

# Caring behind closed doors: six months on

The continued impact of the coronavirus (COVID-19) pandemic on unpaid carers

October 2020





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# About this research

Carers UK carried out an online survey between 11th September and 28th September 2020. A total of 5,904 carers and former carers responded to the survey. This included 5,583 current carers and 321 former carers. 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. As not all respondents completed every question in the survey, a number of the figures given in this report, including those presented here, are based upon responses from fewer than 5,904 carers.

Of current carers who responded to the survey:

- 1% are 0-24, 3% are 25-34, 11% are 35-44, 26% are 45-54, 35% are 55-64, 18% are 65-74 and 7% are aged 75 and over.
- 16% have childcare responsibilities for a non-disabled child under 16.
- 80% identify as female and 19% identify as male.
- 4% describe their ethnicity as Black, Asian or Minority Ethnic (BAME).
- 3% identified as lesbian, gay or bisexual.
- 25% consider themselves to have a disability.
- 63% live in England, 13% live in Scotland, 10% live in Wales and 14% live in Northern Ireland.
- 36% have been caring 15 years or more, 15% between 10 to 14 years, 23% between 5-9 years, 22% between 1-4 years, 2% for less than a year and just 1% since the beginning of the COVID-19 pandemic.
- 73% care for one person, 21% care for two people, 5% care for three people and 2% care for four or more people.

# Foreword



This research provides powerful evidence that 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 care is having on many aspects of their life; their relationships, their mental and physical health, their paid work and their emotional wellbeing. Our first *Caring behind closed doors* report released in April 2020 provided shocking insight into the experiences of carers at a time of national crisis, and this report shows the continued severity of that negative impact, six months on.

Whilst there have been positive innovations in tech-based support for carers and some carers have greatly enjoyed the slower pace of life due to the COVID-19 pandemic, the vast majority have found life significantly more difficult. A decrease in support and sometimes complete closure of local services alongside an increase in care needs has led to most carers having to provide much more care.

This new report provides evidence of the intolerable pressure that carers are feeling and the exhaustion they are facing. This echoes recent findings from the Alzheimer's Society looking into the experience of dementia carers<sup>1</sup> and the Disabled Children's Partnership's research on parent carers<sup>2</sup>. Carers were already seven times more likely to be lonely than the average person<sup>3</sup>, and recent restrictions and shielding have stripped away the support networks carers have, leaving many feeling isolated.

Winter is fast approaching, bringing with it colder weather and the usual pressures on health services. These survey results show that worrying about the coming winter period is causing stress and anxiety for carers, many of whom have had no break from caring for many months and are reaching breaking point. The risk of burnout is especially concerning when so many carers are worried that there is no back-up or contingency support available for the people they care for, should they get ill.

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. Comments shared in this survey show that many feel invisible and forgotten about and that urgent action is needed to step up the support that is available. We need to give back to carers – they are doing incredible things behind closed doors and the invaluable part they play in the national effort against COVID-19 must be recognised and properly supported through a New Deal for Carers.

Carers UK continues to do all we can to support carers and the people they care for at this challenging time. As always, we are hugely grateful to everyone who fills in our surveys and makes our research possible. We value the contribution of each and every one of the 5,904 carers who took time out of their busy life to share their story.

**Helen Walker, Chief Executive, Carers UK**

1 Alzheimer's Society (2020) 'Worst hit – dementia during coronavirus'  
 2 Disabled Children's Partnership (2020) '#LeftInLockdown – Parent carers' experiences of lockdown'  
 3 Carers Week (2019) 'Getting carers connected'

# Executive summary

There were up to 9.1 million unpaid carers across the UK before the COVID-19 pandemic, providing everything from a few hours of support a week to intensive and complex round the clock care.<sup>4</sup> The pandemic has resulted in millions of new carers – 4.5 million new to caring since the start of the pandemic, 2.8 million of whom are juggling work and care.<sup>5</sup>

Caring can have significant costs, and without sufficient support it can take its toll on carers' emotional and physical health, ability to work and have a knock-on effect on their long-term finances. Carers have been hit particularly hard as a result of the COVID-19 pandemic. As this research shows many have had to make extremely difficult decisions about work and family.

## Carers are providing even more care than six months ago

Before the crisis, carers were already providing substantial hours of care. In April 2020, 70% were providing more care.<sup>6</sup> Six months later this has increased further; 81% of carers reported that they were providing more care since the start of the outbreak for one or more reasons. Two in five carers (40%) said they are providing more care because the needs of the person they care for have increased. 38% were providing more care because of local services reducing or closing.

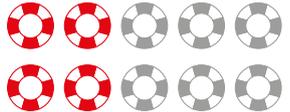
## Needs have increased

The COVID-19 pandemic has changed the nation's lifestyle, with many services closed or reduced and an increase in staying at home leading to a reduction in physical activity. 8 out of 10 (78%) carers reported that the needs of the person they care for have increased since the COVID-19 pandemic. This has led to over half (58%) of carers feeling more stressed and, half saying it had an impact on their health and wellbeing, as well as their ability to take a break.

## Fewer breaks and no breaks

Almost two thirds of carers (64%) have not been able to take any breaks from their caring role during the COVID-19 pandemic. While one in five (19%) said that they had not been able to take as many breaks as they felt they needed. A clear majority of carers (79%) selected at least one of these two options indicating that they had not been able to take any, or sufficient, breaks.

81%   
of carers are providing more care since the COVID-19 pandemic

40%   
of carers are providing more care because the needs of the person they care for have increased

38%   
of carers are providing more care because of local services reducing or closing

78%   
8 out of 10 carers said the needs of the person they care for have increased since the COVID-19 pandemic

<sup>4</sup> Carers Week (2020) Carers Week Research Report

<sup>5</sup> Ibid

<sup>6</sup> Carers UK (2020) Caring Behind Closed Doors: the forgotten families of the coronavirus outbreak

<sup>7</sup> Carers UK (2018) State of Caring 2018

## Worse health and wellbeing

Caring for someone can be challenging and many previous research reports have evidenced the impact on carers' physical and mental health.<sup>7</sup> Alongside the usual stresses, the coronavirus outbreak has added additional pressure. Almost two thirds of carers (64%) say that their mental health has worsened as a result of the COVID-19 pandemic. Just half (50%) of carers said that they feel able to manage their caring role at the moment, while 22% are worried about being able to care safely due to a lack of knowledge, information or equipment.

## Worried about winter

Carers are worried about their ability to continue to care over winter and throughout the ongoing pandemic. Over half (57%) of carers are worried about what happens in case of emergency, as they do not have a contingency plan in place. Over two thirds of carers (67%) are worried about how they would cope if further lockdowns or local restrictions were introduced.

## Exhausted and worn out

Carers are struggling to continue caring and are reporting high levels of fatigue and stress, with almost three quarters (74%) reporting feeling exhausted and worn out as a result of caring during the COVID-19 pandemic. 44% of carers say they are reaching breaking point.

## Struggling financially

Many carers already faced very difficult financial situations due to their caring responsibilities. Over a quarter of carers (28%) are struggling to make ends meet. While more than one in ten respondents revealed they were/had been in debt as a result of caring. For those in receipt of Carer's Allowance, over a third (36%) are struggling to make ends meet.

## Work – a mixed picture

Juggling work and care was challenging before the pandemic – now, a reduction in services and the national shift to working from home has meant employers and employees have had to adapt fast. For some working carers this has been beneficial. Despite the government's intervention in the labour market, 11% of carers reported that they had reduced their hours to manage their caring responsibilities, and 9% had given up work because of caring.

## Digital differences

There has been a huge increase in the availability and use of online services and digital technology. 33% of carers started using new technology and digital services during the COVID-19 pandemic. But there is a growing digital divide with 10% of carers reporting that their ability to use digital technology was limited because they struggled to afford things like equipment, WiFi or data and this rose to 18% for carers who were struggling financially.

## Some positives during caring

Despite facing enormous pressure caring during the COVID-19 pandemic, for some carers a simpler life and more time connecting with family and friends have had a positive impact. Carers have been able to connect with their local communities or religious or faith groups again, alongside having more time for leisure.

64% 

Two thirds of carers have not been able to take any breaks from their caring role during the COVID-19 pandemic

64% 

Almost two thirds of carers say that their mental health has worsened as a result of the COVID-19 pandemic

74% 

Three quarters of carers are feeling exhausted and worn out from caring during the COVID-19 pandemic

# The changing nature of care

Even before the COVID-19 pandemic, carers were providing substantial levels of care with many caring around the clock. In our research in April 2020, 70% of carers told us they were providing more care than normal and the results in this section show this has risen even further.

## Increased levels of care

81% of carers reported that they were providing more care since the start of the outbreak for one or more reasons – an 11% rise in only six months. Only 5% of respondents reported providing less care.

When asked for further details, two in five carers (40%) said they are providing more care because the needs of the person they care for have increased. Local services reducing or closing was another common reason for providing more care, with 38% of respondents selecting this option. 26% of carers said they are providing more care because someone they rely on for breaks was no longer available and 15% said they were providing more care because they were worried about paid health and social care staff having contact with the person they care for.

92% of BAME (Black, Asian and Minority Ethnic) carers reported that they were providing more care since the start of the outbreak. The most common reason cited by BAME carers for providing more care was local services being reduced or closed (49%), with an increase in the needs of the person they care for (42%) being the second most common reason.

77% of carers who are caring for their spouse/partner reported providing more care since the start of the pandemic. In comparison, carers looking after a parent (82%) and parents caring for their disabled or ill son or daughter (87%) were more likely to report an increase in the care they have provided since the start of the COVID-19 pandemic.

The survey findings indicate that carers are providing an average of 10 hours more care, with respondents providing 55 hours a week on average before the start of the pandemic and 65 hours a week since. Many were caring around the clock for more than 90 hours per week.

*“I was concerned that [the care workers] would bring Covid into the household and therefore cancelled the care workers. My family are doing it between us instead until the pandemic is over or a vaccine is introduced.”*

*“It has been the hardest 6 months of my life and I am dreading another lockdown.”*

*“There is nowhere for [my autistic children] to go as all support services are closed or online. This is hard on all our mental health.”*

*“Having to spend more time arranging the practical side of Dad’s care and the emotional side has meant I’ve felt a lot more pressure juggling this with my paid work and the family.”*

## Changes in care needs and impact

8 out of 10 (78%) carers reported that the needs of the person they care for have increased since the COVID-19 pandemic. Just 2% of carers reported that the needs of the person they care for have decreased since the start of the COVID-19 pandemic. Increased care needs have had an impact on carers in a number of ways.

58% of carers reported that this increase has made them more stressed. Half (51%) of carers report that this had an impact on their health and wellbeing. Half (50%) of carers also reported that the increased needs of the person they care for had impacted their ability to take a break, and 41% said the increase in care needs had impacted their relationship with the person they care for. Almost half (49%) of working carers said that this increase had impacted on their ability to juggle paid work with caring. Despite an increase in needs, there have been challenges in getting the right adaptations, even for those who had been waiting since before COVID-19.

- “The people I care for are more demanding than they used to be, because we are around each other 24/7 it becomes difficult to “like” each other and get along.”
- “His hearing has deteriorated and so has his speech. He finds it very hard to join in online socialising and often declines. I feel he is losing contact/interest in his family.”
- “During lockdown my mother’s mobility has decreased due to her not being able to do any activities.... I am trying to work full time from her home whilst caring for her and giving medications a district nurse would do.”
- “I feel very distant and concerned for my relative who is in a care home, I was a very regular visitor and fully involved in supporting with their care (hair washing, nails etc.) – my concern is the lack of contact for nearly six months will have had a massive impact on their dementia and their wellbeing.”

## Experiences of shielding

Three quarters (76%) of carers reported that the people they care for shielded – more than a third (36%) of those receiving care shielded after being formally advised to, while a further 40% chose to shield due to concerns about exposure to COVID-19 or another reason. Many of this latter cohort were people living with conditions or health issues not included on the Government’s shielded patients list, but who chose to shield for their own safety from the virus.

Just 2% of carers reported that people they cared for who were advised to shield had not been able to. Within this group were carers who said their friends or family members struggled with their mental health and needed to leave the home, or had a condition such as Alzheimer’s Disease that meant they did not understand or remember the shielding rules.

Some of the comments from carers suggest that shielding had a detrimental impact on the mental and physical health of people receiving care, which in turn made things more difficult for them.

- “[The person I care for] became physically weaker. Their mental wellbeing suffered.”
- “My husband still feels he needs to shield which I understand. He has lost his confidence to go out which has impacted his mental health more.”
- “It had a very negative impact on Mum, she was bored, agitated and felt I was keeping her a prisoner. Very sad time.”

21% of carers said they were formally advised to shield themselves and many said that they found shielding a stressful and lonely experience. 6% of those advised to shield were unable to, with some of this group citing their caring role as the reason for not shielding, because they had no choice but to leave home to buy food and collect medication for example. 22% of carers chose to shield due to worries about exposure to COVID-19. Many of those who shielded for another reason (14%) also cited that they did so to keep their family safe.

- “I am more anxious about going out than I have ever been in my life. My boundaries have narrowed. It is so lonely.”

Whilst responses suggest that over half (51%) of carers shielded, responses also indicated that there is ongoing confusion amongst carers about the meaning of shielding, with some stating that they shielded, but also that they left their home for essentials.

# Bereavement

Losing the person they care for can be a devastating experience for carers at any time and those who lost someone since the start of the pandemic shared their experience of how COVID-19 affected this difficult time and the impact it had on them. Many carers shared that this has been a very isolating experience.

- “Mum died in April after coming out of hospital and staying in a care home for about five weeks. She had dementia and didn’t understand that we couldn’t then be with her during lockdown. Before that, when she had been in hospital we had visited her daily so she must have felt abandoned and I think this hastened her death by months.”
- “Waving at my terminally ill husband through the hospital window was devastating for both of us. To be allowed to be with him for only the last 40 minutes of his life was useless to both of us, leaving me torn apart with inconsolable guilt and grief.”
- “I feel that I am not able to grieve properly. Although some equipment which mum used was taken away quickly I still haven’t been able to dispose of medicines as our small local pharmacy does not have enough available space. I still have controlled drugs at home.”
- “I had a very upsetting phone call from the consultant explaining that the only option [for my husband] was palliative care, it’s very hard receiving news like this especially as I am by myself but also because of Covid no-one could give me a hug.”
- “Because of Covid I had to [provide end of life care] virtually single handed, I found this very stressful as I wanted to let him die at home as he wished but I felt ill equipped to this. I am proud of myself that I managed to do this but I don’t think I could have coped for much longer by myself.”

# Access to breaks and services

Carers have a right to a life beyond their caring responsibilities but prior to the COVID-19 pandemic, research showed that 40% hadn't had a day off for more than a year, and a quarter (25%) for more than five years<sup>8</sup>. Care and support services provide many carers with a break from caring, however, large numbers of these services have been unavailable in recent months.

## Taking a break from caring

Almost two thirds of respondents (64%) said that they had not been able to take any breaks from their caring role during the COVID-19 pandemic, while one in five (19%) said that they had not been able to take as many breaks as they felt they needed. A clear majority of carers (79%) selected at least one of these two options indicating that they had not been able to take any, or sufficient, breaks during the pandemic.

The reasons given by carers for why they had not been able to take a break were wide ranging, with many pointing to lockdown or shielding restrictions, or not being able to rely as much on friends and family. It is clear that this has had a severe impact on them.

*“I have struggled hugely being with my husband 24/7, unable to have a break from caring. There are times I think I can't go on, but of course I have to. Sometimes I don't want to wake up in the morning.”*

*“My usual activities like fitness class, carers cafe or other social activities either haven't returned or have been limited, which were valuable to my wellbeing.”*

*“I used to get a break by family helping but as they have jobs and their own family they cannot risk helping. It's all down to me now.”*

*“I'm doing at least 14 hours of intense caring a day. I get an average of 5.5hrs sleep and eat most of my meals 'on the move'. Never get to relax or read a book. With increasing restrictions, I can't see my extended family at home, or visit a friend who is my main support.”*

A minority of respondents (27%) indicated that they had been able to take some sort of break during the COVID-19 pandemic, with a variety of different reasons provided.

- I have been able to take a break when my family or friends provide care (15%).
- I have been able to take a break because I formed a support bubble (3%).
- I have been able to take a break when the person I care for goes to a day or other support service (4%).
- I have been able to take a break when the person I care for goes to overnight care services outside the home (eg care homes) (2%).
- I have been able to take a break by accessing home care support (4%).
- I have been able to take a break by accessing online activities (3%).

## Limited access to support services

Carers were also asked about their experiences of accessing different support services during the COVID-19 pandemic and the impact this has had. The responses show that many carers are still unable to access services which they previously relied on, as many of these have not reopened or returned yet, in their area.<sup>9</sup>

|   | This continued throughout the pandemic | This has reopened/ returned but I am getting a lower level of support than before | This has reopened/ returned and I am getting the same level of support as before | This has reopened/ returned but I am not using it | This has not reopened/ returned in my area |
|---|--|---|--|---|--|
| Day services  | 9%                                     | 24%   | 8%   | 10%   | 49%  |
| Care Home   | 23%                                    | 12%   | 7%   | 23%   | 35%  |
| Residential Care  | 16%                                    | 14%   | 6%   | 21%   | 43%  |
| Specialist schools  | 3%                                     | 28%   | 44%  | 16%   | 8%   |
| Before and/or after school provision for a disabled child           | 2%                                     | 15%   | 11%  | 17%   | 55%  |
| Activities provided by a local Carers Organisation                  | 11%                                    | 15%   | 4%   | 8%  | 61%  |
| Activities/support provided by a local charity (eg meals on wheels) | 11%                                    | 12%   | 3%   | 9%  | 65%  |
| Visits from paid care workers                                       | 42%                                    | 21%   | 16%  | 11%   | 11%  |
| Sitting service   | 16%                                    | 13%   | 19%  | 16%   | 36%  |
| Other breaks services   | 3%                                     | 16%   | 7%   | 13%   | 62%  |

“I would normally get 84 respite nights per year. I’ve been offered 12 between now and January 2021. Didn’t get any during lockdown. Day service shut during lockdown but they did provide some support and have now reopened but a shorter day.”

“I share the view of other carers in my situation that we are all crumbling if we can’t get a break of some kind. We also agree that our adult children want a break away from us! Day services gave my son a life, friends, interests and often inspired him to do things on his own. Now they have gone, he is bored, angry, a lot of shouting. It’s exhausting!”

“All respite provision has been withdrawn, no respite since last December! Day care provision was 30 hours a week, presently two hours twice a week with no transport provision.”

<sup>9</sup> Please note the table above includes only respondents who are service users of this particular service, ie people who were using the service before lockdown and/or are using it now

# Health, wellbeing and emotional impact

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<sup>10</sup>. Given the huge increase in caring being provided, and the fact that this is often without any breaks, it is unsurprising that carers are feeling the pressure and seeing an additional impact on their own health and wellbeing.

## Health impact of the pandemic on carers

Almost two thirds of carers (64%) say that their mental health has worsened as a result of the COVID-19 pandemic. This was significantly higher for carers who were struggling financially (74%). 65% of women said their mental health had suffered compared to 58% of men.

58% of carers say their physical health has worsened as a result of the COVID-19 pandemic. This was slightly lower for men (54%) compared with (58%) of women, but carers who were struggling financially had seen a higher impact on their physical health with 70% having seen it worsen as a result of the pandemic.

The impact of the pandemic on carers' health is far reaching with 70% of carers having reduced the amount of physical activity they are taking part in since the start of the pandemic. This rises to 74% of BAME carers and 74% of carers who said that they are struggling financially. Only 29% of carers feel that they have been able to maintain their health and wellbeing during the pandemic and only 43% have been able to maintain a healthy diet.

*My depression and anxiety have rocketed, I haven't been able to follow a healthy diet and I haven't had chance to do any exercise ... the lockdown has ruined so many things."*

*I am putting my health needs on a back burner as all my physical and mental energy goes on caring for my husband."*

*I used to attend Pilates classes which helped with the maintenance of my back and can no longer do this. Someone needs to be here for Mum at all times so I am unable to go out with my husband.... We have looked after my Mum for 20 years and now feel that life is passing us by."*

## Loneliness

Only 30% of respondents reported having a network of people around them to support them, and 48% reported feeling lonely and cut off from people. This is perhaps due to the fact that less than half (48%) of carers feel they are able to keep in contact with neighbours, family or members of their local community.

Carers who were struggling financially were more likely to be facing loneliness with 19% saying they had a network of people around them and 62% saying they feel lonely and cut off from people.

*I am a shadow of what I was before going into lockdown. I am lonely, fed up and depressed, yet I can't show these traits and must carry on my caring duties, no matter what. It worries me that carers who are in the same position as myself will be feeling the same and may do drastic things to escape."*

*I have had to stop my hobbies such as guitar lessons, my friend has not been able to visit, and these two things gave me a chance to forget about my caring role for a few hours. I have really missed being able to talk to someone and feel very worried and anxious because I have no-one to talk to."*

*Mostly, I just feel really lonely. I don't feel that I can tell people about my situation as I feel that it would be disloyal somehow to Mum and I fear that people get bored listening to me moaning on."*

<sup>10</sup> Carers UK (2019) Facts about carers 2019

## Worries about the future and contingency

Whilst 50% of carers said that they feel able to manage their caring role at the moment, 22% are worried about being able to care safely due to a lack of knowledge, information or equipment.

57% of carers are worried about what happens in case of an emergency as they do not have a contingency plan in place – this rises to 63% of carers who have not had any break since the start of the COVID-19 pandemic.

Over two thirds of carers (67%) are worried about how they would cope if further lockdowns or local restrictions were introduced. This is higher for BAME carers, of whom 73% are worried about how they would cope in this situation.

63% of carers are worried about how they will manage this winter with comments indicating that they are worried about the impact of weather, seasonal illnesses, reduced chances to get outside and their own health. This is higher for BAME carers (72%), carers who are struggling financially (78%), working carers (66%) and carers who haven't had any break since the start of the COVID-19 pandemic (66%).

*“I feel my depression has spiralled since this virus started ruining the world, I feel there's no hope for this world a lot of the time and am very, very frightened what the future is going to be for me and the person I look after.”*

*“My sister does provide some help, but she lives further away and with her husband is in the vulnerable age bracket herself. As the winter sets in with reduced number of daylight hours and worsening travel/weather conditions they will be less able to help out.”*

*“My own health issues are always worse during the winter and I am so tired at a point in the year when I've normally had a break and some social time – all of which hasn't happened this year.”*

## Exhaustion

Carers reported high levels of fatigue and stress, with almost three quarters (74%) reporting feeling exhausted and worn out as a result of caring during the COVID-19 pandemic. Shockingly 44% of carers say they are reaching breaking point.

Not having any break during the pandemic clearly has an impact on levels of burnout, with 79% of carers in this position reporting feeling exhausted and worn out and half (50%) saying they are reaching breaking point. 51% of carers who reported that the needs of the person they care for have increased since the start of the COVID-19 pandemic say they are reaching breaking point.

*“I am exhausted. I was caring for two people at the start of the lockdown, sadly one person has now passed away, but the health of the second person has deteriorated further so there is no let-up in the amount of caring required. 24/7 with no breaks.”*

*“I feel distraught and shattered everyday.”*

*“I still feel a burden of responsibility to keep Dad, Mum, my husband and myself free of COVID, and any other infection too. That weighs heavy on my shoulders every day.”*

## Carers' interactions with health services and professionals

65% of carers have put off going to the doctor or another health professional about their health because of the pandemic and 7 in 10 carers (70%) are worried about someone they care for going into hospital, in part due to the reduced opportunities to visit. Whilst there are examples of supportive services across the country, shockingly, only 29% of carers feel that their ability and willingness to provide care is respected by health and social care professionals.

*“I feel my Mum would get more care from health professionals if I wasn't here. I feel the view is ‘she has a carer, she's ok’ and therefore we are just left alone to get on with it. It's a reactive position, not proactive.”*

*“My husband's care needs have become very complicated and I feel out of my depth now. As his carer I feel totally left out of the loop, no-one has spoken to me about what is happening even though I have constantly requested that someone ring me.”*

38% of carers said that their own NHS treatment has been delayed as a result of the COVID-19 pandemic and this has affected their wellbeing. However, 57% said that the treatment had been delayed for someone they care for with the same impact on their wellbeing. The comments from carers make it clear that delays to treatment have an impact for not only the person needing treatment, but a knock-on effect for those providing care for them.

*“The person I care for has had several procedures delayed which has caused anxiety for her and I have been the one bearing the brunt of her anguish.”*

# Financial pressures

Caring often brings with it additional costs, from increased fuel payments, to transport and equipment costs, which can be compounded by having to reduce their working hours or leave employment to provide care.

1.2 million carers were living in poverty before the COVID-19 pandemic<sup>11</sup> and during the earlier stages of lockdown, carers were twice as likely as the general public to have used a foodbank.<sup>12</sup>

Carers UK's recent survey confirms that the financial pressures carers were facing six months ago are still an issue. Over a quarter of respondents (28%) reported that they were "struggling to make ends meet". While more than one in ten respondents (11%) revealed they "were/had been in debt as a result of caring".

This research shows that certain groups of carers were more likely to be struggling with their finances than others. 30% of carers caring for more than 35 hours a week reported that they were struggling to make ends meet compared to 20% of carers providing less than 35 hours of care a week.

*"We are permanently struggling financially and are in debt."*

*"I am constantly using my savings to make ends meet."*

Over a quarter of carers (26%) reported that they are spending more due to COVID-19. This is lower than in our previous *Caring behind closed doors* research in April, but there remains a significant proportion of people seeing an increase in costs.

*"Food shopping has gone up, most nights I don't eat so the children do, bills have gone up due to the children being at home more."*

*"Because I am having to have all necessities delivered, I am faced with delivery charges that have now increased. If I ask someone to get me things they are usually very expensive as they wouldn't shop around."*

*"With my son home full time my household bills have trebled."*

Despite the added financial pressures that carers are facing, Carer's Allowance, the main carers' benefit, is only £67.25 a week (2020/21 rates). It is the lowest benefit of its kind and carers have felt forgotten about after the Government increased some other benefits in response to the pandemic but did not change the rate of Carer's Allowance. 36% of those who are in receipt of Carer's Allowance reported that they are struggling to make ends meet. 15% of carers in receipt of Carer's Allowance also reported being in debt currently or in the past as a result of caring.

*"Carer's Allowance is not anything like enough to pay my bills. Gas, electric, water, spare bedroom tax, takes much more than what Carer's Allowance pays to me."*

<sup>11</sup> New Policy Institute (2016) 'Informal carers & poverty in the UK: An analysis of the Family Resources Survey'

<sup>12</sup> Zhang Y., Bennett M.R. and Yeandle S. (2020) *Caring & COVID-19: Hunger and mental wellbeing*. Sustainable Care: Care Matters 2020/01, CIRCLE, University of Sheffield, Carers UK

# Impact on working carers

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. The events of recent months have had a significant impact on work, with both employers and employees having to adapt quickly to new circumstances. Our previous research in April showed the immediate impact of the pandemic with 9% of working carers unable to work due to social distancing measures, and 13% on the furlough scheme.

Of the 1,374 carers who reported in this survey that they were in paid work before the pandemic, 40% reported that they were working from home, 14% had returned to their normal workplace and 27% were key workers who had been going to work as normal. Many working carers highlighted that working from home gave them the flexibility to manage their caring responsibilities, as well as the reduction in commuting time allowing them to spend more time with the person they care for but others highlighted that they were often working long hours to manage their work and caring.

*“Digital technology has enabled me to be more productive in work as I do not have to travel and I am able to organise my personal care responsibilities around work.”*

*“I cannot always work my normal working hours and find myself instead topping up working hours late at night once my child is sleeping. I am now “living at work” not working from home.”*

The furlough scheme was a significant intervention that supported many carers to manage their caring responsibilities when services were shut and particularly for those caring for someone who was shielding. 5% of working carers remained on the furlough scheme, with 2% of those working part-time on the scheme.

*“My employer has been supportive in allowing me to stay furloughed until shielding finished which allowed me to care for my parents and keep them safe but they have also allowed me to work just one day during local lockdown.”*

Despite the intervention in the labour market, 11% of carers reported that they had reduced their hours to manage their caring responsibilities and 9% had given up work because of caring. Services being closed or reduced during the COVID-19 pandemic often meant that some carers felt they had no choice but to reduce their hours or give up work. The limited return of services continued to have an impact.

*“Our daughter was home for 12 weeks because her care home wouldn't have her back. We went from having her home five days every three weeks to caring for her 24/7. I had to give up paid work.”*

*“Less time for work or anything because of the lack of day services and cut back in hours from my son's support worker (because of shortage of staff from the provider organisation).”*

*“Since day services started again, and because I am doing the driving (just under an hour each way), I now spend four hours x two days a week sat in the cafe near my son's day services trying to get work done on laptop but it's not good for confidential meetings.”*

Carers who were working prior to the COVID-19 pandemic were asked what would help them to stay in, or return to, work. Flexibility in the hours and days they worked and the ability to take paid leave were the most common responses.

- Flexibility in the hours and days I work (43%).
- The ability to take time off from work to care – access to paid Carer’s Leave (42%).
- The ability to work from home part-time (33%)
- My employer being more understanding of caring responsibilities (27%).
- The ability to continue to work from home full time (25%).
- A conversation with my manager about how I manage my caring role with work (24%).
- The ability to access day and support services that are of sufficient quality (23%).
- Affordable and accessible replacement care for the person I care for (23%).
- Clear communication from my employer communicating the steps they have made to make my workplace safe (15%).

Carers highlighted the importance of having a supportive employer and being able to work flexibly and access Carer’s Leave in supporting them to remain in work. However, many others struggled to access the leave and flexibility they need.

“My employer, a local council, has been great. They made me aware of the new Carer’s Leave entitlement and bereavement leave, allowed me to drop a few hours a week to manage earlier in the year and pick back up again. So far I have been able to manage my caring duties effectively.”

“Lucky to have an excellent manager who is incredibly understanding and flexible. However zero service provision locally means I will need to travel to Glasgow with my daughter for her to access suitable day services. This will pose logistical difficulties trying to balance with working.”

“I have been disciplined about the amount of unpaid leave I have had to care so I think it’s safe to say I don’t feel at all supported by my employer.”

“I have explained to my manager how my Mum’s health is deteriorating, and they have not been very understanding. If this continues to happen I will have no choice but to leave work, as caring for my Mum comes before my work.”

For those carers who have given up work or reduced their hours to care during the COVID-19 pandemic, almost half (48%) said affordable and accessible replacement care or access to quality day and support services would help them to stay in or to return to work. Without services returning, and the introduction of measures to support flexible working and paid leave, more carers will have no choice but to give up work to care.

48%



Almost half of carers said affordable and accessible replacement care or access to quality day and support services would help them to stay in or to return to work

# Use of technology

The inability to meet face-to-face during the COVID-19 pandemic has led to a huge increase in the availability and use of online services and digital technology across the country. However, a digital divide has also widened with those without access to digital services and technology being left behind.

33% of carers reported that they had started using new technology and digital services during the COVID-19 pandemic. The most popular type of technology used, by far, was video conferencing.

- I use video conferencing and calling services such as Zoom or WhatsApp more to keep in touch with friends and family and/or connect with other carers – 58%.
- I use video conferencing and calling services such as Zoom or WhatsApp more to access local support services for myself or the person I care for – 15%.
- I have online video consultations for appointments with my GP and for other health and social care services – 16%.
- I use online support groups and forums more to connect with other carers – 13%.
- I use online mental health support services – 5%.

The main benefits identified by carers of using technology and digital services during the COVID-19 pandemic was that it allowed them and the person/people they care for to keep in touch with others and not become isolated.

*“I have always used video calling as a means of communication with family and found it emotional & beneficial during the last and current lockdown.”*

*“[The care team] have interacted with him online which has improved his computer use. He has been less isolated than he could have been thanks to technology and as a result his mental health and skills have not deteriorated too much.”*

However, a significant number of carers revealed that they experienced barriers. 21% of carers reported that it was difficult for them to find a private space and this made it harder for them to utilise digital services to connect with others and 13% said that poor broadband connection and phone signal were other problems for them.

*“As I don't have a private space to communicate as the person I care for is always home, I have found it hard to ring those around me to discuss how I am feeling.”*

*“Poor broadband connection make using Zoom etc impossible. This has made me feel more isolated whilst others can keep in touch.”*

In addition, 10% of carers reported that their ability to use digital technology was limited because they struggled to afford things like equipment, WiFi or data and this rose to 18% for carers who were struggling financially.

33% of carers reported that they would continue to use the digital services and technology they had started using during the COVID-19 pandemic in the future.

# Positives of the pandemic

Carers were asked if the COVID-19 pandemic has had a positive impact on their life in any way. Some respondents shared stories of how they were able to spend more time with their families and had more opportunity for leisure activities.

*“Working from home has made it far easier to care for my Mum. It also means I get more sleep and I feel far less tired than I did before when I commuted for three hours most days.”*

*“My family are the most important thing to me and I’ve enjoyed spending more time with them.”*

*“I have enjoyed more time for reading.”*

*“More time for self-development. I’ve actually enjoyed lockdown to an extent as everything has slowed down and I feel less left behind.”*

*“I have been able to enjoy some of the online activities (online) that my local carers’ organisation have run (art classes, chair yoga, mindfulness).”*

*“We’ve discovered online church services.”*

*“We have found it to be a relaxing time being able to do what we want when we want and not watching the clock for pickup times etc. Lots of help via digital technology for me too again via local Mencap.”*

However, the vast majority of respondents responded that the COVID-19 pandemic has had only negative impacts on their lives and that they feel under more pressure than ever.

# The support carers need

Many carers already faced significant pressures prior to the COVID-19 pandemic, which have now been compounded further by the current crisis. It is clear from survey responses that there is a need for increased support in a wide number of areas.

Carers were asked what additional support they would like to receive in the future, with the following being the most popular options:

1. Clearer/more specific guidance from the government for unpaid carers.
2. Prioritised access to vaccinations for carers and people they care for.
3. More help with contingency planning in case you aren't able to provide care.
4. More government funding for social care.
5. Access to breaks and replacement care.
6. A rise in Carer's Allowance.

Over half of carers (52%) said they wanted clearer and more specific guidance from the government for unpaid carers, showing that carers are clearly still anxious to ensure they are providing care as safely as possible and taking the correct steps to protect those they care for. Many carers also stated that they needed clearer and more specific guidance in certain areas, for example when the people they care for have to go to hospital, or when accessing care homes.

*“Suitable information given in a clear format instead of having to endlessly searching, reading and working out what's best.”*

Almost half (49%) of carers who responded selected 'prioritised access to vaccinations for carers and people they care for' as support they wanted in future. Carers are still very worried about the impact the COVID-19 pandemic is having on their lives, reflecting the central role they play in providing care to the people they support.

*“I particularly think priority for any vaccine that becomes available is very important for carers and the people they care for.”*

Half (48%) of carers who responded said they wanted more help with contingency planning in case they aren't able to provide care. This was a significant worry for many pre-COVID-19, and clearly many carers are very worried about the future, and fear that they won't be able to continue providing care for the people they currently support.

*“If I get ill there is no one else to take over my caring role. No family to help, or social services. We've been told my mother doesn't meet the criteria for adult social care visits, so have been advised to seek private care, which financially is an issue.”*

Just under half (47%) of carers selected 'more government funding for social care', with many carers noting that the current system does not work for them or the people they care for.

*“A care system that has properly funded professionals. Care in the community (in this area) is staffed with minimum wage/only job available. They have little training or skills, with dementia patients. When you leave the house, to work, you want to know your loved one is safe.”*

More than two in five carers (44%) also wanted better access to breaks and replacement care.

*“More than anything I need respite breaks if my husband is not to go into residential care.”*

43% of carers felt that a rise in Carer's Allowance would help them, given the financial pressures they are facing.

*“The Carer's Allowance is ridiculously low. If someone was being paid to cover my carer roles it would cost a fortune. I am happy to supplement but the guidelines for the amount you can earn doesn't add up to even the minimum wage.”*

Other areas that carers said would help them, all of which were selected by at least 10% of respondents, included:

- Increased financial support (40%).
- More support from your GP (40%).
- More support from the local authority (Health and Social Care Trusts in Northern Ireland) and local services (37%).
- Someone to talk to (36%).
- More frequent testing for coronavirus (COVID-19) (34%).
- Better personal protective equipment (PPE) for unpaid carers (27%).
- More advice and information around benefits entitlements (25%).
- More support in the community eg from local volunteers (20%).
- Paid leave from your employer to support the person you care for (19%).
- Better personal protective equipment (PPE) for social care staff (16%).
- More support from community pharmacies (13%).

*“Carers are being greatly affected financially [by the pandemic] and central government have provided very little, if any, financial help and support, instead focussing specifically more on paid workers and supporting employers. Many carers are feeling forgotten about and left behind.”*

*“Day care centres resuming would make a significant impact on mine and my mother’s mental health and respite care for my husband and myself.”*

*“I feel that my GP surgery is not helpful or supportive at all, and they made my life very hard over the lockdown. Getting appointments is a nightmare.”*

*“We need accessible and locally available appropriate regular testing available for asymptomatic paid carers or myself or cared-for person. Until this is provided there is no safety for either cared-for person or myself as vulnerable citizens.”*

*“An entitlement to paid leave when you care for an adult is long overdue.”*

# Conclusion and recommendations

Caring can be challenging, and impacts on all aspects of life from health and wellbeing, to finances. The COVID-19 pandemic has put carers under extreme pressure. Many carers are caring around the clock, without having had a single break since the start of the COVID-19 pandemic. As this report shows, they are exhausted and reaching breaking point.

## Carers UK's response to the COVID-19 pandemic in the last six months

Since our last report in April 2020, we have continued to work to support carers. We have tailored and regularly updated our information and advice, keeping carers up to date with ever changing guidance and responding to their needs for information. We have provided direct support through online Care for a Cuppa Chats, Me Time and Share and Learns and supported more carers through our national helpline and NI Adviceline. Responding to carers' concerns, we have developed new tools such as our contingency planning tool MyBackUp. We are developing and promoting carers' e-learning helping to provide confidence. Good practice by local authorities and innovative ideas from carers organisations has been gathered and disseminated, with a view to sharing knowledge and building carers' recovery. We continue to work with employers to seek out good practice and provide advice on how to support carers better across all four nations of the UK. Finally, we channel carers' voices to the four nation governments directly, through our research and engagement with carers in order to seek change. As a result, a number of changes and measures to support carers have been introduced.

## The risks for carers, their families, friends and society

Without the support of families and friends caring, the response to COVID-19 could have been very different with health and care services becoming quickly overwhelmed. This report clearly shows that carers are struggling to cope with the levels of care they are providing. Organisations, including local authorities and Health and Social Care Trusts, are finding more carers continuing to come forward or being identified with greater levels of stress and increased needs, including carers who have never needed support before.

Without the right intervention the stress and challenges during this time could lead to carer breakdown, with negative impacts on the carer and people needing care lasting long beyond the COVID-19 pandemic.

Governments have put some measures in place, for example, the UK Government included measures to support carers in the Adult Social Care Winter Plan and extra funding through the Infection Control Fund. Yet the scale of need to support carers to care safely and get the breaks they need will be far greater in the future compared with before the COVID-19 pandemic as well as concerns that this may not be sufficient now.

We need immediate action by government, local government, health bodies, and local organisations.

**We need to give back to carers now.** We need a commitment to a **New Deal for Carers** from government – with medium term tangible action and clearly defined support within social care reforms in the future. We recommend that UK and nation governments:

- Ensure that carers are able to take breaks and that the return of essential services is prioritised.
- Place a high priority on guidance, information and advice for carers that is adapted to their needs.
- Ensure that carers and their families are not facing significant financial hardship.
- Provide sufficient funding for local authorities and Health and Social Care Trusts to meet these increased levels of social care need.
- Prioritise carers' and their families safety whilst enabling them to continue caring.
- Ensure that local authorities and Health and Social Care Trusts have sufficient resources to carry out and deliver contingency planning with carers.
- Place a priority on carers' health and wellbeing.
- Ensure that carers are able to continue to remain in work.
- Place digital strategies and services as a core part of delivery for the future.
- Deliver a **New Deal for Carers**.
- Deliver long term reform of social care with carers at its heart.

## In the short term, to support carers through winter, the UK and nation governments should:

### Ensure that carers are able to take breaks and that the return of essential services is prioritised

The majority of carers (81%) are taking on more care since the start of the COVID-19 pandemic, as a result of a reduction in local care and support services, an increase in needs of the person they are caring for, and a reduction in family and friends that are available to help. To prevent carer breakdown the UK and nation governments should:

- Announce an urgent review of breaks provision by government to delve deeper into solutions for carers and ways to provide sufficient capacity for the sector.
- Continue to ensure the Infection Control Fund in England and other capacity funding provides sufficient investment for day and evening service providers to increase face-to-face support to comply with social distancing and infection control measures. This funding should be continued beyond March 2021 to provide the surety for carers that they will be able to get a break and to provide stability in the market.
- Ensure that within any further measures to reduce social contact, families and friends supporting disabled or older people and carers are able to form care bubbles.
- Find solutions for essential overnight respite care where rules restrict this eg 14 day quarantining rule for residential respite care.
- Ensure that core services are returned safely to reduce the pressure on carers, even if they don't provide a break.
- Ensure essential transport services to and from services, education, and healthcare continue or are re-instated where they have stopped.
- Ensure essential aids and adaptation services continue.
- Enabling families to visit care homes should be prioritised, with regular testing of staff and relatives visiting. Governments must assure themselves there is sufficient funding for care homes to enable them to facilitate visits safely.
- Continue to support and encourage local authorities and Health and Social Care Trusts to carry out Carer's Assessments and support planning as part of the assessments, as the current legislation requires.

### Place a high priority on guidance, information and advice for carers that is adapted to their needs

Many carers are unclear about how they keep themselves and the person they care for safe and do not feel they have been provided with enough clear information from their respective nations' governments. As local measures are introduced it is vital that UK and nation governments:

- Ensure that carers are an early part of leadership messaging whether by the government, advisers, or in local lockdowns, recognising their support and contribution, targeting advice quickly for them.
- Refine, update and issue tailored guidance for unpaid carers. This must be provided locally when restrictions on social interaction are introduced, targeted at carers and in accessible formats, languages and easy-read, consulting key communities and groups.

### Ensure that carers and their families are not facing significant financial hardship

Caring often comes with significant costs, and during the COVID-19 pandemic carers have faced additional costs from the availability of low-cost food options, having to pay for equipment or technology to support the person they are caring for, or the increased cost of being at home for longer. Carer's Allowance is the lowest benefit of its kind at just £67.25 a week (2020/21 rates). To ensure that carers and their families do not face significant financial hardship the UK Government should:

- Introduce an equivalent uplift payment to Universal Credit to those in receipt of Carer's Allowance or receive a premium due to underlying entitlement.<sup>13</sup>
- Provide continued flexibility in the claiming conditions for Carer's Allowance.
- Write off any overpayments debts for carers that have occurred during this time where the carer has made a mistake.
- Increase the level of Carer's Allowance and associated premia, to at least the level of Jobseeker's Allowance.
- Extend the Winter Fuel Allowance to those entitled to working age disability benefits and Carer's Allowance.

<sup>13</sup> In Scotland, carers in receipt of Carer's Allowance are paid an additional payment twice per year a Carer's Allowance Supplement. In addition, they have introduced a one off Coronavirus Carer's Allowance Supplement to those eligible for Carer's Allowance Supplement in June 2020

### Provide sufficient funding for local authorities and Health and Social Care Trusts to meet the increased levels of social care need

During the COVID-19 pandemic, there has often been a rise in needs of the person being cared for. As well as this, we are seeing increased needs of carers – particularly in terms of their mental wellbeing. Sufficient funding is needed to continue essential services providing capacity and sustainability of the care and charity sector. The UK and nation governments should:

- Conduct a rapid reassessment and reappraisal of the level of need for social care and housing.
- Ensure that reassessments of need build in funding for rehabilitative services and support considering all conditions and caring situations.
- Conduct an urgent reappraisal of the baseline need in local authorities, and provide sufficient resource allocation for winter, and subsequently for the 2021/22 budgets for local authorities.
- Provide sufficient investment in rehabilitation services to enable people to regain the skills they lost over the COVID-19 pandemic.

### Prioritise carers and their families' safety

Carers remain concerned about their ability to keep themselves and the person they care for safe, and continue to worry about paid care workers entering their homes. To support carers to continue to care the UK and nation governments should:

- Ensure continued priority testing for COVID-19 for carers.
- Deliver a communications campaign to encourage carers' uptake of the flu jab, targeting groups such as working carers, BAME carers and those caring at a distance, that are less likely to have a flu jab.
- Include a key questions in test and trace to identify whether someone is providing unpaid care and signpost to tailored government carers guidance.
- Ensure access to free PPE for specific unpaid carers in key situations modelled on Scotland's scheme, and that there is sufficient free PPE for visitors in care homes, supported living and in hospitals, as well as secure supplies for care workers.
- Prioritise carers for the COVID-19 vaccination, replicating the priority list for the flu jab.

### Prioritise carers' health and wellbeing

The NHS and social care depend on unpaid carers. Yet, carers postpone and delay their own medical treatment because they cannot make alternative caring arrangements for the person they care for while they are undertaking treatment. This is amplified and extended if there is a shortage of care, and shielding groups have to remain under more restricted conditions. To support carers to look after their own health and wellbeing the UK Government should:

- Rapidly upscale and accelerate GP identification of carers. Strengthen and accelerate this with NHSE&I to introduce a basic requirement of all GP practices to have a system in place to identify carers.
- Support local authorities, and ensure they have sufficient funding to deliver targeted mental health support for carers.
- NHS England should deliver new guidance to CCGs and NHS Trusts to ensure that carers are made a priority for planned treatment, working in partnership.
- Provide a focus on physical activity for carers to maintain wellbeing.

### Ensure that local authorities have sufficient resources to carry out and deliver contingency planning with carers.

Carers are worried about what will happen if they are no longer able to care, or they fall ill. Many older carers were particularly worried about their disabled adult sons' and daughters' short-term needs, should this happen. The majority of carers wanted more support to help them create contingency plans.

- UK and nation governments need to ensure that local government (Health and Social Care Trusts in NI and Health and Social Care Partnerships in Scotland) have enough funding to deliver contingency planning support for carers.
- Local government and local organisations need to provide carers with advice and information, and support carers to have a contingency plan that meets their needs and they feel confident they can rely on.

## Ensure that carers are able to continue to remain in work

Until social care services, holiday play schemes, community support and specialist services are fully restored to their former levels, many carers will be unable to return to an office or workplace. To ensure that more carers do not have to give up work to care the UK and nation governments should:

- Introduce targeted support to ensure that where local services have been reduced or not reopened that carers do not have to give up work to care.
- If shielding guidance is reintroduced deliver a targeted scheme like the furlough scheme for people shielding and their carers if they are unable to work.
- Accelerate the introduction of five days Carer's Leave and introduce this as paid leave.
- Continue to support flexibility in the workplace and provide clear guidance for employers.

## Digital strategies and services must be a core part of delivery and the future

The results show that digital is here to stay and brings a number of opportunities with it for carers to connect, combat loneliness, support caring, access services and gain new skills. There is an opportunity to build on tech assisted care with this new approach and openness to digital and tech. We recognise that face-to-face services are also needed, but a blended approach offers the best for everyone in the future.

- National government should continue to encourage the development of digital strategies for support balancing this against practical needs for support.
- Local authorities and health bodies need digital carers' strategies to reach, connect, support and enable. This includes funding for low income carers and others and skills training to be able to use digital resources.
- Local carers' organisations and others need to continue to provide digital support as part of their core and ongoing offer.

## In the medium term

### Deliver a New Deal for Carers and social care reform

There is no doubt that our NHS and social care services could not have coped had carers not provided more care, but the toll it is taking on their lives is enormous. Government needs to give back to carers by delivering a New Deal for Carers to redress the balance. This needs bold and decisive action that delivers a new vision and action for carers.

This New Deal for Carers needs to start with a tangible cross-cutting Government Action Plan and move to strong and robust delivery of support as part of the government plans for the future of social care reform in each of the nations.

In April 2020, carers told us what they wanted to see in the future from the government, including any plans to reform social care. Any future reform of social care must have strong, clear and defined benefits and support for carers. Carers must be involved in the development of these plans as well as delivery. It is the collective nation governments responsibility to see that this is delivered as a priority; as longer-term social care reform is long overdue and extremely urgent.

The majority of adults will care for a family member or friend at some point in their lives, but the impact on their health, finances and wellbeing is often underestimated. Even a small number of hours of care a week can have a significant impact on carers' lives, yet there are thousands of people caring around the clock. During this pandemic many have cared without access to any form of break.

The government should introduce a New Deal for Carers to give back to carers. Each of the nation governments should also develop their own New Deal for Carers which focuses on devolved areas, working together across the UK to agree a shared approach to reserved issues such as employment. This should deliver tangible outcomes in an Action Plan:

- Systematic identification of carers by health and social care professionals, and the introduction of a new duty on the NHS in each nation to identify carers and promote their health and wellbeing.

- Improving carers finances. Raising the level of Carer's Allowance and ensuring that carers do not face a financial disadvantage in retirement.
- Raising awareness of caring and the role of unpaid carers through a public awareness campaign.
- Enabling carers to juggle work and care, including promoting flexible working, introducing paid Carer's Leave and a longer period of unpaid leave.
- Supporting carers' health and wellbeing, including investing in mental health services for carers.
- Supporting carers to lead their own lives alongside caring, ensuring that carers are able to access breaks and support services.
- Explore introducing caring as a protected characteristic.

## For the long term

### Deliver long term reform of the social care system

The government needs to set out plans for a long term, sustainable solution to funding social care that has carers at its heart. A failure to do so will only see social care continue to be in crisis, with knock on effects on hospitals, the economy, families, carers and people who need access to care.

A reformed system and funding solution must guarantee stability and sustainability, deliver improvements to care and be well funded, with sufficient resources to enable the delivery of consistent high-quality care. We want to see care free at the point of delivery under a system of pooled risk, ideally funded through taxation. The plans need to include working age disabled people and older people, as well as key specific measures to support carers.

Carers have also given the message loud and clear that social care reform must go hand in hand with specific measures to support carers. They must also be involved in the development and delivery of these plans.

Anything less than these measures will be falling short of what carers want, need and deserve.

# Caring behind closed doors six months on in Scotland

There were up to 729,000 unpaid carers in Scotland before the COVID-19 pandemic, providing everything from a few hours of support a week, to intensive and complex round the clock care.<sup>14</sup> The pandemic has resulted in millions of new carers, including 392,000 new to caring in Scotland, since the start of the pandemic.<sup>15</sup> The impact of caring without sufficient support takes its toll on carers, who have been hit particularly hard by the COVID-19 outbreak.

Before the crisis, carers in Scotland were already providing substantial hours of care. In April 2020, 78% said they were providing more care than before.<sup>16</sup> Six months on, this has increased further, with 87% of carers now reporting that they are providing more care. More than a third (40%) of carers said they are providing more care because the needs of the person they care for have increased. 45% were providing more care because of local services reducing or closing.

80% of carers in Scotland reported that the needs of the person they care for have increased since the COVID-19 pandemic. This has led to 63% of carers feeling more stressed, and 55% saying it had an impact on their health and wellbeing.

65% of carers in Scotland have not been able to take any breaks from their caring role during the COVID-19 pandemic, while 22% said that they had not been able to take as many breaks as they felt they needed. A clear majority of carers (81%) selected at least one of these two options indicating that they had not been able to take any, or sufficient, breaks. This has affected carers' health and wellbeing, with 66% reporting that their mental health has worsened due to the COVID-19 pandemic.

Carers in Scotland are worried about their ability to continue to care over winter and throughout the COVID-19 pandemic. Fewer than half (49%) of carers said that they felt able to manage their caring role at the moment, with 21% worried about being able to care safely due to a lack of knowledge, information or equipment. 72% are worried about how they would cope if further lockdowns or local restrictions were introduced. More than three quarters (77%) reported feeling exhausted and worn out as a result of caring during the COVID-19 pandemic.

Many carers in Scotland already faced difficult financial situations due to their caring responsibilities. 29% of carers in Scotland are now reporting struggling to make ends meet, while 10% revealed they were/had been in debt as a result of caring. Juggling work and care remains a challenge, with 7% of carers having reduced hours to manage their caring responsibilities, and 7% had given up work to care since the COVID-19 pandemic.

**In addition to the UK wide recommendations, Carers Scotland further recommends that the Scottish Government:**

- Provide a second Coronavirus Payment as part of the Carer's Allowance Supplement (CAS) in December.
- Recognise that not all carers are eligible for CAS, and provide additional ring fenced funding to offer dedicated funding for carers facing hardship. This could be administered by local authorities through the Scottish Welfare Fund or through local carers centres.

<sup>14</sup> Carers Week (2020) Carers Week Research Report

<sup>15</sup> Ibid

<sup>16</sup> Carers UK (2020) Caring Behind Closed Doors: the forgotten families of the coronavirus outbreak

# Caring behind closed doors six months on in Wales

There were up to 487,000 unpaid carers in Wales before the COVID-19 pandemic, providing everything from a few hours of support a week to intensive and complex round the clock care.<sup>17</sup> The pandemic has resulted in millions of new carers, including 196,000 new to caring in Wales, since the start of the pandemic.<sup>18</sup> The impact of caring without sufficient support takes its toll on carers, who have been hit particularly hard by the COVID-19 outbreak.

Before the crisis, carers in Wales were already providing substantial hours of care. In April 2020, 79% said they were providing more care than before.<sup>19</sup> Six months later this has increased further, with 80% of carers reporting that they were providing more care. More than a third (38%) of carers said they are providing more care because the needs of the person they care for have increased, while 37% were providing more care because of local services reducing or closing.

76% of carers in Wales reported that the needs of the person they care for have increased since the COVID-19 pandemic. This has led to over half (54%) of carers feeling more stressed, and 49% saying it had an impact on their health and wellbeing.

60% of carers in Wales have not been able to take any breaks from their caring role during the COVID-19 pandemic, while 21% said that they had not been able to take as many breaks as they felt they needed. A clear majority of carers (78%) selected at least one of these two options indicating that they had not been able to take any, or sufficient, breaks. This has affected carers' health and wellbeing, with 66% reporting that their mental health has worsened due to the COVID-19 pandemic.

Carers in Wales are worried about their ability to continue to care over winter and throughout the COVID-19 pandemic. Less than half (46%) of carers said that they feel able to manage their caring role at the moment, with 21% worried about being able to

care safely due to a lack of knowledge, information or equipment. 68% are worried about how they would cope if further lockdowns or local restrictions were introduced. Over three quarters (76%) reporting feeling exhausted and worn out as a result of caring during the COVID-19 pandemic.

Many carers in Wales already faced difficult financial situations due to their caring responsibilities. More than a quarter of carers (29%) are now struggling to make ends meet, while 11% revealed they were/had been in debt as a result of caring. Juggling work and care remains a challenge, with 16% of carers having reduced hours to manage their caring responsibilities, and 6% had given up work to care since the COVID-19 pandemic.

## **In addition to the UK wide recommendations, Carers Wales further recommends that the Welsh Government:**

- Publishes guidance to local authorities outlining timescales and process by which they should revert to 'business as usual' regarding the carers rights laid out in the Social Services and Wellbeing Act, and ensure that any changes to individuals care/and or support plans are reinstated fully at the earliest opportunity.
- Recognise the additional financial hardship carers have faced and set up a specific fund for carers facing financial hardship.
- Issues specific revised guidance to local authorities ensuring more flexibility in the use of Direct Payments and make it clear that carers and service users can employ family members.
- Reinstates as a matter of urgency its commitment to an awareness raising publicity campaign to identify and inform carers of their rights.
- Welsh Government and Local Authorities to consider the findings and implement the recommendations from our forthcoming Track the Act 5 report.

<sup>17</sup> Carers Week (2020) Carers Week Research Report

<sup>18</sup> Ibid

<sup>19</sup> Carers UK (2020) Caring Behind Closed Doors: the forgotten families of the coronavirus outbreak

# Caring behind closed doors six months on in Northern Ireland

There were up to 212,000 unpaid carers in Northern Ireland before the COVID-19 pandemic, providing everything from a few hours of support a week, to intensive and complex round the clock care.<sup>20</sup> The pandemic has resulted in millions of new carers, including 98,000 new to caring in Northern Ireland,<sup>21</sup> since the start of the pandemic. The impact of caring without sufficient support takes its toll on carers, who have been hit particularly hard by the COVID-19 outbreak.

Before the crisis, carers in Northern Ireland were already providing substantial hours of care. In April 2020, 78% said they were providing more care than before.<sup>22</sup> Six months on, this has increased further, with 85% of carers reporting they were providing more care. Over a third of carers (37%) said they are providing more care because the needs of the person they care for have increased, while 45% were providing more care because of local services reducing or closing.

80% of carers in Northern Ireland reported that the needs of the person they care for have increased since the COVID-19 pandemic. This has led to 58% of carers feeling more stressed, and 53% saying it had an impact on their health and wellbeing.

61% of carers in Northern Ireland have not been able to take any breaks from their caring role during the COVID-19 pandemic, while 17% said that they had not been able to take as many breaks as they felt they needed. A clear majority of carers (74%) selected at least one of these two options indicating that they had not been able to take any, or sufficient, breaks. This has affected carers' health and wellbeing, with almost two thirds (65%) reporting that their mental health has worsened due to the COVID-19 pandemic.

Carers in Northern Ireland are worried about their ability to continue to care over winter and throughout the COVID-19 pandemic. Less than half (48%) of carers said that they feel able to manage their caring role at the moment. With over a quarter (27%) reporting being worried about being able to care safely, due to a lack of knowledge, information or equipment. Almost three quarters (72%) are worried about how they would cope if further lockdowns or local restrictions were introduced. Nearly three quarters (73%) reported feeling exhausted and worn out as a result of

caring during the COVID-19 pandemic. 44% of carers feel lonely and cut off from people.

Many carers in Northern Ireland already faced difficult financial situations due to their caring responsibilities. More than a quarter (28%) are now reporting struggling to make ends meet, while 9% said they were/had been in debt as a result of caring. Juggling work and care remains a challenge, with 9% of carers having reduced hours to manage their caring responsibilities, and 4% had given up work to care since the COVID-19 pandemic.

## **In addition to the UK wide recommendations, Carers Northern Ireland further recommends that the Northern Ireland Executive:**

- Health and Social Care Trusts should ensure carers in Northern Ireland are informed of their right to a Carer's Assessment and encourage uptake through a promotional campaign, alerting carers to the supports available.
- Ensure that carers' rights are maintained and enhanced, and the vital role of unpaid carers in supporting the health and social care system is clearly recognised in the rebuilding, and delivery, of health and social care going forward.
- Co-produce an action plan with carers to restore essential services and support carers to transition back to some sort of normality as lockdown eases and while COVID-19 remains present.
- Ensure funding for short breaks is ringfenced and support organisations providing short breaks to return to delivering their services safely.
- Increase financial support for carers through increasing Carer's Allowance or introduce some form of supplementary payment for carers.
- Identify carers as a priority group requiring emotional support services; and develop an agreed pathway for them to access interventions such as psychological talking therapies.

<sup>20</sup> Carers Week (2020) Carers Week Research Report

<sup>21</sup> Ibid

<sup>22</sup> Carers UK (2020) Caring Behind Closed Doors: the forgotten families of the coronavirus outbreak



# Caring behind closed doors: six months on

The continued impact of the coronavirus (COVID-19)  
pandemic on unpaid carers

October 2020

If you are a carer looking for information and guidance, please visit the help and advice section of our website [carersuk.org/help-and-advice](https://carersuk.org/help-and-advice) or get in touch with our advice team by emailing [advice@carersuk.org](mailto:advice@carersuk.org) or phoning our Helpline on **0808 808 7777** Monday – Friday, 9am – 6pm.



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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