



# Breaks or breakdown

**Carers Week  
2021 report**



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# Introduction and summary

Caring for a family member, friend, or neighbour can be challenging and often comes at significant personal cost. Without sufficient support or meaningful breaks it can take its toll on carers' emotional and physical health, their ability to work and also have a knock-on effect on their long-term finances.

For carers a break is time off from caring and a chance to do things they would like to do, but can't do while they are caring – everyday things such as catching up with friends, going for a walk, or simply catching up on sleep. It could be for 30 minutes, an afternoon, or a week. A break could be provided by accessing care services such as replacement care, sitting services, a day service, or through support from family and friends providing either respite or essential care.

Over the past year, the COVID-19 pandemic has had a significant impact on carers' ability to access breaks. Not only are the majority of carers (81%) providing more care than before the pandemic<sup>1</sup>, while their responsibility has grown the support they used to rely on has reduced.

Many carers have been on call all day, every day in the past year; on duty, never getting a night's sleep, and with no time to themselves or proper time with family or close friends.

Unsurprisingly, many carers are now exhausted and worried about how they will continue to care without increased support.

This research shows the impact of reduced support from both services and family and friends has had on carers' health and wellbeing. It demonstrates that without the right interventions there could be more carer breakdown and why the UK Government should increase funding for carers' breaks, so all carers providing significant hours of care have access to a meaningful break.

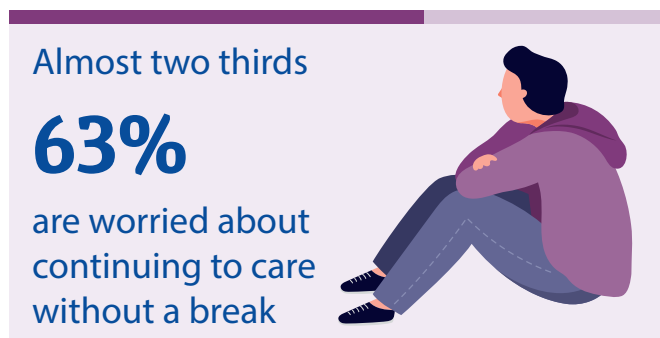


<sup>1</sup> Carers UK (2020) *Caring behind closed doors: six months on*

## Key findings

- Prior to COVID-19, many carers were already struggling to access meaningful breaks.
- Many carers have had to go without the same level of support during the pandemic, with carers losing on average 25 hours a month of support from family and friends and from care and support services.
- Carers are using their time off from caring to do essential things – 26% go to a medical appointment, and 33% to complete practical tasks such as housework.
- Carers are exhausted and worn-out. 35% of carers feel unable to manage their caring role, and their health and wellbeing is impacted.
- Working carers are affected in a similar way to those not working. 75% of working carers are exhausted and 55% are overwhelmed by their caring role.
- Worryingly, just 14% are confident that support they relied on before the pandemic will continue in the future.
- If they had a break, they would use it to focus on their wellbeing (53%) and physical health (52%) and to maintain social connections (50%).
- Carers need to feel confident that they will be supported and have hope for the future.

## Of the carers who responded to our survey



## Access to breaks

During the pandemic many carers have had to go without the same level of support from both family and friends and from care and support services. Carers reported that before the pandemic they had on average 38 hours of support every month from services and family and friends. In comparison, since the pandemic began, carers report having an average of only 13 hours a month. This leaves a gap of, on average, 25 hours of support per month over the past year, or 405 hours since the start of the pandemic.

Even before the pandemic carers were struggling to access meaningful breaks, with 44% of carers saying they did not get the breaks they needed. This situation has worsened during the pandemic, during which 72% of carers have not had any breaks; of those carers who did get breaks two thirds (66%) said they had fewer breaks or insufficient breaks to look after their physical and mental health.

## Breaks during the pandemic

The ability of carers to take breaks affects their capacity to complete essential tasks that others may take for granted. 37% of carers were using any breaks they had to take some exercise. A third (33%) of carers were using breaks to complete practical tasks and chores such as housework.

Worryingly, over a quarter (26%) of carers had used time away from their caring role to attend their own medical appointments.

**26%**

of carers used any breaks they had to attend medical appointments



## 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>2</sup> The COVID-19 pandemic has severely affected carers' ability to take a break, which has impacted on their health and wellbeing. Over two thirds of carers (69%) say that their mental health has worsened because of a lack of breaks. And 64% of carers said their physical health has got worse.

## 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. Nearly two thirds (63%) are worried about continuing to care without a break. Significantly, over a third (35%) of carers feel unable to manage their caring role.

## Worried about future support

Before the COVID-19 pandemic, many carers were struggling to get the support they need for themselves and the person they care for. Carers reported feeling worried and uncertain about the future.

Only

**14%**

of carers said they were confident support will continue into the future



<sup>2</sup> Carers UK (2018) State of Caring 2018

# Caring during the COVID-19 pandemic

Carers have a right to a life beyond their caring responsibilities, but prior to the COVID-19 pandemic many were unable to access the support and breaks they needed.

Before the COVID-19 pandemic, research showed many carers were struggling to access the breaks they needed to have a life beyond their caring responsibilities; 40% of carers hadn't had a day off for more than a year, and a quarter (25%) hadn't for more than five years.<sup>3</sup>

To understand the impact COVID-19 has had on both informal and formal support for carers to have time away from caring, we asked carers how they got a break before COVID-19.

Of those carers who said they were receiving breaks before the pandemic, the majority (64%) reported relying on family and friends to take a break. This shows the importance of informal support from family and friends.

23% of carers received breaks through care services, and 19% through day services, 9% from local age, disability or carers organisations and 8% from residential breaks. A significant proportion of carers (44%) reported that they did not get any breaks before the pandemic.

Carers of disabled children were more likely to be using day services (33%) to have a break, 26% used care services and 14% used residential breaks.



Carers lost

**25**

hours of support every month during the pandemic



**64%**

of carers reported relying on family and friends to take a break



<sup>3</sup> Carers UK (2019) Give us a break

# Dan's story

Dan Murray, 32, recently became a carer for his husband Mark, who was diagnosed with Motor Neurone Disease in October 2020. COVID-19 slowed down the process of Mark's diagnosis as it took a long time to get appointments. Dan gave up his job to care for Mark.

“ I can't be at work, I have to be at home caring for Mark. Mark is my priority and he always will be but at the same time I would love to work. I have spoken to social care and heard about the options I would have if I chose to go back to work. But they wouldn't be able to provide the full-time care that I could give him.

Anything I can do to help Mark, making sure he's got a drink, making him nice meals, whenever he wants to shower or go to the toilet, whatever he wants to do I am at his beck and call any time he needs me. My priority is Mark and I want to keep him as well as possible, for as long as I possibly can.

My other concern is around COVID-19 – if you're seeing three different carers, three or four times a day, they might be seeing 10–15 other people a day and could come in and bring COVID-19 to Mark. I have to protect Mark. We used to love going out to eat on a Saturday, that's not possible now due to COVID-19. At Christmas we both saw nobody as I was petrified that Mark would get COVID-19. If I got ill with it, who would care for Mark? But then you can't see family, you can't see friends, you can't do day-to-day things. With Mark being clinically vulnerable I have to be so careful because I don't want him to fall ill.

“It's so hard because I want Mark to have a normal reality as much as possible and enjoy the time he has left, but at the same time protect him.”

It's so hard because I want Mark to have a normal reality as much as possible and enjoy the time he has left, but at the same time protect him.

I've not had a break. My job from the moment Mark gets out of bed in the morning to the moment Mark goes to bed at night, is caring. That can be 16 hours a day. It's seven days a week. Not that I'm complaining, I want to do it. Mark's my husband and I love him and I wouldn't let anyone else do it. Anyone would do the same if you love someone.



## Impact of COVID-19 on carers' breaks

72% of carers reported not being able to take a break during the pandemic. 66% of carers who had received a break said they had not had enough breaks to protect their health and wellbeing or had had fewer breaks than before the pandemic.

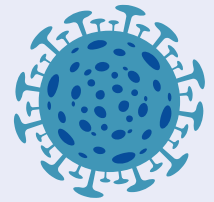
- I have not tried to take a break because it will be too difficult during the pandemic (24%)
- I have not tried to take a break because I'm too worried about catching COVID-19 (21%)
- I have tried to take a break but was not able to because of the pandemic (20%)
- I have had a break but I have had fewer than before the pandemic (10%)
- I have had a break but they have not been enough to look after my own health and wellbeing (8%)
- I have had a break (8%)
- I do not want a break (7%)
- I have had more breaks (2%)

Many carers highlighted that there had been a change in the support they received from family and friends, due to national and local restrictions.

*"My disabled son stayed with my parents sometimes at the weekend, to allow me a break. This hasn't been possible due to lockdown, as they are not in our support bubble. I reached exhaustion and ultimately had to take time off work for stress (two months). As neither of us have had a break from each other, it has reached impossible situations sometimes."*

# 21%

of carers chose not to take any breaks because they were worried about catching COVID-19



A fifth (21%) of carers chose not to take any breaks because they were worried about catching COVID-19. Many highlighted that they reduced services and home care workers entering their house due to the risk of infection. It is of concern that some felt they would not be able to resume these services after the pandemic.

*"When the pandemic broke out, I cancelled services because of the risks. There could have been 30 carers coming in per week which was worrying. I was told if I didn't keep the services going I would lose them. This caused great stress. I kept the services but lost the showering calls and still haven't had them back. I pay someone once a week so at least the family member gets a shower or I have to do it on my own. At 68 years old it is quite demanding physically on me."*

Those caring for someone who was shielding felt they had to reduce the services they used.

*"Would normally split care between myself and siblings and family friends would help out too for longer breaks away. However, since the start of the pandemic I have taken over sole caring duties as I live with the person I am caring for and was able to shield with them. Have therefore not had a break during this time."*



Many carers highlighted that some support services had reduced or stopped completely, leaving them without the support they usually relied upon.

“Respite (overnight) cancelled, and usual social care services not operating. Usually my son accesses community facilities during the week, but the agency completely cancelled all community visits. Some Saturday club outdoor operating during the summer, but this did not continue once lockdown happened again. All understandable, but very stressful.”

“Our paid PA refused to work during the pandemic and left us high and dry. All charity support stopped in person and I was completely alone. Still am over a year later with no active in-person support.”

“My son’s day services all closed. His support worker could only offer a few hours here and there (instead of daily support) because of shortage of staff in the provider organisation. I had to move in with my son because of the collapse in support.”

Where services continued, or were reinstated, they provided a lifeline to many carers who felt able to use them.

“My local VCS carer organisation has been offering a new and terrific project called Time 4 You which has helped me to focus on the impact of my caring role, the need for me to think about self-care and develop some strategies to achieve breaks in my day to keep me going. They also provided a grant to pay for me to buy some things to help me to return to a hobby during lockdown which has been so incredibly helpful. Breaks in my day have been more important to me than ever as I’ve not been able to have a longer break from caring for over a year.”

“Day carers have continued their excellent support throughout the pandemic, allowing me to visit less often than normally.”

Carers spoke about the impact of caring 24/7 without a break. Some made the decision after the first lockdown to ask for more support to protect their physical and mental health. The support they then received was often a small number of hours a week.

“The first lockdown I didn’t get any breaks. I was caring 24 hours, seven days a week for three months. After that I got three hours every week except for Christmas/ New Year. In that three hours I do the week’s shopping so I haven’t had any time just for myself.”

“I had family support during summer 2020 after I had been sole carer on my own for three months with my 101 year old mother. I had become depressed and sought counselling. Now I have a weekly visit from my brother to enable a break.”

## Missing support

Breaks away from caring means different things to different carers; the type of condition, the age of the person in their care and their relationship to them all impact on the amount of services and support the carer and the person being cared for receive. Someone caring for a child with a severe disability may have support for a high number of hours a week while their child is at residential school. Someone caring for an elderly parent may be relying on family and friends to provide time away from caring.

Carers were asked to estimate how many hours on average they had away from their caring role, including both support from family and friends and from support services. Before the pandemic carers had on average 38 hours a month.

Carers were also asked to estimate the amount of time away from their caring role they had during the COVID-19 pandemic; on average they had 13 hours a month.

That means carers on average have had 25 hours less support a month during the pandemic or have lost 425 hours during the pandemic.

Carers told us about the impact of not having the same level of support than before the COVID-19 pandemic. Many highlighted that they were experiencing fatigue and stress and that this was placing a strain on their relationship with the person they care for.

“Last time I had a week’s break it was while my husband was in residential care – early March 2020 just before lockdown. I am fortunate to have care workers in the morning and evening and a Crossroads helper on a Friday morning, while I shop. I feel very fraught and exhausted and desperately need a break.”

“I’m a single parent and my 19 year old son has cerebral palsy. It’s hard both physically and emotionally dealing with his disability and other issues (anxiety, OCD, sleeplessness...). As I haven’t had any breaks, this has caused exhaustion, fall outs between myself and my son, breakdowns, stress, time off work, weight gain and general poor health through lack of self-care.”

Those who were paying for or arranging support themselves raised the challenges of accessing support, particularly at the start of the pandemic.

“Mom had a self-funded care package (two visits for personal care per day) before the lockdown. At onset of lockdown the care company bailed out on me citing lack of manpower and since mom receives family support she is deemed to be “not vulnerable” so care ceased at that point leaving myself to do everything.”

Many highlighted that even if they were getting support from personal care services it was not a meaningful break, often requiring them to be in the home at the same time.

“Personal care services in the home and home visits for essential medical needs have continued throughout. No change other than huge amounts of PPE. BUT this does not refer to respite. Personal care still needs my presence in the home, if not always acting as a second pair of hands. Defining respite care for the carer needs to be redefined. Many carers can (pre-COVID) take time out, leave the home, leave the loved one alone, leave the loved one in the care of family, friends or paid agencies. Some of us do not have that choice. 24/7 care means exactly that. Care support in the home is a bonus as it relieves me of some of the physical stress of doing everything by myself – but does not provide a break, but simply helps me keep up with the essentials of life.”

“My husband has Parkinson’s disease, it’s hard work sometimes 24/7 and without three hours’ respite per week supplied by Crossroads because of COVID, I am exhausted, my home is also my place of work caring for him. I haven’t been able to take that break away from him & home/work since February 2020.”

# Gayna's story

Gayna is a single parent from Bath who cares for her 21-year-old twin daughters, Hannah and Katy. She became an unpaid carer over ten years ago when her mother became ill and Gayna gave up work. Since her mother's death, Gayna has been caring for her twin daughters who have complex disabilities including scoliosis, overgrowth syndrome, disc disease and learning difficulties.

“Caring for two young people with such urgent needs means I have always found it hard to find time for myself. Before coronavirus, I got some support from social services and my local carers centre – Bath and North East Carers Centre – which gave me a few precious hours to myself each week. And I got a much-needed break from my caring role when my girls were at college and with a youth worker.

But last year's lockdown has put a stop to all that. Instead of being at college every day, Hannah has had to stay at home and follow her course online. Studying online without being able to talk to her tutors has made her extremely anxious, and I spend many hours calming her down and helping her adjust to the new way of studying. Katy has also been permanently at home, missing the time she used to spend working on a furniture upcycling project with her youth worker.

Before the pandemic I could never have imagined saying this, but the amount of time I'm spending on caring for the girls has more than doubled. To make matters worse, the girls are awake a lot at night, worrying about the lockdown which has meant I'm not sleeping well.

“Before the pandemic I could never have imagined saying this, but the amount of time I'm spending on caring for the girls has more than doubled.”



I'm really missing getting that all-important break from caring. Even if it's just a trip to the supermarket or sitting in a coffee shop for a few precious minutes; it just gives you some headspace, and the chance to be you without constantly thinking about someone else.

As lockdown restrictions begin to ease, I hope I will be able to get some support again. I'm looking forward to my son Jack being able to come round once more to look after his sisters. But even when I can get a bit more help from family and my local carers centre, things will still be tough for unpaid family carers like me. What we really need is more funding and support so we can get the breaks we need to carry on caring without getting burned out.

# A life alongside caring

We asked carers how they had used any time they had away from their caring role in the last year.

## How carers used their breaks during the pandemic

The top five answers are given below.

- 1 Taking some exercise (e.g. a walk, exercise class, run) (37%)
- 2 Completing practical tasks or housework (33%)
- 3 Attending your own medical appointments (e.g. going to the GP / dentist) (26%)
- 4 Focusing on my wellbeing (e.g. reading a book, time to myself) (26%)
- 5 Catching up on sleep (25%)

Over a third (37%) were using their time away to take some exercise. Carers spoke of the importance of being able to have a walk or take some exercise for maintaining their own health.

*“Have given end of life care for past five months, with my other siblings unhelpful, and nurses thrice weekly plus other medics. I’m always on eggshells/anticipating! A break away, even just a walk, is all that keeps me mentally strong.”*

Worryingly, a third (33%) of carers were using breaks to complete practical tasks such as housework. Over a quarter (26%) of carers had used time away from their caring role to attend their own medical appointments. This shows that carers’ access to breaks affects their ability to complete essential tasks that others may take for granted.



*“Housework, preparing and cooking meals, house maintenance, helping with mobility, making sure medication up to date and administered, taking him to appointments washing him getting up and putting him to bed, dealing with catheter bags, and help during the night are all part of my duties, so any kind of break would be a blessing, including having time for my own medical health and appointments”*

Over a third

**37%**

of carers were using their time away to take some exercise



A third

**33%**

of carers were using breaks to complete practical tasks such as housework



**26%**

of carers had used time away from their caring role to attend their own medical appointments



Over a quarter

**26%**

of carers used a break from caring to focus on their own wellbeing



A quarter

**25%**

of carers had used a break to 'catch up on sleep'



A quarter of respondents (25%) said they had used a break from their caring role to 'catch up on sleep', or to 'spend time with other family and friends'.

"Breaks can be fleeting and sometimes I'm so tired that it's not a restful or restorative break. Catching up on sleep would be unbelievable. I do everything I can like meditation and a routine but it's not enough to feel rested which takes a toll."

"A break from my caring role means being able to speak to people and focus on my own wellbeing, to work through my challenges and get support. It also means having a purpose outside of caring."

Carers' finances can often be a barrier to them being able to take breaks. Previous research showed cost was a big issue, with 38% of carers saying that they cannot afford replacement care and 34% said that they cannot afford to do any activities during their free time.<sup>4</sup>

## Giving carers the breaks they need

We asked carers how they would like to spend time away from caring if they could. The results showed that they want to focus on activities for themselves, and over half (53%) wanted to spend time focusing on their wellbeing.

- 1 Focusing on my wellbeing (e.g. reading a book, time to myself) (53%)
- 2 Taking some exercise (e.g. a walk, exercise class, run) (52%)
- 3 Spending time with other family and friends (50%)
- 4 Taking part in hobbies and leisure activities (49%)
- 5 Going away (40%)

Half of carers wanted to spend time with other family and friends. For those caring for someone with dementia this rose to 60%. Carers told us the being able to have conversations and time with other people was important when caring for someone with memory loss.

<sup>4</sup> Carers UK (2019) Give us a break

“It is so important to have a break away without caring responsibilities. To have stimulating conversations with friends and meeting different people. Living with Alzheimer’s and memory loss is mentally & physically exhausting.”

There is a large difference between what carers would like to use their breaks for and what they are actually using the time for. 49% would like to use a break to take part in hobbies or leisure activities, but only 19% of carers are currently using their breaks for this. Just 8% of carers have used a break to pamper or treat themselves, compared to 29% of respondents who would like to do so in future.

Many carers highlighted that time away and overnight stays were the most important breaks for them, allowing them to switch off and choose how to use their time.

“A couple of hours here and there, though very welcome, makes less difference to me than time when he is away, and the total responsibility of someone else. I breathe again, then.”

“I’ve never had what I consider a break. it would be being away from the caring scenario completely for a period of time, i.e. a week. At present, if I go out for a walk I remain ‘on call’ via mobile if required. Ditto at night, I never know when I will be called for to help. A break for me would be knowing there was a space of time when I would not be called. A totally caring-free space.”

Nearly half

49%



would like to use a break to take part in hobbies or leisure activities

Carers told us about the importance of having time away in benefiting their relationships with the people they care for.

“I’m less stressed and exhausted, so am more tolerant in caring for my elderly mother who has dementia and my fiancé who has a rare lifelong, life-limiting autoimmune disease”

“Recharges batteries / catch up on sleep / feel better, more confident, happier / more able to deal with caring role & less likely to take ill / we both get a break, which helps us both in lots of ways to be happier and healthier.”

Carers highlighted the importance of being able to take time out from caring to improve their mental and physical health.

“It is amazing the difference that even a short walk can make to my wellbeing and my ability to cope. The ability to get out of the house and see friends and family has been crucial for me to be able to maintain my mental wellbeing, and the ability to get out for runs, or to do yoga at home, has really helped with my physical wellbeing”

“Vast improvement in mental health and motivation to continue. I worked in a stressful job, but caring for someone with dementia is far more stressful and many of the stress management techniques don’t work because there is no end in sight nor can anything you do improve the outlook. Having a respite break puts a milestone in place and provides a short-term end point.”

# Chris' story



Chris is a full-time carer to her 80-year-old husband Mike. They have been married for 47 years. Mike was diagnosed with Alzheimer's disease seven years ago. Chris describes her caring role as both physically and mentally exhausting. Mike needs help to stand and walk and needs support with all of his personal care. Chris hasn't been out of the house on her own. When Chris does get out of the house, it's for a drive in the car together. She last had a holiday two years ago.



“ Mike relies on me 24 hours a day. We recently moved to Yorkshire in January, during lockdown to be closer to my brother who is my only support. Our only son lives in Australia and cannot visit or help in any way. He has had to cancel flights to visit his father due to lockdown restrictions. We were struggling in London and socially isolated. Moving has given us both social support. Whereas before if Mike had a fall I would cry, now I can call my brother.

I haven't had a break since my husband deteriorated and can't see myself having one in the foreseeable future. I have been seeing an osteopath for a couple of weeks – that

**“I haven't had a break since Mike deteriorated and can't see myself having one in the foreseeable future.”**

has been my only break. The pandemic has impacted on my ability to take a break. The reality of getting a break right now isn't easy and would involve many steps. My brother has investigated the possibility of a respite break but apart from the cost it would involve my husband being quarantined and COVID-19 tests for both of us and I fear he would be anxious and perhaps come out worse than he went in. I'm not in the frame of mind to take a break right now and it's as hard for me to let go. I'm scared that Mike will deteriorate and become lost in a week away from me.

I would like Alzheimer's/dementia to be treated like any other illness rather than just a 'social care' problem. Carers should not have to assess whether they can afford to provide safe, appropriate care when they need a short break.

# 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>5</sup>

Previous research undertaken during the pandemic has shown a huge increase in care being provided.<sup>6</sup> 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

Nearly two thirds (63%) of carers have not been able to look after their own health and wellbeing during the COVID-19 pandemic. Those caring for someone with dementia were more likely to say they were unable to look after their own health and wellbeing at 68%, similar to those caring for someone with a mental health condition at 67%.

“I adore my son and my father, but it’s at the expense of my own sanity and life that I worry. I’ve been plagued by illness and problems the past year and I fear that if I don’t take care of myself and take regular breaks then something is going to blow up and I fear it might be me!”

Over two thirds of carers (69%) say that their mental health has worsened as a result of the lack of breaks and caring during the pandemic. Women were more likely to say their mental health had been impacted (71%) compared to men at (64%).

**69%**

of carers said their mental health worsened as a result of the lack of breaks and caring during the pandemic



<sup>5</sup> Carers UK (2019) State of Caring 2019

<sup>6</sup> Carers UK (2020) *Caring behind closed doors: six months on*



Carers spoke of their mental health being impacted because of a lack of sleep and constantly keeping an eye on the person they are caring for.

“My husband now needs more care than ever and I don’t think he realises the impact this is having on my own mental, emotional and physical health. The lack of sleep is a big problem as we have to sleep in the same room and he frequently has bad nights. For many the end of lockdown will mean an improvement in their situation but this does not apply to all carers whose lockdown in some ways will continue.”

“Care has become a 24 hour a day, seven day a week concern, and not being able to have a meaningful break from it is having a negative effect on everything. Getting some time to myself feels like an urgent priority just to stop my own mental health floundering.”

64% of carers said their physical health has got worse during the COVID-19 pandemic. Women were more likely to say their physical health had been impacted (66%) compared to men at (61%). Those who had not been able to take a break from their caring role during the pandemic were more likely to say that their physical health had got worse (67%).

Carers highlighted that not being able to take breaks had reduced the amount of physical activity they were doing, resulting in their physical health deteriorating.

“I have arranged a break for one hour a week so I could go for a walk as I was diagnosed with raised cholesterol and it was suggested I tried to do more exercise. I have done this for the last five months. Before this I had no breaks once we started to isolate.”

“The reduction in breaks from my caring duties has resulted in a reduction in my physical fitness and has increased my concern about how much longer I can carry on providing an adequate level of care.”

Caring can also involve physical tasks such as lifting and moving the person you care for. Without the right training and equipment this can have a significant impact on carers’ health.

“Caring for two people in a home which is totally unsuitable with little lifting equipment has really taken its toll physically”

“I have back problems that have gotten worse. Caring alone is becoming a struggle as my husband is completely disabled, physically it is getting too much for me alone.”

## Loneliness

Nearly two thirds of carers (65%) feel lonelier and more isolated than before the pandemic. This is not surprising given the vast majority (81%) have had to provide more care, in many cases in their own homes, with limited outside support.<sup>7</sup> Parent carers were more likely to report being lonelier and more isolated than before the pandemic at 70%. Nearly half of carers (49%) reported not being able to maintain their relationships with others; for those who have not had a break during the pandemic that rose to 55%.

“I feel consumed by my caring role and find it difficult to switch off. I have had to give up work so miss the interaction I had with colleagues and the majority of my friends are not in the same position so it’s hard to talk to them. I’ve definitely isolated myself over the last 12 months.”

<sup>7</sup> Carers UK (2020) *Caring behind closed doors: six months on*

Positively, carers highlighted the role of technology in enabling them to connect with others. 62% said technology enabled them to connect with family and friends.

*"I've always used technology to keep in touch with friends, and I've been able to continue even though I'm caring all the time."*

For some carers, the move to more online support and social activities has benefited them as they were able to take part in activities that were either too expensive or would have required replacement care to attend in if in person.

*"Move to online support has helped as couldn't access support meetings previously due to lack of alternative care and the costs of travel in a rural area. Spending a third of my Carer's Allowance to attend an hour support group wasn't a sustainable option"*

*"I'm less lonely as I've been able to join Zoom activities and talks which I wouldn't have been able to go to physically because of my caring role. I've become a volunteer attending Zoom meetings."*

## Exhaustion

Carers reported high levels of fatigue and stress, with almost three quarters (74%) reporting feeling exhausted as a result of caring during the COVID-19 pandemic. Over half of carers (54%) said they feel overwhelmed by their caring role.

The experience of caring through the pandemic has had a significant impact on carers: 71% feel stressed and anxious as a result of caring. Nearly two thirds (63%) are worried about continuing to care without a break. Worryingly, over a third (35%) of carers feel unable to manage their caring role.

*"It's hard when you're the only person caring for someone. It's all on your shoulders, mentally and physically and emotionally exhausting."*

*"Constantly feeling tired and irritable which is not helpful to the person I care for. As I am getting older it's becoming harder to manage. We have not had any respite or breaks."*

*"It was very tiring to care for a relative even before coronavirus. It is worse now, everyone is exhausted."*

# Elaine's story

Pre-pandemic, Elaine, 71, cared for her husband Michael, 75, seven days a week with the support of paid care workers. Michael suffered a brain injury affecting his speech, mobility, and ability to function day-to-day, as well as living with several other ailments including dementia. He relies on Elaine for almost everything.

“ I truthfully couldn't cope with Michael's dementia without the care workers. They stimulate him, they do crafts. They help me shop because it's difficult for me to push him and a heavy trolley around the supermarket.

The other day they sat with Michael making a pirate ship and I actually read a book, and made a cake. I'd never have had time to do that without their help. Also, they give me the time to sometimes see my granddaughter and my great-granddaughter.

Getting breaks when they are there means I am a better carer when they've gone. If I've been out, when I get back, Michael will ask where I've been, and he's more interested. During the lockdown, when they weren't coming in, it was very difficult and stressful. I had to be on watch 24/7 because Michael's illness isn't just a 9 to 5 one. So if I was up half the night with him, all sorts of things have happened, and I had to cope with it on my own. It's quite hard when you've got nobody to ask, nobody to support you, and nobody is coming in the next day to help you and give you some rest. All these things have happened while I've been caring on my own, and it's been really, really difficult.

Once the care workers came back, it was amazing. I felt I was able to cope a lot better. When I was on my own, I found myself shouting

**“It's quite hard when you've got nobody to ask, nobody to support you, and nobody is coming in the next day to help you and give you some rest.”**



at Michael, being quite cross. It wasn't his fault, but when you're tired, you just want to shut your eyes. When you're caring alone, you just have to keep going. On the day they were due to come back I watched the clock countdown to when they'd arrive.

After the last year, I sometimes think a hundred hours of care wouldn't be enough. But Michael isn't bad all the time, and when the world starts opening up, things will be easier. When things are back to normal, my son has said he'll take me to London for the day, and I so look forward to that, and it's what's inspired me to carry on, really. I'm saving the system thousands looking after Michael, so getting some short breaks is important.

”

# 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. Many working carers reported the challenges of adapting to the new circumstances and the impact it has had on the caring responsibilities.

The majority of working carers (55%) said they feel overwhelmed by their caring role, and three quarters (75%) said they feel exhausted as a result of their caring role.

Carers highlighted that it has felt non-stop during the pandemic, with no breaks or space from either work or caring.

“What does a break look like? I only have a break going to bed for the past 16 months, I’m on demand 75+ hours a week and work and have a toddler.”

“It has felt relentless over the last 12 months. I do still work as well as being a carer. But working from home for 12 months means the lines between work and my caring role can get blurred. It feels pretty much non-stop work and care from the moment I wake up to the moment I go to sleep at the end of the day.”



# 55%

of working carers felt overwhelmed by their caring role



# 64%

of working carers reported feeling more lonely



64% of working carers reported feeling more lonely than before the pandemic and many highlighted the impact of not being able to take breaks or leave for work.

“I have no breaks. Work full time. Care full time for husband and mother. Everything falls on me. I have no life of my own. Pandemic has meant working from home so don’t even escape the house to work. But both worse now so can’t leave house anyway.”

71% of working carers said they felt stressed and anxious as a result of caring during the pandemic. Carers told us that trying to balance work and caring added to their stress levels.

“Part of the stress of the caring role doesn’t come from the caring itself but balancing it with work when something happens. It is hard to maintain a job while caring, especially through COVID when we all have to be extra cautious. I was the first person on my workplace who started remote working because of it.”

“I am working from home part-time. I had to reduce my hours further because of the added expectations on my time while at home.”

Some carers had a positive experience, with their employer highlighting the importance of providing flexibility and carer-friendly policies to enable carers to juggle their caring responsibilities with work.

“It has been challenging. I feel very fortunate that my workplace have been very supportive during the pandemic and this has certainly helped me to manage my caring role which has balanced out the extra stress and anxiety of lack of caring breaks.”

# Paul's story

Paul Marsh, 66 has been married to Julie, 62, for over 40 years. In the early years of their marriage, she was diagnosed with bipolar disorder. Paul was working, and while his job was stressful, it meant he could support Julie and their young family.

Paul later decided to retire, partly so he could take better care of Julie as she was struggling to manage her mental illness. His experiences as a carer also motivated him to support a range of different initiatives for people living with mental illness and their carers. He was a member of the Canterbury and Coastal Rethink Mental Illness Carers Support Group for five years, and in 2020, became a joint coordinator of it. Reflecting on life before the pandemic, Paul said:

"My wife is herself a very caring person. She encourages me to take time out and have a break by planning activities she knows that I enjoy, like fishing and cycling with family and friends. This is so important for my wellbeing. We are fortunate to own a motorhome and since my retirement, when my wife is well, we take short breaks and enjoy different scenery together."

The past year of the pandemic and the restrictions proved difficult, though. "They have prevented us from being able to take breaks and we've only managed one short trip away. It has had a very negative impact on us both. My wife has remained in contact with her friends and virtual social activities arranged by a local choir and her church which has been a lifeline to her. However, both of our local carer groups have been unable to meet because of restrictions and I have not benefitted from my usual stress release valve or had the opportunity of supporting others."

An added strain has been the lack of meaningful engagement and timely access to mental health professionals to reassess the efficacy of Julie's medication.



Over the years, it's been important to tweak this to mitigate length of periods and balance of highs and lows. "This has left us both feeling powerless. It is still unresolved and frustrating."

Yet Paul remains optimistic: "I am determined that the hiatus brought about by the pandemic will be overcome and as soon as our local carers group can meet, we will resume our activities including a new 'Cycle, Walk and Talk' initiative for our members to once again support one another."

"Both of our local carer groups have been unable to meet because of restrictions and I have not benefitted from my usual stress release valve or had the opportunity of supporting others."

# Worries about the future of services

Care and support services provide carers, particularly those providing high levels of care, with an important break from caring.

However, large numbers of these services have been unavailable or operating at reduced capacity in the past year. Even before the pandemic, many carers struggled to access the support they needed.

Carers were asked how confident they were that care and support services they relied on will return after the pandemic. Carers told us they were worried and uncertain about the future, with just 14% confident that the support they relied on would continue.

- I am confident that the support I receive will continue (14%)
- I am worried that the support I used to rely on might be reduced (20%)
- The services I used to use don't exist anymore (8%)
- Prior to the pandemic, I did not receive any or enough support from community or care services (44%)
- I don't know what might happen (32%)

44% of carers highlighted that they were not getting enough support before the COVID-19 pandemic.

“We didn't have enough support before the pandemic. Social Services were advised by a Carer Practice Adviser in March 2019 that we urgently needed at least a week's break but nothing ever came of that. Social Services just don't have enough funding.”

“I did not receive any help from social care prior to the pandemic as they wanted us to pay towards the care and we could not afford it even though they did two financial assessments and deemed us able to spare money BUT we can't. They do not take into consideration important outgoings.”



Many carers told us they felt worried and uncertain about services returning, citing worries about council (Health and Social Care Trusts in Northern Ireland) budgets and social care funding after the COVID-19 pandemic will be cut.

“My respite care support worker is keen to resume having my adult children but I am worried the local authority will try to change the way it is delivered. They have already tried to reduce the package prior to COVID. This arrangement has been in place for 14 years and works very well.”

“I think the situation will become worse and it will be harder financially for people to access this type of break. I feel budgets will again be cut and the disabled people and their family/carers will suffer.”

“The pandemic has emphasized how alone we are in our caring role. This has prompted us to consider that, as we are growing older, we might need to consider moving our son into some kind of independent living arrangement. I dread anything like this happening again. We feel that we have lost over a year of our lives.”

We asked carers what they need to support them in the next six months, to help them to manage their caring role and looking after themselves. Just 11% of carers said getting the same level of support they had before the pandemic is all they need.

“The person I care for is different now after 12 months without services and the services will need to support her new ways – what if they can’t. She needs more care in the home but the waiting time for a real actual reassessment of her needs is so long.”

Some working carers have been able to provide more care than before, due to being able to work from home more or being placed on furlough.

“Pre-pandemic my mum didn’t require much care and I was able to go to work. Since the pandemic I have worked from home around caring, but I worry about when I go back to work, as I will have to, and how I will manage things. For my own sake I need to go back to the office but I can’t see how it’s going to be possible.”

Carers have been essential to supporting the health and social care system during the COVID-19 pandemic. The impact of the year and reduced access to services has come at a significant cost to carers own wellbeing and the health of the people they care for. 78% of carers have reported that there has been an increase in the needs of the person being cared for.<sup>8</sup>

As well as this, we are seeing increased needs of carers – particularly in terms of their mental health. 28% of carers have said they needed more support than before the pandemic.

There will be an increase in demand for services as we move into recovery. This must be recognised. Sufficient funding is essential to provide services and ensure capacity and sustainability of the care and charity sector.

<sup>8</sup> Carers UK (2020) *Caring behind closed doors: six months on*



# Sarifa's story



Sarifa Patel, 61, cares for her husband with angina and their son, who is 36 with complex needs, at home as well as taking care of her elderly mum and neighbours. She lost her father to COVID last year.

“Caring during the COVID pandemic has definitely affected my physical and mental health. During the winter months, my husband would often stay with family in India, and that would give me a break; some respite. But now that it's not possible to travel and the variants are a worry so I don't get that support at the moment.

We've had to remain at home as our son is clinically vulnerable and I can't have anyone come into the house to help care. And his autism means he's not very good with social distancing or being outside on his own. He needs someone to constantly take care of him and keep an eye on him so he's safe. Our other children have their own responsibilities and can't come to visit like they used to and give me a break or be able to stay with them.

I tried to look after my parents too with their needs during last year. But they had COVID so couldn't help. Just too risky with our son. We lost my dad and couldn't go to the funeral. Now it's my five sisters who help with mum so I can concentrate on looking after my husband and son which takes up all my time. I also volunteer to support others with disabilities and carers on the Disability Rep Forum, which is all online now, and keep an eye on an elderly neighbour.

It's a constant battle to get the right funding and support for our health needs. Carer's Allowance just isn't enough and they just don't understand carers and all our health needs.

Having a care service to give me daytime breaks would be amazing. Just knowing my son and husband are safe and looked after and I can relax – it would be heaven!



And finding someone we trust who could safely take our son out to the football matches he loves to watch would make such a difference. He's hated being cooped up at home – lockdowns and not going out have really impacted on his behaviour and mental state. I wouldn't want to leave them overnight but just knowing they're safe with people I can trust in the day would really help with my mental health.

”

**“It's a constant battle to get the right funding and support for our health needs. Carer's Allowance just isn't enough and they just don't understand carers and all our health needs.”**

# Priorities for the future

We asked carers what support would help the most in the future, the following were the top five answers selected by respondents to the survey:

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



Carers' top priority was better access to breaks and replacement care. Many highlighted that this was essential to look after their own health and wellbeing.

*"The level of care I provide, well in excess of the 35 hours per week, is unreasonable and incompatible with personal wellbeing for any individual to provide without assistance and/or a break. The right to a complete break of a week or two a couple of times a year should be a minimal expectation for a carer to have in the context of 52 weeks per years of unrelenting and unbroken caring duties."*

*"Regular respite care provided either at home or in supported accommodation (for older people with mental health issues) so the carer can have a break would be helpful. The person may not have severe physical disabilities but if left alone may not always be trusted to look after themselves properly without adequate help."*

Carers also wanted more funding for social care, with many highlighting the challenges they have faced in the last year with reduced or no access to services, and worries about the expense if they needed residential care.

*"England still doesn't have a worked-through plan for social care, and the complete political disregard shown for unpaid carers during the pandemic does not inspire confidence that the services we rely on are safe even in the short term."*

*"Reform of the social care system is a priority for me. If, heaven forbid, my husband needs to go into a care home I would want it to be a home suited to his needs and not chosen for him by the local authority. We dare not spend our savings because we have no idea what the total cost would be. This creates an untenable situation."*

Carers wanted more help with contingency planning in case they aren't able to provide care. This reflects the deep anxiety many carers have about what will happen to the person they care for if they are no longer able to care. This has consistently been a source of great concern for carers, and only serves to exacerbate their worries about the future.

*"A regular visit from a health visitor to support with the care and help make plans for future care; I now have a heart condition and don't know how long I can go on with my caring role."*

Carers said they wanted clearer and more specific guidance from the government for unpaid carers, while 45% also said they wanted to see a rise in Carer's Allowance to help them manage their increasingly precarious financial situations.

*"Because I work 14 hours a week my earnings are slightly above the criteria to receive Carer's Allowance, so it was stopped and I am now paying back money for being overpaid. My part-time job was not only to earn more money but also as a break for myself and to give me confidence."*

*"Carer's Allowance is not enough to live on at all. It barely covers a weekly food shop, let alone bills and rent! There just is not enough money to spread across usual life expenses."*

Other priorities for carers across all ages and conditions were:

- 6 More support from their GP.
- 7 Increased financial support.
- 8 Reform of the social care system.
- 9 Prioritised access to vaccinations for carers and people they care for.
- 10 More support from health services to care safely.
- 11 Skills/training around caring, e.g. information about disease, moving/handling, coping skills, communication.
- 12 Better personal protective equipment (PPE) for unpaid carers.
- 13 Paid leave from their employer to support the person they care for.
- 14 Better personal protective equipment (PPE) for social care workforce.

*"Paid leave for caring needs from my employer would mean that my annual leave is used to take a break and not just to attend appointments or make more time for the person I care for."*

*"The above all inter-relate. Caring is expensive and costs often escalate as the person cared for needs more support. Sadly, we continue to tinker with the social care system, not giving it the parity of esteem with health which it needs and which would make such a difference to carers."*

# Conclusion

Without the support of families and friends caring, the response to COVID-19 pandemic could have been very different, with health and care services becoming quickly overwhelmed.

This report clearly shows that carers are being pushed to breaking point, and struggling to cope with the levels of care they are providing, without access to breaks and their usual support.

Organisations, including local authorities and Health and Social Care Trusts, are finding that more carers are 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.

There is potential to provide a new vision for carers that enables them to recover from the experiences of the last year and to have a meaningful life outside of caring.

Most striking is the lack of confidence that carers feel about support in the future.

An investment in good-quality care and support for people needing care which provides the breaks that carers need would be an investment in hope, wellbeing and a life outside caring.



# Recommendations

## Increase funding for breaks

The UK Government should increase funding for carers' breaks, so all carers providing significant hours of care have access to a meaningful break.

They should urgently provide an additional £1.2 billion for carers' breaks in England, through an increase in direct payments by £50 a week, to be used flexibly for essential breaks to enable them to continue caring, and recover from the impact of caring during COVID-19.

For carers who do not want to use direct payments the equivalent funding should be provided for to local authorities to support local services to deliver carers' breaks.

The UK Government should provide additional funding for the devolved administrations using the Barnett Formula. Carers' breaks must be at the heart of the health and social care system, and the UK Government should increase the long-term funding for carers' breaks provision to ensure all carers' are able to take a meaningful break.

## Better funding for social care

The UK and Nation Governments should recognise the amount of pressure the system has been under during the pandemic, and the funding shortages that were widely recognised for many years before the crisis.

There must be a significant increase in funding levels to allow the social services to rebuild after the crisis.

The Governments must bring forward plans for long-term reform of social care which places carers at the centre.

Greater investment in care will lead to a healthier and happier population better able to balance important aspects of their lives, including personal relationships, work and family.

## A supportive healthcare system

Carers must be recognised by the system. Carers are still not routinely identified or supported by health and social care professionals.

Greater consistency is needed in connecting carers to the support available to look after their own mental and physical health and wellbeing. A duty on the NHS in England, Wales and Northern Ireland to have regard to carers, and identify and support carers, should be introduced to bring a more systematic approach to improving the health and wellbeing of carers.

NHS Boards and Health and Social Care Partnerships in Scotland should ensure that carers are identified and supported in both primary and secondary health settings and measures taken to ensure that their health and wellbeing is improved.



## End carers' financial hardship<sup>9</sup>

Despite their enormous contribution, too many carers continue to struggle financially – for many carers it presents a barrier to accessing breaks due to the cost of replacement care and the ability to afford activities.

Improved financial support would particularly benefit women, who are more likely to be caring and providing higher levels of care.

The UK Government should immediately increase the basic level of support for carers through a £20 a week Supplement to those entitled to Carer's Allowance. These payments should be backdated to March 2020.



## Carer-friendly employment

The COVID-19 pandemic has long-running ramifications for workers, including working carers, many of whom are already having to balance returning to work and caring for a vulnerable person.

Employers and UK and Nation Governments, should ensure that there are carer-friendly policies in place that enable working carers to balance their caring responsibilities with work.

We fully support the government's plans to introduce an entitlement to take care leave for working carers; our preference would be for this to be paid.



## Add Your Voice and Make Caring Visible and Valued

Carers Week aims to raise awareness and understanding of caring so carers feel visible, valued and supported.

We all have a part to play ensuring carers feel recognised and their role is visible and valued.

This year everyone should **Add Your Voice** in support of unpaid carers.



<sup>9</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.

# About this research

Carers UK carried out an online survey between 8 April and 25 April 2021. A total of 2,850 carers and former carers responded to the survey. This included 2,754 current carers and 96 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 are based upon responses from fewer than 2,754 carers.

- 1% are 18-24, 3% are 25-29, 19% are 30-39, 17% are 40-49, 31% are 50-59, 27% are 60-69, 11% are 70-79, 2% are over 80
- 16% have childcare responsibilities for a non-disabled child under 16
- 79% identify as female and 20% identify as male
- 3% describe their ethnicity as Black, Asian or Minority Ethnic (BAME)
- 4% identified as lesbian, gay or bisexual
- 30% consider themselves to have a disability
- 71% live in England, 8% live in Scotland, 14% live in Wales and 6% live in Northern Ireland
- 34% have been caring 15 years or more, 15% between 10 to 14 years, 24% between 5-9 years, 23% between 1-4 years, 2% for less than a year and just 2% since the beginning of the COVID-19 pandemic
- 73% care for one person, 20% care for two people, 5% care for three people and 1% care for four or more people.



# Breaks in Northern Ireland

For carers a break is time off from caring and a chance to do things they would like to do, but can't do while they are caring – everyday things such as catching up with friends, going for a walk, or simply catching up on sleep.

Over the past year, the COVID-19 pandemic has had a significant impact on carers' ability to access breaks; with many local services closed or severely reduced, and with people having to reduce contact with family members and friends, this has left many carers without access to the support that they used to rely upon.

Many carers have been on call all day every day in the past year, on duty, never getting a night's sleep, and with no time to themselves or proper time with family or close friends. Unsurprisingly, many carers are now exhausted and worried about how they will continue to care without increased support. This research shows the impact of reduced support from both services and family and friends has had on carers' health and wellbeing.

## Access to breaks

Before the pandemic carers in Northern Ireland were struggling to access meaningful breaks, with 44% of carers saying they did not get the breaks they need. 79% of carers in Northern Ireland reported not being able to take a break during the pandemic, and a further 11% have had fewer breaks or insufficient breaks to look after their physical and mental health.

## Breaks during the pandemic

Carers' access to breaks affects their ability to complete essential tasks that others may take for granted. While 28% of carers in Northern Ireland were using any breaks, they had to take some exercise. Worryingly, 30% of carers had used time away from their caring role to attending their own medical appointments, and 29% were using breaks to complete practical tasks such as housework.

**79%**

of carers in Northern Ireland have not had any breaks in the pandemic



**29%**

of carers in Northern Ireland were using breaks to complete practical tasks such as housework





## 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>10</sup>

The COVID-19 pandemic has severely affected carers' ability to take a break. This has impacted on their health and wellbeing.

72% of carers in Northern Ireland say that their mental health has got worse because of a lack of breaks while caring during the COVID-19 pandemic. 67% of carers said their physical health had deteriorated during the COVID-19 pandemic.

## Exhausted and worn out

Carers in Northern Ireland are struggling to continue caring and are reporting high levels of fatigue and stress, with over three quarters (78%) reporting feeling exhausted and worn out as a result of caring during the COVID-19 pandemic.

Over two thirds (69%) are worried about continuing to care without a break. Worryingly, a third (33%) of carers feel unable to manage their caring role.

## Worried about future support

Before the COVID-19 pandemic, many carers were struggling to get the support they need for themselves and the person they care for.

Carers reported feeling worried and uncertain about the future. Just 9% were confident that the support they relied on would continue in the future.

Over a quarter (29%) carers reported needing more support than before the pandemic because the needs of the person they look after have increased, or their own health has deteriorated.



<sup>10</sup> Carers UK (2018) State of Caring 2018

# Aron's story



Aron McKee and his wife Judith, both 40 and based in Northern Ireland, care for their daughter Grace, age 9. Grace has a tracheostomy and autism and has had a number of health problems since birth. Judith gave up work to care for Grace when she was born and the complex nature of her needs have meant the McKee family have had to shield throughout the COVID-19 pandemic.

“ The last year has been very challenging for all of us – Grace’s behaviour has got worse and she has had to shield throughout the pandemic, meaning Judith and I have been at home with no real breaks away – only from nurses. Children’s community nurses come to our home for 16 hours a week to help us, giving us three to four hours four times a week for Judith and I to take a break from caring for Grace. We go for a walk, have dinner together or relax. A lot of times we just catch up on some sleep.

Staying at home is hard for all of us, especially Grace’s older sister Rebecca as she loses out a lot in her life.

Caring during the pandemic has been very emotional and physically draining. The stress of managing has had a toll on my health and particularly this last year, we have felt in a perpetual state of exhaustion – Judith and I have both had our ‘downs’. I feel our government has left families like us behind.

Being able to take a break and spend some time away from our home is good for us all as we are always at home caring for Grace – different surroundings improves our mental and physical health.

We hope we can get somewhere for a short break soon but it will depend on Grace’s challenging behaviour and the support we have.”



“Caring during the pandemic has been very emotional and physically draining. The stress of managing has had a toll on my health and particularly this last year, we have felt in a perpetual state of exhaustion.”

# Breaks in Scotland

For carers a break is time off from caring and a chance to do things they would like to do, but can't do while they are caring – everyday things such as catching up with friends, going for a walk, or simply catching up on sleep.

Over the past year, the COVID-19 pandemic has had a significant impact on carers' ability to access breaks; with many local services closed or severely reduced, and with people having to reduce contact with family members and friends, this has left many carers without access to the support that they used to rely upon.

Many carers have been on call all day every day in the past year, on duty, never getting a night's sleep, and with no time to themselves or proper time with family or close friends. Unsurprisingly, many carers are now exhausted and worried about how they will continue to care without increased support. This research shows the impact of reduced support from both services and family and friends has had on carers health and wellbeing.

## Access to breaks

Before the pandemic, carers in Scotland were struggling to access meaningful breaks, with 41% of carers saying they did not get the breaks they need. 71% of carers in Scotland reported not being able to take a break during the pandemic, and a further 21% have had less breaks or insufficient breaks to look after their physical and mental health.

## Breaks during the pandemic

Carers' access to breaks affects their ability to complete essential tasks that others may take for granted. 36% of carers in Scotland were using any breaks they had to take some exercise, and a further 26% of carers were using their breaks to focus on their wellbeing. Worryingly, over a third (36%) of carers were using breaks to complete practical tasks such as housework. Around a quarter (24%) of carers had used time away from their caring role to attending their own medical appointments.

**71%**

of carers in Scotland have not had any breaks in the pandemic



**36%**

of carers in Scotland were using breaks to complete practical tasks such as housework



## 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>11</sup>

The COVID-19 pandemic has severely affected carers' ability to take a break, which has had an impact on their health and wellbeing. Over seven in 10 carers in Scotland (72%) say that their mental health has got worse because of a lack of breaks while caring during the COVID-19 pandemic. 72% of carers said their physical health had deteriorated during the COVID-19 pandemic.

## Exhausted and worn out

Carers in Scotland are struggling to continue caring and are reporting high levels of fatigue and stress, with over three quarters (77%) reporting feeling exhausted and worn out as a result of caring during the COVID-19 pandemic.

Over two thirds (69%) are worried about continuing to care without a break. Worryingly, over a third (36%) of carers feel unable to manage their caring role.

## Worried about future support

Before the COVID-19 pandemic, many carers were struggling to get the support they need for themselves and the person they care for. Carers reported feeling worried and uncertain about the future.

Just 23% were confident that the support they relied on would continue in the future. Nearly a quarter (24%) of carers reported needing more support than before the pandemic because the needs of the person they look after have increased, or their health has deteriorated.



11 Carers UK (2018) State of Caring 2018

# Marie's story

Marie McWaters has cared for her husband, Colin for more than 37 years. Colin has poorly controlled epilepsy with multiple seizures every day.

“ Colin's seizures are mostly at night during sleep so we're both always tired! We have a Personal Assistant through SDS (Self Directed Support) and that lets me sleep some nights a week and honestly, without this support, I just couldn't cope with all the caring and sleep deprivation – life becomes a bit of a nightmare and surviving the pandemic would have been a lot more difficult for us that's for sure.

Regular breaks both together and alone are essential to help us both keep going. Life is hard and it was made even harder during the pandemic as breaks just weren't possible. There was nowhere to escape to and the walls were closing in for us both. Isolation is tough and caring can be hard work.

Our breaks come in all shapes and sizes. During the lockdown I got a treadmill as I needed timeout in my head, some space to get away from caring when things got overwhelming, so I connected it up to YouTube and walked my way around Europe and blew off some steam.

We stopped isolating and have already disappeared, nowhere too far away, just a few miles up the road but it felt like heaven! A wee oasis of peace and life returning to normal. You'd have thought I'd been abroad or on a great adventure from the mental health benefits this wee break has given me. As things continue to open up more around us, I'm starting to feel a wee bit more connected to the outside world again although I'm not confident of a break further afield this summer as it's still a bit scary after being isolated for so long.

But if things continue to be alright COVID-wise, I'd like a wee respite break with friends and if little, more localised trips are possible, I will grab them with both hands!

Last year was really too long and hard, it was a real struggle. I'm praying for some time out, some laughs with friends and to be able to reconnect with other carers and just... breathe again!”



“There was nowhere to escape to and the walls were closing in for us both. Isolation is tough and caring can be hard work.”

# Breaks in Wales

For carers a break is time off from caring and a chance to do things they would like to do, but can't do while they are caring – everyday things such as catching up with friends, going for a walk, or simply catching up on sleep.

Over the past year, the COVID-19 pandemic has had a significant impact on carers' ability to access breaks; with many local services closed or severely reduced, and with people having to reduce contact with family members and friends, this has left many carers without access to the support that they used to rely upon.

Many carers have been on call all day every day in the past year, on duty, never getting a night's sleep, and with no time to themselves or proper time with family or close friends. Unsurprisingly, many carers are now exhausted and worried about how they will continue to care without increased support. This research shows the impact of reduced support from both services and family and friends has had on carers health and wellbeing.

## Access to breaks

Before the pandemic carers in Wales were struggling to access meaningful breaks, with 45% of carers saying they did not get the breaks they need. 72% of carers in Wales reported not being able to take a break during the pandemic, and a further 22% have had less breaks or insufficient breaks to look after their physical and mental health.

## Breaks during the pandemic

Carers' access to breaks affects their ability to complete essential tasks that others may take for granted. While 32% of carers in Wales were using any breaks they had to take some exercise and a further 25% to spend time with friends and family. Worryingly, one in three (30%) of carers were using breaks to complete practical tasks such as housework.

**72%**

of carers in Wales have not had any breaks in the pandemic



**30%**

of carers in Wales were using breaks to complete practical tasks such as housework



## 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.

The COVID-19 pandemic has severely affected carers' ability to take a break, which has had an impact on their health and wellbeing. Nearly seven in 10 carers in Wales (69%) say that their mental health has got worse because of a lack of breaks while caring during the COVID-19 pandemic. 68% of carers said their physical health had deteriorated during the COVID-19 pandemic.

## Exhausted and worn out

Carers in Wales are struggling to continue caring and are reporting high levels of fatigue and stress, with nearly three quarters (73%) reporting feeling exhausted and worn out as a result of caring during the COVID-19 pandemic.

61% are worried about continuing to care without a break. Worryingly, 40% of carers feel unable to manage their caring role.

## Worried about future support

Before the COVID-19 pandemic, many carers were struggling to get the support they need for themselves and the person they care for. Carers reported feeling worried and uncertain about the future.

Just 11% were confident that the support they relied on would continue in the future.

Over a quarter (28%) of carers reported needing more support than before the pandemic because the needs of the person they look after have increased, or their own health has deteriorated.



# Gill's story

Gill Stafford, 72, cares for her adult physically disabled son Gareth, 35, in Wales. They have a regular care worker come in one day a week which continued during COVID-19 restrictions, meaning they could arrange the same carer for all visits for the most part.

“ Gareth’s care for nine hours one day a week has continued during COVID-19, giving me time ‘off’ and Gareth time to continue his ‘Man Adventures’. He climbed a nearby headland in his wheelchair and watched the Red Arrows practise an air show routine when we were able to travel out of our local area in the summer. I was able to visit a friend in North West England for a few hours before the stay local rules were introduced.

Since then, we both stayed as local as possible in a largely rural area where travelling was necessary to visit a bank and essential shops not available on our small high street.

Zoom proved a boon to me as I no longer had to turn down invites to meetings that were at unsuitable times to leave Gareth. We have no family or nearby friends able to help with care so activities had to fit in with looking after Gareth and now I could attend talks and even ballet lessons virtually.

The worst time for me was when we were only allowed out for exercise once a day as I spoke to no one but my son. I started going down to the beach to photograph the amazing sunsets we enjoy on this coast and to chat to people enjoying a night-time stroll.

The short respite break I should have gone on, just as the pandemic began, was cancelled and the holiday I’d hoped to take

“Time off allows me time to be myself, to follow my own interests, have my hair cut.”

Gareth on to Canada wasn’t possible. In the future, I hope to be able to take time off which has previously been agreed with social services to allow me to travel further.

Having a break, even a few hours a week, means I can carry on with my own interest of photography and travelling to places I can’t take Gareth – or where he doesn’t want to go! Time off allows me time to be myself, to follow my own interests, have my hair cut. As for Gareth, he wants rid of mum for time to do his own things and go on a Man Adventure with his carer!







## About Carers Week

Carers Week is an annual awareness campaign to recognise the vital contribution made by unpaid carers across the UK.

In 2021, Carers Week is made possible through Carers UK working together with five other major charities: Age UK, Carers Trust, Motor Neurone Disease Association, Oxfam GB and Rethink Mental Illness with British Gas the headline supporter, and with Nutricia continuing their support this year.

Find out more and get involved at [carersweek.org](https://carersweek.org)

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