

'I wake up at night in a cold sweat'

Policy briefing: Unpaid carers and the mental health impact of Northern Ireland's cost of living crisis

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In partnership with



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Introduction

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 round-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 the price of energy, food, fuel and more has shot up so drastically. Many carers are unable to work and bring in an income due to the time demands of their caring role, and the social security system offers little relief either.

The data points below paint a picture of the severity of the financial pressures facing our carer population:

- **More than one in four carers in Northern Ireland (27%) are struggling to make ends meet.** ^[1]
- **Fewer than three in ten carers can afford their bills without struggling financially.** ^[1]
- **11% can't afford their utility bills and 16% are struggling to afford the cost of food.** ^[1]
- **Nearly a quarter (23%) of carers are cutting back on essentials like food and heating to get by.** ^[1]
- **One in five households receiving Carers Allowance report living in food insecurity – nearly three times the rate of the general population.** ^[2]

On the ground, this means that tens of thousands of carers in Northern Ireland today do not have enough money to cover their monthly expenses or afford a decent standard of living – having to rely on raiding any savings they have, taking on debt and cutting back on daily essentials.

They are managing the constant stress, anxiety and worry borne out of poverty. And as the pages that follow make all too clear, this can have significant consequences for their mental health and wellbeing.

Levels of good mental health among our caring population were low to begin with. In 2019, just 6% of local carers described their mental health as 'very good', ^[3] and since then, many have lived through *two* mental health crises back-to-back: the first caused by the COVID-19 pandemic, and now by crippling living costs.

This briefing highlights some of the mental health challenges facing local carers as a result of the cost of living crisis, told through their own first-hand accounts. Afterwards, we make recommendations on how government can begin to address the situation.

Methodology

This policy briefing was produced by Carers NI in partnership with Inspire Wellbeing. It draws primarily on testimony and stories from unpaid carers in Northern Ireland about the impact of the cost of living crisis on their mental health. This evidence was collected between July-September 2022. ^[A] Where appropriate, it is supplemented by wider research.

The briefing does not provide an exhaustive account of the mental health impacts of the cost of living crisis on unpaid carers in here. Rather, it offers a snapshot of some of the common experiences shared by carers in Northern Ireland which, we hope, will make a meaningful contribution to the policy debate in Stormont and beyond.

^[A] This testimony was provided in response to Carers NI's State of Caring 2022 survey. The full findings from that survey will be published in November 2022.

Carer's testimony: The cost of living crisis as a driver of mental ill-health

Analysing testimony and stories from unpaid carers in Northern Ireland highlights the myriad of ways that the cost of living crisis is driving and exacerbating mental ill-health among our carer population. Below we provide an overview of some of the common themes and experiences highlighted by local carers.

Heightened stress and feelings of helplessness

Many unpaid carers described the inescapable stress and anxiety caused by growing living costs, which in many cases are just compounding the pre-existing financial pressure that comes with being a carer.

"Finances have been tight since my first autistic child was born. I have had to reduce my hours in work to care for him. He needs therapies that I cannot afford, so he misses out. He needs specific brands of food and toiletries due to sensory difficulties and I have to leave lights on at night [for him], 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." – unpaid carer

"Both the people I care for feel the cold acutely and require the heat on almost all day every day. I am becoming increasingly stressed at how I will manage the increased costs of this." – unpaid carer

"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." – unpaid carer

Feelings of stress not only have a negative effect in their own right, but also increase the risk of depression and anxiety, drive use of health services – including admissions to hospital – and have a multimillion- pound impact on health systems. ^[4]

Other carers revealed a significant fear of what the future holds, with feelings of hopelessness that their financial situation, and associated mental ill-health, would improve in the time ahead. The impact this is having is palpable.

"We have not been turning our heating on for around two months now and are only using it for hot water purposes. If it is cold, we are 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. Each time the interest rate goes up, so too does our mortgage. It terrifies me quite literally." – unpaid carer

"All I do is worry. I've no idea when, or how, I will ever feel okay." – unpaid carer

"We are in debt like never before. My children are suffering, my mental health is suffering." – unpaid carer

What is an unpaid carer?

An unpaid family member, partner or friend who helps a person with daily activities who wouldn't be able to manage if they didn't have help. This could be someone who is seriously ill, disabled or who needs extra help as they grow older. There are over 290,000 adults in Northern Ireland providing some form of unpaid care.



Some carers highlighted that the mental and emotional turmoil they are experiencing is so great, it is even preventing them from sleeping – which can have serious knock-on consequences for their health.

“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]. 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!” – unpaid carer

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

“I have sleepless nights and anxiety.” – unpaid carer

Breaks from caring, social isolation and loneliness

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. 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.” – unpaid carer

Carers discussed the new trade-offs they are facing, where social or leisure activities always come second to

increasingly unaffordable household bills – to the detriment of their 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.” – unpaid carer

“The cost of petrol is a problem, as it means that we are staying at home more and that's soul destroying and causing stress. My husband wants to go for a drive, but we can't afford to.” – unpaid carer

Inevitably, the situation is causing greater levels of loneliness and isolation for some carers. While loneliness itself is not a mental health problem, the two are strongly linked, and feeling lonely has been associated with a heightened risk of mental ill-health – including depression, depressive symptoms, ^[5] stress and anxiety.

Even before the cost of living crisis began to bite, nearly one-third of people providing unpaid care for a disabled person in Northern Ireland reported feeling more often lonely, ^[6] and for some unpaid carers, rising living costs have been a further driver of loneliness and social isolation.

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

“We have less money to spend on social and leisure activities. It leads to isolation and loneliness.” – unpaid carer

“I am existing on my Carers Allowance and if any big, unexpected costs come, I would be in difficulties. Life has shrunk in all aspects.” – unpaid carer

Strained family dynamics

Carer's stories highlight the complex effects of the cost of living crisis on their relationships with those around them – not just the person they care for, but other family members and loved ones too.

Some carers have felt a duty to protect the person they're caring for from the true scale of their financial problems. This leaves them to shoulder the mental and emotional burden alone, which only compounds the impact on their wellbeing.

"Not being able talk to my disabled husband about struggling financially [is having an impact]. I have to be strong for him, so I put a brave face on. I'm so, so worried." – unpaid carer

"I am constantly stressed as the bills have been increasing. I absorb a lot of the stress from my brother, whom I care for, as I want him to have as little stress as possible. I often pay for his utilities as his income does not cover them. He also needs a special diet, which costs a lot more." – unpaid carer

"It [the cost of living crisis] is causing incredible personal stress. My husband isn't aware as he's so ill and this would greatly upset him, as he already feels responsible for our situation." – unpaid carer

Others described the difficulty of trying to prioritise different elements of household spending while meeting caring-related costs, and the strain this causes among their family.

"It affects our mental health and relationship because of more arguments about what we should spend our money on." – unpaid carer

Burnout from juggling work and caring

The latest available data suggests that over 40% of unpaid carers in Northern Ireland are in some form of employment.^[7] While going to work can provide a welcome break from caring for some carers, for many others, juggling the two puts them under immense pressure and contributes to mental and physical burnout. As living costs have continued to rise, carers told us that they're having to work longer and harder just to keep their head above water.

"There is more pressure on me to work long hours to pay the bills. There is a lot of strain and pressure on carers at the minute – financially, mentally and physically." – unpaid carer

"Making ends meet is extremely difficult. It is having an impact on my mental health, as it is a matter of working and existing just to pay the bills. There is absolutely no money for luxuries, any holidays or even days out. I am dreading the winter months as the cost of living is to go up even more." – unpaid carer

"I have already increased my working hours as I couldn't make ends meet. I am completely stretched and have no time for myself whatsoever." – unpaid carer

Other carers highlighted that, while in other circumstances they may have left work in order to provide care, the cost of living crisis has made that option unaffordable. They're left driving themselves into the ground trying to juggle both at the same time.

"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." – unpaid carer

Policy recommendations

This briefing has shone a spotlight on the severe mental health impact of the cost of living crisis on unpaid carers in Northern Ireland. Crippling living costs are causing enormous levels of stress, anxiety and fear among our carer population – forcing them to go without the breaks from caring that are so important to their mental wellbeing and increasing feelings of loneliness and isolation.

Our carer population has now experienced two mental health crises back-to-back. Over two-thirds (69%) of local carers said their mental health had worsened during the COVID-19 pandemic, ^[8] and for many, this is now being compounded as rising prices make it harder and harder to get by.

Unpaid carers make a multi-billion contribution to public finances in Northern Ireland each year, ^[9] without which our health and social care system would collapse in an instant. To begin addressing the mental health impact of the cost of living crisis on our carer population, we are jointly calling for:

1. Urgent restoration of the NI Assembly and Executive

Functioning government institutions are essential to design and deliver a holistic response to the cost of living crisis for unpaid carers in Northern Ireland. This must include individual and coordinated policy interventions from the Departments for Communities, Health and more – targeted directly at meeting the needs of unpaid carers.

2. A multi-year Executive budget

The cost of living crisis, and the scarring effect it has had on the mental health of unpaid carers, cannot be addressed with short-term solutions. To date, such measures (e.g. the Treasury's cost of living payments and temporary energy discounts) have provided light relief for some households, but have repeatedly been outpaced by the rapid worsening of the crisis. The holistic policy response that Northern Ireland needs must be backed with long-term funding commitments in a multi-year Executive budget.

3. Full funding for Northern Ireland's Mental Health Strategy

Unpaid carers, in particular, are at the coalface of this crisis and sustainable change can only come from higher levels. Northern Ireland needs a government and a multi-year budget, one which fully funds all elements of the Department of Health's Mental Health Strategy, not least community-based mental health services. This is an essential component of addressing and reversing the rates of mental ill health seen across our communities, a situation now exacerbated by the prevailing fiscal landscape.



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9. Before the Covid-19 pandemic, the care provided by unpaid carers in Northern Ireland was worth £4.6bn per year. See: Buckner, L and Yeandle, S (2015). Valuing carers: The rising value of carers' support.

Carers NI is Northern Ireland's membership charity for unpaid carers. We work to represent and support the over 290,000 people in Northern Ireland who provide unpaid care for ill, older or disabled family members or friends – fighting for increased recognition and support for all carers and to ensure they have a voice in policymaking.

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Inspire Wellbeing is an all-island charity and social enterprise and our aim is wellbeing for all. We work together with people living with mental ill health, intellectual disability, autism and addictions to ensure they live with dignity and realise their full potential. We campaign to create a society free from stigma and discrimination, creating a culture of compassion that focuses on people and their abilities.

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