

State of Caring 2022

A snapshot of unpaid caring in Northern Ireland

November 2022



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This report explores the key findings from Carers NI's latest State of Caring survey. The annual State of Caring survey has been undertaken for over a decade and is Northern Ireland's most comprehensive research into the lives and experiences of unpaid carers.

The pages that follow include an overview of the survey data and a wealth of stories and testimony provided by carers via open-text responses to the survey. Where appropriate, this is supplemented with wider evidence and research.

The 2022 State of Caring survey was carried out between July and September 2022 and completed by 1,648 unpaid carers across Northern Ireland – the largest sample size in the survey's history. The demographic breakdown of survey respondents is as follows:

- 82% identified as female and 17% identified as male.
- 4% are aged 25-34, 17% are aged 35-44, 33% are aged 45-54, 31% are aged 55-64 and 14% are aged 65+.
- 24% have a disability.
- 98% described their ethnicity as white.
- 28% have childcare responsibilities for a non-disabled child under the age of 18 alongside their caring role.
- 56% are in some form of employment and 18% are retired from work.
- 31% have been caring for 15 year or more, 16% for between 10-14 years, 25% for 5-9 years, 25% for 1-4 years, and 3% for less than a year.
- 46% provide 90 hours or more of care per week, 13% care for 50-89 hours, 23% care for 20-49 hours, and 19% care for 1-19 hours per week.
- 67% care for one person, 25% care for two people, 5% care for three people and 3% care for four or more people.

Not all respondents completed every question in the survey, and this should be considered when reading the results.

Carers NI is indebted to every unpaid carer in Northern Ireland who completed the State of Caring survey and shared their caring experience with us. Doing so helps provide the evidence we need to make the case for change and improve the lives of all unpaid carers here.

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The state of caring: Context

There are over 290,000 people providing some form of unpaid care for a sick or disabled family member or friend in Northern Ireland – around 1 in 5 adults.ⁱ We now have more unpaid carers than before the COVID-19 pandemic, and in many cases, the intensity of those caring roles also increased over the last few years.

Unpaid carers save the public purse in Northern Ireland £4.6bn in care costs annually,ⁱⁱ very often at the expense of their own health, finances and social welfare. If they disappeared for even one day, the Health and Social Care system would collapse, but too often, the support they receive when making such an enormous contribution to society falls far short of what they need.

There is perhaps no greater example of this at present than the cost of living crisis. Our unpaid carers have been among the hardest hit by spiraling household bills, and many are now living hand-to-mouth – struggling to cover their monthly expenses and terrified about what the future holds.

Elsewhere, local carers are still struggling to access the services they need to look after themselves and take regular breaks from caring. They're driving themselves into the ground because, in many respects and despite decades of talking about reform, our social care system is still not fit for purpose and was set back further by the impact of the pandemic.

This report shines a spotlight on these issues and many more, exploring the biggest challenges facing unpaid carers in Northern Ireland today. It paints a bleak picture, showing the extent to which many are sacrificing their own health, wellbeing and life chances in order to care.

And it makes a robust call to action to better support unpaid carers. For too long, our carers have been taken for granted – relied on but not listened to, and expected to give so much but getting little in return. That situation can't continue, so we've set out an extensive range of policy recommendations that must be pursued as a matter of urgency. One of the most important first steps is to restore Northern Ireland's political institutions, form a new Executive and start delivering for unpaid carers.



Our unpaid carers have been among the hardest hit by spiraling household bills, and many are now living hand-to-mouth – struggling to cover their monthly expenses and terrified about what the future holds



Executive summary

This report provides a snapshot of the biggest challenges facing unpaid carers in Northern Ireland today. Unsurprisingly, we found that many are suffering significantly in the face of the cost of living crisis, with 27% of carers struggling to make ends meet – the second highest proportion in the UK behind Wales.



Fewer than 1 in 3 carers said they could afford their bills without struggling financially – less than half the proportion last year – and nearly a quarter (23%) were cutting back on essentials like food and heating to help them cope. Overall, 67% of carers said the increased cost of living was having a negative impact on their physical and/or mental health.

For too many carers, going to work is incompatible with the demands of their caring role, and many of those juggling work and unpaid caring are driving themselves into the ground because of inadequate employer support.

Less than a third of carers (28%) said they had access to paid carer's leave from work, while just over half (54%) said they had been offered flexible working arrangements. These measures are popular with carers and, if more widely available, would make it much easier for them to balance work and caring without having to push themselves to burnout and exhaustion.

Levels of health and wellbeing among our carer population remain a serious concern, particularly among those with the most intense caring roles. 1 in 5 carers reported their physical health to be bad or very bad, rising even further, to 24%, among those who have been caring for ten years or more, and to 25% among those caring for 50+ hours a week.



Similarly, 27% of carers reported their mental health as bad or very bad, rising to 31% among those caring for 50+ hours a week and 32% among those who have been carers for 10 years or more.

Northern Ireland's notoriously long health service waiting lists are having a compounding effect in this context. Over 70% of carers who need specialist treatment or assessment by a doctor have waited for over six months after referral, including 56% waiting for over a year. More than 7 in 10 carers waiting for specialist treatment or assessment said it was negatively impacting their mental or physical health.

Elsewhere, we found that carers are continuing to face barriers to accessing services to support them in their caring role, with 23% saying the care and support services in their area do not meet their needs. Challenges with the Self-Directed Support system persist, as nearly 1 in 6 carers (15%) said a shortage of staff meant they couldn't find care to buy – rising to 19% in rural areas.

This lack of access to support services is leaving many carers with little opportunity for a break or time off from caring. More than a third (40%) of carers hadn't had a break within the last 12 months, leaving many feeling burnt out and exhausted.

The impact of the pandemic is still being felt, with just 9% of carers saying the day services they previously used had fully reopened.

The impact of the pandemic is still being felt, with just 9% of carers saying the day services they previously used had fully reopened. Accessing these services remains a priority for many carers – nearly half (49%) identified more breaks or time off from caring as one of their top needs.

A carer's assessment is one of the primary gateways for carers to access support, but we found that too many carers are either unaware of their right to an assessment or have been left disillusioned with the process after going through it in the past. Less than a quarter (21%) of carers had received a carer's assessment, review or reassessment during the last 12 months – and among those who hadn't, the single biggest reason (53%) was not knowing what a carer's assessment is.

Equally concerning, more than 1 in 10 carers (13%) said they hadn't had an assessment, review or reassessment because they didn't think it would be beneficial for them. This is, unfortunately, a long-term trend, with many carers becoming disillusioned at having taken the time to go through the process, only to receive no additional support afterwards due to funding, service and staff shortages.

This report exposes the severe, wide-ranging challenges facing unpaid carers in Northern Ireland. The situation requires a robust policy response, so we have set out a number of recommendations to help better support the local carer population.

Policy recommendations

To support carers through the cost of living crisis and give them the financial support they need, we are calling for:

- An emergency carer payment of £700 for every person in receipt of Carer's Allowance, providing much-needed short-term relief to support them through the harsh winter months.
- The introduction of a Carer's Allowance Supplement scheme, paid at the same rate (close to £500 per year) as the scheme in Scotland.
- Dedicated energy support payments for unpaid carers, in recognition of the above-average energy bills many face as a result of their caring role.
- Root-and-branch reform of the Carer's Allowance system, namely:
 - *Carer's Allowance to be uprated in line with inflation.*
 - *An increase in the Carer's Allowance earnings threshold to (at least) the equivalent of 21 hours per week at the National Living Wage.*
 - *The introduction of a taper to the Carer's Allowance earnings threshold, allowing carers to keep part of their payments as they earn more.*
 - *Additional Carer's Allowance payments for those who care for more than one person.*
- An inflation-matching uplift in other carer, working age and disability benefits.
- Development of a new cross-departmental Fuel Poverty Strategy for Northern Ireland, co-designed and produced with key at-risk groups, including unpaid carers.
- Minimum living standards for all unpaid carers, enshrined in a Northern Ireland Bill of Rights.

To ensure all carers get the support they need to take regular breaks from caring and look after their own health and wellbeing, we are calling for:

- Legislation to legally enshrine carers' rights to social care support, based on identified needs.
- Immediate action to fully restore day services, respite and short break provision to pre-Covid levels, as a minimum.
- Urgent progress on delivering reform of the adult social care system, with the necessary funding to make this a reality, and prioritisation of the carer-related proposals within that process – particularly a new Carers Strategy, Carers' Register and appointment of a Carers' Champion.
- Greater information and administrative support to households considering/using Self-Directed Support, including dedicated SDS Navigators in each Trust area.
- Regular inflation-linked uplifts in the value of Direct Payments, to ensure carers can continue to buy all of the care they need without being out of pocket.
- A review of the suitability of the NI Single Assessment Tool for carrying out holistic Carer's Assessments.
- New direct payments or vouchers for carers to spot purchase non-HSC assessments, physiotherapy, counselling and similar services.
- A new statutory duty on Health and Social Care bodies to treat unpaid carers as strategic partners in care and involve them in care planning and decision-making.

To help more carers to better balance work and unpaid caring, we are calling for:

- Legal entitlement to five days paid carer's leave from work, making it easier for carers to juggle work and caring without driving themselves into the ground or being forced to leave their jobs to meet the demands of their caring role.
- A day-one right to flexible working arrangements for all unpaid carers.
- Delivery of a robust Childcare Strategy and affordable and accessible childcare options for unpaid carers.

Financial impact of caring



Unpaid carers have been among the groups hardest hit by the cost of living crisis in Northern Ireland. Even before the price of daily essentials began to rise so steeply, many carers already faced above-average household bills linked to their caring role – often including large electricity costs to run medical equipment in their home; higher heating bills to keep the person they’re looking after warm around-the-clock; greater spending on food due to their nutritional needs; and the extra transport costs of taking them to and from health appointments.

These pre-existing financial pressures have only been compounded as living costs have shot up so drastically. As this chapter shows, this is leaving tens of thousands of carers in Northern Ireland without enough money to cover their monthly expenses or afford a decent standard of living.

“Finances have been tight since my first autistic child was born. I have had to reduce my hours in work to care for him, as he needs special care and many care givers cannot provide this to him. He needs specific brands of food and toiletries due

to sensory difficulties and I need to leave lights on at night, burning electricity. I already cut back on all luxuries a number of years ago and was barely making ends meet. The cost of living crisis is breaking me.”

“It’s brutal with the cost of living rises. Everyone is struggling, but we have extras to pay for. Our electric bill includes things [i.e. medical equipment] to manage life, so we have higher bills anyway. I am on my knees. If there is a way through this, I cannot see it. We need help.”

“I am waking at night worrying about what the winter will bring. My son needs a higher level of care, especially when attending any extra-curricular activities, which I have to pay for. These are essential for managing his ASD [autism spectrum disorder]. The cost of living is already just crippling. I am currently working extra jobs to try and build up some sort of savings for the winter. I am a teacher and I never thought I’d worry about affording the basics. But I am not just worried – I am terrified!”

The growing financial pressures facing unpaid carers

Unsurprisingly, our 2022 survey findings suggest that the financial pressures facing Northern Ireland's carer population have worsened significantly since last year. Nearly all carers (95%) said their energy bills had increased, while 89% were spending more on food and drink, 76% were spending more on transport, and 24% were spending more on housing costs (eg rent or mortgage payments).

This left fewer than 1 in 3 carers (30%) saying they could afford their bills without struggling financially, less than half the proportion in 2021 (62%). More than 1 in 10 (11%) said they couldn't afford utility bills like electricity or gas, 16% were struggling to afford the cost of food, and the same proportion are, or have been, in debt as a result of caring.

All-in-all, 27% of carers told our survey that they were struggling to make ends meet – the second highest proportion in the UK (behind only Wales).

“The cost of food and energy in Northern Ireland has increased so significantly over the last 12-18 months that we are still in shock and trying to readjust. We have had to cut back on pretty much everything. Travel has become almost impossible to the point that I have had to cancel appointments with specialists just because I cannot afford to go to them. If something doesn't give soon, I am not sure we will survive.”

“All our savings have gone now. We're living month to month in the hope that we survive.”

While few have been unaffected by the cost of living crisis, our findings suggest it is having a disproportionate impact on some groups of carers. Firstly, those who are not in paid employment and are receiving Carer's Allowance were much more likely to be struggling to make ends meet than carers overall (48% vs 27%), and much less likely to feel they could manage their monthly costs (16% vs 30%).

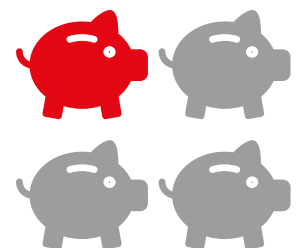
This isn't surprising. Many carers rely on Carer's Allowance as one of the few sources of financial support available – with paid employment impossible to fit around the demands of their caring role – but the benefit is among the lowest of its kind and the value of weekly payments (currently £69.70, the equivalent of less than £2 per hour at most) has fallen vastly behind current living costs. When we asked carers about the financial changes that would make the biggest difference to their lives, 46% said increasing the value of carers' benefits – the most popular response.

“I cannot afford much with Carer's Allowance, but that was the choice I had to make as my mother needed full time care and I felt it was my time to look after her. I recently had to pay over £200 for dental fees, which was a struggle. Getting my teeth sorted was a treat. I then had more pain and couldn't afford to go, so was just taking Ibuprofen to ease the pain.”

“Living on Carer's Allowance and associated benefits means there is no way I can budget for an unexpected expense. Before I had to leave work to care for my parents, I always had the option of an extra shift any time I needed money. Being tied to the house and my mum 24/7 means I have no way of earning any money to pay the rising bills. I'm very worried that the house won't be warm enough.”

27%

of carers told our survey that they were struggling to make ends meet – the second highest proportion in the UK



We also found that the financial pressures facing working age carers with young families were, in many cases, greater than those experienced by their older peers. While 12% of carers aged 65+ and without childcare responsibilities said they were struggling to make ends meet, this was considerably higher (34%) among working age carers who were also raising non-disabled children. Similarly, these carers were more likely to be:

- Unable to afford utility bills (14% vs 5%)
- Struggling to afford the cost of food (21% vs 6%)
- Extremely worried about managing their monthly costs (76% vs 50%); and
- In/have previously been in debt as a result of caring (22% vs 6%).

These trends are likely explained, at least in part, by the fact that it can be very expensive to juggle caring-related costs alongside the likes of childcare, education-related fees (ie uniforms and school trips) and the day-to-day costs of raising a child. While the State Pension has been protected by the ‘triple lock’ policy, the value of working age benefits – including Carer’s Allowance and others – has declined due to below-inflating uprating, and wages in most sectors of the economy have similarly failed to keep pace.

“The cost of living is getting harder having left my job to be a carer. I have three children at school, in different schools, and travelling there via car has gone from costing £20 bi-weekly to £60. We are struggling to have meals that are healthy due to the cost of meat and vegetables. The heating does not go on as much unless [we’re] fully clothed with jumpers, socks, blankets.”

“After monthly outgoings, including rent, diesel and electricity, I’ve very little to feed five kids and a child with Cerebral Palsy and feeding issues. We need help.”

Finally, our findings illustrate that those providing unpaid care while living with a disability of their own (24% of all respondents) are often hit with a double blow. They face the extra costs associated with both disability – estimated to be hundreds of pounds per month on averageⁱⁱⁱ – and caring at the same time. Compared to their non-disabled peers, carers living with their own disability were more than twice as likely to be struggling to make ends meet (48% vs 21%), to be unable to afford utility bills like electricity or gas (20% vs 8%) and to be struggling to afford the cost of food (29% vs 12%).

“As I’m severely disabled myself, I depend on a leased car that I drive from my wheelchair. It gets me to the two people I care for, enables me to get my disabled brother to and from work, to get to my hospital appointments and gets my mum and brother to theirs. Half my money goes on diesel for necessary trips. I have been able to do without heating for the past three months. Now that it’s colder I don’t know how I will keep warm, as I can’t [afford to] eat, drive, heat the house and use electric. I just don’t know what is going to happen.”

Coping mechanisms in the cost of living crisis

Worryingly, we found that many carers are deploying unsustainable and damaging practices to help them cope with spiraling living costs. Nearly 1 in 4 carers (23%) said they were cutting back on essentials like food or heating – more than double the proportion last year (11%). Small, but notable, numbers said they were using food banks (4%) and falling into housing arrears (3%).

“I am going without so my kids don’t have too. They think I’m trying to lose a bit of weight as I’ve cut back on my food, but it’s really because it’s more important that they eat.”

“I’m sitting in the dark at night to save electric.”

Nearly 1 in 4 carers

23%

said they were cutting back on essentials like food or heating – more than double the proportion last year



“Never missed rent in 15 years – until this month. Needed oil, couldn’t do both.”

“We haven’t been turning our heating on for around two months now and are only using it for hot water purposes. If it is cold, we’re using blankets. I worry how we will cope in the winter and am actively seeking higher paid jobs. We have absolutely no funds to fall back on in an emergency. I am permanently stressed. We are currently on a tracker mortgage and each time the interest rate goes up, so too does our mortgage. It terrifies me quite literally. Some days I am unable to bring a lunch to work and have skipped meals.”

Nearly a fifth (18%) of carers were using their bank account overdraft to help them cope, 31% were using their savings and 19% were using credit cards to get by. These behaviours provide only limited and short-term solutions, leaving many carers with depleted financial resources and greater debt later down the line.

“It’s a spiraling monthly situation, where each month we [take on] more debt to cover living costs. We can pay the bills but every month we get further into our overdraft or use more of our credit card.”

“I’m using a credit card and overdraft to buy groceries. I had cleared debt from before but it’s starting to build up again.”

Impact on health and wellbeing

It is hardly surprising that growing poverty and the crippling impact of the cost of living crisis is damaging our carers’ health and wellbeing. Nearly 70% of carers said that the increased cost of living was having a negative impact on their physical and/or mental health. While 27% of all carers described their mental health as bad or very bad, this shot up to 45% among those who were struggling to make ends meet.

“We are in debt like never before. My children are suffering. My mental health is suffering.”

Many described the inescapable stress, anxiety and fear caused by growing living costs, with feelings of hopelessness that their financial situation, and associated mental ill-health, would improve in the time ahead. The impact this was having is palpable.

“We are living hand to mouth, needing to give serious thought before making any purchase, be it food, fuel for the car, heating. We are having to make choices we never had to make in the past. It does cause us a lot more stress.”

“All I do is worry. I’ve no idea when, or how, I will ever feel okay.”

For some carers, the mental and emotional turmoil they are experiencing is so great, it is even preventing them from sleeping.

“The cost of food and bills is driving me crazy. I wake up at night in a cold sweat.”

“I have sleepless nights and anxiety.”

The cost of living crisis is making it even harder for many carers to take breaks from caring and engage in the social activities that are so important to maintaining their mental wellbeing. Nearly half of carers (48%) said they were coping by cutting back on hobbies or leisure activities, and 34% said they were cutting back on seeing friends and family. For many people, caring is a 24/7, all-year-round role, and the opportunity to do things for themselves and take part in hobbies can be a lifeline that has been cruelly diminished by rising living costs.

“The cost of living increases are eating into my disposable income, which I use to make caring for my family bearable and [which] help me cope. The loss of disposable income will lead to a reduction in activities that I need to help sustain my mental health.”

“I gave up any little pleasures for myself, like a cup of coffee with a friend or much needed gym class, which have been my only escape from caring. I will cut everything I need and give up more if I have to, just to be able to provide for my kids.”

Inevitably, the situation is causing greater levels of loneliness and isolation for some carers.

“Housing costs account for almost 75% of my total income. We are fast turning into hermits – prisoners in what should be a home.”

Support and services



Carers rely heavily on health and social care services to support them in their caring role, but the system has been on its knees for a long time, inevitably creating care gaps that are usually filled by unpaid carers. Unsurprisingly, we found that many carers are still struggling to access the right care packages when they need them, with particular challenges navigating the Self-Directed Support system.

Access to care packages

For years, Northern Ireland's HSC system has been plagued by long waiting times to access social care packages, with the number of people waiting for a care package at home reported to have increased by over 60% between October 2021 and August 2022 alone.^{iv} Inevitably, carers told us that long waiting times for care packages was putting more pressure on them.

- “Waiting for a care package for 18 months and still only have access to a rapid response team due to no availability of a care package in our location.”
- “On discharge from hospital two months ago I was told a care package was being arranged but this may take time. I have not heard anything else since. This would be up to four times a day to get her [the cared for person] up, washed and dressed in the morning, a call to give meals during the day, and a last call in the evening to help undress and prepare for bedtime. This would take a lot of pressure off me.”

Geography is playing a role in access to services, with 23% of carers saying the care and support services available in their area do not meet their needs, and a further 16% saying they had been told there were no care and support services available in their area, increasing to 21% among those living in rural locations. This issue is explored further below in relation to Self-Directed Support.

“ He [the person being cared for] is currently in a Health Trust-funded nursing home because the care package he needs to live at home isn’t available.”

Even when care packages are delivered, they may not always be appropriate. Too often, services are based around short, task-focused and inflexible appointment times instead of personalised support – with staff running in and out of people’s houses so they can get to their next appointment on time. This fails to meet the needs of the cared-for person and puts even more pressure on unpaid carers.

“ When my husband came out of rehab, a care package was put in place which comprised two care workers calling four times a day. They helped my husband to dress and undress, get washed and take him to the toilet. Sometimes they arrived quite early when my husband was still sleeping and most evenings they had him ready for bed at 8.30pm. The package didn’t include showering, which is the help that would have been most beneficial. I got an occupational therapist to teach me how to shower him and when I was confident enough to do it, I cancelled the care package.”

Getting away from this requires, among other things, an understanding of the true cost of care, so that services can be commissioned and delivered in a sustainable way that meets people’s needs. This was identified as an integral part of the social care reform process and must be delivered as a priority.

Discharge from hospital

Among those carers responding to this year’s survey, many had experienced admissions to hospital for the person they provide care for – and later, their discharge home again. With their often unrivaled knowledge of the person’s needs, intimate understanding of the situation at home, and likelihood that they will be playing an integral day-to-day role in the person’s care when they get out of hospital, carers should be treated as expert partners in the discharge planning process. However, we found disappointing evidence of many being excluded from decision-making, with detrimental effects on the carer and cared-for person.

Less than 40% of carers said they were involved in the decisions about discharging the person from hospital and what care and treatment they needed. This was often followed by inadequate care being put in place upon discharge, with less than a fifth (16%) of carers saying they received sufficient services to protect the health and wellbeing of the person as well as their own health.

“ My father was discharged, and the health professionals did not involve next of kin in any discussions about what he needs. He is 81, vulnerable and does not remember the conversations. He also doesn’t like to be a nuisance, so would have turned down any support that might have been offered to him. I feel he needs the involvement of an Occupational Therapist to assess his mobility needs. He lives alone and has never received a visit from any health professional since having a quadruple bypass in April 2021. His mobility has deteriorated considerably.”

“ [They were] discharged suddenly without any community support in place, despite a new stoma,* double incontinence and the fact they could barely walk.”

23%

of carers say the care and support services available in their area do not meet their needs



* A stoma is an opening on the abdomen that can be connected to either a person’s digestive or urinary system to allow waste to leave the body.

In the majority of cases, the carer's ability to continue caring after discharge seems to have been largely ignored, with just 21% saying they were asked about their ability and willingness to care, and even less (16%) saying they felt listened to about their ability and willingness to care. Worse still, only 13% of carers agreed/strongly agreed with the statement 'I was under no pressure to care and felt fully prepared and supported'.

These experiences are, perhaps, the inevitable result when Health Trusts are under such extreme pressure to free up hospital beds. Local Trusts have even been making public appeals for families to take on extra care responsibilities, in lieu of care packages being in place, so that patients can be discharged promptly^v – putting greater pressure on many carers who have already reached the point of exhaustion.

“ I had no input in the decision to discharge my husband from hospital and felt unsure of my ability to cope.”

“ The care package to be arranged by social services on discharge has not been mentioned some two months later. I have no hope nor faith in the system and simply have the attitude that I need to suck it up and get on with things.”

Taken together, this data paints a very concerning picture about the lack of priority being attached to shared decision-making with carers when their loved ones are being discharged from hospital. Unpaid carers are not a resource to be tapped without consultation, relied on but not listened to, in order to take pressure off hospitals or other parts of the HSC system. Doing so risks worse outcomes for both the cared-for person and carer alike. Indeed, the effect may be to put even great strain on services, with carers unable to cope, being burnt out and needing care themselves, or patients having to go back into hospital because the care they received upon discharge failed to meet their needs.

“ Terrible experiences where my parents have been discharged with no care packages in place, and have been readmitted several times.”

Challenges with Self-Directed Support

Carers NI's engagement with unpaid carers in Northern Ireland has shown that many are supportive of the principle and concept of Self-Directed Support (SDS). While it will always remain the case that some households will prefer to have services directly arranged by their Health Trust – and that option should remain for anyone that wants it – for others, SDS can offer greater levels of control and personalisation of care services.^{ix}

In practice, however, many carers also tell us that the reality of the SDS system does not match the theoretical benefits that it can, or should, provide. Firstly, the system imposes a high administrative burden on carers, turning them into employers who must manage all of the paperwork and bureaucracy that comes with that, when there already aren't enough hours in the day to juggle all the pressures they're facing.

“ I receive 17 hours a week allowance from the Trust to employ a carer for my husband. I have to operate a payroll system, payments to HMRC, quarterly returns to the Trust on top of caring for my husband. There is very little support once you receive Direct Payments but a lot of rules to obey.”

“ I use Direct Payments to hire a carer. The paperwork is horrendous and I have to pay someone to do HMRC [processing tax etc.] as I don't understand it.”

Many also struggle to find suitably experienced and qualified staff to meet the needs of the person they're caring for, and this seems to be a particular challenge in rural areas. When we asked about barriers to accessing support services, 15% of carers said a shortage of care workers meant they could not find care to buy, rising to 19% among those who live in rural areas.

“ We have received no support in nearly two years for my disabled son. I cannot get Direct Payments – the process is too time consuming as I work full time, and because I live in a rural area, no [providers are] interested. It is really exhausting.”

“ I have to care for my daughter as we can't recruit [paid] carers. I'm 72 and worried about future.”

“ We regularly inquire about buying additional care, but none is available. There is essentially market failure in our area.”



“ I have funding sitting in a bank account for respite through the WHSCT for Direct Payments, but we haven’t had access to any [paid] carers for four years.”

Finally, some carers also highlighted that the value of the Direct Payments available was not keeping up with the cost of buying care services, leaving them with either reduced access or having to meet the difference out of their own pockets.

“ The funding you receive is not enough to use an agency because their hourly rate is more than you receive per hour. You would have to top up your Direct Payments from your own money.”

“ My son gets Direct Payments for a carer to help him go out to promote independence and develop social skills. The Direct Payments have not come in line with the increased costs of the caring company, so he now has reduced hours available.”

Carers' health



Caring for someone can be an incredibly demanding role and often with a big impact on carers' health and wellbeing. Across Northern Ireland, many are caring round-the-clock with little opportunity for a break, constantly worrying or in a state of stress, prioritising the cared-for person's needs above their own and experiencing countless sleepless nights and loneliness – all contributing to physical burnout and mental exhaustion. As this chapter shows, too many carers are missing out on the support they need to look after their own health and wellbeing while providing care.

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Physical and mental health

Carers' lives are usually very full-on. Day-to-day, they may be responsible for lifting, moving, washing and dressing the person they care for, helping them use the toilet, cooking all their meals and maintaining the home. It is a physically demanding job, especially for those who are caring for a long time or into their older years, when the physicality of a caring role is mixed with the declining health that often comes naturally with aging. In this context, it is no surprise that 1 in 5 carers reported their physical health to be bad or very bad, rising even further, to 24%, among those who have been caring for ten years or more, and to 25% among those caring for 50+ hours a week.

“ [I get] no support whatsoever. I'm exhausted to the point I am now becoming unwell.”

“ I care for two people, both living in separate houses. I am working full time as I do not receive any financial assistance. The demands on my time are high. I am physically exhausted. I have my own health issues and growing older has made caring more difficult. The stress is all consuming.”

For many carers, the 24/7 nature of their caring role means that regular sleep is unattainable. They may need to be up frequently throughout the night and early hours to help administer medication, check on medical equipment or help the person they're supporting to settle. Over one third of carers (34%) said they were worried about not getting enough sleep, and poor or irregular sleep is linked to a host of health effects – not just exhaustion, but elevated stress, lower immune function and increased risk of cardiovascular disease.^{vi}

“In the last five years, I've had two nights of unbroken sleep on my own terms.”

A large proportion (27%) of carers reported their mental health as bad or very bad. Again, this rose to 31% among those caring for 50+ hours a week and 32% among those who have been carers for 10 years or more. Carers widely reported the stress, anxiety, depression and fear that is often driven by their caring role, with some, understandably, turning to unhealthy behaviours to provide a bit of relief.

“I'm at a bit at a loss here. My daughter and wife's needs are creeping up all the time, while my own physical and mental resilience is fading. [I'm] prone to depression and drinking alcohol to excess.”

“I'll be honest, I'm about ready to be locked up somewhere, as dealing with my child 24/7 is extremely hard work and is having a massive impact on my mental health.”

“I have had no support in the past year. I look after my nephew and his needs alone 24/7. I am struggling so much at present. Depression and anxiety are gripping me every morning, as I don't know what the day might hold.”

While it is not a mental health condition itself, loneliness is associated with a heightened risk of mental ill-health – including depression, depressive symptoms,^{vii} stress and anxiety. Nearly 30% of carers told our survey that they often or always feel lonely, and this was linked to difficulties getting breaks from caring (see below), the impact of the cost of living crisis, which has made the kind of social activities necessary to combat loneliness unaffordable for many carers; and the demands of being a carer, which leaves them with little time to see family and friends.

“I had to leave my job after 10 years to care for both my children. Now I'm isolated, lonely.”

“It can be a lonely world as a carer.”

Nearly 40% of carers identified support to prevent or reduce loneliness as one of their top needs as a carer, while over 50% said being able to take regular breaks from caring would help them feel less lonely.

The importance of breaks and respite from caring

Our findings point to a clear link between access to breaks from caring and better health outcomes among unpaid carers. While just 36% of all carers said their physical health was good or very good, this rose to 44% among those who had had a break from caring within the last 12 months. Similarly, 27% of carers said their mental health was good or very good, increasing to 35% among those who had had a break within the last year. Carers reported a host of benefits from taking a break from caring, including the chance to recharge their batteries and do things for themselves.

“I had a 3-day break paid for by my extended family and really found it cathartic and energising.”

27%

of carers reported their mental health as bad or very bad



“ I felt human again.”

“ It left me feeling recharged and more mentally relaxed.”

Unfortunately, however, these experiences are not universal. More than a third (40%) of carers said they had not had a break within the last 12 months, and many told us about the severe consequences for their health and wellbeing.

“ Haven’t taken one [a break] yet, as the need to be a carer exists as long as there is a person to care for. The impact is little disappointments in life. Can’t go to this, can’t go to that, can’t meet, can’t sleep much.”

“ I haven’t had a break for three years. I really need one, as I have been unwell from Covid-19 and haven’t made a full recovery. Sometimes I feel like running away.”

“ I have only had three overnight breaks in the past four years. I’m physically and emotionally exhausted.”

Many carers have long experienced significant challenges to accessing respite, short breaks and day services, but this situation has only deteriorated due to the COVID-19 pandemic. Services were severely disrupted when the outbreak began, and many have failed to return to their pre-pandemic capacity over two-and-a-half-years later. For example, just 9% of carers told our survey that day services had fully re-opened, and only 5% said sitting services had fully re-opened. All of these services provide not only critical sources of support for patients, but also a lifeline for unpaid carers, who have suffered considerably from the lack of opportunity for regular breaks from their caring role.

“ One daycare centre which my mum attended three days [per week] pre-Covid has just re-opened for one day. The other centre is not opened at all. Really struggling to get access to respite. Those services are very slow to reopen. They’re essential but almost unattainable.”

“ Respite has not resumed full time and the breaks are irregular and at short notice.”

“ Reduced day care makes every day more difficult.”

“ My son normally attends a day centre run by the local Health Trust. It is still running at reduced capacity. We have access to 3 days [per week]. Prior to the pandemic, we had 5 days.”

“ Respite has been reduced. We aren’t really getting any.”

“ I had to campaign and make a nuisance of myself to get access to my husband’s services. Respite was shut throughout the pandemic, and I have had to put my case to our social worker to get access to respite for my husband. A respite break for my husband is respite for me.”

“ We are still waiting for my daughter going into respite. I am waiting for surgery and don’t know how to get help.”

The long delay in remobilising day services, short breaks and respite – and the varied approaches being taken to this across Health Trusts – is a source of deep frustration for carers. They look to other aspects of public services and social life that have seemingly returned to pre-Covid normality and, understandably, feel that they’ve been forgotten about.

Access to these services is a major priority for our carer population. When we asked about their top needs as a carer, nearly half (49%) identified more breaks or time off from their caring role, while the same proportion said more support from the health service/health professionals.

40%

of carers said they had not had a break within the last 12 months



Access to specialist HSC treatment or assessment

Even before the onset of the COVID-19 pandemic, waiting lists in Northern Ireland's health service were the worst in the UK, and among the worst in Europe.^{viii} State of Caring 2022 highlighted the scale of this problem among unpaid carers, with 71% of carers who required specialist treatment or assessment by a doctor waiting for over six months after referral, including 56% waiting for over a year.

Over 70% of carers who were waiting for specialist treatment or assessment said it was negatively impacting their mental or physical health. Some carers told us that this was compounded by the strain of a caring role, chipping away at their quality of life and creating a vicious cycle of ever-deteriorating health and wellbeing.

“ I can't sleep with immense pain. It has led me to feel depressed and with suicidal thoughts, as I'm exhausted and I'm in so much pain. I still have to get up and get on with caring and carrying on as normal when I'm struggling. I'm burnt out. Worrying about my loved one is the only reason I continue putting up with the pain. The doctor referred me to pain management, but the waiting list is years long. Carers are only human. I can only take so much more of this.”

“ I am in constant pain awaiting surgery. Lifting and turning my son puts pressure on my back and contributes to my nerve pain and cramps. We cannot get domiciliary care staff to work with the nurse, so generally it is left up to me to help with turns and hoisting.”

“ I am extremely worried that I have now developed a potentially life changing or shortening illness [due to the wait for treatment] and I'm stuck at home caring and worrying, not getting to enjoy life before things get worse.”

“ I have been needing a hysterectomy since 2018 for a prolapsed womb and cervix, which has become painful with lifting my now 12 year old son.”

Also concerning in the context of the cost of living crisis, over 40% of carers who were waiting for specialist treatment or assessment said it was starting to affect their ability to work – risking their financial resources at a time when many can least afford it. Indeed, nearly 40% of those waiting for specialist treatment or assessment said they were struggling to make ends meet – higher than carers overall (27%).

“ I have had to go on long term sick and leave my job.”

“ My health is deteriorating so I'm struggling to work and be a carer.”

Exercise and leisure services

Exercise, even light physical activity, can have many benefits for a person's health, but many carers told us they lack the time and/or money to devote to this. Just 7% of carers said they used local leisure facilities often, while 72% said they have never used leisure facilities. Time constraints are an issue, with 60% of carers stating that they don't have enough time for these activities, while 34% also said leisure facilities were too expensive.



Carers' assessments



In Northern Ireland, the 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. These are carried out by a health or social care professional and examine a person's situation to see if they are entitled to any services that would make their caring role easier.

A carer's assessment should cover a range of topics including the carers' health and wellbeing, access to breaks, finances, housing situation and more. It is often a vital first step in identifying carers' needs and connecting them to sources of support, but we found that too many carers are either unaware of their right to an assessment or have been left disillusioned with the process after going through it in the past.

Access to carers' assessments

Disappointingly, less than a quarter (21%) of carers told our survey that they had received a carer's assessment, review or reassessment during the last 12 months, a small drop compared to 2021, when the proportion was 26%. A further 6% had requested one but were waiting for it to be carried out.

Among those who hadn't had an assessment, review or reassessment during this time, the single biggest reason was not knowing what a carer's assessment is (53%) – suggesting that Health Trusts are not always fulfilling their legal obligation to offer assessments to carers. It also reinforces the importance of having robust systems in place to identify carers, make them aware of their rights and sign-post them to the information and support they need.

“ I didn’t know that I was entitled to one.”

“ Never heard of it.”

“ I thought my social worker would have recommended it if it would help me.”

Equally concerning, more than 1 in 10 carers (13%) said they hadn’t had an assessment, review or reassessment because they didn’t think it would be beneficial for them. This is, unfortunately, a long-term trend, with many carers becoming disillusioned at having taken the time to go through the process in the past, only to receive no additional support afterwards due to funding, service and staff shortages.

“ I received [a] Carers Assessment approximately 4-5 years ago. It appears to be a tick box exercise with little impact.”

“ I had one done about 8 years ago but nothing came of it, as there was no budget for carers’ needs. It was a waste of time.”

“ Completed one many years ago but it made no difference.”

“ The assessment was very considerate of my needs and the person carrying it out took [everything] on board. She reported everything, but the support which was then offered from the providing body came nowhere near being able to meet my needs. [She] felt frustrated with her efforts not being followed up.”

These experiences reinforce the urgency of new legislation to put carers’ right to support on a legislative footing. The current situation, where carers are legally entitled to an assessment but not to the services or supports required to meet their identified needs, is a historic policy anomaly that should have been addressed a long time ago. Until our carers have greater confidence that there is some benefit to going through a carer’s assessment, many will continue to avoid them and face their caring role with little-to-no help or support.

Experiences of carer’s assessments

Many carers who had had a carer’s assessment, review or reassessment during the last 12 months reported a worryingly poor experience. Time and again, local carers reported that the process had not adequately considered or addressed the big challenges impacting on their lives.

Fewer than 1 in 5 carers (18%) felt that the support they needed to look after their own mental and physical health alongside caring was thoroughly considered by their carer’s assessment or reflected in the support they received afterwards. This was the lowest proportion of anywhere in the UK and a decline on 2021, when 24% of respondents in Northern Ireland said that this had been thoroughly considered.

Even worse, just 15% of carers said their need to have regular breaks from caring was thoroughly considered during the carer’s assessment or reflected in the support received afterwards. This was, again, the lowest rate in the UK and a drop compared to last year, when the proportion was 21%.

“ I am in need of respite, the main reason why I had the Assessment. However, the [waiting] list is long and there aren’t enough places.”

Of particular concern in the context of the cost of living crisis, just 1 in 10 carers told us that their carer’s assessment had thoroughly considered the support they need to manage their finances; while just 7% said it thoroughly considered the support they need to juggle work with paid employment.

The Northern Ireland Single Assessment Tool (NISAT) is often used to carry out carer’s assessments, and wider engagement with carers from Carers NI uncovered mixed feedback about the tool. Some felt the tool was not fit for purpose and that a bespoke alternative assessment tool should be developed that is designed and used only for carers. Other carers had a more favourable view of NISAT and said it is a comprehensive tool but, in too many cases, isn’t being used properly.^{ix}

In both readings, the end result is that too many carers do not feel their holistic needs are being fully considered when NISAT is used for carer’s assessments.

Employment



According to the most recent complete data available, 43% of people with unpaid caring responsibilities in Northern Ireland are also in full or part-time employment.^x For many carers, paid work offers a financial lifeline that they couldn't afford to live without, but as this chapter shows, juggling work with caring can take a heavy toll on their health and wellbeing. Other carers would like to be able to work, but the round-the-clock demands of their caring role make this impossible and the support they need to be able to juggle the two is too often out of reach.

Barriers to employment

The proportion of carers in employment in Northern Ireland is estimated to be 20 percentage points lower than the general adult population,^{iv} and in 2019, nearly 130,000 people had either given up work, or reduced their hours to part-time, to care for someone.^{xi} Understandably, many carers told us that it is impossible to provide hands-on practical and personal care for someone 24/7, manage their appointments, maintain the home and hold down a full-time job all at the same time.

“I had to drop out of my nursing [career] to care for my daughter, as she has severe complex needs.”

“I did work full time, but needed to reduce my hours as it was all getting too much.”

This balancing act has, in some ways, become even harder due to the disruption to replacement care and social care services (eg day centres) caused by the COVID-19 pandemic. 1 in 10 carers said that, if the care services they used to rely on do not return, they are at risk of having to reduce their hours or give up work altogether. Even more carers (14%) said that without affordable and accessible alternative care, they'd be at risk of having to reduce their hours or leave their jobs.

Carers being forced to withdraw from/stay out of the labour market makes it even harder for them to survive financially, especially considering the low value of carer benefits like Carer's Allowance. Unsurprisingly, the proportion of carers who were struggling to make ends meet was much higher among those not working (43%) than carers overall (27%).

“When I stopped work to become a fulltime carer, my independence was totally taken away from me. Because I was married, I wasn't entitled to anything more than Carers Allowance. Which doesn't even cover petrol. It is not practical for me to work as somedays I'm on call 24/7 and some nights not getting to bed until around 4am. Other nights it's broken sleep, so I can't commit to a job.”

Experiences of juggling work and care

Those who are juggling work and caring highlighted the multitude of effects that this has – including on their health, wellbeing and more.

When we asked carers about balancing work and care, 75% said that they felt tired at work because of their caring role, and 78% said they were worried about continuing to juggle the two. Carers told us that working and caring at the same time was leaving them increasingly burnt out, struggling with their mental wellbeing and with no time for a break, especially when they're forced to use their holiday leave to perform caring duties.

“I am either working or caring. There is no time for me. I find my caring role and my work stressful, so I am anxious no matter what I am doing and worry that I am not good enough at either role.”

“You are tempted to go off sick with chronic fatigue or stress, but I don't want to do that as it reflects badly on your record. So, you just keep going, but it just means I am tired all the time. Something has to give!”

“As an employed carer, I feel that I am being financially, mentally and physically punished for working. Employed carers need greater support and recognition of the added difficulties of caring and working. I shouldn't have to make a choice between working and caring effectively.”

“I have continued working as well as caring and this is starting to take a toll on both my mental and physical health. I am scared to leave work as I cannot afford to.”

Other carers explained that the demands of their caring role had negatively impacted their career prospects, with 64% saying they had given up opportunities at work because of caring. The proportion was slightly higher among female carers (67%), possibly reflecting the greater unpaid care burden facing women and the still-present, and incredibly unjust, expectation that female members of a household will sacrifice their working lives to provide unpaid care.

“It is becoming more and more difficult. I have had to pull out of two internal recruitment drives with promotion prospects in the last year due to caring responsibilities.”

“We could be much more secure financially if we were not carers. I have turned down promotions and work less hours [due to caring].”

Many carers also highlighted the punitive impact of the harsh Carer's Allowance earnings threshold, which was preventing them from earning a decent income or progressing their careers.

“The Carers Allowance earning constraint is too low. It is very difficult to find meaningful work and progress my career. Realistically, there's very little point applying for internal jobs as the number of hours I work is constrained by this ceiling. I have a 1st class Master's degree and can only earn minimum wage.”

Supporting more carers to better juggle work and caring

We asked carers about the support they need to stay in the labour market and better juggle work with unpaid caring responsibilities. Over 60% said that working from home had enabled them to balance work and caring more effectively – highlighting a silver lining from the COVID-19 pandemic that has helped many carers.

“As a carer, I have greatly benefited from working from home. There has been no impact on the business, but removing the commute from my day has allowed me to increase my hours and pay whilst still being able to juggle caring responsibilities.”

Conversely, 63% of carers told us that returning to the office would make caring more challenging, and 41% said that not being able to work from home would make them consider leaving their job. There was evident worry among many of those carers whose employers were moving back to office-based working, with fears that it would lead to more pressure and exhaustion as they tried to balance work with caring.

“My confidence is at an all-time low. My employer is insisting all staff work more in the office, for at least 40% of the time, whereas I was originally allowed to just go in one day per week. I leave home at 7am and get back in at 6.45pm, totally exhausted. The amount of assistance I can offer my mum and child on the days I am in the office are greatly reduced. Whatever I do for them is at a personal detriment to me due to the exhaustion.”

Less than a third

28%

of carers said they had access to paid carer's leave from work



“I have really benefited from working from home. We will imminently be moving to 3 days in the office, and this will create further stress and angst for me. It will be nigh on impossible to manage my care commitments. I fear I will have to give up work.”

It is important to recognise that for other carers, moving back to office-based working would be considered a good thing. Ensuring carers have a choice over how they can work to best suits their needs is key.

Elsewhere, just 4% of carers said they had access to affordable and accessible alternative care, less than a third (28%) said they had access to paid carer's leave from work, and just over half (54%) said they had been offered flexible working arrangements. All of these measures are popular with carers and, if more widely available, would make it much easier for them to balance work and caring, without having to push themselves to burnout and exhaustion.

“I would be more inclined to stay in work if I had some paid carer's leave.”

Supporting more carers to enter, and stay in, the labour market is not only of benefit to them, but also makes business and economic sense too. Employers face significant costs associated with absence, lost productivity and recruitment whenever their staff's ability to work is impacted by caring responsibilities. Across the UK, research suggests that that cumulatively, companies could save up to £4.8bn a year in unplanned absences and a further £3.4bn in improved employee retention by adopting flexible working policies to support those with caring responsibilities.

Conclusion

This year's State of Caring survey paints a bleak picture of the challenges facing Northern Ireland's unpaid carer population.



They have been among the hardest hit by the cost of living crisis; are continuing to face major obstacles to accessing the health and social care services they need; are still dealing with the effects of the COVID-19 pandemic; and are living with ever-worsening physical and mental health – often running themselves into the ground without regular breaks from caring, proper sleep or the chance to have a life of their own.

Our unpaid carers save the government £4.6bn every year in Northern Ireland.ⁱⁱ Without them, the local health service – and wider public finances – would collapse, but far too often, the help and support they get in return for this enormous contribution is either paltry or non-existent.

We cannot tackle the challenges carers face without a sitting NI Executive, which is not in place at the time of writing. No Executive means no Ministers to deliver policy interventions for carers, spend money on the support carers need or implement the HSC reforms that carers have been crying out for. As the cost of living crisis continues to bite and the health and social care system faces pressure like never before, this situation is unconscionable and must change urgently.

A new Executive must prioritise unpaid carers – delivering the reform they need in the spheres of Health and Social Care, social security, employment rights and beyond. Our unpaid carer population deserves nothing less.

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