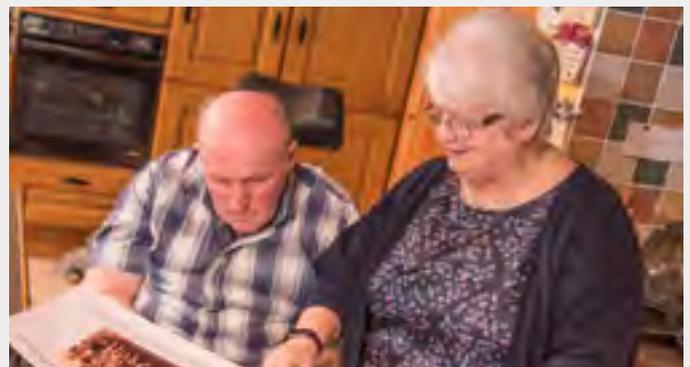
12%



reported that 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



Respite allocation has been drastically cut. Instead of six beds being open there are two now for same number of families. We have not been able to get the breaks we have requested, and what we do get is half of what we used to. We are exhausted.





The cost of care has increased hugely as my father is mainly self-funding. Due to budget cuts, there is less help available from Social Services and NHS so, if we need something quickly, we pay for it rather than wait 6-18 months. This seems unfair on those people who can't afford to do this and have to wait.



Continuous cuts in direct payments mean reductions in all care and support. These cuts happen every time there is a review even though the assessed care needs are the same.



The cost of his two-day day care has increased we have to cut down on food and heating to meet cost.



An increase in support has made a huge difference to my life for the better.



Night sitting increased permanently from three nights to five a week. Better nights sleep for me.



Support for emergencies and contingency planning

Many carers worry about what will happen in case of an emergency where they are unable to care or the person they care for needs urgent treatment. The NHS Long Term Plan for England outlined an intention to support up to 100,000 carers to have contingency planning conversations about getting appropriate back-up support in place when they need it.

Across the nations, carer's assessments, which carers are entitled to, should already look at the support needed in case of emergencies.

Planning for contingency and emergencies

The survey asked carers about emergencies and found that only 1 in 6 carers (17%) have had a conversation with an NHS professional (eg a GP or a nurse) about what to do if the condition of the person they care for deteriorates, or they are no longer able or willing to provide care for them.

Carers experiences of talking to NHS staff are varied with some saying that there is excellent support available while others have struggled to have the issue taken seriously or don't know where to start with this conversation.

Only one in six carers

17%



have had a conversation with an NHS professional (eg a GP or a nurse) about what to do if the condition of the person they care for deteriorates or they are no longer able or willing to provide care for them



GP is very good – I have monthly home visits and I'm encouraged to ring if any queries or earlier visit needed. Also the District Nurse Team ring weekly to ask if any help needed.



I have emergency numbers to ring and we have an emergency care plan but nothing in place if I break down.



No one appears interested. I've been told numerous times we will deal with that when the time comes!



I worry about this a lot because my health is deteriorating and due to cut backs I no longer feel alternative support would be adequate for him should I be unable to continue.



Nobody is interested. I have had several emergencies over the years, and we have just had to get on with things, even when we have asked for support.



I have a care plan in place with a local provider who can be contacted in the event of illness or hospital admission that will come in and provide emergency cover for up to two days.





Emergency hospital admissions

Just over a third of carers (37%) said that the person they care for had been admitted to hospital in an emergency (ie an unplanned admission) at some point in the last 12 months. Half of carers (50%) felt that their emergency admission could have been prevented with more care or support in some form. This means that one in five of all carers responding to the survey (19%) had an emergency admission in the last year which they thought could have been prevented.

Of carers who'd had an emergency admission for the person they care for, 29% felt that the admission could have been prevented if they'd had more care and support for the person they care for and 18% felt that more support for them as the carer (eg breaks from caring) would have prevented the admission.

A quarter (24%) felt that higher quality care for the person they care for would have prevented the admission, whereas 11% felt adaptations in the home of the person they care for would have made a difference. 13% felt that the emergency admission could have been prevented if they had access to a district nurse.

1 in 10 carers (11%) felt that following a previous discharge from hospital, not enough time was taken to put in place adequate care and other arrangements that could have prevented the subsequent emergency admission. 6% of carers thought that telecare or telehealth services (eg monitoring equipment, alarms and sensors which remotely check the health of an older, sick or disabled person and that they haven't wandered, had a fall or accident) could have prevented the emergency admission, and a further 6% thought replacement care when the carer needed medical treatment would have prevented it. 2% of carers thought it could have been prevented if they'd had access to a hospice.



I called his GP and they said they couldn't talk about the person I care for without his permission. At that point he had no capacity and then sadly was sectioned. I felt helpless and frustrated. No one was there for me when there was an emergency.



29% 

of carers felt that an emergency hospital admission could have been prevented if they'd had more care and support for the person they care for

1 in 5 of all carers

19%     

had an emergency hospital admission in the last year which they thought could have been prevented



Access to mental health crisis team and listening to my concerns would have prevented hospital admission.



GP not interested. Called them during surgery hours, they told me to ring 111. 111 told me to insist on a GP visit. Ended up with three calls to 999 and emergency admittance. It is scary having to make up big decisions for another without any medical support or advice.



Planning for the future



For many carers, whether their caring responsibilities start suddenly following a diagnosis, or they develop over time as an older relative needs more support, they can find their future plans affected – in particular their future retirement plans.

Planning for retirement

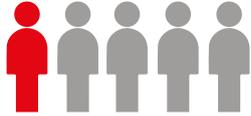
We asked carers **who are not retired** about how they intend to pay for their retirement. The most common source of income for retirement was a state pension with 75% of carers expecting to use this.

Other sources of money which carers are planning to use for retirement include:

- workplace pension 46%
- personal savings 18%
- a main home you could downsize from 16%

One in five carers

22%



don't know how they are going to pay for retirement

53%



of carers said that they are not able to save for their retirement



However one in five carers (22%) don't know how they are going to pay for retirement. Carers who are over 50, and therefore closer to retirement age, are less likely to say they don't know how they are going to pay for their retirement with 15% of over 50s saying this compared to 31% of under 50s.

Carers who are not retired and are struggling to make ends meet are less likely to have made financial plans for the future – 31% don't know how they are going to pay for retirement.

There were some notable differences between how male and female carers are planning to pay for their retirement. For male carers of all ages, 52% have a workplace pension and 80% plan to use their state pension to pay for their retirement, but the numbers are lower for women – 46% and 75%.

More men were also expecting to rely on personal savings (24% compared to 17% for women) and women are over three times more likely to be relying on what their spouse or partner has arranged (13% of women compared to 4% of men).

Carers who are not yet retired were also asked about their future plans and 53% said that they are not able to save for their retirement. This rises to 57% of carers who are regularly using their own income or savings to pay for care or support services, equipment or products for the person they care for. 73% of those who describe their financial situation as struggling to make ends meet are not able to save for retirement. Three quarters of those who are receiving Carer's Allowance (75%) are not able to save for retirement.

Some carers are saving or have saved less for their retirement with 17% saying they did this because their working hours were reduced. 17% said that they have saved less or were saving less because their short-term financial needs are too great to afford to save for the long term.

Only 1 in 6 carers (17%) responding to the survey said that their ability to plan or save for retirement had not been affected by caring. This is even lower for carers who have been caring for over 15 years or more (10%) and carers who care for over 50 hours a week (10%). Of carers who are already retired, 2 in 5 (38%) said that their ability to plan or save for retirement had not been affected by caring, suggesting that their caring roles started after they retired.

Planning for carers' future care needs

Almost two thirds of carers (64%) say that they have focussed on the care needs of the person they care for, and not on their own needs.

A third of carers (33%) say that they worry about their care needs in the future but cannot do anything about it. For carers who have been caring for over 15 years this is even higher with 40% reporting that they worry about this but cannot do anything about it.

Only 3% of all carers feel that they have prepared for any care needs they may have in the future for themselves.

Almost two thirds of carers

64% QQQ

say that they have focussed on the care needs of the person they care for, and not on their own needs



I really haven't thought about it, my focus is on my parents.



I am also in need of care. I had to take Medical Severance 22 years ago at the age of 50. We were looking after each other but my wife's needs have taken full priority.



I am already using my life savings and they won't last much longer so I don't know how I will survive.



Because I stopped work early it had a negative effect on my private pension and of course my earnings.



I am very scared about the future. I have no children to care for me.



It's often too upsetting to think about the future. In terms of finances, we are always on the back foot. Years of reduced working hours means we have done little to modernise or maintain our house and depleted any savings long ago.



Health and wellbeing



Caring can have a significant impact on health, with carers often finding that both their mental and physical health are affected. When asked about how their health is in general, carers described their physical and mental health as follows:

| All carers | Very good | Good | Fair | Bad | Very bad |
|-----------------|-----------|------|------|-----|----------|
| Physical health | 7% | 27% | 43% | 18% | 4% |
| Mental health | 6% | 23% | 44% | 21% | 6% |

Given the immense personal cost that comes from providing round the clock care it is unsurprising that carers who care for more than 50 hours a week reported poorer health with 25% reporting bad or very bad physical health and 29% reporting bad or very bad mental health.

Carers who have been caring for over 15 years were more likely to report poorer health with 28% describing their physical health as bad or very bad and 27% describing their mental health as bad or very bad.

Carers looking after disabled children under the age of 18 reported significantly poorer mental health – 36% described their mental health as bad or very bad. 26% of these carers described their physical health as bad or very bad.

The most recent GP Patient survey in England found that carers are more likely to report having a long term condition, disability or illness – 61% of carers compared to 50% of non-carers. In the same survey 62% of carers reported trouble with day to day activity compared to 57% of non-carers⁷.



I was admitted to hospital after a breakdown due to exhaustion and chronic pain. If I had had more breaks from my caring role or adequate mental health support I might not have had the breakdown at all.



I feel isolated because I am the only person responsible for mum.



⁷ 2018 GP Patient Survey

When asked about physical exercise, 81% of carers responding to the survey said that they are not able to do as much physical exercise as they'd like to do. Carers UK will be working with Sport England to look at ways to support carers over the age of 55 to take part in more physical activity as a way to reduce loneliness and improve their health and wellbeing.

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.

Loneliness and wellbeing

This year, the Carers Week research report highlighted the impact of caring on people's loneliness and wellbeing.

Carers are seven times more likely to say they are always or often lonely compared with the general population.⁸ Over half (54%) of the population say they are never or hardly ever lonely compared with just 1 in 6 (18%) unpaid carers. Overall, 8 in 10 (81%) of all carers reported having ever felt lonely or isolated as a result of their caring role.

The research report also revealed that carers in the UK are nearly twice as anxious as the general population. Carers placed their levels of anxiety at an average of 5.4 out of 10 compared with a population average of 2.9. Carers in the UK reported levels of happiness over a third (37%) lower than the general population. Carers placed their level of happiness at 4.7 out of 10 compared with a population average of 7.5.

81% 

of carers responding to the survey said that they are not able to do as much physical exercise as they'd like to do

81% 

of all carers reported having ever felt lonely or isolated as a result of their caring role

“

I have felt isolated because people often don't understand the impact of living with someone who has mental health issues.

”



⁸ Carers Week (2019) Getting carers connected



It has taken all my energy to provide for my son's needs, to the extent that my health has declined and continues to decline.



I had been caring for my mother for years and my health was deteriorating and it got to the point when I had stress and could not cope.



As an 82 year old I have health issues and do not make it the priority I should.



I am still fighting to get treatment and help for the person I care for. If she had the proper care and treatment, I could step back and deal with my own health.



Juggling work and care



Image - © Olivia Hemingway

More working carers responded to the survey than in previous years – in 2019 39% of respondents were juggling paid work with caring compared to 31% in 2015.

Recent research by Carers UK found that the number of those juggling work and care could be far higher than previously thought – around 4.87 million (compared with 3 million in the Census 2011). This is one in seven of all workers⁹. There are different numbers of people who are juggling work and care in the different employment sectors, for example it has been estimated that one in five of the NHS workforce in England is an unpaid carer¹⁰.

2 in 5 carers (39%) responding to the survey reported being in paid work. These working carers can be broken down as follows:

- 44% are full-time employees
- 42% are part-time employees
- 4% are self-employed full-time
- 11% are self-employed part-time¹¹

Carers often find that it can be a struggle to balance their responsibilities in work with their caring responsibilities. 38% of all carers reported that they had given up work to care and 18% had reduced their working hours. 1 in 6 carers (17%) said that they work

the same hours but their job is negatively affected by caring, for example because of tiredness, lateness, and stress. 12% of carers said that they have had to take a less qualified job or have turned down a promotion to fit around their caring responsibilities. Just over 1 in 10 carers (11%) said that they had retired early to care. Only 4% of respondents of all ages said that caring has had no impact on their capacity to work.

Only one quarter (25%) of carers who aren't yet retired and had an assessment in the last year felt that their need to combine paid work and caring was sufficiently considered in their carer's assessment.

Carers UK is working with forward thinking employers to improve carers support in the workplace. The Carer Confident benchmarking scheme assists employers to build a supportive and inclusive workplace for staff who are, or will become, carers and to make the most of the talents that carers can bring to the workplace. For more information visit employersforcarers.org

Similarly, the appropriate scheme for employers in Scotland to engage with is the Carer Positive employer recognition scheme which is sponsored by the Scottish Government and operated by Carers Scotland. For more information visit carerpositive.org

⁹ Carers UK (2019) Juggling work and unpaid care

¹⁰ www.carersuk.org/news-and-campaigns/press-releases/quarter-of-a-million-nhs-workers-juggle-job-with-caring-unpaid-for-loved-one

¹¹ Due to rounding, these do not add up to 100



I have to take unpaid leave frequently for all her hospital appointments and therapy appointments.



Leaving work left me isolated. My caring role has changed my support network dramatically – I had to seek out a new support network.



I work the same hours but my company have been very flexible with arrangements and know that I may call at the last moment and not be able to get in. They have done everything possible to support me.



I work for a carer friendly employer who were very supportive when my role was more intense a couple of years ago.



I gave up a very well paid full time job to fulfil my caring role and the massive amount of paperwork it comes with. I was self-employed for a while, but have since had to give that up too, due to the volume of ‘work’ required by my role as a parent carer.



I’m fortunate to work in a very progressive organisation that has complete flexibility with working hours. When I look after my brother for days at a time, I work remotely from the home where he lives.



Carer’s Allowance keeps carers in poverty by only allowing you to earn a set amount each week, go over by any amount and you lose Carer’s Allowance. I can only work 15 hours per week at minimum wage, whereas I’ve held several managerial roles in the past and could earn much more than the minimum wage.

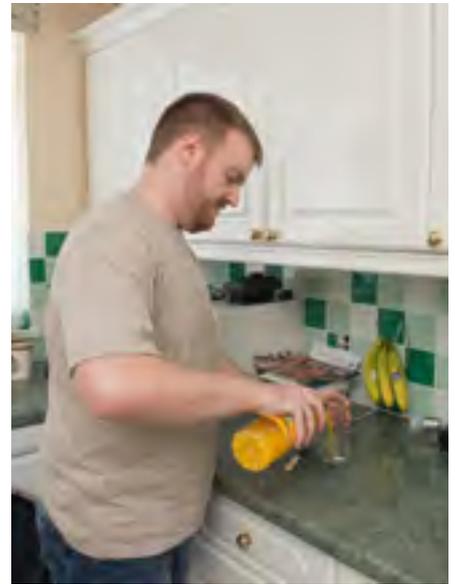


Recommendations

Concrete action needs to be taken across all levels of Government in order to put in place the support that carers need both urgently in the shorter term and over the longer term, to ensure the sustainability of the health and social care system.

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

- Carer's Allowance, just £66.15 on 2019/20 rates, must be raised across the rest of the UK to the same level as 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 staying in work.
- To auto-enrol carers in a second pension – a Carer's Pension that recognises the value of unpaid work and ensures that they do not suffer financial hardship later in life.



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

- A new duty is needed on the NHS in England, Wales and Northern Ireland to put in place policies to identify carers and promote their health and wellbeing, including their own employees who are juggling work and care. Ensure that all staff are trained to know about carers and how to support carers.
- Increase identification and support through primary care.
- Ensure carers are better prepared for caring and can get support early to look after their own health and wellbeing with easily available advice and information as well as learning and training for carers to help them plan, prepare and provide care.
- The roll out of the NHS England Long Term Plan should ensure integrated services and support for carers.



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 they are able to have a good quality of life alongside their 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.



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

- Increase and ring-fence funding for carers' breaks. Funding should also be transparent so carers know what they 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 they need for their own health and wellbeing.



Ensure carers are able to juggle work and care, if they 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 their caring role.
- Work with employers to include carers in health and well being 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.





Across the UK today 6.5 million people are carers - supporting a loved one who is older, disabled or seriously ill.

Caring will touch each and every one of us in our lifetime, whether we become a carer or need care ourselves. Whilst caring can be a rewarding experience, it can also impact on a person's health, finances and relationships.

Carers UK is here to listen, to give carers expert information and tailored advice. We champion the rights of carers and support them in finding new ways to manage at home, at work, or in their community.

We're here to make life better for carers.

Carers UK

20 Great Dover Street

London SE1 4LX

T 020 7378 4999

E info@carersuk.org



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



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