

State of Caring 2021

A snapshot of unpaid care in the UK



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

Over **8,500** carers and former carers shared their experience of what it's like to be a carer.

This report provides a snapshot of caring in 2021 by only including the responses from the **8,119** people who are currently providing care.

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

About this research

Carers UK carried out an online survey between August and September 2021. A total of 8,676 carers and former carers responded to the survey – we have only included responses from the 8,119 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:

- 72% live in England, 8% live in Scotland, 10% live in Northern Ireland, and 10% live in Wales.
- 79% identify as female, 19% identify as male and 0.5% describe their gender identity in another way.
- 28% consider themselves to have a disability.
- 3% are aged 0-34, 10% are aged 35-44, 23% are aged 45-54, 36% are aged 55-64, 20% are aged 65-74, and 7% are aged 75 and over.
- 3% identified as lesbian, gay or bisexual.
- 4% described their ethnicity as Black or minority ethnic.
- 16% also have childcare responsibilities for a non-disabled child under 18.

- 34% are in paid work. Of those, 46% work full-time and 39% part-time.
- 33% have been caring for 15 years or more, 15% for between 10-14 years, 23% for 5-9 years, 26% for 1-4 years, and just 3% have been caring for less than one year.
- 48% care for 90 or more hours every week, while 14% care for 50-89 hours, 23% care for 20-49 hours, and 13% care for 1-19 hours a week.
- 76% care for one person, 18% care for two people, 4% for three people, and 2% care for four or more people.

As not all respondents completed every question in the survey, a number of the figures given in this report, are based upon responses from fewer than 8,119 carers. This, together with the sample sizes of different groups, should be taken into consideration when reading the results.

Unfortunately, we are not able to include any analysis on transgender carers due to the small sample size. However, we are interested in the experiences of transgender carers and will be undertaking more in-depth research about the experiences of the LGBT+ community in our Making Carers Count project.

Thanks

Carers UK would like to thank each and every carer who contributed to this survey, from those who helped us develop and test the survey to every single person who took the trouble and time to tell us about their experiences. Your experiences will be used to help build a society that recognises and supports carers more.

Contents

The state of caring in 2021: context	04
Carers' finances	06
Support and services	12
Carers' health and wellbeing	18
Physical activity	24
Carer's assessments	26
Digital, data and technology	30
Juggling work and care	34
Conclusion and recommendations	37

State of Caring in 2021: context

The COVID-19 pandemic continues to have a monumental impact on unpaid carers' lives – not only because of the increased amount of care that many are having to provide, but because of the far-reaching effect that providing this level of care is having on many aspects of their lives: their relationships, their mental and physical health, their paid work and finances, and their emotional wellbeing.

We estimate that overnight, an additional 4.5 million people became unpaid carers in March 2020, meaning 1 in 4 (26%) UK adults were providing unpaid care to an older, disabled or ill relative or friend at the height of the pandemic.¹ Although we expect these numbers to decrease slightly, the numbers of unpaid carers have been rising significantly as the population ages and healthcare continues to improve. Increasing support for carers, whether it's practical or financial, must be at the heart of how we address the recovery from the COVID-19 pandemic.

Governments across the UK have taken a range of actions to provide carers with help and support, but this report shows how this support has fallen short and that more must be done. Many services in the UK had already reached crisis point before the pandemic, with unpaid carers facing the consequences of local cuts to budgets through reduced support. The situation has significantly worsened during the pandemic, with carers continuing to take on more hours of care than before March 2020. Many are now extremely worried about the increasing staffing crisis in social care preventing them from accessing the support they need.

This report provides evidence of the intolerable pressure that carers are feeling and the exhaustion they are facing. Carers were already seven times more likely to be lonely than the average person and restrictions, the impact of shielding and the increasing needs of the people they are caring for have all contributed to a stripping-away of the support networks carers have, leaving many feeling even more isolated and worried about how they will continue to cope.

Carers' support has been valued at a staggering £530 million per day during the pandemic, or £193 billion a full year² – outstripping the value of the NHS. But this comes with high personal costs. Many carers find that their relationships are impacted, that they often struggle to balance work and care, and that they are facing their own health problems as a result of their caring role. This is in addition to the financial cost of caring, with 31% 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. The average carer looking after someone outside of residential care faces a financial penalty of over £114 a month.

Caring is still often thought of as being part and parcel of women's lives, and 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 older. 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.

Increasing numbers of employers are recognising the importance of supporting carers in their workforce to continue working, so they can retain talented and

¹ Carers Week (2020), Carers Week Research

² Carers UK (2020) Unseen and Undervalued



experienced staff. But we are at a critical turning point for workplaces and it is now essential that employers maintain flexibility in the hours and place people work, alongside the carer-friendly policies they have introduced, as we transition out of the pandemic restrictions.

Carers are extremely worried about the future. When asked about services, over 6 in 10 of carers felt uncertain about what practical support they may be able to access in the next twelve months, and 62% were worried that services will be reduced. Many carers are desperately worried that they will not be able to get the level of support they had before the pandemic.

The UK Government has committed to social care reform in England, including taking steps to ensure that carers have the support, advice and respite they need, fulfilling the goals of the Care Act. The Welsh, Scottish

and Northern Irish Governments have also committed to reform. For example, the Scottish Government has committed to the establishment of a national care service.

To build a society that recognises, values and supports carers and to create a system that works, carers' voices, opinions and experiences must be heard, listened to and acted on – and form a key part of the forthcoming English White Papers on social care reform. It is of paramount importance that the recovery from the COVID-19 pandemic 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 2021 and through the pandemic so far, capturing the impact that caring has on carers' lives and evidencing the policy recommendations that would improve this.

Carers' finances



Many carers face additional costs, from equipment and care costs to increased fuel payments. These can be compounded by carers having to reduce their working hours or leave employment. As a result, many carers

face precarious financial situations. Our latest findings show that many carers are continuing to face increased financial pressures and that they are worried about how caring will continue to impact on their finances.

An overview of carers' finances

We asked carers about their current financial situation and 31% of carers said they were struggling to make ends meet. A further 18% are in or have been in debt as a result of caring, and 6% cannot afford utility bills like electricity, gas, water or telephone bills.

“One of my biggest caring tasks is endlessly juggling money, bills and moving stuff around so we can get by.”

Carers who were providing more hours of care per week were much more likely to be struggling financially. Whilst 84% of those providing under 10 hours a week said they can afford their bills without struggling, fewer (77%) of those caring for up to 35 hours a week, and only around half (56%) of those providing more than 35 hours of care per week can afford their bills.

This was similar for carers who said they are in or have been in debt as a result of caring – only 8% of those caring for less than 35 hours per week said they had been or were in debt, compared to over a third (35%) of those providing more than 35 hours of care.

“I always pay bills first and then if anything left that will go on food so I technically never struggle to pay bills, I just don't have much money left for anything else.”

Carers who are struggling financially often have to make difficult decisions and cut back on spending, including seeing friends and family.



Table 1: How carers who are struggling financially said they were managing:

Cutting back on luxuries	38%
Cutting back on hobbies or leisure activities	37%
Cutting back on seeing family and friends	27%
Using savings	24%
Using credit cards	14%
Cutting back on essentials like food and heating	13%
Using an overdraft	13%
Borrowing money from family and friends	12%

Of those carers who are struggling to make ends meet, nearly a quarter (24%) are having to use their savings to get by. More than 1 in 10 are using credit cards (14%), while others are having to cut back on essentials like food and heating (13%), use an overdraft (13%), or borrow money from family and friends (12%).

“I don’t have luxuries, can’t afford life, car insurance or house insurance. At 60 I shouldn’t be using food banks and made to feel inadequate because I can’t afford petrol.”

Female carers were more likely to be cutting back on hobbies or leisure activities (38%) than men (35%). Women were also more likely to be using credit cards (15%) than men (12%), and more likely to be using an overdraft to get by (13%) than men (10%).

“I am close to losing my full-time employment as a result of my caring responsibilities, which will result in me not affording my mortgage. I am a single parent and have always worked, I feel the system of support really discriminates against women, especially single parents.”

Those in receipt of Carer’s Allowance are also more likely to be making sacrifices to ensure they can cope financially. Over a quarter (28%) are having to use their savings, a fifth (20%) are having to cut back on essentials like food or heating, while 19% are using credit cards or having to borrow from family and friends (also 19%).

“I would not be able to pay bills on my Carer’s Allowance. Bills and household expenses are paid from my Mum’s pension as this is her home and I gave up my home and job to come and care for her.”

Energy prices have soared across the UK and 11 million households have on average faced an increased fuel bill of £139, rising to £153 for another 4 million households that use prepayment meters.³ Alongside the removal of the £20 uplift to Universal Credit and the end of the furlough scheme, there is widespread concern around finances and carers are no exception. Indeed, carers are more likely to be in financially precarious situations and less able to cope with these additional costs. These worries were repeated by many carers who spoke of the importance of heating for managing the health conditions of those they care for, making the increases in fuel bill even more challenging.

“Crippled further by heating/electric going up even further to £177 a month. We have managed without heating in the past, I suspect we will again now.”

“The heating bill is horrendous but my husband needs the heat due to being on warfarin.”

³ BBC News article: <https://www.bbc.co.uk/news/business-58746953>

Impact of COVID-19 on carers' finances

We asked carers how their financial situation had changed since the start of the COVID-19 pandemic. Over a third of respondents (36%) said that their financial situation had got worse since March 2020. Over half of respondents said that their financial situation had not changed (57%), while only 7% said their financial situation had improved.

Those who said they are struggling to make ends meet were almost twice as likely to report that their financial situation has got worse (67%) compared to all respondents (36%), while almost half of those in receipt of Carer's Allowance (46%) also said their financial situation had got worse.

The amount of care people provide each week has also had a significant impact on their financial situation during the COVID-19 pandemic. Those caring for less than 35 hours a week were significantly less likely to say that their financial situation had worsened (28%), compared to those caring for more than 35 hours a week (39%).

“COVID has drained every penny I'd saved over my lifetime. My accommodations were at 4 degrees C some days during this past winter – I had to choose between food for my kids or utilities. We all slept in one room, wearing four layers of clothing and two duvets and three blankets each.”

Almost two-thirds of respondents (63%) said that they were now spending more on household bills, shopping and everyday items than before the COVID-19 pandemic. Two-fifths of respondents (40%) said that their own health has deteriorated and, as a result, they were having to spend more on household expenses (eg cleaning, help with garden, more expensive products). A quarter of respondents (25%) said that they were spending more on equipment or products for the person they care for.

“If we hadn't paid for aids like a self-loading mobility scooter, a bath lift, modifications to the garden and the house and replacement beds (to make it a better height for him) I wouldn't have debts. Servicing them takes up a third of our joint monthly income.”

Almost three quarters (74%) of those who said they were 'struggling to make ends meet' said they were spending more on household bills, shopping and everyday items than before the pandemic, compared to 71% of those who are in receipt of Carer's Allowance, and 63% of all respondents.

Those caring for less than 35 hours were significantly less likely to be spending more on equipment or products for the person they care for (17%), than those caring for over 35 hours per week (28%).



The cost of caring

Caring can be expensive and with increased fuel bills, transport costs are already impacting on the finances of people being cared for and their carers. Almost two-thirds (63%) of carers are spending their own money on care or support services or products for the person they care for.

The potential catastrophic costs faced by some people needing long term residential care and their families has often been highlighted. Outside of the costs of residential care, many carers are having to contribute to care services and products. Half (50%) of carers told us they are worried about the impact their caring responsibilities is having on their finances.

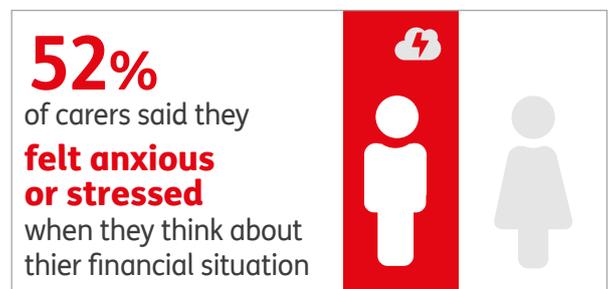
The financial penalty carers face is significant; the average monthly spend for carers is an estimated £114.16, rising to an estimated £145.84 for carers from a Mixed or Multiple ethnic background and £158.88 for Asian carers. Worryingly, those receiving Carer's Allowance are spending an estimated £104.74 each month. With high rates of inflation and a rising cost of living, this extra spend is likely to further financially disadvantage carers in the short and longer term.

Financial concerns

A significant minority of carers are extremely worried about their financial situation. 2 in 5 (21%) carers did not feel confident that they will be able to manage financially over the next 12 months, and nearly a quarter (23%) of carers do not feel they have enough money to cover their monthly expenses.

Carers are worried about how they will be able to plan for their future. Almost two-thirds of carers (65%) say they are worried about their ability to save and plan for the future. Women are more likely to have to take on caring responsibilities at an earlier age, often at a time that they would expect to be in paid work. This often affects their participation in paid work and reduces their lifetime earnings, a factor in why women are more likely than men to experience low income in later life, including after their caring role has ended.

“I don't even think about my own financial future as I have no option but to deal with things as they are now and hope I will be okay in my own old age.”



Worries about finances are also impacting on carers' health and wellbeing. Over half (52%) of carers said they feel anxious or stressed when they think about their financial situation, and more than half (51%) did not know where to go for help with their finances.

Unsurprisingly, carers who said they are struggling to make ends meet, or who are in receipt of Carer's Allowance, were more anxious and worried about their finances. Of those struggling to make ends meet, over half (52%) were not confident that they could manage financially over the next 12 months, 58% said they didn't have enough money to cover their monthly expenses, and more than three-quarters (78%) were worried about the impact their caring responsibilities are having on their finances. Almost 9 in 10 (87%) said they felt anxious or stressed when they think about their financial situation.

“To date I have sold both of our pensions, shares and insurances to maintain our living standards, they have all gone now so I had to start claiming UC last year. I have nothing left to sell and I am anxious we are going to live in poverty for the rest of our lives.”



Of those who are in receipt of Carer's Allowance, a third (33%) were not confident that they could manage financially over the next 12 months, while 37% said they didn't have enough money to cover their monthly expenses. Many carers told us that they were anxious about covering even basic costs this coming winter.

Carer's Allowance is so low that my teeth are starting to fall out because I can't afford the dentist for me and my son. Energy prices are escalating – I dread my Winter fuel bill."

Improving financial support for carers – their views

We asked carers what financial changes would make the most difference to their experience as a carer. More than 3 in 5 respondents (61%) said that they wanted to see an increase in the value of carers' benefits, while more than half (53%) said they wanted to see the eligibility criteria for carers' benefits widened to enable more people to access them.

Just under half (48%) of respondents said they wanted to see an increase in the earnings limit for claiming Carer's Allowance, while over a quarter (29%) wanted to see other sources of financial support, such as a hardship grant, introduced for carers. Just under a quarter (24%) wanted digital access to manage their own benefits and the benefits of the person they care for.

The cost of living has increased a great deal over the last 18 months, yet Government do not increase Carer's Allowance or other carer related benefits to a level that is in line with inflation."

Research has consistently found that a significant proportion of carers are struggling financially, and that caring comes with a financial penalty that can impact on carers' finances now and in the future. This situation has been exacerbated by the COVID-19 pandemic and the economic consequences for many are severe.

The results show that providing significant amounts of care is clearly linked to higher levels of financial stress and decreased financial resilience. Carers across all income brackets are worried

about the impact of caring on their finances and the impact of caring on their ability to save.

A significant proportion of carers are struggling to make ends meet and are turning to unsustainable solutions to manage financially, such as accruing debt or cutting back on things that are integral to their wellbeing. As we enter a winter with high levels of inflation, food and fuel shortages and increasing energy prices, more and more carers will likely struggle to cope.

Support and services

Carers make a huge contribution to the lives of the people they support and to the communities around them. However, carers often need practical and emotional support to enable them to care safely and well for people as well as look after their own wellbeing. This ranges from paid care workers who assist with practical care tasks such as bathing and dressing, to local voluntary and community services who provide activities and support for the people who are being cared for.

Before the COVID-19 pandemic in 2019, one in five carers (21%) didn't receive any support in their caring role.⁴ Since March 2020, many services have had to move online or adapt by reducing capacity to cope with the COVID-19 restrictions. Others have had to close due to funding constraints or loss of donations. This is likely to have led to more carers than ever not receiving support. Carers' comments suggest that the workforce shortages are impacting on service provision, making it harder to get the support they need.



4 Carers UK (2019), State of Caring 2019

Current state of services

We asked carers which services had fully re-opened in their local area and which they were still struggling to access. Carers were also asked whether the response options were not applicable to their situation. The responses are summarised in the table below.

Table 2: State of services and support for carers where this option or service applied to them

	This is fully re-opened	I still have reduced access to this	I have significantly reduced access to this	I have chosen not to use this service	This service has closed
Day services	14%	16%	19%	32%	20%
Care homes for short respite breaks	9%	9%	15%	52%	15%
Residential care	8%	7%	8%	68%	8%
Activities provided by local carers' organisation	9%	23%	24%	28%	16%
Activities and support provided by a local charity	11%	23%	24%	25%	17%
Support from paid care workers	45%	14%	13%	23%	5%
Sitting services	17%	10%	14%	46%	13%
Other breaks services	7%	11%	23%	41%	18%
After-school services for disabled children and young people	6%	10%	17%	40%	27%
NHS funded care	24%	17%	23%	24%	11%

Although the service most likely to have fully re-opened was support from paid care workers, access was still very low, with less than half (45%) of carers stating that they had full access to this. Day services for adults and after-school services for disabled children and young people were the most likely to have closed, with 20% and 27% of carers respectively reporting these were no longer available.

Carers' access to support also differed depending on how much care someone was providing and whether they were caring for someone in their own home or not.

Over half (51%) of carers providing less than 35 hours of care each week had full access to paid care workers, compared to only 43% of those providing more than 35 hours of care each week. This may be because those caring for under 35 hours are more likely to be caring for someone outside of their own home, and therefore the person is more and has been more reliant on paid care workers throughout the pandemic. 50% of those caring for someone who did not live in the same home as them had full access to paid care workers.

When discussing access to support services many carers unsurprisingly spoke about the impact of COVID-19. In particular, many carers told us that services had not returned to their pre-pandemic levels, and that they were not able to access as much support as they had done in the past.

“My daughter attended adult day centre four days a week, six hours a day. From March 2020 we had to shield as the person I care for is clinically extremely vulnerable. We shielded until June 2021. So no services used at all. We returned on June 2021 but with only 50% of original hours previously offered. Now in September 2021 we are still only receiving 50% of the hours originally offered. It's gone from four days a week down to two days a week. With no information on when this will increase back up again.”

The staffing challenges in social care have been well reported. The Home Care Association found that 78% of homecare providers were finding recruitment harder than ever before.⁵ These staff shortages were clearly impacting unpaid carers, many of whom reported that they were struggling to restart care after the pandemic.

“My son is 24 and uses a powered wheelchair and needs support to hoist etc. We paused his care during the height of the pandemic to keep my parents safe (they were shielding). Now we are trying to restart his care and no company is picking up the procurement request from the local authority due to the shortage of carers / the carer crisis.”

However, many carers also spoke positively of the support they had received during the pandemic, particularly from local volunteering groups or from carers' networks.

“Skipton Step Into Action (SSIA), a local group of volunteers, started up in March 20 to support people in the community and outlying villages with shopping, prescriptions and befriending during the pandemic. They then received charity status and developed incredible free opportunities for local people to access [...] Being able to accompany the young person I care for to these wonderful weekly sessions for 20 weeks, and experience them myself too, has been so helpful regarding both our mental well-being.”

“Carers network in my local area have been absolutely fantastic. Received so much support with lockdown I continued to do so many activities on zoom literally nearly every day through lockdown. They haven't stopped working so hard to make sure that we weren't isolated. They were superstars they have been such a lifeline to me.”

Barriers to accessing support

When carers were asked what barriers they faced in accessing support, they reported the following:

- I don't know about the services that are available in my local area (38%)
- I am worried about the person I am caring for catching COVID-19 (30%)
- The care and support services available in my area do not meet our needs (28%)
- The cost is too high (24%)
- The quality of the care is not good enough (15%)
- There is no transport available to take the person I care for to services (12%)

Overwhelmingly the largest issue was a lack of access to information, which rose to 43% of carers struggling to make ends meet. This is particularly concerning as the respondents to the survey tend to be providing higher levels of care and have been caring for longer.

The pandemic has also made accessing services more challenging for carers, particularly as those they care for may be at higher risk from COVID-19. Close to a third of carers (30%) stated that they were not accessing services because they were worried about the person they care for catching COVID-19, making this the second highest concern. Surprisingly, this didn't vary substantially depending on the relative risk level of the carer or the person they were caring for. 31% of carers looking after those over 65 and 32% of carers looking after someone who was at high risk of complications from catching COVID-19⁶ stated this was a barrier to access. This suggests that there is relatively consistent concern across all carers around catching COVID-19 and its consequences.

⁶ For this, we selected carers who were looking after someone with “a learning disability”, “needs that arise from being older”, “dementia”, “diabetes”, “asthma” and “cancer” as each of these have been identified as leading to a higher risk of complications and death from Covid-19

Other carers reported that the services in their local area are not meeting their needs. This is especially true if carers are from a marginalised background or under-represented communities. In total, 28% of carers reported that services were not meeting their needs – the table below demonstrates how this fluctuates depending on carers’ ethnicity, sexual orientation and whether or not they are disabled.

Table 3: Percentage of carers who say that care and support services do not meet their needs by equalities

The care and support services in my area do not meet our needs.	
All carers	28%
Ethnicity	
White British Carers	28%
Other White Background	35%
Asian / Asian British Carers	29%
Black / Black British Carers	32%
Carers from a Mixed / Multiple ethnic background	28%
Sexual orientation	
Heterosexual Carers	28%
Gay / Lesbian Carers	30%
Bisexual Carers	33%
Disability	
Non-disabled Carers	27%
Disabled Carers	33%

61% of carers  **felt uncertain about what practical support they may be able to access in the next year**

Concerns about the future

When asked about the future of services, 3 in 5 (61%) carers felt uncertain about what practical support they may be able to access in the next twelve months, and 62% were worried that services will be reduced. Carers under the most financial pressure were the most concerned, with 64% of carers struggling to make ends meet expressing worry that services would be reduced, compared to 59% of those who can afford their bills without struggling.

When asked about their thoughts on future practical support, many carers commented on service closures due to the COVID-19 pandemic and others highlighted the impact this was having on their health, wellbeing and ability to remain in employment.

“I have had to take on more caring responsibilities and I constantly battle to get extra support which is impacting on my health and my stress levels have increased greatly. I am a different person than I was and everyone has noticed a change in me. I have had to reduce my hours at work and even working part time has become a struggle – I may have to give up work.”

Almost half (47%) of carers were worried that they would lose access to voluntary sector services due to funding constraints and this concern was reflected in the comments.

“Our local council is bankrupt and have been cutting funding for both their statutory services and the voluntary sector in which they fund. The borough is on its [knees] and I worry for the carers and the vulnerable in the borough.”

The support carers need

We asked carers to tell us about their current needs for support.

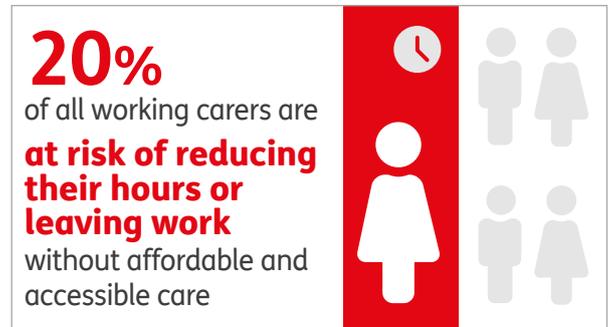
- More support to be able to look after their own health and wellbeing (66%)
- Understanding and recognition of unpaid carers from the general public (66%)
- Better recognition from their local council of their needs as a carer (56%)
- Better recognition from the NHS (52%)
- More breaks or time off from their caring role (50%)
- More support from the social security system (50%)

It is significant that looking after their own health and wellbeing now tops the list of priorities – previously this has not been the case. This is a worrying development and probably reflects the extreme stress that carers' health and wellbeing has been under during the pandemic.

Carers who are struggling to make ends meet or are in receipt of Carer's Allowance were more likely to say they wanted more support to be able to look after their own health and wellbeing (77% and 72% respectively) than all carers (66%). Those who are struggling to make ends meet were also three times more likely to say they wanted better support to return to paid work (24%) than those who said they were not struggling financially (8%).

Black carers (77%) were significantly more likely to prioritise better recognition from their local council of their needs as a carer than carers who are from a White British background (56%).

Issues related to work were also given more importance by carers from a Black, Asian or Mixed ethnic background. Asian carers (29%), Black carers (28%) and carers from a Mixed / Multiple ethnic background (25%) were significantly more likely to prioritise better support to return to paid work than carers from either a White British (13%) or any other White background (16%).



A shortage of care is putting working carers' livelihoods at risk

We asked carers in paid employment what they needed to continue to work and whether not getting a service would place them at risk of reducing their hours or giving up work altogether.

Overall, 1 in 5 (20%) of all working carers in this survey said that if they didn't get affordable and accessible care to support them, they would have to reduce their working hours or be at risk of giving up work altogether. 9% said they would have to reduce their working hours and 11% said they would be at risk of giving up work altogether.

We asked working carers about being able to work and services they relied on returning. 1 in 10 (10%) of all working carers in this survey said they needed care services they relied on to return otherwise they would have to reduce their working hours or were at risk of giving up work altogether. 4% said they would have to reduce their working hours and a further 6% said they would be at risk of giving up work altogether.

“I need day care services to resume fully so that I can carry on working.”

“It is a constant juggle. Local services continue to exist but are understaffed Because my daughter still lives at home, she is less at risk than other clients, and it is her shifts that are left unfilled or cancelled. It is all last minute, and requires an enormous amount of time on my part to mitigate.”

Priorities for social care reform

Carers UK has long called for a reformed and sustainable social care system fit for the 21st century; one which enables the delivery of consistent high-quality care to those that need it. While we welcome the additional funding to be provided by the Health and Social Care Levy, there will not be substantive changes to social care funding this winter. In England, the Government has pledged a White Paper on social care reform that is co-produced with carers and has said that reform for carers will look at advice and information, support and breaks services, amongst other things. In Scotland, the Government is proposing to develop a new national care service and increase investment to deliver a more cohesive human rights based social care system, including a right to a break for carers.

We asked carers about their priorities for social care reform and the following are their responses:

- Having access to more personalised and better quality care for the person I care for (70%)
- Having access to suitable breaks from my caring role (55%)
- Having access to care that is tailored to my needs (50%)
- Having a choice about caring and how much care I provide (41%)
- A reduction in charges to care (35%)
- Having access to good quality and appropriate housing, including the right adaptations (27%)
- Better access to replacement care (17%)

Those providing fewer hours of care each week were significantly less like to prioritise breaks; only 39% of those caring for under 35 hours a week selected breaks as a priority, compared to 59% of those providing 35 hours or more.

It is clear that carers are not currently receiving the practical support they need. There has been a slow re-opening of services, many of which have not returned to the same level of support as before the COVID-19 pandemic. This has left carers concerned about the future and has further disadvantaged marginalised carers whose local services are not meeting their needs. Without an increase in the practical support carers are receiving, many more are likely to reach breaking point.

The lack of services will also impact on carers' ability to juggle work and care – with a significant number at risk of reducing working hours or giving up work altogether, placing their livelihoods and financial futures at risk.

Care must be seen as contributing positively to carers' health and wellbeing, but also their work and financial futures.

Carers' health and wellbeing



Carers' physical and mental health is often impacted by their caring role. The 2011 Census and the more recent GP patient survey by NHS England have shown that carers were more likely than non-carers to have poor health before the COVID-19 pandemic.⁷ The COVID-19 pandemic has seen 81% of carers take on increasing hours of care, often with less or no outside support⁸. This has had a significant

and detrimental impact on carers' health and wellbeing; over two-thirds of carers (69%) reported that their mental health has worsened, and 64% of carers said their physical health has got worse as a result of caring in the pandemic.⁹ Our results confirm that the pandemic is continuing to have a negative impact on carers' own health and wellbeing and they are facing additional health inequalities.

7 Carers UK (2021) GP Patient Survey Analysis

8 Carers UK (2020) Caring Behind Closed Doors: 6 months on

9 Carers Week (2021), Breaks or Breakdown

Physical health

When asked about their physical health in general, carers described their physical health as follows:

Table 4: Carers' reports of their physical health

	Very good	Good	Fair	Bad	Very bad
Physical health	6%	25%	44%	21%	4%

A quarter (25%) of carers say their physical health is bad or very bad compared to 22% of carers in 2019.¹⁰ Given the significant personal cost of caring full time, it is unsurprising that this rose to 28% of those caring for over 35 hours a week classifying their physical health as bad or very bad.

When discussing their physical health, carers spoke about the impact of lifting the person they care for and lack of sleep on their health.

“My mum requires around the clock care and is often up, sometimes twice, during the night so I am often tired. I suffer from backache which isn't helped by the day to day caring my mum needs.”

“Heavy lifting impacts my back and causes pain and my mental health is worse and I feel low much more than I did.”

These findings are reinforced in the 2021 GP Patient Survey, which found that carers are more likely to be in poor health than the general population, with 6 in 10 (60%) of carers surveyed stating they had a long-term condition, disability or illness compared to 50% of those who weren't caring. Of these carers, almost two-thirds (64%) report that this condition reduces their ability to carry out day-to-day activities.¹¹



Mental health

When asked about their mental health in general, carers described their mental health as follows:

Table 5: Carers' reports of their mental health

	Very good	Good	Fair	Bad	Very bad
Mental health	4%	21%	44%	23%	8%

Overall carers ranked their mental health as worse than physical health, with almost a third of carers (30%) stating that their mental health is either bad or very bad, and just a quarter (25%) as good or very good.

This shows a worrying trend towards poorer mental health, especially given that this figure has increased from 27% in just two years since 2019. Like physical health, the picture is even worse for those caring more than 35 hours, as over a third (34%) consider their mental health bad or very bad.

Similarly, the longer someone has been caring the worse their health. 31% of carers who had been caring for over five years reported their physical health as bad or very bad and over a third (36%) reported their mental health as bad or very bad.

“Due to the decreased mobility and increased pain, it takes a lot more to help mum. Obviously she gets frustrated about the situation, I already have some mental health issues which are worsened by everything getting worse.”



¹⁰ Carers UK (2019), State of Caring 2019

¹¹ Carers UK (2021) GP Patient Survey Analysis

Carer's assessments are an opportunity to explore the needs of the person caring and to establish potential support they may need. With the worsening picture of carers' physical and mental health this should be considered, yet only a third (30%) felt that their mental/physical wellbeing was thoroughly taken into account during their carer's assessment. 44% of carers who are struggling to make ends meet felt that their physical and mental health was not considered.



Loneliness

Carers are feeling lonelier and more isolated than before the pandemic, with the vast majority (90%) reporting that they have felt lonely, increasing from 81% in 2019.¹² Worryingly, over a third (34%) of carers said that they often or always feel lonely. Carers spoke of the challenges of having to be in constant contact with the person they care for.

“*There is a special kind of isolation to having to always be close or contactable by the person you care for ... I regularly feel both suffocated and totally isolated.*”

Female carers are more likely to report being lonely (93%), compared to 87% of male carers. 2 in 5 women providing care said that not being comfortable with talking to friends about caring has made them feel lonely and socially isolated, compared to just 29% of male carers.

“*Not having carers support groups meeting up anymore has exacerbated the loneliness. Online, no matter how convenient, is no substitute.*”

LGB carers are slightly more likely to feel lonely (93%) than heterosexual carers, while LGB carers are also more likely to say that not being able to get out of the house has made them feel lonely and socially isolated (63%), compared to 52% of heterosexual carers.

General happiness

Carers are less satisfied with their life, less happy, and more anxious compared to 2019. This shows the profound impact of the pandemic, during which many carers have had to take on increasing hours of care alongside reduced social contact, less support, and worries and concerns about keeping the person they care for safe.

Carers placed their satisfaction with their life now at an average of 4.4 out of 10, slightly down from 4.7 in 2019, with an average of 4.4 out of 10 rating for how happy they felt yesterday compared to 4.7 in 2019.

Carers also rated the extent to which they feel the things they do in life are worthwhile at an average of 5.6 out of 10. These figures are considerably worse than the general population average rating for general happiness which is 7.09 out of 10, and 7.2 out of 10 for the feeling in life that things are worthwhile¹³.

Carers also feel more anxious than in 2019, perhaps reflecting their concerns about keeping the person they care for safe during the pandemic and their concerns about managing in the future. Carers rated their level of anxiety at 6.4 out of 10, compared to 5.4 out of 10 for the general population¹⁴. We also found a significant gender difference, with female carers reporting their anxiety as an average of 6.5 out of 10 compared to male carers whose average is 5.0 out of 10.

“*The stress and anxiety of caring and worrying about my daughter has impacted my mental health. I am on antidepressants and strong painkillers. I'm not sleeping and feel exhausted most of the time.*”

¹² Carers UK (2019), State of Caring 2019

¹³ Opinion and Lifestyle Survey (Aug 2021)

¹⁴ Ibid

GP awareness

The role of GPs in supporting carers through various elements of their life, from the transition to being a carer through to ongoing help and guidance on their health, is key. Three-quarters (75%) of carers said their GP knew they were a carer. It is concerning, especially given that the carers in this survey are more likely to be caring for significant hours, that a quarter of carers reported not being known to their GP.

The 2021 GP Patient Survey found carers had lower levels of overall satisfaction with their local GP service than the wider population. Almost 1 in 10 (9%) carers rated their experience as poor or very poor, compared to 6% of those who were not caring. This number is steadily increasing from 7% of carers rating their GP practice as very or fairly poor in 2018 and 8% in both 2019 and 2020.¹⁵

COVID-19 vaccine

The pandemic has had a significant impact on carers, with many making different choices about accessing support, seeing family and friends and work to reduce the risk to themselves and the person they care for. The vast majority of carers were overwhelmingly positive about being able to receive the COVID-19 vaccine to reduce the risk of infection for themselves and the person they care for. We asked carers how they were called forward for the COVID-19 vaccinations and if they had received it.

Identifying unpaid carers so they can be prioritised for the COVID-19 vaccine has involved unprecedented collaboration between Governments and government departments, local government, our health and care services and the voluntary sector. The success of this program is demonstrated in the fact that 47% of the carers who responded to the survey said they had the vaccine as a result of being contacted due to their caring role. There is an opportunity to use these data proactively to ensure that carers get the information, advice and support they need early enough.

Table 6: Percentage of carers who have received the COVID-19 vaccine and the route they were offered the vaccine

Yes, I was offered the vaccine for another reason such as my age or an underlying health condition	49%
Yes, because declared I was an unpaid carer	21%
Yes, I was contacted by my GP as I am an unpaid carer	15%
Yes, I was contacted by the National Booking Service or by letter as I am an unpaid carer	11%
No, I have decided not to have the COVID-19 vaccine	4%
No, but I would like to have the COVID-19 vaccine	1%

¹⁵ Carers UK (2021)

The vast majority of carers (96%) had received the COVID-19 vaccine. Only 3.8% decided that they did not wish to have the vaccine, and under 1% either weren't offered or did not know how to get a vaccine. Carers from a Mixed or Multiple ethnic background were more likely to have declined to have the vaccine (7%) and more likely (2%) to have wanted to have it but were not able to access it.

Carers discussed the sense of relief in having had the vaccine and feeling more protected against COVID-19.

“Becoming double-jabbed gave me a feeling of relief, that if I caught it, I would not be as badly affected and would be back caring for my family as soon as was possible.”

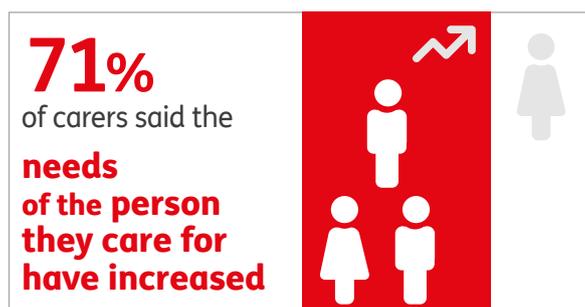
“I feel so much better by having the vaccine. My stress levels have been reduced.”

Despite carers being prioritized there was feedback about the difficulties and obstacles that some carers had to overcome just to be able to receive the jab.

“I had to get support from a carers charity to lobby my GP for access to the Covid vaccine.”

Impact of worsening conditions

The COVID-19 pandemic has seen healthcare delayed, has restricted access to support services and has changed people's levels of physical activity. This has had an impact on the condition of the person being cared for with over 7 in 10 (71%) of carers saying the needs of the person they care for have increased, just 1% have said the condition of the person they care for has got better.



We asked carers who said the condition of the person they care for had deteriorated about the impact on their health, wellbeing and ability to have a life outside of caring. Their answers were as follows:

- My levels of stress and anxiety have increased (91%)
- My ability to take breaks from my caring role has got worse (78%)
- My mental health has got worse (77%)
- My physical health has got worse (67%)
- My ability to undertake physical activity has got worse (69%)
- My confidence in my ability to continue to care has got worse (48%)

Carers commented that as the condition of the person they cared for got worse, their levels of exhaustion and anxiety were impacting on their own health and ability to have time away from caring.

“I also find myself becoming exhausted more and more often. His condition has worsened in the last 18 months and the burden on me has only increased. I find that I tend to neglect my own health worries and issues as I try to focus on his wellbeing.”

“I am constantly exhausted, stressed and weighed down with the demands and responsibility of looking after my parents, day in day out, and it is taking its toll on me. I get increasingly bad tempered, irritable and resentful that I have no freedom and no life of my own. I can see no end to it and some days I just feel I cannot go on any more. It’s relentless hard work, long hours and lack of sleep. I am anxious and have developed IBS, hip and back pain and feel under par all the time now.”

Carers who are struggling to make ends meet were the most likely (95%) to say they were experiencing stress and anxiety as a result of the condition of the person they are caring for getting worse.

“I was so stressed with caring for my mother with cancer and autistic child up until March this year, that I got Bell’s Palsy and still struggle with fatigue even now I am only caring for my child. The more stressed I get for example worrying about my child losing his DLA and the financial consequences on all benefits as a result, the more fatigued and anxious I get.”

Over half (54%) of carers in paid work said that the condition of the person they are caring for getting worse was impacting on their ability to work. Carers highlighted the challenges of focus at work, while caring for increasing needs.

“Dad’s dementia has got worse, along with the double incontinence for which he needs constant assistance. This means I am often unable to concentrate on complex work tasks that require deep concentration for long periods as I am constantly interrupted.”

Worryingly, 48% of carers say the condition of the person they are caring for getting worse has impacted on their confidence to continue to care. This rose to 54% of carers who are struggling to make ends meet.

The poorer health outcomes for carers from caring have been exacerbated through the pandemic. Health inequalities are deepening, including in the groups of carers with even less resilience such as those on low-income, carers from particular ethnic minority backgrounds and those caring for people with certain conditions.

The worry around the impact of the deterioration of the condition of the person being cared for is of great concern and shows where prevention services need to be invested to bring carers’ health and wellbeing and ability to care to a better position.

The vaccination programme shows what a highly valuable and successful initiative which identifies and recognises carers can look like. Whilst many GPs do recognise carers, the fact that 1 in 4 are not recognised when this sample is providing some of the most significant amounts of care is a concern and shows that there is room for significant improvement. Longer term, this has benefits for prevention.

Physical activity



Carers UK has identified and promoted the important role of physical activity in the lives of unpaid carers, through its Carers Active project research and pilot work. Like many areas of carers' lives, there is a clear difference between the physical activity levels of carers and those without caring responsibilities, as carers face many barriers which prevent them from prioritising their own health and wellbeing.

Levels of physical activity

The Chief Medical Officer recommends that adults take part in at least 150 minutes (or 2.5 hours) of moderate intensity cardiovascular activity each week, or 75 minutes of vigorous intensity activity. Moderate intensity activity raises the heart rate and makes breathing faster and a person feel warmer. We asked carers about the amount of physical activity they do during the week.

Table 7: Level of physical activity amongst carers

	Less than 30 minutes	30-60 minutes	1-2 hours	Over 2 hours
Vigorous activity	61%	17%	9%	12%
Moderate activity	34%	25%	16%	25%
Light activity	26%	17%	14%	43%

We also asked carers about the number of days a week they do light, moderate or vigorous activity. 20% of carers said that they do moderate physical activity seven days a week, meaning a fifth of carers have a level of regularity and consistency to some form of activity each day of the week. Similarly, 41% do light exercise seven days a week, which affirms the issue of carers not undertaking sufficient activity.

Previous research found carers who are providing 35 hours or more care a week are less likely to do physical activity.¹⁶ This is a trend we would expect to see given the time and energy required to carry out unpaid care and the lack of respite services and limited opportunities for breaks. Many carers commented that they are overwhelmed with caring duties and are therefore sacrificing their own physical activity, exercise and sport interests as a result. This has then led to a knock-on effect of worsening health.

“I am absolutely exhausted. I have lost all the fitness I had before the pandemic, I have lost muscle tone, I have put on weight, I get more migraines.”

Disabled carers reported doing under 30 minutes of vigorous (61%) and moderate (34%) activity during the week which was lower than for all carers, showing the further barriers to physical activity for this demographic of carers. It demonstrates the importance of inclusive physical activity opportunities to be developed and promoted to provide equal access.

Carers who reported very bad or bad physical health have unsurprisingly responded that they do vigorous or moderate exercise very infrequently. Three-quarters (75%) of carers said they do less than 30 minutes of vigorous activity a week; 51% said they do less than 30 minutes of moderate activity a week and 40% said they do less than 30 minutes of light exercise a week. Carers in bad physical health is a group who are at risk of further health issues and so developing physical activity support and initiatives for this group is especially important.

The number of carers doing over two hours of vigorous (14%) and moderate (25%) activity slightly increases for those who are in full time employment, suggesting that perhaps that there is some time to be able to fit that in around a work structure.

¹⁶ Carers UK (2021), Carers And Physical Activity

¹⁷ Sport England and Savanta ComRe (2021) COVID-19 Briefing: Exploring attitudes and behaviours in England during the Coronavirus Pandemic

¹⁸ Carers UK (2021), Carers And Physical Activity

¹⁹ Ibid

²⁰ Ibid

Impact of the COVID-19 pandemic

The COVID-19 pandemic has impacted people's ability and motivation for physical exercise. Just over a third (35%) of carers said that they are doing the same amount of physical activity as before the pandemic. However, 27% are doing over two hours less physical activity than before the pandemic, while only 4% are doing one to two hours more physical activity than before the pandemic. Research by Sport England found that in February and March 2021 34% of adults report doing less physical activity than before the pandemic¹⁷.

Given carers' relatively low levels of physical activity pre-pandemic, this is an increasing concern and shows why supporting carers to be more physically active is so valuable. Our work pre-pandemic investigated carers' barriers as well as motivations to do physical activity and although we have not looked at these again, we can see from the other results in this survey that they would have been increased over the pandemic. A full list of the barriers and motivations can be found in our previous report *Carers and Physical Activity*¹⁸.

Carers' mental and physical wellbeing can be improved as a result of regular physical activity. Yet carers are much less likely to be active (14% of carers compared with 54% of all adults)¹⁹. There are barriers and factors that impact carers' ability to undertake all forms of physical activity including walking, dancing or at-home exercise classes. The majority (88%) of carers report not having the time to take part in physical activity²⁰; other barriers include guilt, anxiety, tiredness, injury or illness. They also include a lack of understanding about how much and which types of physical activity to do to maintain health and wellbeing. Addressing the profound health inequality between carers and non-carers and enabling carers to live healthy lives needs to be a part of the national and local health prevention agenda, and carers should be considered when devising strategies for public health, including social prescribing policy and strategies.

Carer's assessments



In England, the Care Act 2014 gives anyone over the age of 18 who is looking after another adult who is disabled, ill or elderly the right to a carer's assessment. Young carers and parents of disabled children also have the right to an assessment by their local council under the Children and Families Act 2014. These assessments

are carried out by Local Authorities and should cover topics such as carers' mental and physical health, their ability and willingness to care, and their relationships with others. The experiences of carers in Wales, Scotland and Northern Ireland are available in each of the nation results of State of Caring 2021.



Access to carer's assessments

Despite all carers in England having the right to an assessment on the appearance of need, only 24% of carers surveyed reported having a carer's assessment or re-assessment in the last 12 months. This is a decrease from 27% of carers in 2019 and 31% in 2016. While the majority of these carers (81%) waited less than six months for a carer's assessment, 19% of carers were still left waiting for over 6 months to have their needs assessed by their local council. This fits with official statistics measuring decreases in the number of carers' assessments over time²¹ and also fits with the Association of Directors of Social Services (ADASS) recent research showing that waiting times for assessments had increased²².

Carers struggling to make ends meet were less likely to have received a carer's assessment, with just 21% of these carers reporting an assessment in the last 12 months. Without an up-to-date carer's assessment, these carers are unlikely to be able to access they need. Access to carer's assessments varied depending on the condition of the person they care for. While 32% of those caring for someone with dementia reported having a carer's assessment, only 19% of those caring for someone with cancer did. Those caring for someone with a mental health condition (26%) were also marginally more likely to have had a carer's assessment than those caring for someone with a physical health condition (23%).

The number of hours of care someone was providing each week also had an impact on whether or not they'd received a carer's assessment; over a third (36%) of those caring over 35 hours a week having received an assessment, compared to a quarter (26%) of those caring less than 35 hours. Just 21% of those caring for someone who did not live in the home with them received a carer's assessment or re-assessment.

21 <https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/2018-19>

22 Adass (2021) Adass Spring Survey 2021

Barriers to carer's assessments

We asked carers who had not requested a carer's assessment or re-assessment their reason for not doing, they told us

- I don't know what a carer's assessment is (37%)
- I don't think it will be beneficial to me (20%)
- I requested one but I am still waiting (6%)
- My assessment was delayed or postponed (2%)

Not knowing what a carer's assessment was even higher for certain groups of carers, with 39% of carers struggling to make ends meet and 42% of Asian carers saying they did not know. Worryingly, this lack of knowledge was seen even among carers who were registered with their GP or in contact with their Local Authority, and who should therefore have been informed of their right to a carer's assessment.

“I didn't know about the carer's assessment. Even though my doctor knows I am a carer she has never mentioned it.”

“I've never known about a carer's assessment from our council or anyone else.”

A fifth of carers (20%) also reported that they had not requested a carer's assessment as they didn't think it would be beneficial to them. This is often due to previous poor experiences, or there being inadequate funding for local provision of support or a lack of signposting.

“I had an assessment once and it didn't achieve anything. It was completely unhelpful and I didn't understand anything about my rights or entitlements afterwards.”

“I had a carer's assessment about eleven years ago with my local authority, they said they couldn't offer any help and I haven't heard from them since.”

Experience of carer's assessments

Carers who have had an assessment or re-assessment in the last 12 months did not feel that their needs were thoroughly considered during the process. We asked carers about various aspects of support, such as their ability to provide care, support required to maintain employment or education and their ability to have breaks, and how well these had been considered during the carer assessment process.

“I had my assessment today, although some things were discussed most weren't. I wasn't asked about any of the above.”

Carers reported that out of all things considered during their assessments, their willingness and ability to provide care was best considered, with 38% of carers stating that this was thoroughly considered in their assessment. However, this dropped to 27% of carers struggling to make ends meet and just 24% of those caring for someone with Autism Spectrum Disorder.

“Too many assumptions are made about your willingness to care and the types of support available. You feel you are being inducted into a system – well-meant on the part of individuals but not sufficiently tailored to your specific needs, personality and life experiences. You feel your life is being taken over without your permission and that your partner's disability is disabling and limiting your own life too.”

Less than a quarter (24%) of carers felt that their need to have regular breaks from caring was thoroughly considered within the assessment process and this number decreased to just 14% of those caring for someone with alcohol or substance misuse and 13% of those providing palliative or end-of-life care. While 28% of male carers felt that their need for regular breaks was thoroughly considered during the assessment process, only 22% of women felt this way.

Similarly, many carers reported that their ability to have time to themselves was poorly considered during the assessment process, with around a quarter (26%) answering that they felt this aspect was thoroughly considered. This number dropped to just 17% among those carers struggling to make ends meet.

Breaks are vital for carers as they allow carers to engage in activities that are essential for their wellbeing, such as exercise, hobbies or even the chance to get on top of essential non-care tasks such as attending GP appointments. Even before the COVID-19 pandemic, carers were struggling to access meaningful breaks – in 2017, 25% of carers said they hadn't had a day off from caring for more than five years²³, and Carers UK also found that 72% of carers had not had any breaks during the pandemic, leaving 74% of carers exhausted as a result.²⁴

²³ Carers UK (2017) State of Caring 2017

²⁴ Carers UK (2021) Breaks or Breakdown

Finally, only 32% of carers felt that their assessments thoroughly considered what needed to be put in place to support the person they care for in the case of an emergency. Among those struggling to make ends meet, this number reduced to just 24%. This is particularly worrying considering the necessity to have a contingency plan in place during the COVID-19 pandemic due to the risk of carers falling ill themselves. In April 2020 we found that over half (57%) of carers were worried about what would happen in the case of an emergency as they did not have a contingency plan in place²⁵.

When discussing the assessment process, many carers spoke about how the practical support after the assessment often did not come to fruition and this made the assessment process seem futile.

“It doesn’t matter how good the assessment is if the finance is not there to actually deliver support for the needs which are identified.”

“Kind and supportive people. The problem is the high cost of care for self-funding people which was a barrier. Nothing free or low cost. Needed night care so I can sleep but none available and I ended up in hospital with exhaustion trying to do it all 24/7 365 days a year.”

Ultimately, the experiences carers shared with us suggest that the Care Act 2014 and the Children and Families Act 2014 are failing to meet their intended purposes and Local Authorities are unable to meet their statutory duties. Many carers who require support are not receiving assessments, and many of those who have had assessments in the last 12

months have found that the process fails to properly consider some of their most important needs. In instances where support requirements are recognised there often isn’t sufficient funding or resources available to provide the practical, long-term and affordable solutions that carers so desperately need.

Digital, data and technology

When the COVID-19 pandemic began, many services moved to digital provision. For some carers, this change was welcomed as it reduced travel times and meant they could access support as well as health and social care services in their homes. However, the digital divide is widening, with those without access to digital services and technology being left behind and without provision. Good use of data and systems has the power to positively change lives and target support where it is most needed, and with reform on the agenda for health and social care we asked carers what their priorities were.



Table 8: Carers' experiences of using digital technology in their caring role

	This makes my caring role easier	Neither easier or harder	This makes my caring role harder	I don't use this
Remote health care such as online GP appointments, repeat prescriptions	42%	23%	14%	21%
Online video consultations for health and social care eg Zoom, Teams, FaceTime, WhatsApp	23%	16%	14%	48%
Online mental health services	9%	11%	8%	72%
Being able to see an online summary patient record	13%	14%	2%	71%
NHS App	12%	23%	3%	62%
Apps such as for pain management, mood management, care co-ordination	4%	9%	2%	85%
Environmental monitoring such as heating and lighting control, door video systems, smart appliances	10%	9%	1%	80%
Remote monitoring and alerts such as motion sensors, fall detectors, personal alarm, GPS trackers	15%	9%	1%	75%
Voice assisted devices eg Amazon Echo (Alexa), Google Home	15%	19%	1%	66%
Digital ways of keeping in touch with friends and family / the person I care for eg Zoom, Teams, FaceTime, WhatsApp	39%	32%	3%	26%

Current use of digital technology

We asked carers to reflect on various technologies or digital solutions and the impact these had on their caring role.

Remote healthcare such as online GP appointments was overwhelmingly the most popular technology listed, with 42% of carers stating that this made their caring role easier. However, a significant minority (14%) of carers stated that this made their caring role harder, indicating the importance of offering a choice when it comes to healthcare.

Despite the impact of the COVID-19 pandemic, many other digital technologies were not widely used by carers. For instance, only 15% of carers are using apps, 28% are using online mental health services and 20% are using environmental monitoring such as door video systems or smart appliances. This has increased significantly from 2019 when 4% of carers were using apps, including those which help with pain management, mood management and care co-ordination, and 8% of carers were using environmental monitoring such as heating and lighting control, door video systems, or smart appliances.²⁶ This shows that there is great potential for continuing to use technology of all different kinds to support carers.

The use of digital technology stayed relatively constant across carers regardless of the amount of care they provide or whether they are in work, suggesting that it may be down to a personal preference of carers rather than situational factors.

There were, however, some slight differences due to age. Only around 4 in 10 (41%) of carers aged 65 or over were using online video consultations for health and social care compared to 53% of carers aged between 18 and 64. Similarly, around 1 in 5 (20%) of carers aged over 65 stated that they felt unable to use digital technology due to a lack of skills compared to 10% of carers aged 18 – 64.

However, we saw the opposite when carers were asked if they felt excluded from using digital technology due to their financial situation. Only 4% of the older cohort agreed or strongly agreed, compared to 8% of younger carers. This rose to nearly 3 in 10 (29%) of carers struggling to make ends meet.

Changes to digital technology

When asked to consider how their use of technology had changed during the pandemic and their hopes for the future, carers were very mixed in their opinions.

The same percentage (29%) of carers would like to continue accessing support services digitally in the future as those who would not. Carers were more supportive of accessing health and social care services digitally, with almost half (45%) saying they would like to continue accessing health and social services in this way.

In addition, digital technology seems to have been helpful for carers socially, but detrimental for their physical activity levels. Almost 6 in 10 (59%) of carers stated that digital technology had made it easier for them to connect with friends and family. On the other hand, around 4 in 10 (38%) said it had made it harder for them to be physically active.

When asked to comment on their use of digital technology, carers identified many barriers to access such as a lack of privacy and not having access to up-to-date devices that could support applications like Zoom. Other carers also commented on the value of having face-to-face support either instead of, or in addition to, support that was provided digitally.

“I tried Zoom to keep up with groups I am part of but found my husband who has dementia would interrupt or become annoyed when I was using it so I had to stop.”

“I have a hearing problem which makes using group zoom meetings difficult. I feel it is very important that we have access to face-to-face consultations in order to ensure that assessments are successfully completed. Technology is wonderful but only when you have been able to benefit from instruction about how to use it.”

“We’ve had to do a number of ASD related assessments virtually and it does not give the assessor a true reflection of him as he is distracted by the screen and things on it, and finds it very hard to communicate via Zoom etc.”

On the other hand, some carers identified the benefits of digital technology for feeling supported and helping them in their caring role.

“Having digital technologies is brilliant. When dad was more able having Tapo cameras in his living room, bedroom, and kitchen assured me he was safe and I was able to call him on a Facebook Portal if I saw him doing something dangerous or if he had forgotten to do something.”

“On-line support group has been so positive to understanding my partner’s condition, supporting others, identifying with other carers.”

Carers and their data

We asked carers about how they would like their own data and that of the person they care for to be used by public services.

Carers were overwhelmingly positive about the potential for data to improve their experiences of interacting with health and social services. The most popular potential use of data was for them being a carer flagged on either their own record or the record of the person they are caring for.

Table 9: How carers want their data to be used (percentage of all respondents)

Data systems to flag that I’m a carer on the records of the person I care for	78%
Data systems to flag that I’m a carer on my patient and care records	77%
Systems that make managing appointments and speaking to health and care staff easier	72%
Confidence that my data will be stored safely and that there is transparency about how it is used	70%
Digital access to my own patient and care records (eg see appointments and test results)	69%
Digital access to the patient and care records of the person I care for	69%
Information shared so I don’t have to repeat information again and again	67%
The confidence to know that everyone has up to date records about me and the person I care for	66%
Services to automatically highlight information that could be useful to me so that I don’t miss out on support	61%
The ability to update the record of the person I care for with their needs or preferences	57%
Confidence that my data will be stored safely and that there is transparency about how it is used	57%
The ability for me to share information about the person I care for, if they choose, that would improve their wellbeing eg diet, sleep, exercise	49%
The ability to update my patient and care record with any additional information, my needs and preferences	49%
The ability to share information about myself, if I choose, that would improve my wellbeing eg diet, sleep, exercise	37%
The ability to share information about myself, if I choose, about my genome (a genome is a complete set of genetic information)	20%

We also asked carers how digital access to health and care services and patient and care records would make a difference to them.

- Help me to be more in control of my own health and wellbeing (66%)
- Enable me to manage caring better (60%)
- Help to personalise care and support for the person/s I care for (58%)
- Improve the health and wellbeing of the person/s I care for (51%)
- Reduce our costs of travelling to appointments/ parking, etc. (46%)
- Reduce stress and the hours I spend caring (43%)
- Improve my own health and wellbeing (41%)
- Help the person I care for to be more in control of their own health, wellbeing and care (37%)
- Improve my confidence about caring (32%)
- Make juggling caring and paid work easier (24%)

Despite a significant proportion of carers not wanting to access health and care services digitally in the future, or saying that it makes their caring role harder, these results suggest that the majority of carers see benefits in digital access to health and care services and patient and care records.

The diversity of opinions and experiences when it comes to accessing services digitally highlights the importance of offering choice to carers and people who use care. Many support services have moved online successfully and are preferred by some carers, but they also frequently spoke of the benefits of face-to-face support that cannot be translated into a digital environment. There are also clear barriers for many carers, particularly those who are older or who are struggling financially, who are at risk of being left behind. There is an opportunity to support carers with greater skills, but also a programme that bridges the digital divide – investing in hardware for carers, as well as Wi-Fi, data or faster internet connections.

Carers want to ensure that data identifies them and that it is used positively to be able to help them care. It is clear that they want the ability to include data to personalise care. They are clear that this will help them to care better. If improved data use and knowledge is seen as a benefit for the paid workforce, then this must also be considered for unpaid carers whose care far outstrips that provided by any formal provision. The results show considerable potential for growth and development including the potential for experience-led AI which is already being used in some information and advice services.

Whatever improvements are delivered through digital and data solutions, it is also crucial that health, social services and wider support provision offer the choice of both online and face-to-face services and support.

We are keenly aware whilst exploring digital and data improvements that this goes alongside digital inclusion – including for people who cannot afford digital access and hardware. There should be investment to enable those carers to access online products and services. We need to ensure that there are constant skills programmes to enable carers to learn as technology adapts and shapes. Finally, we needed blended services so that carers who wish to continue to receive support face-to-face or through telephone connections, are able to do so.

Juggling work and care



The COVID-19 pandemic has had a wide-reaching impact on work, with the Government making significant interventions in the labour market and both employers and employees having to adapt quickly to new circumstances.

We look at the continued impact of the pandemic on carers' ability to juggle work and care. We will be publishing further data in 2021 on working carers' experiences and employers' reactions to supporting carers.

Growing numbers of working carers

Working carers represent a significant proportion of the working population and at the height of the pandemic, Carers UK estimated that over a quarter (26%) of all workers were juggling work and care.²⁷ In some sectors the proportion is even higher, with one in three NHS staff juggling paid work and unpaid caring²⁸. Over 1,500 respondents to the 2021 State of Caring survey were carers in paid employment, representing 42% of working age respondents. 20% were in full-time employment, 17% were working part-time and 6% are self-employed.

Unsurprisingly, the amount of care people were providing each week had a significant impact on carers' employment status. Of working age carers who provide under 35 hours of care per week, nearly three-quarters (72%) are in paid employment, with 43% in full-time paid employment. By contrast only 32% of carers who provide over 35 hours of care per week are in paid employment with only 1 in 8 (13%) in full-time paid employment.

Our survey found that female carers are more likely to be working carers; 43% of female carers aged 18-65 are in employment, compared to 38% of male carers. This reflects the long-term trend that women are more likely to take on caring responsibilities over a decade earlier than men. Half of women will care by the age of 46, compared to half of men who can expect to care at 57.²⁹

Homeworking

There has been a significant move towards working from home either full- or part-time during the pandemic, with 47% of working carers now working from home either all or some of the time.

Full-time workers are more likely to be working from home with 49% working from home all the time and a further 14% working from home some of the time. This is significantly higher than part-time employees, of whom only 6% are working from home all the time, and 34% working from home some of the time.

Carers' experiences working from home varied. Some carers reported that working from home had improved their work life balance and made balancing work and care easier, while others found work a respite from their caring role and that they struggled to be able to concentrate on work while at home.

“Don't think I can return to my previous part time hours if I have to go back to the office and not work from home. It has made such a difference to my health/stress levels. You can only appreciate how much something has impacted on you when you have stopped doing it but my employer is eager to get staff back to the office as soon as possible.”

“I have found working from home more difficult as I am pulled more into the care environment due to elderly parent not understanding that I am working from home and not off work. This is very difficult and a balance is hard to achieve, I have found that my parents are becoming more and more dependent on me because I am there.”

“I love my work as it gives me a break from caring, however, I am really beginning to struggle working from home full time. I would love to hot desk two days a week so that I can get out of my house.”

27 Carers Week (2020), Carers Week Research Report 2020

28 NHS Staff Survey 2020

29 Carers UK (2019), Will I Care

Balancing work and care

The challenges of balancing work and care often have a negative effect on carers' careers, with our previous research finding that 40% of working carers had passed on opportunities at work and 25% had moved roles to help them manage.³⁰ Worryingly, 1 in 8 carers (13%) have had to reduce their working hours during the pandemic. In addition, almost a quarter (23%) of working carers have had their employment situation negatively affected during the pandemic; by reducing their working hours, having their hours reduced by their employer, losing their job, losing business as a self-employed carer, or leaving their job due to concerns about catching COVID.

Full-time working carers (20%) are more likely to have reduced their working hours during the pandemic than part-time carers (3%), perhaps reflecting that part-time working carers may have already reduced their hours to help them manage.

When discussing reducing their hours or turning down job opportunities, carers spoke about the additional worries of COVID-19 infection and the impact of worsening conditions on continuing to balance work and care.

- ☞ *My contract in a school ended and I chose a part-time working from home role, to be safe from covid and to manage my caring role."*
- ☞ *I have had to reduce my hours due to increased caring responsibilities, my husband recently had a mild heart attack and I'm having problems dealing with my mother's worsening dementia."*

Impact on work of reduced social care services

Services being closed or reduced during the COVID-19 pandemic meant that some carers felt they had no choice but to reduce their hours or give up work. The limited return of services continues to have an impact. One in five (20%) of carers stated that if care services did not return, they would either need to reduce their working hours or give up work entirely. Affordable and accessible care and the ability for services to support carers is essential if they are to remain in paid work. In England, this has been acknowledged in the Impact Assessment for the Health and Care Bill relating to the Discharge to Access Model. The document states "there is an expectation that unpaid carers might need to allocate more time to care for patients who are discharged from hospital earlier. For some, this could require a reduction in work hours".

Carers also spoke about the importance of support services to enable them to continue to work and the challenges of the staff shortages preventing services from returning.

- ☞ *As it is impossible to find a paid carer to look after my adult daughter between 3pm-6pm, hence allowing me to continue work in the NHS. It is a constant juggle."*
- ☞ *Need local authority to increase service levels. Can't return to the office until this happens. Manager is trying to be supportive, but doesn't truly understand the stress of caring and working."*

As the number of people providing unpaid care increases, so does the number of people juggling work and care, and with one in three people in the NHS now juggling work and care it is a problem that cannot be ignored. Working carers were already struggling before the COVID-19 pandemic, trying hard to balance providing practical and

emotional support, managing appointments, and keeping an eye on the person they care for – all alongside paid work.

We are currently at a turning point for work as employers, employees and the Government adapt to the easing of national and local restrictions. It is vital that the positive lessons from

COVID-19 pandemic are learnt and flexibility in the hours and places people work is maintained to ensure that working carers can stay in paid work. It is essential that in order to support carers to stay in paid work there is investment in social care and that affordable and accessible care is available.

Conclusion and recommendations

The pandemic has had a huge impact on everyone's lives, but for carers in particular. We have reported on their struggles, fears and positive developments in our reports, *Caring behind closed doors: six months on* and *Breaks or breakdown: Carers Week 2021 report*. They have shouldered much of the pandemic's impact.

This year's *State of Caring 2021* report shows the longer-term impacts of managing in a very difficult environment for a prolonged period of time. Carers' finances are more stretched than before. Carers' own health and wellbeing has risen to the top of their priorities – something we have not seen before – highlighting the real strain carers feel they've been under.

Carers who were already finding it tough to do physical exercise pre-pandemic have found it even harder. Services are still a long way off returning to pre-pandemic levels and even then, they were not sufficient to provide the level of support needed by carers. This support is critical to carers' health and wellbeing, their and their families' quality of life and their ability to juggle work and care.

Social care and health systems are under reform in all four nations of the UK. For example, in England, the Prime Minister has promised to "fix social care" – an issue that is critical to carers' lives and the lives of their families and has the potential to significantly improve people's lives. It is right to focus on this now and longer-term reform must provide more support for carers.

The NHS is also seeing huge changes across the different nations of the UK. We are seeing a stronger focus on health inequalities; this should include the impact of caring which is a social determinant of health. Whatever reforms in health are delivered, including through integration, the clear message from carers is that they want their health and wellbeing to be considered more. Carers UK believes it's time to boost the duties that the NHS has towards carers.

We've seen huge changes in the way that people work and juggle work and care – some carers finding it extremely challenging. There are a number of new positives and new potential with the consultation on day one rights to flexible working and the pledge by Government to introduce Carer's Leave into legislation.

Carers' approach to digital and data shows mixed experiences, but there is a significant proportion who prefer this type of approach and contact and for whom it makes caring easier. Whilst a mixed and blended approach towards services needs to be taken and robust strategies need to be in place to ensure that digital inclusion is pursued, there is great potential for digital, data and technology changes to help carers further.

The overall message from carers is that equality, support and recognition are all connected and high on their agenda. They want to be recognised and valued for what they do, to have the information to be able to care well and safely and make the right decisions for them and their family. They want their family to have great services that provide choice and independence. They want their health and wellbeing to be as good as it can be and to have regular breaks from caring. They want to have the opportunity of working for as long as possible, to be protected from poverty and have a decent income and standard of living. Having given so much, it is right that they are supported, too.

Recommendations

Carers and their finances

- Government should increase the level of carers' benefits including Carer's Allowance so that it is no longer the lowest benefit of its kind.
- Government should explore the possibility of an additional payment for carers over state pension age.
- Government should consider a Winter Fuel Allowance for people in receipt of Personal Independence Payment and Carer's Allowance.
- Government should look at how digital means can be used to improve carers' experience of claiming and managing their Carer's Allowance, as well as helping to link to other services across national and local Government.
- Income maximisation programmes remain critical to ensure that carers continue to claim all their entitlements and to help them plan better through crises.

Support and services

- The UK Government needs to continue to ensure that there is sufficient baseline funding for social care over the next three years and to ensure that the Health and Care Levy delivers this for carers. This includes any consequential funding for Wales, Scotland and Northern Ireland.
- The UK Government must ensure that the assurance programme through the Health and Care Bill looks at the sufficiency of supply of services in order to meet needs.
- The UK Government should be investing an additional £1.5 billion in carers' breaks so that they have the confidence that good-quality services will be available when they need them.
- HM Treasury must have a specific focus regarding investment in care which looks at the value of social care to helping carers and disabled people to remain in work, as well as providing investment in local areas.
- The Dilnot reforms proposed by Government should consider the role and impact of carers, including the costs borne by family members.
- The UK Government should invest in innovation in carers' support.
- To make sure that information and advice services are joined up and enable carers to find what is needed at the right time.
- To ensure that carers are supported at key points of their caring journey: when they are new to caring, throughout major changes of care, at key points such as hospital discharge, when caring comes to an end and life as a former carer.
- The NHS needs to systematically identify carers and ensure that they are consulted and have the right support. This should build on the gains made by the COVID-19 vaccination programme using more data sharing with permissions.
- The NHS needs to build on its public health programmes by supporting carers more, including the annual flu jab where take-up targets could be increased for carers and a longer-term approach considered where all over 50s are offered the flu vaccination.
- Health and social care systems need to ensure that the benefits of social prescribing are fully realised, ensuring that they are clearly identified and outcomes measured.
- Employers need to include carers' support as a targeted part of their staff wellbeing approaches, using the good practice from Employers for Carers.
- Carers UK will be publishing additional work on diet and nutrition later in the year with specific recommendations for different bodies.

Health and wellbeing

As this is carers' top priority along with recognition of caring by the general public, greater attention now needs to be focussed on this area.

- Caring has been identified as a social determinant of health by Public Health England and needs to be considered by national and local governments, by employers, by the third sector and all service providers.
- The UK Government and other nation governments should introduce a duty to have regard to carers within the NHS and to promote their health and wellbeing.

Carers and physical activity

- Local government and health prevention services could include carers' access to physical activity within commissioning decisions.
- Local voluntary organisations should consider their offer to carers including physical activity.
- For the sports and leisure community to understand carers' needs and make their offer accessible to them – putting in to practice our recommendations in our *Carers and Physical Activity* report.

Carer's assessments

- A new stream of work needs to support local authorities with more innovative and carer-centred ways of undertaking carer's assessments that focuses on the outcomes they want to achieve and what matters to them.
- With the proposed Dilnot-style reforms, consideration must be given to where carer's assessments fit in.

Digital, data and technology

- The UK Government, NHS, local authorities and public bodies need to look at how digital and data opportunities could be maximised in line with carers' preferences.
- Identification of carers in key data sets is essential to ensure that systems have the best knowledge available to look at experiences, outcomes, health inequalities and improving systems.
- Investment in carers' skills and knowledge must be ongoing to ensure that they are able to maximise their potential use of technology.
- Ring-fenced investment must be adopted to ensure that carers who want to connect digitally but are unable to because of low incomes are supported with hardware, Wi-Fi and sufficiently fast broadband.
- Super-fast broadband is essential to maximise the potential for carers accessing services and remote working for carers.

Juggling work and care

- The UK Government should bring forward its pledge to introduce Carer's Leave at its earliest opportunity. The NI Executive should consider legislation as soon as possible.
- The UK Government should implement a day one right to request flexible working as this would help carers to juggle work and care, potentially return to work and would help foster a better culture. The NI Executive should consider this alongside Carer's Leave.
- The UK Government should raise the level of the earnings limit on Carer's Allowance and peg it to the National Living Wage so that they benefit from year on year rises in wages, rather than making work less attractive. We recommend that the NI Executive follows suit.
- Employers should adopt Carers UK's Carer Confident benchmark, run by Employers for Carers, to move towards becoming a carer-friendly employer. In Scotland, we recommend employers using Carer Positive run by Carers Scotland.

- Carers UK would encourage all employers to become early adopters for unpaid Carer's Leave or improvers – seeking to provide paid Carer's Leave because it provides additional support for carers helping to retain them in the workplace.
- The UK Government and nation Governments should consider a refresh of work around carers' returners, skills recognition and later life apprenticeships where carers are able to juggle work and care.

Equality, recognition and combatting loneliness and isolation

Throughout this report, carers have talked about the inequalities they face, the struggle they have to be recognised and the fact that they often feel very undervalued. They also talk about the huge difference recognition, value and access to services and support can make in their lives. This is borne out through the vaccination programme, free flu jabs, good quality care, voluntary organisations' support, supportive employers helping carers to juggle work and care and digital services that better meet carers' needs. There is a need for a step change in the way that carers are recognised and supported, which has been highlighted more than ever during the pandemic but is a building block for any ageing society.

- Carers UK believes that caring should be made the 10th protected characteristic
- There needs to be systematic awareness raising through key professions or in key settings such as all levels of the NHS.
- Awareness campaigns, like Carers Week, Carers Rights Day and other initiatives to work together to reduce the time it takes for a carer to identify themselves and seek support at the right time.



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.

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