



The experiences of poverty among unpaid carers in Northern Ireland

August 2023

A report from the Carer Poverty Commission NI

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About the Carer Poverty Commission NI

The Carer Poverty Commission was established to better understand the causes of poverty among Northern Ireland's unpaid carer population and to deliver the fresh thinking needed to address it. The Commission is led by Carers NI and has two key goals:

- To examine the scale and drivers of poverty among unpaid carers in Northern Ireland; and
- To design new policy recommendations for the Stormont Assembly and Executive to help tackle that poverty wherever it exists.

For more information, visit: carersuk.org/CarerPovertyNI

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 carersuk.org/CarerPovertyNI  povertycommission@carersni.org  [@CarersNI](https://twitter.com/CarersNI)

About Carers NI

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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 wpieconomics.com  info@wpieconomics.com  [@wpi_economics](https://twitter.com/wpi_economics)

Executive Summary

Unpaid carers are a diverse group – from child and young adult carers through to carers of pension age – who care for people with a wide range of physical health conditions, mental ill-health, learning disabilities and more. A common experience shared by far too many unpaid carers is poverty. The Carer Poverty Commission NI was established by Carers NI to better understand the scale, drivers and nature of that poverty, and to design new policy solutions to help tackle it.

New research conducted by WPI Economics for the Carer Poverty Commission NI suggests that one in four unpaid carers in Northern Ireland (25%) are living in poverty – significantly more than Northern Ireland's non-carer population (16%) and higher than the carer poverty rate across the UK (23%).¹ This means around 55,000 unpaid carers are living in poverty.²

This report focuses on the experiences and perspectives of those unpaid carers living in poverty. The research findings have been shaped by focus groups and semi-structured interviews conducted in May and June 2023 with carers from across Northern Ireland. It explores the major drivers of poverty; carers' lived experiences; and policy solutions that carers believe would be effective. Each are summarised below and detailed in the pages that follow.

On the major drivers of poverty, our qualitative research found:

- **Carers in Northern Ireland struggle to combine paid work with unpaid care.** Many carers spoke of having to leave the labour market to meet the demands of their caring role, a decision with immense financial and personal costs. Carers that do remain in work often work fewer hours than they would like to. Those who leave the labour market struggle to re-enter, as finding a job flexible enough to accommodate their caring responsibilities is often very difficult.
- **The current social security system provides an inadequate level of support.** Carers expressed major disillusionment with the low value of Carer's Allowance, as well as the inflexibility of the eligibility criteria. The social security system was also seen as insensitive, undignified and complex to navigate, preventing people claiming what they were entitled to. However, carers still see Carer's Allowance as an important – if inadequate – recognition for the role that they provide and are keen for its expansion, along the lines of the approach in Scotland.
- **The inescapable extra costs of providing care, including additional food, energy and transportation costs, are crucial to understanding the difficulties unpaid carers face.** These extra costs make carers more vulnerable to the hardships of the cost-of-living crisis, which is further squeezing already tight budgets. Carers are often unable to cut back any further. Without support to ease the financial pressure they're facing, many carers have no way to make ends meet and are making increasingly desperate decisions to get by.
- **Sandwich carers, those caring for the longest each week and for multiple people, are often under the most financial pressure.** These carers are dealing with high cost pressures on multiple fronts and the severe "time cost" of their caring role is a big barrier to employment.

On the key lived experience indicators, our qualitative research found:

- **As a result of the demands of their caring role and the poverty they face, carers are isolated and lonely.** Many have no significant social networks and often suffer from strained family relationships as a result of the financial and time pressures associated with caring.
- **Carers face limited education and learning opportunities.** The impact of providing care at a young age has a negative impact on educational attainment, impeding labour market opportunities in later life. Carers also have limited opportunities to access life-long learning.
- **Many carers suffer from poor mental health as a result of the demands and financial pressure of caring.** Carers often put the cared-for person's wellbeing before their own, which can negatively impact on their health. They may become locked in a vicious cycle of care demands leading to poor mental health outcomes, which has financial

consequences and, in turn, further worsens their mental health. This is only exacerbated by difficulty accessing support services.

- **Carers are often living in precarious financial situations.** With limited income and social security support, carers have no financial safety net. They are unable to cover any unexpected additional expenses and live in a state of constant financial anxiety. For many carers, living in financial precarity is their “normal”, and many are resigned to a bleak financial future.

Unpaid carers suggested a number of potential policy solutions to help tackle poverty, including:

- The introduction of a Carer’s Allowance Supplement for those in receipt of Carer’s Allowance and for younger carers who are currently ineligible for Carer’s Allowance;
- Wholesale reform to the eligibility and value of Carer’s Allowance;
- The introduction of a Carers Essentials Payment to help make the cost of essential food, energy, clothing and travel more affordable; and
- Improved workplace culture, policies and placement/training schemes to support carers, as well as legislative changes to introduce paid carer’s leave and day-one rights to flexible working.

This report creates a space for the voices of unpaid carers to be heard and uses their powerful testimony to offer an insight into the realities of unpaid caring and poverty in Northern Ireland. It is the first in a series of reports from the Carer Poverty Commission NI and will inform the future work of the Commission.



Introduction

In Northern Ireland, over 220,000 people are estimated to be providing unpaid care.³ Unpaid carers are a diverse group that include child and young adult carers through to carers of pension age. They care for people with a wide range of physical health conditions, mental ill-health, learning disabilities and more. Some care for family members, friends or neighbours, and some for multiple people at the same time.

Within this diverse population, a common experience shared by far too many is poverty.

As a group, carers face immense challenges in combining their caring role with paid work – leaving many outside the labour market or underemployed, and therefore at a significant risk of poverty. Carers often face significantly higher costs and receive inadequate levels of financial support through the social security system. All these factors contribute to an incredible pressure on carers, a situation that has only been made worse by the ongoing cost-of-living-crisis, and which is leaving them making increasingly desperate decisions to get by.

Despite how vital unpaid caring is to our society and the functioning of Northern Ireland's Health and Social care system, the contributions of unpaid carers often go unrecognised. Carers frequently report feeling forgotten, invisible and overlooked by policymakers, employers and society.⁴ It is in this context that the Carer Poverty Commission was established by Carers NI, to better understand the scale, drivers and nature of poverty among unpaid carers in Northern Ireland, and to design new policy solutions to help tackle this poverty.

New research conducted by WPI Economics for the Carer Poverty Commission, using the Social Metric Commission's (SMC) measure of poverty,⁵ has found that 25% of unpaid carers in Northern Ireland are living in poverty, around 55,000 people. This is significantly higher than the poverty rate for non-caring adults in Northern Ireland (16%) and more than the proportion of carers in poverty in the rest of the UK (23%). Quantitative analysis of carer poverty in Northern Ireland will be published later by the Carer Poverty Commission.

Alongside quantitative analysis, WPI Economics has conducted a programme of qualitative research with unpaid carers to hear directly about their lived experiences of poverty, the impact this has on their daily lives and the solutions they would like to see to address this poverty. This report provides the space for the voices of unpaid carers to be heard and uses



Qualitative Methodology

The experience and perspective of unpaid carers were gathered through three focus groups and a small number of semi-structured interviews conducted in May and June 2023. In total, twenty unpaid carers from Northern Ireland took part in our qualitative research.

Qualitative research participants provided good coverage of a number of key demographic diversities among unpaid carers, including the conditions of the individual(s) being cared for, the relationship to the person being cared for, the number of people being cared for in the household, the length of time an individual had been providing care, the employment status of the carer, the age of the carer and whether or not the carer received Carer's Allowance.

However, as with all qualitative research, there are limitations to the coverage within the sample. Among the participants, female carers were over-represented, as were those who were providing a high number of caring hours. It was also difficult to recruit carers who lived in rural parts of Northern Ireland. Practical, ethical and safeguarding challenges also meant we were unable to speak to child or young adult carers for this report. However, additional qualitative research will be conducted to ensure this important carer demographic are engaged with as part of the Carer Poverty Commission NI's work.

their powerful testimony to provide an insight into what it is like to provide unpaid care and live in poverty in Northern Ireland.⁶ The pages that follow examine:

- Key drivers of poverty among unpaid carers, which include: (i) difficulties combining paid employment with unpaid care, (ii) the inadequate support offered to unpaid carers through the social security system, and (iii) the unavoidable extra costs of providing care for a sick or disabled person.
- The impact of poverty on unpaid carers across a range of lived experience indicators, such as family and community life, labour market and educational opportunities, health outcomes and family finances; and
- Policy solutions that unpaid carers would like to see implemented by the Stormont Assembly and Executive, employers and wider society to address and tackle the poverty they experience.

“This is my normal... I’ve always been used, basically, to poverty... That’s literally all I’ve ever known.”



The drivers of poverty among unpaid carers

Managing paid work and care is challenging

Many carers want to remain in work

Taking on a caring role can be a sudden and dramatic change to an individual's life, with a significant impact on their ability to continue working, especially in a full-time role. In the 2021-22 Family Resources Survey, just 34% of people with caring roles in Northern Ireland were full-time employed or self-employed, compared to 47% of the general adult population.⁷

Overwhelmingly, the carers who took part in our qualitative research were keen to remain in work for the financial security and dignity it provided. However, to have the time necessary to perform their caring role, many carers have had to make substantial changes to their working patterns. This meant either leaving work entirely or cutting down their hours – resulting in reduced incomes, a detrimental impact on future career progression, promotion opportunities, earning potential and their pension.

One carer, who had recently begun to care for her husband following a stroke, was forced to reduce her working hours, resulting in her income being cut by a third. It was imperative that she continued to work to pay the household bills, which were rising and now solely being met by her wage packet:

"I was working full time... bringing home probably £2,000 a month just on my own, which was fantastic. And then, when my husband came home from hospital after his stroke and he really doesn't like to be left on his own. So, I just spoke to my employer and said, 'I don't want to quit work. I can't. I have to pay the mortgage. There's only my wage. So, would you agree to me reducing my hours?' So, that means I take home about £15,500-£16,000, which sounds like a load. But then I've got all the bills coming out of my wage, everything. So, I pay for all of the groceries. I pay for the petrol. I pay for the mortgage. I pay for the car insurance, home insurance, my insurance, phones, everything. So, at the end of it, I have very little left. And really, with the cost-of-living-crisis and the price of just basic groceries and petrol going up so much, it's a struggle. It's a big struggle."

Another said:

"It really wears on you because you really want to earn, even though you're working 24/7 in your caring role. The amount of carers that I know that just say I would take four hours a week just to get out and meet other people, work in a cafe or whatever, just to have human connection. The social element that would have for carers would be massive."

Among carers who had left paid employment altogether, many had previously worked in well-paid and secure jobs, including within the civil service, healthcare and the higher education sector. Many had initially attempted to combine work and care, however the needs of the person being cared for became incompatible with working, and the physical and mental toll of combining care and work became too difficult to manage. As one parent carer explained:

"I went from maternity leave, to career break, to resigning because the caring role was just too much around work."

Sandwich caring – where a carer is supporting people from different generations at the same time (e.g., a child and a parent) – is particularly demanding, often with little or no respite. For example, whenever their child is at school, the carer devotes their time to the other relative in need of help. This can result in caring taking up all of their waking hours, with no time for work:

"I'm a carer for my daughter, but I'm also caring for my mother who has dementia... Caring has exhausted me so much that I've had to give up my job and retire... So, yeah, it's been tough... I just couldn't carry on doing it anymore."

Carers said that the unsympathetic and inflexible attitudes of employers towards caring situations is also driving people out of work. In one striking example, a carer was forced to give up a long-standing career when she asked to work five hours less a week to provide care to her young child, which was rejected and saw her leave the job:

"I worked as a middle line manager... But when I asked to work 5 hours less a week, they said no, which obviously was a massive stress because you just lose [your] entire career. And I was saying, I can produce medical evidence that my son was really very sick. He was being hospitalised at that time. I was very much in a very bad, anxious, depressed state."

Being forced out of work is financially disastrous for many carers

A significant number of carers who participated in our qualitative research had to leave full-time employment altogether – with a disastrous effect on household finances. In these experiences, the onset of caring responsibilities was often sudden, with little time to consider the implications of giving up work to provide care. Carers become increasingly reliant on others within their household as the sole or major income earner, and being unable to work prevents them from affording anything beyond the essentials needed to fulfill their caring role.

"I'm now just in a complete flux, because there is no salary after 27 years so I can care for my mum. So, I don't know where I'm going to be going as regards paying for the basic bills, keeping the car on the road."

Older carers who are forced to retire early find themselves with a significant income gap between the time that their wages stop and when they start receiving their pension. One carer in this scenario described "a horrible sense of impending doom and anxiety" as she faced years before reaching pension age, leaving her "falling... with no safety net."

For those carers who had to stop working in their later years, the realisation that they may never work again was felt particularly strongly. One carer in her late 50s spoke of having to give up "several brilliant jobs" to care for different family members at different stages of her life. Being out of work in her late 50s had left her resigned to the fact that she would be unable to enter paid employment again and was left to live the rest of her life in poverty:

"I'm skint. I now have a future of poverty... I do not know what I'm going to do... Why is it that I have poverty to look forward to at 59...?"

Reduced incomes due to caring and ill-health leave families without the disposable income and quality of life they used to enjoy – which one carer described as "soul-destroying".

The loss of work for those with caring responsibilities not only brought with it financial pressure, but also came at considerable personal cost in terms of a lost career and an important sense of identity and dignity that was attached to working. As one carer explained:

"I just lost my entire career ... So, a monetary cost is probably I was earning late 20s [thousand pounds], probably into the 30s. And there's sort of seven years of earnings, which is an awful lot of money. But also, there's a personal cost to me because I lost my identity, I lost everything because I was needed at home."

The recent rise in work from home helped many carers stay in employment

While some carers had to leave their paid role entirely, others were able to remain in work. For some, the transition to home working as a result of the Covid-19 pandemic helped, as they found themselves able to work full-time jobs and be on hand to provide necessary care. This often required a sympathetic employer; those who were able to work from home felt that without that option, they would almost certainly have to leave their job to meet their caring responsibilities.

"If I did not have the working from home option, I would be screwed. Absolutely. Because in between the working at home, I'm nipping in and out... and checking everybody's okay and checking everybody's been fed and giving everybody their medication."

Working from home was not always a positive experience, however, as it left some carers feeling more isolated and cut off from society and a life outside of caring:

"I'm trying to juggle working from home, working from [the office], and caring full time. And it was tough before the pandemic, but since the pandemic, it's just escalated because nobody cares. And the poverty is not just financial poverty, it's poverty and the fact that you can't even get out to have a conversation with people."

Even carers who can remain in work are constantly anxious about the future

Anxiety about the future financial implications of leaving work was shared by carers who were still in employment. They described an underlying sense of "dread" about having to leave paid employment or retire early if the needs of the person they cared for intensified. The financial and emotional uncertainty of when this would happen created feelings of fear.

"I'm working two days a week, but there is a sense of dread. I know that the time [of having to give up work] is coming. I don't know when, but it's sooner rather than later... I'm going to have to give that [work] up and then I will be in this precarious position and it's quite scary."

For some carers, this was compounded by the pressure of being the only source of income in the household:

"Well, I am the sole earner in my family ... But my wage is not a big one. And I am paying the entire bills for the entire house, technically supporting three people on one wage, which is just about coming in at £22,000 net every year. And honestly, I am struggling."

Those who remain in employment often suffer from guilt when leaving the person they care for

There was also a sense of guilt among some carers for having to go out to work and not being able to, from their perspective, commit all of their time to the person they were caring for. This sense of guilt was often felt strongly by those who were passionate about their careers and the enjoyment they derived from working:

"I don't think people get that you go to work to make enough to pay your bills. I also go to work because I enjoy what I do. I like what I do. But the guilt of leaving the person that you care for to go to work, but you've no choice. It's just a mad cycle."

Carers need understanding and flexibility from employers to help them juggle work and caring

The nature of caring is not static, and people's caring needs will often fluctuate. This may open the door for carers to re-engage with the labour market, however many said they encountered numerous barriers when they tried to do so.

Several parent carers explained that they had been turned down for part-time jobs as a result of employers requiring availability during evenings and weekends, and being unsympathetic to the needs of their caring role and the pressure on their time:

"I can't even get a job. I applied [unsuccessfully] for a job in [a high street chain store], stacking shelves eight hours a week... I can be discriminated against because of my care [role]. Because they want someone who's flexible and can work whenever they want, not whenever I can."

A consensus emerged among most carers that employers were often unaware of the full extent of the demands placed on a carer, and better understanding and recognition would go a long way in supporting and encouraging them to remain in, or re-enter, the workforce.

In addition, there was a desire to see the implementation of carer-friendly workplace policies – most notably the right to some form of paid carer's leave. Those carers who had to take leave to provide care or take respite often did so out of

their holiday entitlement or as unpaid leave, which creates additional financial pressure:

"I work in the private sector, so anything I took, I took out of my own holidays. When my mother was in hospital last September, I had to take a month off to sit in the hospital with her because I couldn't depend on the hospital looking after her. But that was unpaid."

Social security support for carers is inadequate

Exacerbating the challenges of unpaid carers being unable to work, or working reduced hours, is the inadequacy of the social security they receive. Unpaid carers criticised both the strictness and lack of flexibility in benefit eligibility criteria, the monetary value of available support and the bureaucratic and undignified nature of accessing support, which only heightened financial difficulties and experiences of poverty.

Carer's Allowance is not enough

Carer's Allowance is available to those aged 16 and over who care for an ill or disabled person for at least 35 hours a week. Payments are withdrawn if a carer earns more than £139 per week and it is not available for carers in full-time education and for many carers in receipt of their State Pension. At the time of writing, Carer's Allowance is paid at a rate of £76.75 per week – the equivalent of around £2 per hour at most. In Carers NI's State of Caring survey, nearly 40% of carers receiving Carer's Allowance said they were struggling to make ends meet.⁸

Carers that we spoke to described the value of Carer's Allowance as an "insult", "terrible" and "degrading", as it did not provide enough to afford a dignified standard of living, especially considering the additional inescapable costs they face:

"It's not great, Carer's Allowance... It's very difficult to make ends meet. ... I always go to Oxfam or second-hand shops. But you just know that your money is never going to do. You're always looking for smart price in Asda."

"It's absolutely terrible. I'm in receipt of Carer's Allowance. There just aren't words to describe how unbelievably bad it is."

"I think Carer's Allowance is an insult. It is indeed an absolute insult to everyone. There's no point in even talking about the value of it because it's a disgrace."

Despite carers' overwhelming dissatisfaction with the value of Carer's Allowance, many saw the benefit as an important – if inadequate – recognition for the vital role they provide. It was in this context that many carers called for the monetary value of Carer's Allowance to be increased. Many cited the Scottish Government's Carer's Allowance Supplement, which was identified as a "perfect starting point" for improving social security support for carers in Northern Ireland.

The Carer's Allowance eligibility criteria unfairly exclude people in need and are difficult to navigate

Many carers felt that Carer's Allowance shouldn't be means-tested:

"I think personally, Carer's Allowance should be not means tested. And I think everybody who cares for more than 35 hours a week should be entitled to it and should get it automatically. That would help alleviate some of the poverty that people are going through. It wouldn't cure it, but it would go towards an electric bill or putting oil in your tank."

The earnings threshold in Carer's Allowance isn't tapered, so those who earn one penny more than the threshold lose their full payments entirely. Perversely, then, working more has the potential to lower carers' incomes. This created what was described as a "cliff edge" that can act as a barrier to carers seeking paid employment and traps them in poverty:

"I know I could get a potential job that I would be interested in. I know there's a couple that I've looked at... but then I'll lose my Carer's Allowance. So, I won't be able to afford the opticians. I won't be able to afford the dentist."

Another carer said:

"The really irritating thing about going back to work... I lost my Carer's Allowance, because I earn too much money... It's quite a cliff edge. So, you're sort of going back to working... and you kind of lose that money straight away... that has been fairly challenging."

Some carers proposed separate payments, such as a Carer's Working Allowance, to support those who continue to juggle unpaid care and work on part-time or reduced hours, as a form of "top up" to their wages. As one carer who had recently had to cut back her hours to care for her elderly mother suggested:

"If there was something where there was a Carer's Working Allowance which rebalanced things so that you could maybe reduce your working hours to three days a week, but you were still working and paying tax and then getting some sort of top up while you were looking after the person. You'd have more time to do that and you're still working."

With students in full-time education ineligible for Carer's Allowance, those who are suddenly faced with caring responsibilities may have to choose between forgoing much-needed financial support or their education. The latter can have a devastating effect on their future earning potential. As one carer explained:

"The first time I became carer, I was a young carer. I was 17 years old, I was in my A levels at the time and was probably quite academically capable at that time. There was literally zero help for the position that I found myself in. There was literally no support for having to subsequently care for my dad while I was at school. So that had a massive impact. I kind of completely messed up my A levels. I would say when I think back, the impact I think that's had on earning potential and professional qualifications."

The way in which Carer's Allowance interacts with other benefits was also felt to be unnecessarily harsh, leaving carers worse off:

"The Carer's Allowance, ... it is just degrading. I got it for a while when I wasn't able to work. But the process when you do apply for ... Carer's Allowance, it's deducted off Universal Credit. You just get the same as Universal Credit. Basically, the only positive to getting Care's Allowance for me in the short term was ... that I didn't have to go into the job place every two weeks, which is degrading in itself."

The social security maze is difficult to navigate at the best of times, but carers are a particularly vulnerable population due to the immense pressure they're under every day – making it even more difficult for them to stay on top of what support they are entitled to. During one of the focus groups, a carer highlighted her understanding that she could not get Carer's Allowance at the same time as Personal Independence Payments. Other participants advised that it is possible to receive both benefits simultaneously – highlighting that the system is so complicated that even people who have to interact with it throughout their lives are not entirely certain how it works.

Receiving benefits is stigmatised, despite the vital role carers play

Carers said they often felt a stigma associated with relying on welfare support:

"I think when you're coming from working, never having to rely on benefits, and the stigma around that ... makes me more militant."

"There's a whole issue of stigma. And finance was something no one would talk about. It was just the stigma and the shame of it was so great."

Applying for benefits is an often undignified process

Aside from the amount that can be claimed, carers said the process of applying for welfare support is complicated and can feel degrading. Carers were frustrated at having to repeatedly discuss the same information about the cared-for person's ill-health as part of the process of applying for Personal Independence Payments. If this ill-health or disability was caused by an accident or a sudden illness, the carer may have to continuously revisit traumatic days and memories, which can be very difficult. Families may also have to re-apply for PIP regularly, even in cases where the illness is incurable, causing distress and worry about future finances if the application is turned down.

"My child is not going to change. There's no improvement. His diagnosis will not go away. And yet, I constantly have to go and fill out these forms again with the fear of, what if I don't get them? What's the impact of that? It's just so stressful."



The extra costs of care

The extra costs carers face are wide-ranging – and increasing

The already limited income carers have at their disposal as a result of minimised income through paid work, and inadequate social security support, is being squeezed even further by the inescapable extra costs associated with caring for a sick or disabled person.

All of the carers who participated in our qualitative research outlined significant and numerous additional costs that they faced as a result of their caring role, which were only rising as a result of the cost-of-living crisis. The following infographic summaries the struggles carers are facing with a wide range of extra costs.



Food

Special nutritional or dietary needs can substantially increase the food costs faced by carers

“You go to the supermarket, and you put your card in the machine, and you’re almost sitting there with a silent prayer saying, ‘please let there be enough money there, please, so that I don’t have to leave some of this stuff’ ... Food has especially increased I have noticed. I would sooner that I didn’t eat so that my son could eat and my partner could eat.”

“At different points my children needed different sorts of allergy related foods, and they cost a fortune. And there’s never offers on those. And we all know that inflation is through the roof and has been for such a long time ... We just couldn’t afford the cost of it. Food prices are just depressing.”



Electricity and heating

People with disabilities and other conditions often require warmer homes all year round, and may need medical equipment running in the home, all of which drives up energy costs

“My son can’t regulate his temperature. So, we’re high electricity users, we’re high gas users. There’s a lot of electrical equipment that’s on all the time in in the house and that helps him regulate [his temperature]. So those costs have been huge.”

“My son requires water therapy. So, we purchased a hot tub and it’s on all the time. He’s in it every day, but the running costs of that are astronomical. But it meets my son’s needs, it makes him happy. It may look like a luxury, but it’s not. But the running cost of our electric has gone up by at least £200 a month.”

“The electricity bill has doubled in the last year because I have four pieces of equipment that have to be on 24 hours a day, so the electric has skyrocketed.”



Transportation costs

Getting to and from medical appointments, health services and other essential places can be very costly

"I get no help with the petrol to and from hospital appointments. He has to go to three different hospitals with his condition. And you're up and down. And it's not just the petrol, it's the car parking. So those are additional costs."

"It's got gradually more and more difficult. [The person I care for] often needs very specific foods. Because we live quite rurally, I often do a 30 to 40 miles trip to get everything that I need."



Therapies

Many carers are having to meet the cost of vital therapies out of their own pocket

"For my husband with a brain injury, he's engaged a private physio who specialises in brain injury. But we're looking at almost £400 a month. And he pays that out of his benefits and that's money that could help me with the house, but I don't feel right taking it from him because it's helping him physically. So that cost is massive."



Toiletries and clothing

People with disabilities may have special clothing requirements, which represent a significant cost

"[The person I care for] struggles with incontinence and that side of things. And then the cost of replacing bed sheets and pyjamas constantly and underwear, and then just holes in clothes because they wear differently. I have to buy about ten pairs of joggers every couple of months just from the wear."

"I calculated it last year that I spent £630 on school uniforms. He was in school two weeks, and he ruined his shoes and that was another £115 because he needs specialist adapted shoes."

Rising costs are driving some carers to desperation

The insufficient income and rising costs facing carers is forcing many to cut back on essentials, live in cold homes and contemplate emergency help, such as food banks. They talked about how “*humiliating and embarrassing*” poverty is. One carer who has taken care of his wife with MS for more than 20 years said:

“Last winter the expense of everything was just getting too much and I couldn’t afford oil for the tank. And the children come around and say, ‘Why?’ And I’m too embarrassed to say I haven’t got the money to put in the tank. I just don’t know where it’s going to go. The price of everything in the shops now [has] went through the roof... Food banks are the last option. You don’t want to do that, but that’s going to have to be looked into.”

The rising costs of providing care were also leading carers to contemplate heartbreaking decisions to get by. As one carer explained:

“If I looked through my bank statement, the cost of caring is all around. The roof over our head, food, childcare, my son’s care. My son only eats very specific things. And I’ve also got a dog that he likes. But I hate the cost of dog food and cat food because it’s really expensive, but those are the things that make my son happy. And I can’t get rid of the dog. Sometimes I wish the cat wouldn’t come back.”

Another carer tried to remortgage their house, but was told by the bank that they didn’t have enough money:

“I was going to lose my house... So, the tiny bit of stability that I have to ensure that my children don’t grow up in poverty was being taken away from me.”

For others, the pressure is so severe that they are forced to borrow money from illegal money lenders to help them afford the things the cared-for person needs:

“The amount of carers that I am even aware of that go to loan sharks in August, just so that they can afford to buy their children a uniform, is a really horrific look on our society.”

Carers talked about living in constant fear of any unanticipated expense that may push them over the edge of their financial resilience:

“Carers are always one white good appliance away from destitution. And that’s always in the back of your head. You don’t drive far away in case you get a parking ticket or caught speeding. You don’t use your white appliances as much because you’re terrified that one day they’re just going to give up on you. And there’s just so much at stake. It’s not just the stress of caring, it’s the stress of not being able to afford to replace things if things break.”

The Social Metric Commission's Lived Experience Indicators and unpaid care in Northern Ireland

The SMC's measure of poverty assesses a wider set of factors and outcomes that affect the lived experiences of people in poverty, across a number of domains:

- Family, relationships and community;
- Education and labour market opportunity;
- Health; and
- Family finances.

The testimony captured during the focus groups and interviews sheds some light on how these different domains impact and interrelate with experiences of poverty among unpaid carers in Northern Ireland.

Family, relationships and community

Carers described the way that feelings of isolation and loneliness are exacerbated by experiencing poverty. The combination of struggling to juggle work and care and affording the extra cost of care left them with limited time and resources to enjoy themselves. One carer described her lack of social life as "fortunate" from a financial point of view, as it meant she was not spending money, but admitted the lack of social connections was not good for her own mental wellbeing. As she described it:

"The poverty is not just financial for me, it's the poverty of actually just existing instead of living."

This was a sentiment shared by a number of carers:

"It is the poverty of not being able to go places and do things with your own friends... You just don't have the time to do things for yourself and you don't have the money."

"Not only are we living in fear, financial fear, poverty, worrying about keeping things floating, paying bills. We're also trying to continue with our own basic life through a poverty of support and understanding and a poverty of isolation and loneliness."

"There has been a high social cost to me. Kind of losing friendship groups and not being able to do some of the activities that I'd like to do."

To help support them to remain connected within their local community and with friends, carers were keen to see some form of concession offered by community or leisure centres and cultural attractions, to minimise the financial cost.

Carers also highlighted that family relationships may suffer as a result of the pressures of providing care. A number candidly described the breakdown of their marriages and how this exacerbated feelings of isolation and loneliness, as well as financial pressure:

"Subsequently, my marriage broke down so I became a single parent carer. So, finances became even more precarious ... That kind of marriage breakdown, there's another enormous cost that you have to pay for that which you didn't see coming. It's just really tough."

Others talked about the expectation that caring responsibilities should be taken on by women within a family, which often strained relationships with male relatives. A carer who had cared for multiple different family members at different times of her life was the only woman among her siblings, and spoke of her anger at having to leave work to provide this care while her brothers continued to work and enjoy financial stability:

"I'm the youngest of five children. They're all brothers. I'm the only girl. I feel so angry that I never had a conversation with my mum about paying me for what I did, living with her. I never had a conversation with my brothers. And so now I'm the one of the five of us who has nothing left and they've all got their pensions. So, I'm really angry at my siblings."

Education and labour market opportunities

Some of the difficulties of combining paid employment with unpaid care were covered earlier in this report. In addition to these issues, some carers felt that the challenges they face in the labour market are linked to inhibited educational outcomes due to taking on caring responsibilities at a young age. Research has shown that young carers have significantly lower educational attainment than their non-caring peers.⁹ The educational and longer-term employment implications of this were outlined by one carer, who first provided a caring role for her father at 17 years old. She explained that she went from being "probably quite academically capable at that time" to "completely messing up my A-levels". She felt this lack of educational grounding affected her earning potential and it was only through additional learning that she overcame this barrier:

"I suppose I was resilient enough to kind of find work and capable enough to do that but then, I spent an awful lot of time doing additional learning, like after school, after work. So, I never really had that good grounding in education I think, which most definitely helps your earning potential."

The importance of lifelong learning in opening up greater work and earning opportunities was outlined by another carer. She felt that having a university degree was key to securing jobs with hybrid working options, but obtaining a degree is difficult for carers given the time and cost involved, and with limited availability of carer scholarships:

"I know that there are hybrid working opportunities, but again, you have to have a degree for that... It's being able to afford to do it in the first place. If you could get your degree... and then be able to look about jobs that would offer hybrid solutions, or work from home solutions, that would be phenomenal. Like, the amount of doors that would open up [for] carers to get them out of destitution would be massive."

Health

The demands of providing unpaid care, coupled with the number of financial pressures carers face, can take a big emotional and mental toll. The fear of being unable to pay essential bills, and the dread of a brown envelope, were common and recurring anxieties among carers:

"I just felt like I was stuck there, and I wasn't looking after my own mental health. I was so focused on my mum and dad.... It just was a real struggle in the bills... I really wasn't on top of bills in terms of what goes out. And every time we settled a bill there always seemed to be another bill around the corner. Whether it was rates or something like that... It was a real struggle."

One carer talked about living under chronic stress, with the need to be hyper vigilant about the cared-for person's health around the clock only exacerbated by worries about family finances.

Many other carers similarly said they suffered from poor mental health, but this was sidelined in order to prioritise their caring role and keep the household running.

"I have to remain upright. Because if I don't remain upright, the whole thing goes to hell in a handcart, really. So regardless of how I feel, and most days, honestly, it's not great, but I put the mask on and off. It's not conducive to a quality of life. No, it's not at all."

Carers explained how caring-related mental ill-health – including severe conditions like depression and PTSD – meant they could not work, risking financial hardship which, in turn, caused further worry and stress about the future. Describing this type of vicious cycle, one person caring for her daughter and both of her parents said:

“I’ve been a nurse for 35 years, but I’ve actually got physically and mentally sick because of my caring role. So much so that I’ve had to take retirement from my job because I just couldn’t carry on working and caring at the same time ... So, yeah, I don’t know how the future is panning out. That’s why I have to get help for my mental health now, because my caring role has made me sick, and I can’t work anymore. So, I really don’t know. And that’s the worrying thing... I don’t know what the future is going to be for me. I really don’t know.”

The financial pressures facing some other carers led them to suffer severe burnout and nervous exhaustion as they tried to bring enough money in while caring.

“The only reason, technically, that I am surviving at the minute is that there’s a lot of overtime. But last year, I basically had worked myself to the point of nervous exhaustion because I was working about 65 hours a week, every week. I had what we shall euphemistically refer to as a little bit of an episode. So that was a little bit of a wakeup call for me. I am still doing overtime, but less overtime, and it’s still impacting financially.”

All of the carers who raised concerns with their own mental health spoke about how they wanted to seek medical and other help, but affording this self-care – whether it be private counselling or exercise activities – was difficult:

“My mother and my uncle would probably have got a better experience had I had less going on in my head and [not] been so stressed ... I think we should be getting a GP referral to free access to the gym for unpaid carers. Why not? I’m living on Universal Credit. I cannot afford to pay for private counseling. I cannot afford to go to the gym. I cannot afford to go to the local leisure center. It’s far too expensive.”

Family finances

For far too many carers, being in a financially precarious position was “normal” and taking on a caring role was seen as going hand-in-hand with experiencing poverty. In some circumstances they were reliant on the income of others in the household to support the family financially while they provided the caring role. This was considered a vulnerable state of affairs:

“I had a professional career at a university that I had to give up to care for my children ... My husband works, so we’re a couple and two children, but on one wage and benefits. It’s not a lot. And there really is that stigma about benefits, but it’s ridiculous that there’s a stigma about it because I would love to be at work. I wish there was childcare for my children because I know I’d be a better mum for it and the financial pressures in the house would be eased.”

Carers who had recently taken on a caring role spoke of struggling to adjust their financial expectations. A carer who had been looking after her husband for the past three years following a stroke explained that, as a result of losing her husband’s income and reducing her own hours, they were now in a position of balancing the books rather than having a good level of disposable income they could spend. She described how her husband still had “very unrealistic expectations” of what they could afford and found it “soul-destroying” that they were unable to live as they previously had.

A recurring anxiety was around future financial security, and how taking on a caring role is often incompatible with financial planning – a caring role is often a sudden change in circumstances that cannot be prepared for or financial protected against. Many had, in fact, never considered their financial future until taking on their caring role. A significant number of the carers who participated were resigned to the fact they would have a reduced pension compared to what they were expecting. As one carer explained:

"I never thought to the future. Well, I'm absolutely reeling now. Absolutely reeling. I'm absolutely raging because I never thought about the loss of my National Insurance contributions. I will not get a full state pension. I will now not get a full work pension."



CHAPTER 4 Policy solutions

The ideas put forward by unpaid carers in this qualitative study, along with wider evidence, support a suite of policy recommendations to help tackle the poverty facing unpaid carers in Northern Ireland. These are summarised below and some of the policies will be further developed, and their potential impact modelled, in later work by the Carer Poverty Commission NI.

For the Northern Ireland Executive and Stormont Assembly

The introduction of a Carer's Allowance Supplement scheme. This would be delivered under the same terms and conditions as the scheme in Scotland:

- A targeted payment of £270.50 twice a year for carers receiving Carer's Allowance. Unpaid carers considered this a good starting point for reforming the social security system and the policy has previously been recommended by the Independent Review of Welfare Mitigations.¹⁰
- The Carer's Allowance Supplement would also be delivered to young carers who are ineligible for the standard Carer's Allowance payments.

Review of the value and eligibility criteria of Carer's Allowance. This could include:

- An increase in the Carer's Allowance earning threshold and the introduction of a taper, similar to Universal Credit, to better support carers in work.
- Introduction of a working carers element to Carer's Allowance that provides a top-up for carers working reduced or part-time hours.
- Reforming overlapping benefit rules to allow more older people to receive Carer's Allowance alongside their State Pension, as well as allowing those in full-time education to access Carer's Allowance.
- Allowing multiple Carer's Allowance payments to recognise the higher costs of caring for more than one person.

The introduction of a monthly Carers Essentials Payment. This would help carers to better afford the inescapable higher costs they face for the likes of transport, food, energy and clothing (including school uniforms). It was suggested that this payment could be linked either to an hours-spent-caring threshold, or to recipients of Carer's Allowance.

For employers in Northern Ireland

There are both voluntary actions that employers could take to improve their workplace culture and policies for carers, as well as legislative changes to employment law to help people juggle work and caring:

- **Greater engagement from employers with carers and carer organisations to introduce carer-friendly policies and more supportive workplace cultures for carers.**
- **Employers signing up and co-designing work placements and training schemes to support carers to enter the labour market.**
- **Legislation to enshrine unpaid caring as a protected characteristic under equality law.**
- **The introduction of flexible working as a day-one right for working carers.**
- **The introduction of statutory paid carer's leave that is separate to holiday entitlement.**

For other stakeholders

- **Community centres, leisure centres and cultural attractions should offer concessionary rates for carers and the people they care for.**
- **Greater access to joined-up health, social care and community services.** This would give carers the time and space to do things outside of caring, including going to work, and help them access support for their own health and wellbeing.
- **Improved support for carers to access further and higher education.** Providers should work with carer organisations to provide tailored and bespoke schemes that are accessible for carers.



Endnotes

- 1 The proportion of unpaid carers identified as being in poverty across the three year period 2020-22, based on the Social Metrics Commission's measure of poverty. See here for more on the measure of poverty: <https://social-metricscommission.org.uk>
- 2 Based on 25% of 222,000 unpaid carers. NI Statistics and Research Agency (2023). Census 2021.
- 3 NI Statistics and Research Agency (2023). Census 2021.
- 4 Coalition of Carers Organisations (2023). A New Deal for unpaid carers in Northern Ireland: Co-designed policy solutions to support the unpaid carer population.
- 5 For more on the Social Metric Commission's measure of poverty see: <https://socialmetricscommission.org.uk>
- 6 To protect carers' identity, their testimony is presented anonymously and certain personal details have been protected.
- 7 Department for Communities (2022). Family Resources Survey 2021-22 – Carers, careers and disability.
- 8 Carers NI (2022). State of Caring 2022: A snapshot of unpaid caring in Northern Ireland.
- 9 Allision Jane Campbell (2020). The educational impact of being a young carer aged 16 – 24 in Northern Ireland.
- 10 Department for Communities (2022). Welfare mitigations review: Independent Advisory Panel report.



WPI Economics Limited

5-6 St Matthew Street
London
SW1P 2JT

@WPI_Economics

wpieconomics.com

WPI Economics Limited, registered address 28 Church Road, Stanmore, Middlesex, England, HA7 4XR, is a registered as a limited company in England and Wales under company number 10086986.

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