

# State of Caring

A snapshot of unpaid care in Northern Ireland



2019

## State of Caring 2019

Each year, Carers UK carries out a survey of carers to understand the state of caring in the UK. This is the largest State of Caring survey carried out by Carers UK to date and the response from carers in Northern Ireland was overwhelming.

Over **8,000** carers and former carers shared their experience of what it's like to be a carer. Of those, 762 were from Northern Ireland. Thank you to everyone who took the time to respond.

This report provides a snapshot of caring in Northern Ireland in 2019 by only including the responses from the **694** people who are currently providing care. All data collected from current and former carers will be used throughout the course of our work in lobbying for better rights and support for carers in Northern Ireland.

The full Carers UK State of Caring report for 2019 can be found at [carersuk.org/stateofcaring](http://carersuk.org/stateofcaring)

## About the research

Carers UK carried out an online survey between March and May 2019. A total of 8,069 carers and former carers responded to the survey – 762 of whom were from Northern Ireland. We have only included responses from the 694 people who are currently providing care in this report.

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

Of respondents to the survey:

- 83% identify as female and 16% identify as male.
- 26% consider themselves to have a disability.
- Less than 1% are aged 0–24, 5% are aged 25–34, 16% are aged 35–44, 36% are aged 45–54, 28% are aged 55–64, 11% are aged 65–74, and 4% are aged 75 and over.
- 30% also have childcare responsibilities for a non-disabled child under 18.

- 57% are in paid work. Of those, 59% work full-time and 41% part-time.
- 32% have been caring for 15 years or more, 15% for between 10–14 years, 24% for 5–9 years, 24% for 1–4 years, and just 4% have been caring for less than one year.
- 42% care for 90 or more hours every week, while 15% care for 50–89 hours, 22% care for 20–49 hours, and 21% care for 1–19 hours a week.
- Most (66%) care for one person, 28% care for two people, 4% for three people, and 3% care for four or more people.

As not all respondents completed every questions in the survey, a number of the figures given in this report, including those presented in this Appendix, are based upon responses from fewer than 694 carers. This, together with the sample sizes of different groups, should be taken into consideration when reading the results.

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## Context: The state of caring in 2019



Recent polling published by Carers UK has suggested there could now be as many as 8.8 million adult carers in the UK<sup>1</sup>, compared to 6.3 million adult carers recorded in the 2011 Census. This polling shows that around 272,000 people in Northern Ireland (that's around 1 in 5 of us) are providing care for a family member or friend, over 58,000 more than the 2011 Census records show. The number of people aged 65 years or over who are caring has grown from 1.4 million to potentially over 2 million UK-wide. This is a 43% increase from 2011 to 2019. Improving support for carers whether it's practical or financial must be at the heart of how we address our ageing population.

Whilst other nations in the UK have made positive policy developments for carers in the past few years (including the NHS Long-Term Plan and Cross Government Carers Action Plan for England or the increase in the rate of Carers Allowance in Scotland), policy developments in Northern Ireland have been slow to surface. With the Caring for Carers Strategy now over 13 years old and the Carers and Direct Payments Act of 2002 in need of updating, several attempts to move the issue of supporting carers have been stalled due to the lack of an Assembly and Department Ministers, Brexit and the ongoing crisis in health and social care.

Recommendations under the recently published Power to People Report highlight the need to find a way of supporting, understanding and valuing the role of carers more<sup>2</sup>. It also emphasised the importance for carers to have access to the right information at the right time,

the availability of short-term breaks and for carers to be acknowledged and recognised as a valued partner in the adult care and support system.

Despite this, carers here and the people they care for, continue to face economic and societal pressures. Many services have reached crisis point with unpaid carers facing the consequences of budget cuts and delayed funding solutions. The results of this year's survey show clearly why system-wide reform is needed to ensure carers are properly supported and able to have a life alongside their caring responsibilities.

Carers' support in Northern Ireland is valued at £4.6 billion a year<sup>3</sup>, but this comes with high personal costs. Many carers are suffering from loneliness and social isolation, need support to help them stay in work, and are facing their own health problems as a result of their caring role. This is in addition to the financial cost of caring; with 39% of this year's respondents saying that they are struggling to make ends meet, and over two thirds reporting that they regularly use their own income or savings to pay for care or support services, equipment or products for the person they care for. With the end of the Mitigation Scheme approaching in 2020 more carers here are set to face financial hardships.

A higher state pension age means that people are working for longer and are more likely to be working alongside caring. Increasing numbers of employers are recognising the importance of supporting carers in their workforce to

continue working, so they can retain talented staff rather than incurring the costs of recruiting and retraining new employees. Recent polling by Carers UK suggests that 1 in 7 employees in Northern Ireland are carers<sup>4</sup>. But with workplace support still very varied, nearly half a million people across the UK have had to give up work over the past two years as a result of caring. This equates to around 600 people every day<sup>5</sup>.

Caring is still often thought of as being part and parcel of women's lives and, within families, women are still most likely to be providing care and most likely to be providing more hours of care. Women make up the majority (58%), of carers and 20% of women aged 45 to 54 are providing unpaid care to someone with a disability or illness, or who is older<sup>6</sup>. Providing support for carers, especially those looking to stay in, or return to, paid work, is essential if women are to be able to participate fully in the economy and live a life free from poverty in older age.

When asked how they expect their quality of life to change over the next year, 12% of carers said they expected it to get better, 36% expected it to get worse, and 52% expected it to stay the same. This shows that

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

The Northern Ireland Assembly has previously committed to valuing, recognising and supporting carers<sup>7</sup>, but if this is truly to become a reality then carers' voices, opinions and experiences must be heard, listened to and acted on. It is of paramount importance that even in the current challenging political context, the next Assembly focuses on supporting carers and ensuring a sustainable future for our health and social care system.

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



<sup>4</sup> Carers UK (2019) Juggling Work and Unpaid Care, Yougov polling

<sup>5</sup> Carers UK (2019) Juggling work and unpaid care, Yougov polling

<sup>6</sup> Census 2011

<sup>7</sup> Dept Health NI (2016) Health and Wellbeing 2026: Delivering Together

<sup>1</sup> Carers UK (2019) Juggling work and unpaid care, Yougov polling [www.carersuk.org/images/News\\_and\\_campaigns/Juggling\\_work\\_and\\_unpaid\\_care\\_report\\_final\\_0119\\_WEB.pdf](http://www.carersuk.org/images/News_and_campaigns/Juggling_work_and_unpaid_care_report_final_0119_WEB.pdf)

<sup>2</sup> Kelly and Kennedy (2017) Power to People: Proposals to reboot adult care and support in Northern Ireland

<sup>3</sup> Carers UK (2015) Valuing carers – based on 2015 carer projection

# Financial pressure

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

When asked how they would describe their financial situation, almost 2 in 5 (39%) carers say that they are struggling to make ends meet.

Carers who have been caring for 15 years or more and those who care for more than 35 hours a week are more likely to say that they are struggling to make ends meet, with 41% and 46% saying that respectively. Over half of carers who are receiving Carer's Allowance (55%) are also struggling to make ends meet.

Almost 2 in 5

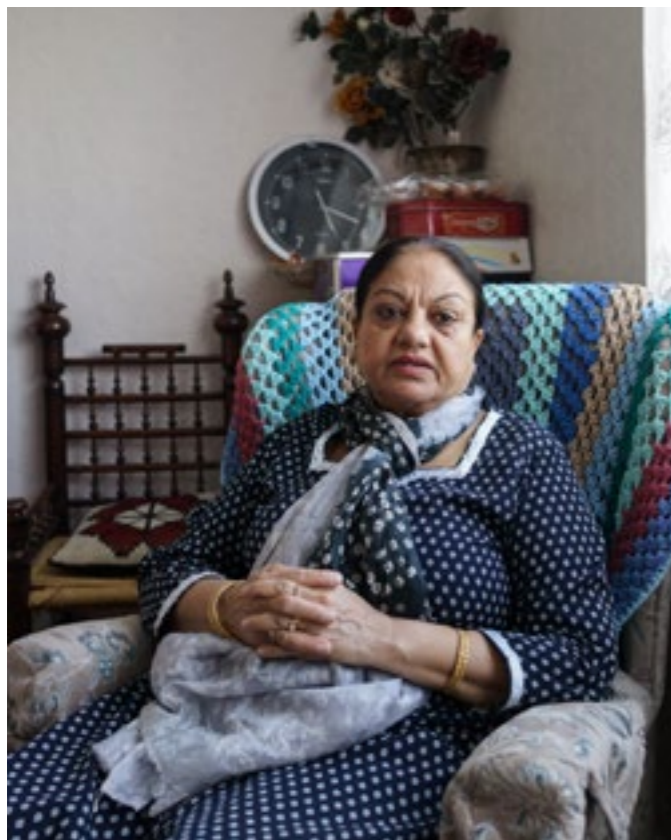
**39%**

carers say that they are struggling to make ends meet

Over half

**55%**

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



I skip meals so my boyfriend gets to eat. I have to walk miles to pick up his tablets because I can't afford the bus.



I am going to end up bankrupt. I cannot sleep at night for worrying about how I can get back on my feet financially.



I eat from a foodbank occasionally.



Just under half of all carers (47%) say that they can afford their bills without struggling financially, but 20% are or have been in debt as a result of caring, 5% cannot afford utility bills and 3% cannot afford their rent/mortgage payments.

Carers who are struggling financially often have to make difficult decisions and cut back on spending. Of those carers who are struggling to make ends meet, 40% are relying on their savings and 47% are using credit cards. A third of carers who are struggling financially (36%) are using their bank account overdraft, 8% are falling into arrears with utility bills, and 7% are falling into arrears with their housing costs ie rent or mortgage payments.

Many carers find that cutting back on household spending is an essential part of balancing their budget. Whilst 80% have cut back on luxuries, 42% of carers have also had to cut back on essentials like food and heating.

Almost three quarters of carers who are struggling financially (72%) have had to cut back on hobbies and leisure activities and 57% have cut back on seeing family and friends. 10% have even had to cut back on the support services which help with caring. 6% of carers who are struggling to make ends meet have said that they have used food banks and 4% have used pay day loans.



I am paying my bills but it is a constant struggle and I have taken on another part-time job.



I do not have anyone to ask for help and currently use my savings which are rapidly running out. When they do I will be at the mercy of universal credit, a situation I dread and fear.



**I had to sell my house to pay debts.**



# Practical support with caring

Carers make a huge contribution to the lives of those they care for and to our wider society. Despite this, too many are going without the support they need and all too often they are going without any support at all. This year's survey found that one in five carers (19%) neither buy or receive support with caring. Whilst the figures in this section are largely similar to last year, there is still a large level of unmet need, with many carers struggling without any support at all.

Carers were asked what type of practical support they receive or buy. The most popular type of support was equipment in the home of the person they care for (like hoists, grab rails or easy-grip handles on taps) with 45% receiving or buying this.

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

- help from family or friends 39%
- practical support from care workers coming in to help 30%
- a Motability vehicle 21%
- technology (eg alarms, sensors or remote monitoring to help with caring) 20%
- a break from caring 14%
- use of a day centre for older/disabled people 14%
- help with other household chores (eg shopping or cleaning) 10%
- help managing or co-ordinating care 6%



Shockingly, two thirds of carers



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

Of those struggling to make ends meet



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



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



In this year's survey we asked carers about spending their own money on support. Shockingly, two thirds of carers (66%) regularly use their own income or savings to pay for care or support services, equipment or products for the person they care for. This is even higher for those struggling to make ends meet (86%).

When asked how they feel about the practical support they may receive in the future, only 13% of carers say that they are confident that the support they currently receive will continue in the future. Just under a quarter of carers (21%) worry that the support might be reduced and two thirds (66%) don't know what might happen.

Carers were asked if they or the person they care for get a cash sum from their local Health and Social Care Trust to pay for care and support services directly eg a direct payment or personal budget. More than 7 in 10 (73%) carers don't receive a cash sum for either themselves or the person they care for. However, for 5% of respondents they receive a cash sum for them as the carer, and for 20% the cared for person receives a cash payment. For just 2% of respondents both the carer and cared for person receive a cash sum.

## Technology

Carers responding to the survey were asked if either they or the person/people they care for use any technology to support care and caring. Almost two thirds of carers (65%) reported using one or more types of technology. Surprisingly, this number was slightly lower (63%) for distance carers who do not live in the same home as the person they care for.

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

Of those carers who use technology, the internet was the most popular type with 80% using it as a source of information and 34% using it as a form of communication or online support.

Remote health care such as online GP appointments, repeat prescriptions, online video consultations, or online mental health services was another popular way to use technology with 21% of carers saying they use this.

18% of carers who use technology said that they used remote monitoring and alerts such as motion sensors, fall detectors, personal alarm, or GPS trackers, whilst 12% use medication management tools such as medication dispensers or medication reminders.

# 65%



Almost two thirds of carers reported using one or more types of technology

6% of carers are using environmental monitoring such as heating and lighting control, door video systems, or smart appliances. 10% of those who use technology use vital signs monitoring such as blood pressure monitor, blood glucose monitor, and heart rate monitors.

5% of carers are using apps, including those which help with pain management, mood management and care co-ordination.

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



## Carer's Assessments in Northern Ireland



# 26%

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



Under the Carers and Direct Payments Act NI (2002) carers have a right to be informed of their right to a Carers Assessment<sup>8</sup>. These assessments look at the impact of carers' caring role on all aspects of their life and what support they and their families need as a result.

Only 26% of carers in Northern Ireland reported that they had an assessment, or a review of their assessment, in the last 12 months. 26% of Parent carers had received an assessment/review in the past 12 months whilst only 29% of rural carers said they had received an assessment. Shockingly, only a third of those caring for 50+ hours per week said they had received an assessment or review in the last 12 months.

Out of all carers who received an assessment in the last year, 77% waited less than six months for this assessment but 23% waited longer than six months.



I honestly felt like the assessment was lip service only.





No support has been received. I think my carers assessment has been filed away as I have not had any feedback about it.



I felt quite judged!



My assessment was done nearly 2 years ago with no review.



It was great. We chatted through everything.



### Experiences of assessments

Of all the support aspects looked at in assessments, carers were most likely to say that the suitability of housing was thoroughly considered, but only half (50%) of carers reported that. Even fewer carers said that other aspects of their needs had been thoroughly considered:

- carers' ability and willingness to provide care was only thoroughly considered and reflected in support in 43% of assessments;
- only 32% of carers felt that their need for support to look after their own physical and mental health alongside caring had been thoroughly considered;
- almost a third (32%) said their need to have regular breaks from caring was thoroughly considered;
- 34% said the support they need to juggle care with work or return to work was thoroughly considered;
- 27% said emergency planning was thoroughly considered in the assessment or in the support they receive.

The experiences that carers have shared suggest that the majority of carers here (74%) have not received a Carers Assessment or review in the past twelve months. Even for those carers who had a positive experience of the assessment itself, often there is not support available locally following on from it to relieve any of the issues they have raised.

50%

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

Almost one third of carers

32%

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

Only

32%

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

# Costs, cuts and closures

When asked about changes in care and support services over the last year, 29% of carers reported that they had experienced a change in the amount of services that they receive. Of these carers who experienced a change, for 28% this was because the amount of care or support arranged by social services was reduced, whilst for 9% of respondents the care or support service was closed with no replacement offered. 3% of respondents reduced the amount of care or support received because the cost increased, and 2% reduced the amount of care or support received because the personal budget no longer covers it.

However, 36% of respondents who experienced a change in the amount of care or support arranged by social services saw an increase because the need for support increased, and for 4% of carers there was an increase even though the needs stayed the same.

Of all carers responding to the survey, 1 in 9 carers (11%) reported that they or those they support received less care or support services during the previous year due to a reduction in the amount of support from social services.

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

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



My mother is no longer able to attend day centres we were awarded 5 hours sittings service weekly in 2018 but so far my mothers social worker has been unable to get anyone to do this for us.



Use of community transport has been reduced.



1 in 9 carers

11%



reported that they or those they support received less care or support services during the previous year due to a reduction in the amount of support from social services



We did get extra childcare but it stopped.



Our need has increased but social services has no resources.



Support stopped due to cuts.



District Nurse no longer attends my elderly, disabled, vulnerable housebound father, unless we request they attend.



My uncle has had to go into a nursing home.



No budgets and long waiting lists means support services have been taken away.



I have had so much support recently. My social worker gave me carers register form and I have been going to so many classes in Ballymena Coleraine Antrim and have met so many other carers.





# Support for emergencies and contingency planning

Many carers worry about what will happen in case of an emergency where they are unable to care or the person they care for needs urgent treatment.

Carer's assessments should already look at the support needed in case of emergencies.

## Planning for contingency and emergencies

Our survey asked carers about emergencies and found that just under 1 in 6 carers (18%) have had a conversation with an NHS professional (eg a GP or a nurse) about what to do if the condition of the person they care for deteriorates, or they are no longer able or willing to provide care for them.

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



We liaise with our GP and specialist cancer nurses who are available at any time.



We liaise with our GP and specialist cancer We were advised about 'independent living' for my adult son.



I was told that is the role of friends and family.



Chatted to my parents' GP and practice nurse about getting in home helps in the future, and also got advice and guidance on the personal care I was providing by myself.



It was recommended that I visit various care homes with a view to putting my husband's name down should he require a place in the future.



The social worker thinks I should put my severely autistic adult son into a residential unit, but I am not prepared to do that yet.



We left the meetings more concerned than entering. It is as if social care for disabilities is an add on and will only be enacted at crisis point.



Have discussed this with GP... but no solutions.



My GP suggested that my role as a carer was untenable over a year ago. Despite my and his social worker efforts this hasn't as in unlikely to change.



## Emergency hospital admissions

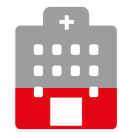
Over a third of carers (39%) said that the person they care for had been admitted to hospital in an emergency (ie an unplanned admission) at some point in the last 12 months. Half of carers (50%) felt that their emergency admission could have been prevented with more care or support in some form. This means that one in five of all carers responding to the survey (19%) had an emergency admission in the last year which they thought could have been prevented.

Of carers who'd had an emergency admission for the person they care for, 29% felt that the admission could have been prevented if they'd had more care and support for the person they care for and 16% felt that more support for them as the carer (eg breaks from caring) would have prevented the admission.

Almost a quarter (22%) felt that higher quality care for the person they care for would have prevented the admission, whereas 11% felt adaptations in the home of the person they care for would have made a difference. 10% felt that the emergency admission could have been prevented if they had access to a district nurse.

Fewer than 1 in 10 carers (9%) felt that following a previous discharge from hospital, not enough time was taken to put in place adequate care and other arrangements that could have prevented the subsequent emergency admission. 7% of carers thought that telecare or telehealth services (eg monitoring equipment, alarms and sensors which remotely check the health of an older, sick or disabled person and that they haven't wandered, had a fall or accident) could have prevented the emergency admission, and a further 5% thought replacement care when the carer needed medical treatment would have prevented it. 1% of carers thought it could have been prevented if they'd had access to a hospice.

29%



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

1 in 5 of all carers

19%



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

## Planning for the future



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

### Planning for retirement

We asked carers **who are not retired** about how they intend to pay for their retirement. The most common source of income for retirement was a state pension with 73% of carers expecting to use this.

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

- workplace pension 59%
- personal savings 16%
- a main home you could downsize from 15%



15% of carers don't know how they are going to pay for retirement. Carers who are over 50, and therefore closer to retirement age, are less likely to say they don't know how they are going to pay for their retirement with 10% of over 50s saying this compared to 19% of under 50s.

Carers who are not retired and are struggling to make ends meet are less likely to have made financial plans for the future – 25% don't know how they are going to pay for retirement.

Carers who are not yet retired were also asked about their future plans and 46% said that they are not able to save for their retirement. This rises to 55% of carers who are regularly using their own income or savings to pay for care or support services, equipment or products for the person they care for. 72% of those who describe their financial situation as struggling to make ends meet are not able to save for retirement. Almost three quarters of those who are receiving Carer's Allowance (72%) are not able to save for retirement.

Some carers are saving or have saved less for their retirement with 12% saying they did this because their working hours were reduced. 15% said that they have saved less or were saving less because their short-term financial needs are too great to afford to save for the long term.

Only 1 in 4 carers (25%) responding to the survey said that their ability to plan or save for retirement had not been affected by caring. This is even lower for carers who have been caring for over 15 years or more (19%) and carers who care for over 50 hours a week (16%).



I cannot have care needs, who would look after my young adult disabled children?



### Planning for carers' future care needs

Almost two thirds of carers (62%) say that they have focussed on the care needs of the person they care for, and not on their own needs.

Almost a third of carers (30%) say that they worry about their care needs in the future but cannot do anything about it.

Only 1% of all carers feel that they have prepared for any care needs they may have in the future for themselves.

Almost two thirds of carers

**62%** QQQ

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



My partner and I plan to look after each other if at all possible.



I want to buy a home so that I can afford to retire but have no spare cash to save plus I am too old for a mortgage.



I have not considered my future care needs.



It's hard to know what to plan going forward! A life time of working full time! A retirement of caring and sickness!



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



## Health and wellbeing



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

All carers	Very good	Good	Fair	Bad	Very bad
Physical health	7%	29%	42%	17%	5%
Mental health	6%	25%	44%	20%	5%

Over a third of carers (36%) responding to the survey reported that their physical health was good or very good and 31% reported their mental health was good or very good.

Given the immense personal cost that comes from providing round the clock care it is unsurprising that carers who care for more than 50 hours a week reported poorer health with 26% reporting bad or very bad physical health and 31% reporting bad or very bad mental health.

When asked about physical exercise, 82% of carers responding to the survey said that they are not able to do as much physical exercise as they'd like to do.



I have to do exercise at home to be here for my daughter as going to the gym for example would mean being out of the house for longer and would put financial strain on me.



Started a c25k, difficult to manage time. Really enjoy it but puts more stress on you trying to fit everything in.



## Loneliness and wellbeing

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

Carers are seven times more likely to say they are always or often lonely compared with the general population<sup>9</sup>. Over half (54%) of the population of the UK say they are never or hardly ever lonely compared with just 1 in 5 (21%) unpaid carers in Northern Ireland. Just over 7 in 10 (74%) of all carers reported having ever felt lonely or isolated as a result of their caring role.

The research report also revealed that Carers in the UK are nearly twice as anxious as the general population. Carers in Northern Ireland reported significantly lower life satisfaction and lower happiness compared with the NI average and their anxiety levels were almost twice as high as those reported by the population of Northern Ireland as a whole (5.3 compared to 2.7). However, compared with carers across the UK, carers in Northern Ireland reported being 8% happier (5.1 compared to 4.7) and 8% more satisfied with their life at the moment (5.1 compared to 4.7).



<sup>9</sup> Carers Week (2019) Getting carers connected

82% 

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

74% 

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



Have lost contact thru inability to get out. Bank and public holidays are long and lonely times.



I have developed anxiety which I am sure is because of my caring role and no longer enjoy socialising.



All my social contacts have disappeared. It is just me and the people I care for.



It affects my mental health and mental wellbeing as I get frustrated at times from the lack of "freedom" to do anything for myself.



# Juggling work and care



Image - © Olivia Hemingway

Recent research by Carers UK found that the number of those juggling work and care could be far higher than previously thought – around 4.87 million (compared with 3 million in the Census 2011). This is one in seven of all workers<sup>10</sup>.

Over half of carers (57%) responding to the survey reported being in paid work. These working carers can be broken down as follows:

- 56% are full-time employees
- 39% are part-time employees
- 2% are self-employed full-time
- 3% are self-employed part-time<sup>11</sup>.

Carers often find that it can be a struggle to balance their responsibilities in work with their caring responsibilities. 28% of all carers reported that they had given up work to care and 20% had reduced their working hours. Over a quarter of carers (29%) said that they work the same hours but their job is negatively affected by caring, for example because of tiredness, lateness, and stress. 12% of carers said that they have

had to take a less qualified job or have turned down a promotion to fit around their caring responsibilities. Just under 7% said that they had retired early to care. Only 8% of respondents of all ages said that caring has had no impact on their capacity to work.

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

Locally, Carers NI provide information and training to employers and staff on support for staff who are caring. Please contact [advice@carersni.org](mailto:advice@carersni.org) for more information.

<sup>10</sup> Carers UK (2019) Juggling work and unpaid care

<sup>11</sup> Due to rounding, these do not add up to 100



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



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



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



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



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



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



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



# Recommendations

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

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

- Carer's Allowance, just £66.15 on 2019/20 rates, must be raised across the rest of the UK to the same level as Scotland, with equivalent increases to carer premia to ensure that those on the lowest incomes benefit. In the longer term, financial support for carers must be increased significantly.
- The earnings threshold for Carer's Allowance needs to rise year on year in line with the National Living Wage, pegged at least to the equivalent of 16 hours a week so carers don't have to choose between Carer's Allowance and staying in work.
- To auto-enrol carers in a second pension – a Carer's Pension that recognises the value of unpaid work and ensures that they do not suffer financial hardship later in life.



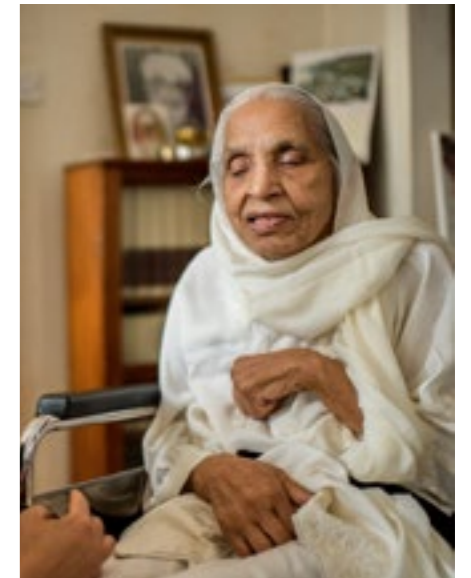
## Deliver a National Health Service that recognises, values and supports carers

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



## Put in place enough funding so that older people and people with disabilities are able to access the quality and affordable care they need and that they are able to have a good quality of life alongside their caring roles

- An urgent and significant increase in funding for care services is needed now or the role of families and friends caring will become increasingly unsustainable as carers are pushed to breaking point by a lack of support.
- Consideration of new funding models for social care and the priorities for future NHS spending must have carers' contribution, both financial and practical, at their heart and deliver a sustainably funded health and care system that is fairer for families.



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

- Increase and ring-fence funding for carers' breaks. Funding should also be transparent so carers know what they are entitled to, and ensure greater consistency in what is available. A choice of appropriate and good quality care must be available or carers cannot get the breaks they need for their own health and wellbeing.



## Ensure carers are able to juggle work and care, if they wish to, with support to return to work alongside or after caring

- Create a new right to paid time off work to care of at least 5-10 days.
- Put in place tailored support for carers looking to return to work, including recognising the skills carers have developed through their caring role.
- Work with employers to include carers in health and wellbeing support at work.
- Recognise that good quality and affordable care services are an essential part of enabling carers to remain in or return to work alongside caring.





Every year over 70,000 people in Northern Ireland become carers, looking after family or friends who are older, disabled or seriously ill.

However caring affects you, we're here.

For information and tailored support, contact the

Carers NI Adviceline:

**E** [advice@carersni.org](mailto:advice@carersni.org)

**T** 028 9043 9843

Carers NI, 58 Howard Street, Belfast BT1 6PJ

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