

State of Caring 2021

A snapshot of unpaid care
in Northern Ireland



About carers

A carer is anyone, including children and adults who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid.

64% of carers are women; 36% are men. Any one of us has a 6.6% chance of becoming a carer in any year. There are currently 318,000 carers in Northern Ireland and this is expected to grow to at least 400,000 by 2037¹.

About this research

Carers NI carried out our State of Caring survey² between August and September 2021 as part of an annual spotlight on the circumstances of carers across the UK. State of Caring has been undertaken for over a decade and is the UK's most comprehensive research into the lives and experience of carers. The latest UK wide research report can be found [here](#).

This report is based on the responses from 776 people in Northern Ireland currently providing care.

Profile of respondents

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

- 82% are female and 17% are male.
- 27% consider themselves to have a disability.
- 4% are aged 0-34, 15% are aged 35-44, 31% are aged 45-54, 33% are aged 55-64, 14% are aged 65-74, and 2% are aged 75 and over.
- 2% identified as lesbian, gay or bisexual.
- 2% described their ethnicity as black or minority ethnic
- 26% also have childcare responsibilities for a non-disabled child under 18.
- 46% are in paid work. Of those, 67% work full-time and 33% part-time.
- 35% have been caring for 15 years or more, 16% for between 10-14 years, 21% for 5-9 years, 25% for 1-4 years, and just 4% have been caring for less than one year.
- 51% care for 90 or more hours every week, while 12% care for 50-89 hours, 22% care for 20-49 hours, and 15% care for 1-19 hours a week.
- 70% care for one person, 24% care for two people, 5% for three people, and 1% care for four or more people.

Not all respondents completed every question in the survey. Therefore, some figures given in this report are based upon responses from fewer than 776 carers. This, together with the sample sizes of different groupings, eg those carers in receipt of Carer's Allowance, should be taken into consideration when reading the results.

1 *It could be you: a report on the chances of becoming a carer*, Carers UK 2001

2 This was part of a survey across the UK produced by including a report, providing from 8,676 carers and former carers and providing recommendations for action and change

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Introduction

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

Prior to the COVID-19, there were 220,000 unpaid carers in Northern Ireland³. It has been estimated that an additional 98,000 people started caring during the pandemic⁴. Even before this, the numbers of unpaid carers have been rising as the population ages and people live longer into older age with greater health needs. Increasing practical and financial support for carers must be at the heart of how we address the recovery from the pandemic.

Many services in Northern Ireland were already reaching crisis point for carers before the pandemic. The situation has significantly worsened, with carers continuing to take on more hours of care, as statutory services have declined. Many are now extremely worried about the impact of the growing staffing crisis in health and social care, which has prevented many of them from accessing the services and support they need.

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

Carers' support in Northern Ireland has been valued at a staggering £19 million per day during the pandemic, or £6.93 billion for a full year⁵ – outstripping the value of the NHS.

Despite this huge contribution, carers face high personal costs, simply because they care. Many carers find their family and personal relationships are impacted, they often struggle to balance work and care and, and face poverty and health problems because of their caring role.

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

Caring also remains a gendered issue. It is still often thought of as being part and parcel of women's lives and within families, women are still most likely to be providing care and most likely to be providing more hours of care. Women make up the majority of carers (64%) and around 1 in 5 women aged 45 to 54 are providing unpaid care to someone with a disability or illness, or who is older. Providing support for carers, especially those looking to stay in, or return to, paid work, is essential if women are to be able to participate fully in the economy and live a life free from poverty in older age.

Increasing numbers of employers are recognising the importance of supporting carers in their workforce to continue working, so they can retain talented and experienced staff. It is now essential that employers maintain flexibility in the hours and place people work, alongside the carer-friendly policies they have introduced, as we transition out of the pandemic restrictions.

This report contains a snapshot of what caring was like in 2021 and through the pandemic so far, capturing the impact that caring has on carers' lives and evidencing the policy recommendations that would improve this.

3 Census 2011

4 This research is based on polling carried out by YouGov plc in May 2020

5 Carers UK (2020) *Unseen and Undervalued*

Carers' finances



Many carers face additional costs because they care, including for example, buying equipment, care costs and increased food, energy and transport costs. These costs can be compounded by carers having to reduce their working hours or leave employment. As a result, many carers face precarious financial situations.

We asked carers about their current financial situation and 29% of carers said they were struggling to make ends meet. A further 17% are in or have been in debt as a result of caring, and more than 1 in 20 said that they cannot afford important bills like gas, electricity, rent/mortgage. Only 47% said that they currently have enough money to cover their monthly expenses; a situation likely to change as the cost of living continues to rise in 2022.

- “I am just about making ends meet. Have no debts but I have no savings either.”*
- “I am about to cut my working hours due to caring. I don't know how I'm going to manage financially.”*
- “I am over £10,000 in debt on my credit card which I use to pay for basic living expenses like food and utility bills (which I can't always pay) and have no means to pay any more than the minimum monthly payment which is only paying off the interest on the money I owe - it is not paying off any of the actual debt.”*

Carers often have to make difficult decisions on spending, including more than 1 in 10 cutting back on essentials like food and heating and a third cutting back on seeing friends and family.

For those on Carer's Allowance, almost half (46%) were struggling to make ends meet and more than a quarter (27%) are or have been in debt because of caring. Only a third (32%) of those in receipt of Carer's Allowance said that they felt confident that they would be able to manage financially over the next 12 months.

Energy prices have soared across the UK and 11 million households have on average faced an increased fuel bill of £139, rising to £153 for another 4 million households that use prepayment meters⁶. These bills are expected to increase even further in 2022. There is widespread concern around finances, particularly for those on the lowest incomes, and carers are no exception. Indeed, carers are more likely to be in financially precarious situations and less able to cope with these additional costs or be able to reduce these costs in any way. For example, many carers talked about the importance of heating for managing the health conditions of those they care for, making the increases in fuel bills even more challenging. They simply cannot “turn the heating down”.

- “The heating bill is horrendous but my husband needs the heat due to being on warfarin.”*
- “Our biggest outlay is heating as my husband's health issues mean he cannot endure the cold weather “*

Worry about finances is also impacting on carers' health and wellbeing. Over half (55%) of carers said they feel anxious or stressed when they think about their financial situation, 36% of carers did not know where to go for help with their finances.

- “Due to my caring commitments, I can't work and I am falling deeper into debt. The stress of living in poverty, whilst trying my best to care for two people is ruining my mental health.”*

⁶ BBC News (October 2021) Energy price cap: Millions of households face higher gas and electricity bills: www.bbc.co.uk/news/business-58746953

Impact of COVID-19 on carers' finances

We asked carers how their financial situation had changed since the start of the COVID-19 pandemic. Just over a third of respondents (35%) said that their financial situation had worsened since the start of the pandemic, with 70% saying they have had to spend more on household bills, shopping and everyday items. Almost a quarter of respondents (23%) said that they were spending more on equipment or products for the person they care for.

For those on Carer's Allowance, the situation is even more stark, with almost a half (46%) saying their financial situation had worsened and more than three quarters (78%) spending more on necessities.

“Since the pandemic began prices for household staples have greatly increased, this means benefits don't go as far as they used to so it has been a real struggle.”

“The money I have coming in is less than what I pay out for heating, food, car expenses. It is very worrying indeed.”

“I rely on savings, when I run out of them, I will be struggling greatly to afford everything that's needed. The pandemic has caused enormous increase of everyday items and utility bills.”

The results from State of Caring show that providing care is clearly linked to higher levels of financial stress and decreased financial resilience. Carers across all levels of income brackets are worried about the impact of caring on their finances and the impact of caring on their ability to save.

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

Improving financial support for carers – their views

We asked carers what financial changes would make the most difference to their experience as a carer.

- 59% said that they wanted to see an increase in the value of carers' benefits
- 52% said they wanted to see the eligibility criteria for carers' benefits widened to enable more people to access them.
- 58% said they wanted to see an increase in the earnings limit for claiming Carer's Allowance
- 37% wanted to see other sources of financial support such as hardship grants for carers

Support and services

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

Before the COVID-19 pandemic in 2019, one in five carers (19%) didn't receive any support in their caring role⁷. Since March 2020, many services have had to adapt by reducing capacity to cope with the COVID-19 restrictions. Others remain closed. This has led to more carers than ever not receiving support. Carers' comments suggest that the workforce shortages are impacting on service provision making it harder to get the support they need.



7 Carers UK (2019), *State of Caring 2019*

Almost half of carers (48%) told us they faced reduced day services, 29% reduced paid care worker support, 36% reduced short break services and 26% reduced after school services for their disabled child. Only limited numbers of carers told us that services had fully reopened to pre-pandemic levels, for example, just 12% of day care services, 5% of after school services and 18% of sitting services to provide a break from caring.

- “My son’s day centre has still not fully reopened, during the lockdowns he developed depression which has required therapy and medication.”*
- “My daughter received one hour swimming per week school term. This was through the charity Positive Futures. She loved it. Sadly due to COVID it had to stop. Rural areas in N Ireland are very badly catered for as regards services for disability. This is my experience. All charities congregate in multiple groups in towns.”*
- “Sadly, once you live so many miles away you are told the service does not go that far out. Why would all the money go to small focus areas. We all pay taxes and we all need help.”*

The pandemic has made accessing services more challenging for carers, particularly as those they care for may be at higher risk from COVID-19. Over a third of carers (40%) stated that they were not accessing services because they were worried about the person they care for catching COVID-19. This is reflected in the significant number of carers who said they have chosen not to use some services that they may have previously used. For example, 29% have chosen not to use day services, 55% not to use care homes for residential respite and 24% not to use support from paid care workers.

- “As I have been working from home we have decided that we will not use any services were possible to reduce foot fall to essential requirement only in the home.”*
- “My daughter has one day a week in a day centre. We’re not sending her as it’s not essential and too risky. Her place is being used by someone else.”*
- “All care has been provided by myself. I have not had respite or residential care for at least 13 years. Since March 2020 I have chosen not to use daycare services or paid care carers due to the risk to the people I care for.”*

Carers continue to face other barriers to accessing support. Nearly half (44%) of carers do not know about the services that are available in their area, with more than a quarter (28%) saying that the services in their area do not meet their needs. Importantly, particularly in rural areas, more than 1 in 10 (12%) said there was no transport to take the person they care for to services.

Staffing challenges in social care remain a significant issue in providing support for carers. The Home Care Association found that 78% of homecare providers were finding recruitment harder than ever before⁸. The impact of the staffing shortages was clearly affecting unpaid carers, many of whom reported that they were struggling to restart care after the pandemic or were awaiting any support at all.

- “I have lost all day care, lost my one visit a day from my care workers from March to Oct of last year. The support has been non-existent and I have become somewhat of a recluse as I can’t get a proper break.”*
- “Due to the pandemic we are still on waiting lists for sons assessments which means we are not eligible for any support packages.”*

Working carers

A shortage of care support is **also** putting working carers livelihoods at risk. When we asked carers in paid employment what they needed to continue to work and whether not getting a service would place them at risk of reducing their hours or giving up work altogether.

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

“My daughter has only received support from her school and myself. Her paid PA left and I haven't been able to source anyone else for this role. No support from social services about any services available in the local community, I've had to take term time out of my job during summer months to ensure she got the care she needed over the summer months, which lead to increasing my hours when she is back at school, to enable the financial impact not to be as damaging to our family unit.”

“Lockdown has extremely affected my son and we have still not had access to a lot of services. This has meant I have had to leave work which has had a negative impact on my mental health.”

Carers' priorities for social care reform

Carers NI has long called for a reformed and sustainable social care system fit for the 21st Century. The Executive in Northern Ireland has committed to social care reform⁹, with proposals focused on building a more stable, sustainable system, with valued staff and support based on individual choice and control with people who use social care and their unpaid carers at the heart of reform. It includes commitments to develop a new carers strategy and appoint a new carers champion. Importantly, it also focuses on prevention – vital in reducing the many negative impacts of caring on carers. Carers are very clear about their priorities moving forward:

- Having access to more personalised and better-quality care for the person I care for (79%)
- Having access to care that is tailored to my needs (57%)
- Having access to suitable breaks from my caring role (54%)
- Having a choice about caring and how much care I provide (36%)
- Having access to good quality and appropriate housing, including the right adaptations (28%)
- A reduction in charges to care (21%)
- Better access to replacement care (13%)

It is of paramount importance that the recovery from the pandemic and social care reform in Northern Ireland focuses on supporting carers, delivering high quality care and ensuring a sustainable future for our health and social care system.

⁹ www.health-ni.gov.uk/consultations/consultation-reform-adult-social-care

Carers' health and wellbeing



Carers' physical and mental health is often impacted by their caring role. The 2011 Census showed that carers were more likely than non-carers to have poor health. The pandemic has seen 85% of carers take on increased hours of care, often with less or no outside support¹⁰. This has had a significant and detrimental impact on carers health and wellbeing; over two thirds of carers (69%) reported that their mental

health has worsened, and 64% of carers saying their physical health has got worse as a result of caring in the pandemic¹¹. The impact of COVID-19 is continuing to have a negative impact on carers' health and wellbeing and they are facing additional health inequalities which must be addressed.

¹⁰ Carers UK (2020) *Caring behind closed doors: six months on*

¹¹ Carers Week (2021) *Breaks or breakdown*

Physical health

When asked about their physical health, 25% said their physical health is bad or very bad compared to 22% of carers in 2019¹². Given the significant personal cost of caring, it is unsurprising that this rose to 29% of those caring for five years or more.

When discussing their physical health, carers spoke about a range of issues impacting on their health, including lifting the person they care for and lack of sleep.

- “I am suffering from depression, I feel isolated, and I’m stressed because of low income. I can only see things getting worse in the future. I have back pain from lifting and I am starting to have problems with my walking. I don’t know how much longer I can cope.”*
- “My daughter’s condition has not changed but her care needs are greater now as she has finally learnt to walk. Physically she requires a lot of lifting and my body is sore and tired.”*
- “I struggle on but it’s hard mentally. I don’t get much sleep because of my anxiety and this affects my mood and mental health.”*

Mental health

When asked about their mental health in general, carers described their mental health as worse than their physical health, with over a third of carers (33%) stating it is either bad or very bad. This has increased from 25% two years ago, further reflecting the impact of the pandemic has had and suggesting a worrying emerging trend.

Like physical health, the picture is even worse for those who have been caring for longer periods with over a third (37%) of those caring five years or more experiencing bad or very bad mental health.

- “I now suffer from anxiety. My daughter’s mental health care has been poor, and I’m emotionally exhausted trying to get someone to listen to me. I feel many health care professionals have a very poor understanding of what it’s like to be a carer, unless you have been a carer yourself.”*
- “I’m at rock bottom and so fearful for the future and what lies ahead. There is no light at the end of the tunnel. I feel quite angry sometimes and abandoned. The anxiety I feel is all consuming both mentally and physically. I have tried yoga but it didn’t fit in with my caring role and was quite expensive, although I liked the social aspect of it.”*
- “I feel I am operating physically emotionally and mentally at the very limits of my capability - sometimes over and feel I have a very limited existence.”*

Carers’ assessments are an opportunity to explore the needs of the person caring and to establish potential support. With the worsening picture of carers’ physical and mental health this should be considered, yet only 30% felt that it was.

Loneliness

There is significant evidence of the impact of loneliness and social isolation on both mental and physical health. Loneliness is associated with an increased risk of mortality (26%) and likelihood of heart disease, stroke, depression and cognitive decline such as dementia¹³. It is concerning therefore that carers, who were already isolated, have told us that they are feeling lonelier and more isolated than ever. Over a third (36%) of carers said that they often or always feel lonely. Carers spoke of the challenges of having to be in constant contact with the person they care for.

“I feel isolated and very alone. I’m in my 30s and have a health condition. I find caring such a challenge. It’s hard to function to best of your ability when you’re not in good shape yourself. In general, there is very little on means of support for carers... your just left to get on with it.”

“I am ready to die, as soon as my wife passes. My stress levels have gone through the roof, and at times I feel so lonely and I feel that no one cares, I am only 66.”

Carers have decreased life satisfaction and happiness and increased anxiety. Carers told us they were less happy, felt that their lives were less worthwhile and felt more anxious than when the pandemic began. Carers:

- said their satisfaction with their life was now an average of 5 out of 10 (slightly down from 5.1 in 2019). This is far less than the general population: 7.09 out of 10.
- rated the extent to which they feel the things they do in life are worthwhile at 6 out of 10, considerably worse than the general population at 7.2 out of 10.
- were more anxious than in 2019, rating their level of anxiety at 6 out of 10, compared to 5.4 out of 10 for the general population¹⁴.

“It does affect my mental health as feel like a hamster on a wheel. Have had 2 days off in the last 8 years.”

“The years of caring responsibilities without support or breaks has taken a physical and mental toll. I don’t know how much longer I can keep giving from a nearly empty box.”

GP awareness

The role of GPs in supporting carers through various elements of their life, from the transition to being a carer through to ongoing help and guidance on their health, is key. Around two thirds (61%) of carers said their GP knew they were a carer but it is concerning, especially given that the carers in this survey are more likely to be caring for significant hours, that 39% of carers reported not being known to their GP.

More than half (57%) of carers did not recognise themselves as unpaid carers for over a year. Worryingly, a quarter did not recognise themselves as carers for five years or more, missing out on vital financial and practical support.

As GPs are often the first and main contact with health and care services that carers have, their role is crucial in identifying carers, adding them to carer registers and referring them for support cannot be underestimated.

¹³ www.campaigntoendloneliness.org/threat-to-health/

¹⁴ Opinion and Lifestyle Survey (Aug 2021)

Carer's assessments



In Northern Ireland, Carers and Direct Payments Act 2002 gives anyone over the age of 16 who provides “substantial and regular care” the right to a carer’s assessment. Young carers under and parents of disabled children also have the right to an assessment under the Children (NI) Order 1995.

These assessments are carried out by Local Health and Care Trusts and should cover topics such as the caring role; health; feelings and choices about caring; work, study, leisure and housing.

Access to Carer’s Assessments

Only 26% of respondents had received a carer’s assessment or re-assessment in the last year, 8% had requested one and 4% said that their assessment was delayed or postponed.

Of those who had not received an assessment, by far the biggest barrier was that they did not know what a carer’s assessment was. This reinforces the necessity for ongoing awareness raising of caring and identification of carers to ensure that they can access the support they need.

“I’ve never heard of a carer’s assessment before.”

“I didn’t know I was entitled to a carers assessment. I would imagine there’s a long waiting list though.”

“I have had one carried out a number of years ago - I have never had a review but I would like one.”

14% reported that they had not requested a carer’s assessment as they didn’t think it would be beneficial to them. This is often due to previous poor experiences, or there being inadequate funding for local provision of support or a lack of signposting.

“Past assessments have delivered no change to my daily life.”

“I did have an assessment but it didn’t help my needs or with my caring role.”

Experience of Carer's Assessments

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

“The support offered was tailored to what they had available rather than what would actually be helpful to me or the person being cared for.”

“The Carer Assessment in the WHSST Area of NI is nothing more than a Tick Box Exercise. I have had 18 Carer Assessments and every single one recognises my need for regular breaks yet in 18 years, I have only ever received 3 single day breaks from caring.”

“My needs were identified but remain unmet.”

Only a third (37%) of carers who had had an assessment felt that their need to have regular breaks from caring was thoroughly considered within the assessment process. The same number (37%) reported that their ability to have time to themselves was poorly considered during the assessment process. Nor were the demands of others responsibilities such as a non-disabled children sufficiently considered, with only a quarter (25%) saying that it was.

Breaks are vital for carers as they allow carers to engage in activities that are essential for their wellbeing such as exercise, hobbies or even providing a chance to get on top of essential non-care tasks such as attending GP appointments. Even before COVID-19, carers were struggling to access meaningful breaks. In 2017, 25% of carers said they hadn't had a day off from caring for more than five years¹⁵, and Carers NI also found that 61% of carers had not had any breaks during the pandemic, leaving 73% of carers exhausted as a result¹⁶.

Given the significant impacts of caring on employment, only three in 10 carers said that it had been thoroughly considered in their assessment.

Finally, less than half (41%) of carers felt that their assessments thoroughly considered what needed to be put in place to support the person they care for in the case of an emergency. This is particularly worrying considering the necessity to have a contingency plan in place during pandemic due to the risk of carers falling ill themselves

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

“I made a carers assessment application in June 2020 remotely & have still had no outcomes or completion from our senior social worker.”

¹⁵ Carers UK (2017) *State of Caring 2017*

¹⁶ Carers UK (2021) *Breaks or breakdown*

Juggling work and care



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

We looked at the continued impact of the pandemic on carers' ability to juggle work and care.

Growing numbers of working carers

Working carers represent a significant proportion of the working population and at the height of the pandemic, Carers UK estimated that over a quarter (26%) of all workers were juggling work and care¹⁷. In some sectors the proportion is even higher, with one in three NHS staff juggling paid work and unpaid caring¹⁸. 273 respondents to the 2021 State of Caring survey in Northern Ireland were carers in paid employment, representing over half (54%) of working age respondents. 64% of these respondents were in full time employment, 32% were working part time and 4% were self-employed.

Homeworking

There has been a significant move towards working from home either full or part time during the pandemic. With 64% of working carers now working from home either all or some of the time. Carers' experiences working from home varied. Some carers reported that working from home had improved their work life balance and made balancing work and care easier, while others found work a respite from their caring role and that they struggled to be able to concentrate on work while at home.

- “Working at home has been a game changer, it has allowed me to balance my life.”*
- “Due to Covid I am able to work remotely from home, this has definitely improved my health too as I'm not trying to juggle so much of my time and I don't spend 2 hours plus travelling back & forth to work daily. The work/life balance and the addition of caring for my husband has greatly improved. I have more energy and quality time too.”*
- “I have found working from home more difficult as I am pulled more into the care environment due to elderly parent not understanding that I am working from home and not off work. This is very difficult and a balance is hard to achieve. I have found that my parents are becoming more and more dependent on me because I am there.”*

¹⁷ Carers Week (2020), *Carers Week Research Report 2020*

¹⁸ NHS Staff Survey 2020

Balancing work and care

The challenges of balancing work and care often has a negative effect on carers' careers, with our previous research finding that 40% of working carers had passed on opportunities at work and 25% had moved roles to help them manage¹⁹. Worryingly, 10% have had to reduce their working hours during the pandemic. In addition, 16% of working carers have had their employment situation negatively affected during the pandemic; by reducing their working hours, having their hours reduced by their employer, losing their job, losing business as a self-employed carer, or leaving their job due to concerns about catching COVID.

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

“I will shortly have to stop working (I have resigned) because of increased demands for me in my caring role and no longer able to balance work and caregiving.”

Impact of reduced social care services

Services being closed or reduced during the COVID-19 pandemic meant that some carers felt they had no choice but to reduce their hours or give up work. The limited return of services continues to have an impact.

One in four (40%) of carers stated that if care services did not return, they would either need to reduce their working hours or give up work entirely. Affordable and accessible care, and the ability for services to support carers is essential if they are to remain in paid work.

“The only practical support I've received was regular phone contact from my daughter's day care provision (which pre-pandemic she used one day a week). I am really looking forward to the situation stabilising so that I can return to office working.”

“I have been able to go back to work now that the schools are open.”

As the number of people providing unpaid care increases, so does the number of people juggling work and care and with one in three people in the NHS now juggling work and care it is a problem that cannot be ignored. Working carers were already struggling before the COVID-19 pandemic, trying hard to balance providing practical and emotional support, managing appointments, and keeping an eye on the person they care for – all alongside paid work.

We are currently at a turning point for work as employers, employees and the Government adapt to the easing of national and local restrictions. It is vital that the positive lessons from COVID-19 pandemic are learnt and flexibility in the hours and places people work is maintained to ensure that working carers can stay in paid work. It is essential that in order to support carers to stay in paid work that there is investment in social care and that affordable and accessible care is available.

Conclusion and recommendations

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

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

Whilst the Health Minister recently announced the return of day centre and short break provisions and services, they are still a long way off returning to pre-pandemic levels and even then, they were not sufficient to provide the level of support needed by carers. This support is critical to carers health and wellbeing, the quality of life for them and their family and their ability to juggle work and care.

The reform of Adult Social Care is an issue that is critical to carers and their families and has the potential to significantly improve people's lives. It is right to focus on this now and longer-term reform must provide more support to carers. We particularly welcome proposals focused on building a more stable, sustainable system with support based on individual choice and control. Carers and people who use social care and their unpaid carers must be at the heart of reform, with a Carers Champion in the Executive focusing on improving their rights, their support and measures to reduce the many negative impacts of caring on carers.

Across society, we are seeing a stronger focus on health inequalities and this should include the impact of caring which has been recognised as a social detriment of health. Whatever reforms in health and social care are delivered the clear message from carers is that they want their health and wellbeing to be considered more.

There have been huge changes in the way that people work and those juggling work with care are finding it extremely challenging. There are new positives and new potential with the UK Government's consultation on day one rights to flexible working and the pledge to introduce Carer's Leave into legislation. We need to see this replicated in Northern Ireland within the next Assembly mandate.

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

We would strongly encourage the next Executive to consider:

Carers and their finances

- In the absence of an increase in the level of Carers Allowance from Westminster, the Department for Communities must consider exploring the possibility of an additional payment for carers (similar to the Carer's Allowance Supplement introduced in Scotland) as well as increasing the earnings limit on Carers Allowance so that more carers across NI can receive financial support.

Support and services

- The Executive needs to ensure that there is sufficient funding for social care and the proposals within new social care legislation are well-resourced to deliver meaningful change for carers and those they care for.
- The Executive should be investing additional and ring-fenced funding for carers' breaks so that carers that need a break can access good quality services when they need them.
- The Executive should ensure that information, advice and support services, across all sectors, are joined up to identify carers, enable carers to find what information and support is available, at the right time, particularly at key points in their caring journey including for example, when new to caring, on hospital discharge and when caring comes to an end.

Health and wellbeing

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

- Caring has been recognised as a social determinant of health²⁰ and needs to be considered by national and local governments, by employers, by the third sector and all service providers.
- The Executive should introduce a duty to have regard to carers and to promote their health and wellbeing including more focused prevention and early intervention initiatives.

- We need to see a full return of day centre and short break provisions for carers and those they care for, similar to pre-pandemic levels.
- The system needs to better identify carers and ensure that they are consulted and have the right support. This should build on the gains made by the COVID-19 vaccination roll-out programme and existing HSC Trust carers lists using more data sharing with permissions. A voluntary centrally held register of carers should be introduced and held by the HSC Trusts.

Juggling work and care

- The Department for the Economy should consider introducing legislation on Carers Leave and a day one right to request flexible working as soon as possible.
- The Department for Communities should raise the level of the earnings limit on Carer's Allowance and peg it to the National Living Wage so that they benefit from year on year rises in wages, rather than making work less attractive.
- Employers should adopt Carers UK's Carer Confident benchmark, run by Employers for Carers, to move towards becoming a carer friendly employer. The Executive should fund projects to support employers to achieve appropriate carer benchmarks.
- The Department for the Economy should support and introduce a new Employability Programme for carers and former carers supporting returners, skills recognition and later life apprenticeships where carers are able to juggle work and care.
- Employers need to include carers' support as a targeted part of their staff wellbeing approaches, using the good practice from Employers for Carers.

20 [Caring as a social determinant of health: review of evidence - GOV.UK \(www.gov.uk\)](https://www.gov.uk)

Equality, recognition and combatting loneliness and isolation

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

- There needs to be systematic awareness raising through key professions or in key settings such as all levels of the HSC Trusts that carers are recognised as a Section 75 group.
- Awareness campaigns, like Carers Week, Carers Rights Day and other initiatives to work together to reduce the time it takes for a carer to identify themselves and seek support at the right time.
- We join with our colleagues in the Action Group on Loneliness Policy to call for the introduction of a loneliness strategy in Northern Ireland, with carers a priority group.
- We need to see greater collaborative working across government Departments as well as working alongside the community and voluntary sector and most importantly, with carers themselves.
- We support the commitment of Department of Health to produce a new Carers Strategy, as part of its proposed reform of adult social care. This must include ring-fenced funding for resources to deliver on it.
- We support the Department of Health's commitment to introduce a new independent Carers Champion, as part of its adult social care reform proposals. This appointment must be made as early as possible in the next mandate.

Thank you

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



Carers Northern Ireland is part of Carers UK. Carers UK is the national membership charity for carers. We work to represent and support the 6.5 million people in the UK who provide unpaid care for ill, older or disabled family members, or friends.

We will continue to fight for increased recognition and support for all carers, and to ensure they have a voice. Our mission is to make life better for carers by delivering lasting change.

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Carers UK is a charity registered in England and Wales (246329) and in Scotland (SC039307) and a company limited by guarantee registered in England and Wales (864097). Registered office 20 Great Dover Street, London SE1 4LX.

Publication code: NI4100_0322 © Carers NI, March 2022.