

State of Caring 2024

The impact of caring on finances and employment

January 2025



About this research

Carers NI, as part of Carers UK, carried out an online survey with unpaid carers between June and August 2024.

A total of 1,202 unpaid carers responded to this survey in Northern Ireland. This report summarises their responses. As not all respondents completed every question in the survey, some figures are based on responses from fewer than 1,202 people.

The survey was promoted extensively amongst carers and organisations which support carers across Northern Ireland and the rest of the UK. It was shared on the Carers NI website, Carers NI social media channels, and with Carers NI members, volunteers, previous survey respondents, and campaigners.

Of respondents to the survey:

- 100% are currently providing unpaid care.
- 58% are caring for over 50 hours per week, 26% are caring for between 20 – 49 hours and 15% are caring for 19 hours or less.
- 82% were aged 18 – 64 years old, and 19% were aged 65 and over. The biggest proportion of respondents were in the 45-64 year old category (66%).
- 41% of carers care for a parent or parent in law; 39% for a son or daughter or son/daughter in law and 25% for a spouse or partner.
- 82% of respondents were female, 17% were male.
- 26% of respondents stated that they had a disability.

Thank you

Carers NI would like to thank every unpaid carer who took the time to complete this survey, as well as the carers who helped us test the survey.

Your responses will be used to shape all of our policy and campaigning work over the next year.

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Introduction

There are currently over 220,000 unpaid carers in Northern Ireland providing care and support for family members, friends or neighbours who have a long-term illness, disability, or who are getting older. The care they provide currently saves the Northern Ireland Economy £5.8billion annually [1] in care costs, and yet many carers are living lives defined by financial hardship and are overwhelmed as a result of their caring role.

Unpaid carers are a diverse population, encompassing child and young adult carers through to carers of pension age – and support people with health conditions including cancer, stroke, progressive neurological conditions and visual impairment; mental ill-health; learning disabilities; terminal illnesses, and more. For some, their caring role will be lifelong, for others it will be a sudden, perhaps unexpected, role change. The intensity of care provided also varies; for some it can be a few hours per week, others are caring around the clock. In fact, research has shown that NI has the highest proportion of unpaid carers in the UK and also the highest proportion of people providing 50+ hours of unpaid care per week -the most intense level of caring [2].

Previous research by the Carer Poverty Commission has shown that more than 1 in 4 (28%) carers currently live in poverty. This is much higher than unpaid carers in the rest of the UK (23%), and considerably higher than the poverty rates amongst adults in Northern Ireland who do not have caring roles (17%) [3].

This report is the first in a series and will outline the key findings from the State of Caring Survey 2024, with a focus on how unpaid caring impacts on an individual's finances and employment. A summary of the key statistics is followed by Carers NI's policy recommendations for the Northern Ireland Executive.

Carers NI is calling on the Northern Ireland Executive to address the devastating impact that poverty and financial hardship is having on unpaid carers. The recommendations included within this report, also aimed at businesses, would help to alleviate the current financial strain that many unpaid carers are under, and we urge the Northern Ireland Executive and businesses to take immediate action.

[1] www.carersuk.org/news/unpaid-carers-saving-ni-s-health-service-5-8-billion-per-year-research-shows/

[2] Carers NI (October 2023). 'Policy measures to tackle poverty among unpaid carers in Northern Ireland'

[3] Carers UK and Centre for Care (November 2024). 'Valuing Carers 2021/22: the value of unpaid care in the UK'

Key Statistics

Impact of caring on finances

- 1 in 4 carers (28%) are struggling to make ends meet. This figure rises to 44% for those carers who are in receipt of Carer's Allowance.
- The ongoing cost of living crisis means many carers are struggling to afford essentials. 58% of respondents told us they are struggling to afford electricity and gas, 48% are finding it difficult to afford clothes and shoes, and 34% say they are struggling to afford food.
- Of those carers who are struggling to afford food 62% tell us they have skipped a meal, 54% have reduced the size of their meals in order to get by, and 35% have said they felt hungry but didn't eat.
- The additional costs of care mean many carers are turning to unsustainable solutions to manage their finances. 52% have used their savings, 31% are using credit cards and 27% have used their bank account overdraft.
- The financial strain carers are under means that 72% are worried about the impact this is having on their ability to save for the future.
- Financial insecurity is having an impact on carers mental health and wellbeing. 62% of respondents say they feel anxious or stressed when they think about their financial situation.
- For those who are struggling to make ends meet, 57% describe their mental health as bad or very bad (compared with 34% of all respondents).
- Carers are telling us they need more support in order to cope with the pressures of their caring role. 52% have said they need more financial support to help them access support services for themselves, such as therapy and counselling.
- 33% of respondents are currently in receipt of Carer's Allowance, but many carers feel excluded from receiving the benefit due to the strict eligibility criteria and the earnings threshold.
- 76% of respondents feel that the current rate of Carer's Allowance, £81.90 a week, is insufficient to meet their financial needs.
- 65% of respondents would like more information and advice about which benefits they are entitled to. With 41% saying they do not know who to contact or what social security benefits they might be entitled to.

More than 1 in 4 carers are struggling to make ends meet.



Key Statistics

Impact of caring on employment

- 55% of respondents are currently in employment (35% working full-time and 20% part-time).
- Of those currently in employment 75% say they find it stressful juggling paid work with care.
- Caring is having a significant impact on carers' ability to maintain meaningful employment:
 - 27% of respondents tell us they have reduced their working hours to care and;
 - 14% tell us they have had to take on a lower paid or more junior role in order to balance work and care.
- 29% of unpaid carers have had to leave paid employment altogether.
- This is having an impact on carers' ability to plan for and save for the future. 32% say their caring role has impacted on their ability to save for retirement and 22% have had to change their plans for retirement (either retiring earlier or later than planned).

29% of unpaid carers have had to leave paid employment because of their caring role.

- When carers were asked what would help them to juggle paid work and care:
 - 83% said a working carers passport, which would help them to document and share their caring responsibilities with their employer.
 - 82% said paid carer's leave (with 65% saying they could not afford to take carer's leave if it was unpaid).
 - 78% said changes to Carer's Allowance criteria, which would allow them to work more hours and take on higher paid work.
 - 74% said more affordable, accessible and reliable replacement care.

Policy Recommendations

Recommendations for the Northern Ireland Executive:

- Implementing a Carer's Allowance Supplement scheme, within this mandate. If delivered in the same way as the equivalent scheme in Scotland, this would increase the value of Carer's Allowance by £541 per year (via two lump sum payments each year) [4].
- Review of the value and eligibility criteria of Carer's Allowance, including:
 - Uplifting Carer's Allowance to £120 per week (an increase of £38.10 per week) to match the Joseph Rowntree Foundation's Essentials Guarantee [5].
 - Raising the Carer's Allowance earnings threshold to the equivalent of 21 hours per week at the National Living Wage and introducing a taper, similar to Universal Credit, to better support carers in work.
 - Reforming the 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 for those caring for more than one person, to recognise the higher costs of caring for additional people.
- Introduction of statutory paid carer's leave, which is separate and additional to holiday entitlement, paid fully by the Northern Ireland Executive and at the employee's full wage. This leave should be available to all employees who are providing or arranging care for someone with a long-term care need.
- Introduction of flexible working as a day one right for working carers.
- Develop tailored employability programmes to support and retrain carers who wish to return to employment after a caring role has ended or reduced.
- Introduce an employer accreditation scheme for organisations to demonstrate that they are carer-friendly, similar to the Carer Positive scheme established in Scotland.

[4] Joseph Rowntree Foundation & Trussell Trust, February 2023, *An Essentials Guarantee*.

[5] Department for Communities (2022). *Welfare mitigations review: Independent Advisory Panel report*.

- Reform the social care system to provide reliable, consistent, high quality replacement and support care, including domiciliary care, respite, day services and services for young adults with special needs. Appropriate social care provision would enable more unpaid carers to remain in or return to the workforce.

Recommendations for business:

- Engage with carers and carer organisations to introduce carer-friendly policies and more supportive workplace cultures for carers.
- Raise awareness of unpaid caring within the workplace, including sources of advice, information and support for carers.
- Identify and support staff who have caring roles – including through line manager training on recognition and support of adult and young carers entering the labour market for the first time.
- Co-design work placements and training schemes to support carers to enter the labour market.

Theme 1: Carer's financial situation

Key points:

- Over a quarter of carers (28%) are struggling to make ends meet. This figure rises to 44% for those in receipt of Carer's Allowance.
- 37% of carers do not feel confident that they will be able to manage financially over the next 12 months.
- 63% of carers are worried about living costs and whether they can manage in the future.
- 72% of carers are worried about their ability to save for the future (e.g. retirement).
- 15% of carers tell us they are in debt because of their caring role.

A significant proportion of carers are struggling financially. Over a quarter of carers (28%) are struggling to make ends meet. With 63% worried about living costs and whether they can manage in the future.

"I have no life as pretty much every penny I earn goes on basic living essentials. I've accrued debt and have just managed to keep my head above water last year but unsure if I'll get through the next year as everything just keeps going up."

"I am always in debt and stressed, affecting my physical and mental health, there is no break from this and I feel no one cares."

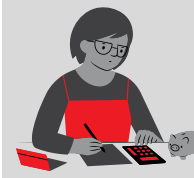
"We are just managing, but if something unexpected happens, or utilities, petrol or food go up, I don't know how we'll manage. I am unable to work, as I need to be here for my partner."

"I am in a constant state of worry about money."

**More than
1 in 4 carers are
struggling to make
ends meet.**



**63% are worried
about living costs and
whether they can
manage in the future.**



Carers are also worried about the future. Over a third (37%) do not feel they will be able to manage financially over the next twelve months. With 72% telling us that their caring role is impacting on their ability to save for the future.

“As a full-time worker I am not entitled to any financial benefit and my mother currently does not receive Attendance Allowance. I am still waiting for assistance with incontinence products and have had to spend all my savings to ensure my mother does not suffer from a lack of resources.”

“I am 69 and really need to think about properly retiring, but then I would be struggling financially.”

“As I had to leave work I no longer can keep up a pension so that has implications on my future years and income.”



Theme 2: Struggling to afford essentials

Key Points:

- 58% of respondents told us they are struggling to afford electricity and gas. With 45% saying they are struggling with other heating costs (e.g. heating oil).
- 48% of carers are finding it difficult to afford clothes and shoes.
- 34% say they are struggling to afford food.
- Of those who are struggling to afford food 62% tell us they have skipped a meal, 54% have reduced the size of their meals in order to get by, and 35% have said they felt hungry but didn't eat.

The financial pressure carers are under means many are having to make difficult decisions about what to spend money on. Providing unpaid care often comes with inescapable additional costs, with carers often having higher electricity, heating and food bills, as well as additional transport costs, which all add to the financial strain they are under.

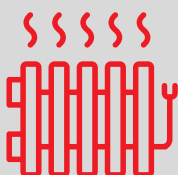
This situation is even worse for those in receipt of Carer's Allowance, with 44% of those in receipt of Carer's Allowance saying they are struggling to make ends meet (compared with 28% of all unpaid carers). Unpaid carers in receipt of Carer's Allowance are also more likely to be struggling to afford essentials, such as electricity and gas (64%), clothes and shoes (60%) and food (44%) (see Figure 1 on page 12).

“We regularly have to turn off heating, we need to be careful with car diesel. I never buy myself new clothes or shoes, opting instead to sew them up.”

“I cannot go without heat and electricity but bills are extortionate and making it difficult to provide other things which I have had to cut back on.”

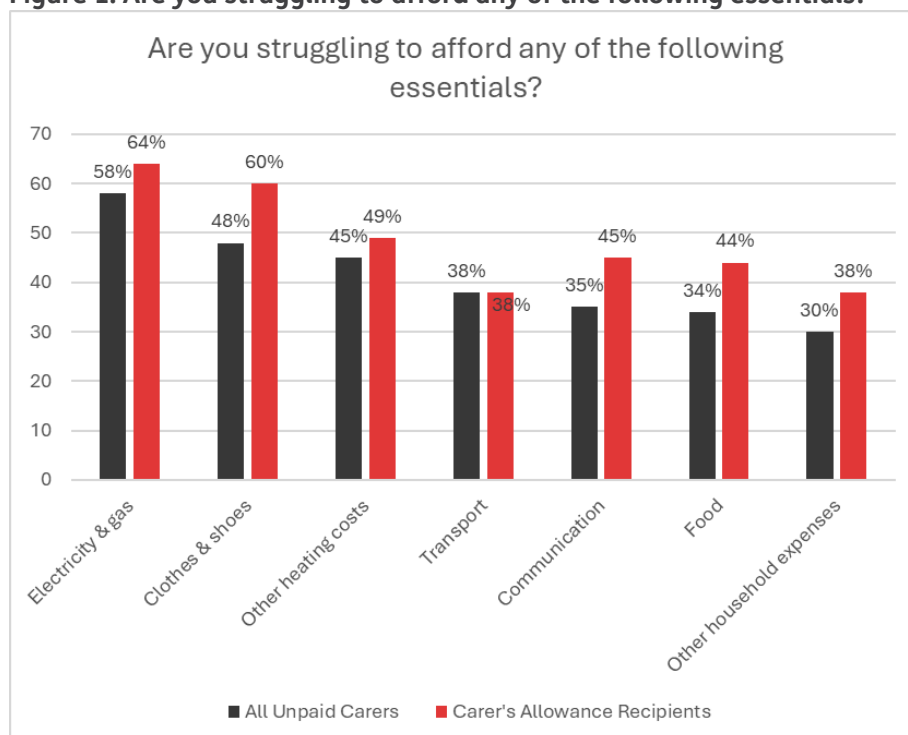
“I have cut back the food shop to essentials only. Shoes have holes and kids are outgrowing their clothes.”

“Just cutting back on everything for myself and using any money for groceries, bills and things / services needed for my children.”



58% of respondents are struggling to afford electricity and gas, with 45% struggling with other heating costs.

Figure 1: Are you struggling to afford any of the following essentials?



Some carers tell us that they are hiding the reality of their financial situation from the people they care for, and that they often choose to go without themselves in order to afford the necessities needed to keep the person they care for healthy and well.

“Having young children as well as caring for elderly parents means that I go without on a lot of aspects, just so that both my children and parents have what they need.”

“I don’t have money to buy a coffee much less clothes. I haven’t had so much as a day trip away in 5 years. My degree has gone to waste, but my parent is more important. I keep our finances secret so as not to worry them.”

Worryingly, carers also told us they are turning to unsustainable methods for managing their finances, with more than half (52%) of all respondents telling us they have had to use their savings in the last twelve months, and over a quarter of carers (31%) telling us they are using credit cards.

“Have nowhere else to go for help. You mentioned savings I have none now and no chance of ever having any.”

“Using credit cards to pay electricity and oil bills. Credit card is almost maxed out! Credit card companies are reducing my credit limit because of my financial situation which makes it more stressful.”

Theme 3: Impact of caring on employment

Key Points:

- 55% of respondents are currently in employment (35% working full-time and 20% part-time).
- Of those currently in employment 75% say they find it stressful juggling work with care.
- 27% have reduced their working hours to care and 14% have had to take on a lower paid or more junior role in order to balance work and care.
- 29% have had to leave the workforce altogether.
- Of those in employment, 77% say they are worried about how their caring role has impacted on their ability to save for the future (e.g. retirement).

When asked what would help carers to balance work and care:

- 82% said paid carer's leave;
- 78% said changes to Carer's Allowance criteria, which would allow them to work more hours and take on higher paid work;
- 74% said more affordable, accessible and reliable replacement care.

Unpaid caring can have a devastating impact on an individual's ability to remain in or return to work. Nearly two thirds of carers tell us that they are finding it stressful balancing their caring responsibilities with paid work, with one in four carers having to reduce their working hours to care, and more than one in four having to leave the workforce altogether.

“I gave up my full time job to care for my daughter 24/7.”

“Can't work enough hours to satisfactorily make a good life. Currently just an existence.”

“I need to work longer hours to make ends meet but then I lose my allowance, it's a vicious circle.”

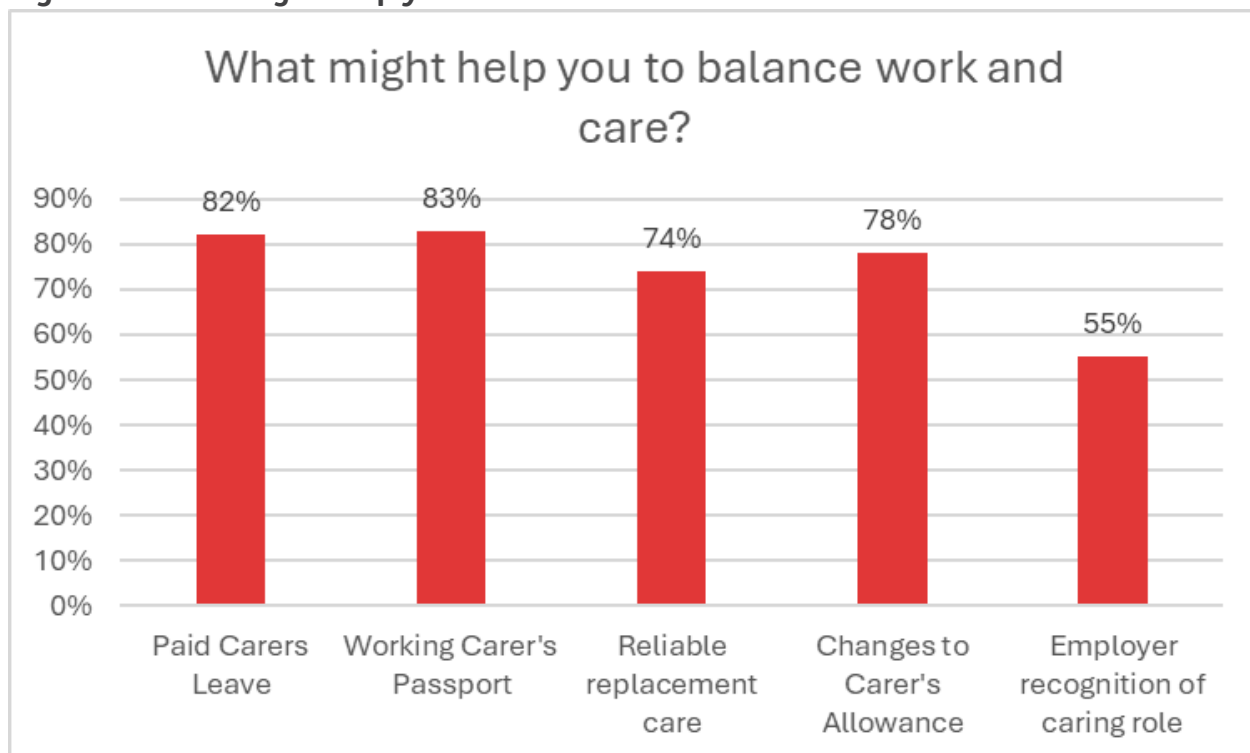
“When my young person leaves school it's unlikely that I will be able to continue working and earning a salary. I am very worried about paying for essentials when that happens.”



Recent research from the Carer Poverty Commission has shown that being out of paid employment is the most significant driver of carer poverty [6]. The introduction of statutory paid carer's leave and flexible working as a day one right could bring between 6,800 to 14,700 additional carers back to employment, reducing the Government's benefit spend by over £40 million.[7]

Figure 2, below, shows the main ways in which respondents feel both governments and businesses could support unpaid carers to balance work and care.

Figure 2: What might help you to balance work and care?



[6] Carers NI (October 2023), 'Policy measures to tackle poverty among unpaid carers in Northern Ireland'

[7] Carers NI (November 2024), 'Making the case for change: supporting unpaid carers in Northern Ireland'

Theme 4: Support needed with finances

Key points

- When asked what support would help carers currently, 58% said more financial support.
- 33% of respondents are currently in receipt of Carer's Allowance, but many feel excluded from receiving the benefit due to the strict eligibility criteria and the earnings threshold.
- 76% of respondents feel that the current rate of Carer's Allowance, £81.90 a week, is insufficient to meet their financial needs.
- 65% would like more information and advice about which benefits they're entitled to. With 41% saying they do not know who to contact or what social security benefits they might be entitled to.
- 56% would like more support with understanding the rules around claiming specific benefits.

Over half of all unpaid carers surveyed stated that they need additional financial support, with 76% of carers stating that Carer's Allowance is insufficient to meet their financial needs.

The majority of carers require further information and advice about the benefits they're entitled to, and more than a quarter were unsure where to turn for help with the cost of essentials.

“I only get Carers Allowance which is way less than the minimum wage, and I provide 24/7 care without any breaks or perks of working, I find I struggle to pay for essential things. For example, recently I paired back on a personal cleaning product choosing a cheaper brand and I ended up with skin irritation and eczema. Very often I am in extreme pain, but I have to keep going. I am not entitled to time off because I live with the person I care for. I am cold a lot in winter because I can't afford to put the heating on. I worry about bills and having enough to pay them.”

76% of respondents feel that the current rate of Carer's Allowance is insufficient to meet their financial needs.



“So hard with a small amount of Carer’s Allowance to make ends meet at times.”

“I am a carer and my partner works full time but his wage is just above the amount that allows for any benefit claim, which means we are essentially a single income household with no support especially during the cost of living crisis.”

Whilst over 28% of all carers surveyed are struggling to make ends meet, this figure rises to 44% for those in receipt of Carer’s Allowance. Additional financial support for carers is therefore crucial if we are to lift them out of poverty.

“Carers should get paid just as working carers do, we do more hours we never switch off we never get time to clock off, and we need more help with the effects it has on us. We need more support to lighten the load.”

Conclusion

The survey results highlighted in this report paint a stark picture. Carers are facing significant financial pressures which are impacting on their ability to afford essentials, their potential to ensure that they will be financially secure in the future, and their capacity to retain or return to meaningful employment.

Unpaid carers make a multi-billion-pound contribution to Northern Ireland's health and social care system, propping up a system which is on the brink of collapse. Unpaid carers should not be living in poverty or facing financial strain. This Executive needs to take action to address the growing number of unpaid carers who are struggling to make ends meet.

We urge the Executive to prioritise the needs of unpaid carers within the draft Programme for Government and to replace the 2006 Carers' Strategy with an updated and robust carers' strategy containing clear and achievable actions to ensure a cross-departmental approach to tackling the growing pressure that unpaid carers are under.

Addressing unpaid carers needs cannot wait - it is essential for supporting our debilitated health service, and it will boost the Northern Ireland economy through increased workforce participation and a reduction in benefit spending [8]. It is time to pay more than just lip-service to the over 220,000 unpaid carers in Northern Ireland who deserve meaningful recognition for the invaluable care they provide day-in and day-out for family members and friends.

[8] Carers NI (November 2024), 'Making the case for change: supporting unpaid carers in Northern Ireland'



Carers NI,
58 Howard Street,
Belfast,
BT1 6PJ
T: 028 9043 9843

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