



State of Caring 2023

The impact of caring on health in Northern Ireland

November 2023



About this research

Carers NI carried out an online survey between June and August 2023. A total of 1,024 unpaid carers responded to the survey.

Of respondents to the survey:

- 81% identified as female and 18% identified as male
- 2% are aged 25-34, 13% are aged 35-44, 27% are aged 45-54, 35% are aged 55-64, and 23% are aged 65+
- 28% have a disability
- 47% are in some form of employment and 24% are retired
- 2% have been caring for less than a year, 23% have been caring for 1-4 years, 25% have been caring for 5-9 years, 16% have been caring for 10-14 years, and 33% have been caring for 15 years or more
- 17% provide 1-19 hours of care per week, 23% provide 20-49 hours of care per week, 14% provide 50-89 hours of care per week, and 46% provide 90 or more hours of care per week
- 70% care for one person, 22% care for two people, 6% care for three people and 2% care for four or more people.

Thanks

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

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Introduction

Across Northern Ireland, over 220,000 people are providing unpaid care for a sick or disabled family member, friend or neighbour – around 1 in 8 people. ^[1] They provide hundreds of thousands of hours of care each week, supporting the cared-for person's personal, practical and emotional needs, with some also juggling paid employment, child-rearing and more at the same time.

Our unpaid carers play a critical role in the survival of the Health and Social Care (HSC) system, with evidence suggesting that, as statutory services in Northern Ireland have deteriorated more and more, unpaid carers are increasingly stepping in to fill the gaps. As Census figures show, the number of people performing the most intense unpaid caring roles in Northern Ireland has shot up drastically during the last 20 years (Chart 1), and the care they provide is estimated to be worth billions of pounds per year.

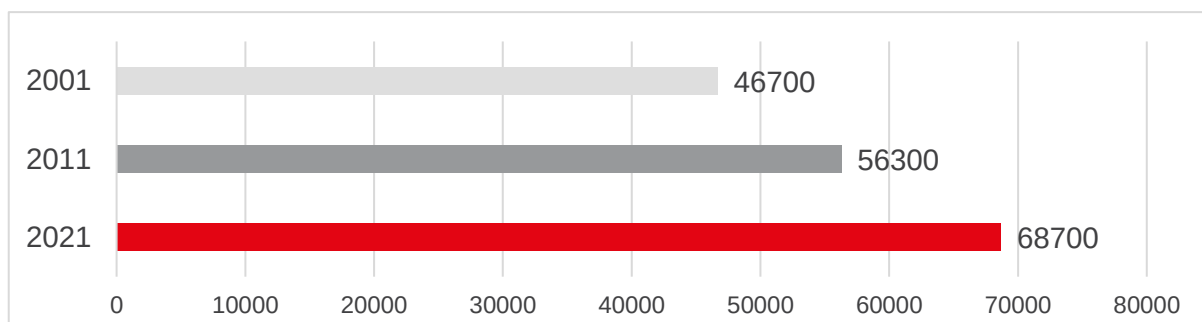
The state may be increasingly reliant on unpaid carers' commitment to those they care for to keep services from collapse, but this often comes at a severe cost – particularly to carers' own physical health and mental wellbeing. This report shines a light on these impacts, based on data and carer testimony from Carers NI's State of Caring survey 2023.

It shows that many local carers are suffering devastating levels of mental ill-health, chronic loneliness, deteriorating physical wellbeing, burnout, and more. It shows that a common thread in many of the negative health outcomes associated with unpaid caring is the lack of opportunities carers have for regular breaks and respite.

It puts forward a suite of policy measures to address the unacceptable ill-health carers are living in, with practical and policy recommendations to ensure carers have the time and space they need to prioritise their own health and take breaks from caring.

- *"I feel lost. In poor mental and physical health. Abandoned and alone."*
- *"I'm physically and mentally exhausted all the time."*

Chart 1: People providing 50+ hours of unpaid care per week in Northern Ireland ^[1]



Mental health



There are major levels of mental ill-health among Northern Ireland's carer population

Unpaid caring is a major driver of mental ill-health, with **1 in 4** carers describing their mental health as bad or very bad. These levels were worse among those with the most intense caring roles, including those who have been caring for ten years or more (29%) and who spend 50 or more hours per week providing care (30%).

Looking at how this mental ill-health manifests, carers reported significant rates of anxiety and stress (84%), low mood (84%), irritability and mood swings (80%), the inability to switch off from worrying about caring (80%), feelings of hopelessness (72%), fear or dread (71%) and depression (49%). The impact can be debilitating, affecting carers every minute of the day and keeping them awake at night.

- *"I don't want to get out of bed [in the morning] to face it all again. I'm constantly stressed."*
- *"I can't sleep. I'm always fearful and worried."*

The pressure facing carers is leaving some considering extreme courses of action, with **24%** of carers saying they have had thoughts related to suicide or self-harm. ^[1] One carer indicated this was a regular feature of their life, stating that *"suicidal thoughts are never too far away."*

¹ Throughout the time when the State of Caring survey was live, Carers UK staff closely monitored responses for any safeguarding concerns, particularly in regard to carers' mental health. Any such safeguarding concerns were forwarded to our Safeguarding Leads to be actioned.

Carers don't have time to prioritise their own mental wellbeing

A recurring theme among many carers was that their lives and caring roles are too hectic to carve out any time to look after their own mental wellbeing. A large majority (76%) said they had continued providing care despite feeling like they were at breaking point, and when we asked about the barriers to seeking help for their mental health, **more than half (53%)** of carers said they were too busy caring – the most common response.

- *"My mental health has to take a back seat. I just don't have time to stop and think about it."*
- *"I'm worn out. I rarely get an unbroken night's sleep. I need counselling, but am unable to leave my daughter unattended."*
- *"Caring is full time, so my needs have to come second."*

As with so many of the challenges facing unpaid carers, improving carer mental health is therefore closely linked to expanding their access to replacement care, breaks and respite from their caring roles.

The health system isn't giving carers the mental health support they need

It is deeply concerning that, when asked about the sources of help they've accessed to manage their mental health, the most frequent response from carers (44%) was that they haven't received any help at all. The second most common answer was help from partners, friends or relatives (26%). In other words, a **significant majority (70%)** of carers either haven't had any help with their mental health or are relying on informal support from people they know – nearly three times the proportion who said they'd accessed support from the Health and Social Care (HSC) system (24%). Across every jurisdiction in the UK, only Wales has fewer unpaid carers accessing mental health support from the statutory health system.

Long waiting lists to access help are a big issue, with **a third of carers (33%)** saying concern about long waiting times was preventing them from seeking help with their mental health – the highest rate in the UK. We heard from carers who had faced years-long waiting lists to access services.

- *"I asked for help last year... Still waiting."*
- *"[I've been told there is a] 4-year waiting list."*

1 in 4

carers described their mental health as 'bad' or 'very bad'



33%

of carers said concern about long waiting times prevented them from seeking mental health support



Others had essentially fallen at the first hurdle, as they were unable to speak to their GP about their mental ill-health and secure an onward referral.

- *“I know my mental health is poor. Getting to see a doctor is just too hard. It is like jumping through hoops and discussing everything with a receptionist is off-putting... The last time I called the doctor it took more than 600 attempts. Almost two hours of trying.”*

Some carers had struggled to access help, and when they eventually got their turn, were disappointed by the limited services offered.

- *“[There are] no services available. Six weeks counselling is no use to anyone.”*

Finally, lack of awareness of the help that exists is another barrier, with **nearly 1 in 5 (18%)** carers saying they hadn't accessed support for their mental health because they don't know where to go to ask for it. This is, again, the highest rate in the UK.

Our findings therefore strongly suggest that we need to both boost the provision of existing mental health services for carers and undertake improved awareness-raising and communication about where carers can turn when they're experiencing mental ill-health.

These objectives are shared with the NI Mental Health Strategy 2021-31 ^[iii] and we would support the call for that strategy to be funded and delivered in full by the Department of Health.

Loneliness



Caring is a significant driver of loneliness and social isolation

A wealth of research has identified unpaid carers as one of the groups with a heightened risk of experiencing loneliness. Half of carers told our survey that they feel lonely sometimes, with **nearly a third (29%)** saying they feel lonely always or often – significantly higher than the equivalent proportion across the general population in Northern Ireland, which was 6% in 2021-22 (the most recent figure available). ^[iii]

For many carers, this loneliness was linked to lost or depleted friendships and social networks due to the pressures of their caring role. They said caring meant they often lacked the time, energy and finances to see friends or take part in social activities, leaving them “isolate[ed] from the outside world.”

- *“I am rarely out of the house, as it is not safe to leave my husband on his own.”*
- *“I have lost contact with friends as a I can’t socialise very often.”*
- *“I am completely isolated from family, friends... personal relationships.”*
- *“You lose a lot of your social circle and learn that you are your own support system.”*

Other carers described a form of self-exclusion from their social circles, driven by a fear of letting friends down when they can’t commit to plans because of the unpredictable nature of their caring responsibilities, and concern about putting them off by talking about the realities of their life as a carer.

- *“[It’s] isolating, as I don’t want to endlessly go on to friends or constantly let them down by having to back out of things... So, I end up just not planning.”*

Mental health outcomes are worse among carers who feel lonely

Loneliness is associated with a heightened risk of mental ill-health, and in our survey, there was a stark difference in the mental health outcomes reported by carers who experience greater levels of loneliness compared to those who don't (Table 1).

Carers who said they feel lonely always, often or sometimes were **over three times more likely** to describe their mental health as bad or very bad than those who never or hardly ever feel lonely. They also reported much higher levels of depression, stress, anxiety, and more.

Help to feel less lonely is a priority for carers

Unsurprisingly, addressing loneliness is a big priority for unpaid carers – with **1 in 3** identifying support to prevent or reduce loneliness as one of their main needs. Northern Ireland lags behind the rest of the UK as the only jurisdiction without a dedicated Loneliness Strategy. This should be a priority for a restored Stormont Executive, delivered on a cross-departmental basis and taking inspiration and learnings from international best practice to support unpaid carers and other groups experiencing chronic loneliness in Northern Ireland.

Many carers also experience loneliness because they lack the time to take part in social activities or see friends alongside their caring role. Delivering a robust and fit-for-purpose social care system – which provides the reliable replacement care unpaid carers need to be able to lead a life outside of caring – will therefore make a huge difference to tackling loneliness among the local carer population.

Table 1: Mental health outcomes and loneliness among unpaid carers

Mental health outcome	Carers who always, often or sometimes feel lonely	Carers who never or hardly ever feel lonely
Mental health bad or very bad	28%	8%
Feel depressed	57%	15%
Feel stress or anxious	89%	64%
Feelings of hopelessness	76%	36%
Continuous low mood	88%	45%
Regularly feeling tearful	66%	45%
A sense of fear or dread	74%	36%

50%

of carers said they feel lonely at least some of the time



Physical health



Unpaid carers are living with deteriorating health and burnout

Providing unpaid care can be a physically tasking role, with around-the-clock demands, inadequate help, and little sleep or rest leaving many carers increasingly burnt out and in deteriorating health. **Over half (52%)** said their physical health has suffered due to caring and 21% said they had experienced injuries as a result of their caring role – in many cases compounded by mental ill-health, too.

- *“Due to caring for three people with a host of physical and mental health problems, as well as receiving zero support from the [Health Trust], I suffered two strokes and a heart attack... Even after that, I received little-to-no help while recovering!”*
- *“I have inflamed tendons in my arms from lifting and holding my husband many times a day. I cry very easily with the stress... I’m overwhelmed.”*
- *“I am constantly exhausted.”*
- *“I was hospitalised several times due to my own conditions.”*
- *“My conditions started when I took on the caring role while trying to maintain work... I now live with fibromyalgia, degenerative disc disease and mental health issues.”*

Older carers also highlighted the cumulative physical impact of years spent caring – an important issue given our ageing population and the likelihood that more and more people will be caring in later life.

- *“At 70 years of age I now feel the impact of wear and tear and degenerative changes in my physical health from all of the years of caring.”*

Caring demands stop carers tending to their own health needs

A concerning theme from many carers in our survey is that the demands of caring often stop them from tending to their own health needs, with more than **1 in 3 (39%)** saying they had put off health treatment because of their caring role.

- *“I was unable to book a scan as I was having to travel to Belfast. That would mean too many hours away.”*

Others said caring pressures meant they were unable to properly manage their own conditions, including their medication and diet.

- *“I have an auto-immune condition, which, prior to my caring role becoming full time, I had under control. I took my medication and managed by symptoms with a good diet. Since my caring role [intensified], my symptoms have worsened. I regularly forget to take my own medication and my diet is inconsistent. Added to this my sleep is very poor, which has a knock-on effect.”*
- *“As a cancer survivor, I need to ensure I keep certain aspects of my body healthy... I don't have the time nor the energy to do that simple thing.”*

Carers' physical health won't improve without new services and support

The help carers ask for to improve their physical health is far from unreasonable. Over 70% said that getting a good night's sleep would make a difference, so we would reiterate the call – already made elsewhere by carers ^[iv] – for greater access to overnight sitting services.

Unsurprisingly, taking breaks from caring was another big priority to help improve carers' health (58%), and this must be delivered as part of the wider move to reform the adult social care system and give carers the access to community care, replacement care, and respite they need.

Finally, 6 in 10 carers also said that being physically active would help improve their health, however nearly half (48%) said they don't have the opportunity to because of barriers, including, but not limited to, affordability. In April 2023, Carers NI's campaigning secured a new concessionary rate for leisure services for carers in Antrim and Newtownabbey council, and we would call on all other local councils across Northern Ireland to follow suit. ^[2]

- *“I'm always tired. Completely worn out. I'm doing the role of three people and it's so difficult. I've no independence.”*

² Antrim and Newtownabbey Borough Council introduced a near-35% discounted rate for all carers with a valid Health Trust Carer Card.

Breaks and respite



Too many carers are missing out on the breaks they need

Many carers in Northern Ireland struggled to access regular and meaningful breaks from their caring roles even before the COVID-19 pandemic severely disrupted the provision of respite, day services and short break opportunities. Despite a remobilisation process across all Health Trusts, carers have continued to report below-pandemic access to these services, with **fewer than two-thirds (59%)** telling our survey that they have had a break from caring during the previous 12 months – the lowest rate in the UK.

Many reported that they had gone years without a break.

- *“I have only had one day off with my partner from our extensive caring role in 21 years, and no break away.”*
- *“I have not had a full day off in the last four years.”*
- *“I have never had a holiday and it does not look like I ever will. Why do I have to beg to get a week or two off?”*
- *“[I’m] denied access to a normal life and time out... No holidays for years.”*

Some highlighted that a lack of access to services for the cared-for person – including health services, replacement care and education opportunities – meant there was never any time for them to have a break and stop being a carer, with an enormous impact on their wellbeing.

- *“I feel like a caged animal, especially during the winter months. My nephew is totally dependent on [my] support to enable him to have a quality of life. Being housebound with him is taking its toll on my mental health... [I've] just lost the will to live because of the pressures on me.”*
- *“The stress of fighting for my child to have an accessible education has had a terrible toll on my physical and mental health. While my child hasn't attended school I have had her 24 hours a day, 7 days a week, without a break. There is no off button. No down time. It is hard not to become fatigued.”*

Inadequate social care provision is a particular problem, as **44%** of carers disagreed/strongly disagreed when asked if the services they receive enables them to take a break from caring.

- *“I have had two cataract surgeries and surgery for a detached retina. No respite support for any of the surgeries... I haven't had overnight respite since 2018.”*
- *“There is a limited amount of respite hours provided to me. [Paid] carers come in... but that doesn't give me any freedom. In fact, that ties me down to being in the house. It's difficult to keep up your own life, hobbies, see grandchildren when you have limited respite time.”*

Some carers have been able to access a break, but advance notice is very limited, making it difficult to make meaningful plans and utilise the opportunity fully.

- *“My son attends a respite unit. It very much varies when he can go so it is almost impossible to make plans.”*

For others, the break still involved bringing the person they care for, meaning they were unable to switch off from their caring role. Perversely, the change in routine even exacerbated the person's needs in some cases.

- *“There should be access to some respite care to allow a long-standing carer to get a holiday from caring duties. When I do get a short break, I have to take my husband with me, thereby taking my caring duties with me too. And these often increase when he is in an unfamiliar setting.”*

Even limited breaks may help improve health outcomes among carers

A wealth of research has illustrated that breaks from caring can support better health for unpaid carers, including improved physical, mental and emotional wellbeing^[v] and enhanced resilience.^[vi] Our survey reflected these trends, with improved outcomes across many key metrics of health and wellbeing among those carers who had accessed a break compared to those who hadn't (Chart 2).

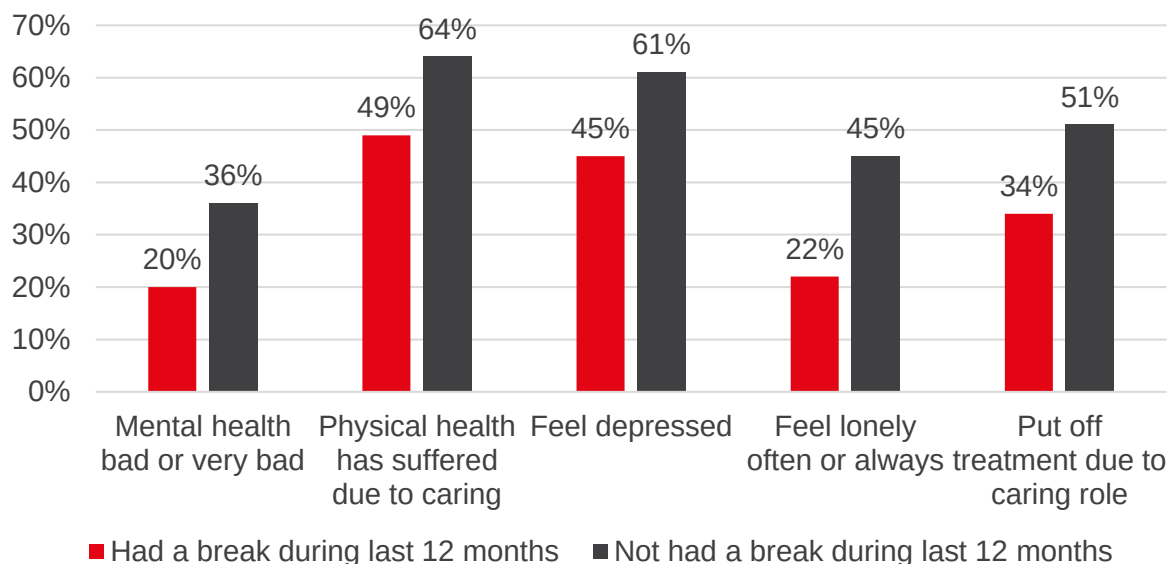
These carers were **more than twice as likely** to report good mental health, and also reported lower rates of physical ill-health, depression and loneliness.

While wider factors undoubtedly contribute to this, there is a clear case for boosting access to breaks as a means of improving health and wellbeing among local carers and potentially reducing pressure on HSC services as a result.

More than 45% of carers identified more breaks or time off as one of their main needs as a carer, and in wider research, local carers supported the introduction of a legal right to breaks from caring ^[iv] – as is being delivered in Scotland through the new National Care Service.

Elsewhere, we should take inspiration from Scotland's Respite scheme, which connects unpaid carers with hospitality, tourism and leisure businesses that donate free short breaks or respite opportunities. ^[vii] The scheme provides carers with access to breaks that would have otherwise been unavailable – valued at over £100,000 in 2022 ^[viii] – while imposing only a small administrative cost on central government and helping local organisations and businesses achieve their corporate social responsibility objectives.

Chart 2: Access to breaks and health/wellbeing outcomes among carers in Northern Ireland



45%

of carers identified more breaks as one of their main needs as a carer



Policy recommendations

The evidence presented in this report underlines the devastating levels of ill-health that exist among unpaid carers in Northern Ireland. For too many of our carers, lack of opportunities for a break, inadequate or non-existent support services, and the pressure of their caring roles mean daily life is defined by physical and mental exhaustion, isolation and loneliness.

To begin reversing these trends and protect the health and wellbeing of unpaid carers in Northern Ireland, we are calling for:

- **Delivery of the adult social care reform agenda set out in the Power to People report and subsequent consultation by the Department of Health, with a particular focus on expanding access to high quality community and replacement care services**
- **Development of a cross-departmental Loneliness Strategy for Northern Ireland**
- **Full funding of the Northern Ireland Mental Health Strategy 2021-31**
- **Greater access to overnight sitting services for unpaid carers**
- **Concessionary rates for leisure services in all council areas of Northern Ireland**
- **A new legal right to breaks for unpaid carers**
- **The introduction of an equivalent scheme to Scotland's Respite programme.**

While some practical measures can be delivered to help carers in the immediate term, most of these recommendations require policymaking and legislation from the NI Assembly, which is not sitting at the time of writing. It is unacceptable for this situation to continue while our unpaid carers are driven to ever-worsening health by a system that doesn't provide the support they need.

We are not arguing that a sitting government will fix these challenges overnight – some solutions will take a lot of time and investment – but it is an indisputable fact that we cannot deliver the strategic change that unpaid carers need without an Executive in place. Carers need their legislators in Stormont to make their lives better, so as a prerequisite to delivering the policy reforms outlined above, we are calling for the urgent restoration of Northern Ireland's political institutions.

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This is the second in a series of reports based on data from the State of Caring 2023 survey in Northern Ireland.



Carers NI is Northern Ireland's membership body for unpaid carers. We're here to listen, to give carers expert information and tailored advice. We champion the rights of Northern Ireland's 220,000 carers and support them in finding new ways to manage at home, at work, or in their community. We're here to make life better for carers.

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