

A New Deal for unpaid carers in Northern Ireland

Co-designed policy solutions to
support the unpaid carer population



A report from members of the Coalition of Carers Organisations Northern Ireland



The Coalition of Carers Organisations

The Coalition of Carers Organisations is a collective of community and voluntary sector groups and trade unions that support and advocate for unpaid carers in Northern Ireland. This report is published by the following members of the Coalition: Carers NI, Action for Children, Action Mental Health, Age NI, Angel Eyes, Barnardo’s, CAUSE, Macmillan Cancer Support, Marie Curie, Mencap, MND Association, MS Society, NIPSA, Parent Action, Parkinson’s UK NI, Stroke Association and Women’s Support Network.

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Introduction

There are over 220,000 people providing unpaid care for a sick or disabled family member or friend across Northern Ireland – representing around 1 in 8 people.¹



Unpaid carers are a diverse population, encompassing child and young adult carers through to carers of pension age – and support people with health conditions like cancer, stroke, progressive neurological conditions and visual impairment; mental ill-health; learning disabilities; terminal illnesses, and more.

Together, these carers save the public purse billions of pounds in care costs per year, without which the local Health and Social Care system would collapse. The contribution they make is truly immense, but for too many, the support they get in return falls far short of what they need to keep themselves well and enjoy the opportunities many of us take for granted.

They tell us that they're being driven to breaking point by unrelenting caring duties, few opportunities for a break and patchy support from statutory services. That they're being pushed into poverty by sky-high caring costs, barriers to employment and inadequate social security provision. That they're being forced to stay in unsuitable or substandard living conditions while waiting years for appropriate housing. And that they're expected to struggle by as a largely forgotten and invisible population – asked for so much, yet given so little in return.

The last Carers Strategy for Northern Ireland was published nearly two decades ago. It is significantly out of date and doesn't reflect the lives and needs of our unpaid carers today. A new strategic direction is desperately needed – one that gets to grips with the challenges facing carers of all age groups and circumstances, and drives a holistic approach to fixing those challenges in the time ahead.

In short, we need a New Deal for unpaid carers in Northern Ireland. This report, which has been co-designed with over 240 local carers, sketches an outline of what that could look like.

It draws exclusively on the views of a diverse mix of carers to:

- Identify the biggest issues impacting on their lives
- Outline the priority changes they feel would make a difference in the realms of health and social care, welfare, housing, employment and more.

Some of these recommendations are low cost and of a practical nature, while others would require major investment and legislation from Stormont. We do not shy away from that latter fact, nor the reality that many of the challenges facing unpaid carers have been deeply ingrained for years and – even with the required resources and political will – cannot be fixed overnight.

But it is high time that we made a start, and finally begin to treat unpaid caring as a strategic priority for the government and wider society in Northern Ireland.

Because for far too long, unpaid carers have been at the back of the queue when policy priorities are being set. For far too long, they've been asked to quietly prop up public services when the money runs out or staff can't be found. And for far too long, they've had to accept sacrificing their own wellbeing and quality of life as the price of being a carer.

We shouldn't tolerate that any longer, so we hope this report can make a meaningful contribution to the local policy debate and act as a catalyst for the change that unpaid carers have been crying out for.

Methodology

The policy recommendations within this report were co-designed with unpaid carers in Northern Ireland. Their views, experiences and ideas were gathered via:

- An online co-design workshop in March 2023; and
- A supplementary qualitative survey, which ran for four weeks between March and April 2023.

In total, over 240 unpaid carers from across Northern Ireland contributed to the report, and the recommendations within it came exclusively from them. Their testimony is quoted directly throughout the pages that follow – offering powerful firsthand insights into what it means to be an unpaid carer in Northern Ireland today. Where appropriate, this is supplemented by wider research and data.

Like any similar project, this research has its limitations. Northern Ireland's unpaid carer population is very diverse, and it was not possible to engage with every carer group to the extent we would have wished in co-designing this report. Reaching child and young adult carers was especially difficult, and further research is required to better understand the challenges that they, and other groups of carers, face in Northern Ireland.

Supporting unpaid carers through the Health and Social Care system

Unpaid carers are providing hundreds of thousands of hours of care for sick and disabled people every week across Northern Ireland.¹



While they should be entitled to a range of health and social care support to relieve some of that pressure and help them provide care safely, the overwhelming majority of carers we spoke to described an immense struggle to access this help in a system buckling under staff and funding pressures.

‘Fight’, ‘argue’, ‘beg’ – consistently the words carers used about their experience of trying to access services to support them in their caring role. Whether it is getting a high-quality care package in place, accessing the information and advice they need, or even the basic task of speaking to a health professional on the phone, carers told us that the system is badly letting them down and leaving them with little to no support to make their caring role easier.

“From minute one, day one, it’s a fight. You’re fighting for everything. Your life as a carer in Northern Ireland is just one big, never-ending fight.”

“It’s very poor. You have to beg for any support.”

“Support is always lacking. You have to fight for the help you have a right to. It’s so mentally exhausting.”

“We feel totally let down. I feel like a burden for asking for help. I have got to the point of struggling in silence because I feel so unsupported and like an inconvenience to the system.”

Getting community care packages right

Access to community care packages in Northern Ireland was a struggle for many families a long time before the COVID-19 pandemic put the Health and Social Care (HSC) system under even more pressure. Carers told us about the long delays they face to get a package in place and the limited nature of what is offered – with a service model based on short, rigid appointment times that often don’t meet the needs of the cared-for person or offer much relief for their unpaid carers. Some even had to pay for care out of their own pocket to ensure the person’s need were met.

“ We haven’t had any domiciliary care support since 2016. We registered as having unmet need in 2016. It is still unmet in 2023.”

“ In the early stage of mum’s dementia, we received four calls by carers during the week. This was enough at the early stages, but now she requires 24-hour support, and we don’t have anything in place for this. We can’t access a fuller care package as there aren’t enough staff available to provide it. Not a good experience. It’s extremely stressful.”

“ The support is basic – 20 minutes, twice a day, to help them get up in the morning and get into the wheelchair at teatime. It is well below standard.”

“ I asked for help for years, to no avail. We had to actually go into debt to get the basics we needed in physical care.”

Other carers identified a postcode lottery of provision across Northern Ireland, with services in rural communities particularly lacking.

“ My mother is 88 and lives alone. She was discharged from hospital after a fall with no care package and no support. Myself and my sister were just left to it. No care available in the area. We haven’t heard from the social worker since.”

“ It’s not good enough to simply say that rural areas are struggling to find care options. Funding and staffing need to be raised in rural areas so we are on a par with towns.”

Even if a decent care package is put in place, many carers highlighted the regular turnover of staff – which offers no continuity of care and worse outcomes for them and the cared-for person.

“ I would like to see all care staff trained and paid at the same level. The current regime is haphazard and lacks continuity. My mother has dementia, and we have an ever-changing cast of carers, which distresses her.”

The policy direction set out in the review of adult social care in Northern Ireland is to make Self-Directed Support (SDS) the norm in delivering care packages for people in the community.² In theory, many carers recognise the value of SDS, and the added choice it can offer. In reality, however, many also described an overly complex system that is too difficult to navigate along with the other pressures they’re under.

“ All the Trust offer is Direct Payments, but that adds to the workload I already struggle to keep up with. They are just heaping the pressure on. It’s all consuming.”

“ I need help to find Personal Assistants. The Trust shouldn’t just hand out Direct Payments and have me juggling all the complexities of being an employer as well as holding down my own job and being a carer too.”

“ Direct Payments are a mess. It is just too much stress and anxiety to employ someone, with all the associated paperwork and bank accounts. And that is if you can actually find someone to do the job!”

Other carers also highlighted that the value of Direct Payments is too low to attract the suitably qualified and experienced staff their loved ones need. The end result is care demands that are being met by unpaid carers because suitable staff or services aren’t in place.

“ Direct Payments seem like the only option that is flexible, but the hourly rate is rubbish. I can’t attract any good candidates, never mind a suitable, qualified care assistant.”

Co-designed carer recommendations:

- Expansions and greater flexibility in the provision of community care packages, to move away from the traditional model of rigid and short appointment times. This could include different models of replacement care, overnight sitting services and more.
- Reform of adult social care to:
 - » Ensure greater consistency in high-quality service provision across the whole of Northern Ireland.
 - » Improve the pay and terms and conditions of social care workers, to help deliver a suitably qualified workforce and eliminate regular turnover.
- Expansion in the Self-Directed Support navigator roles in each Health Trust to support families using the system.

Information, advice and training provision

A consistent call among many of the carers we spoke to was for much greater provision of information, advice and training to help them in their caring roles. Some had become carers quite abruptly – sometimes overnight – and the experience of suddenly being responsible for looking after someone with no training on the different components involved, and little idea around what comes next, was very overwhelming.

“You aren’t taught how to be a carer in school. So much of this is all brand new. It feels like being thrown in the deep end, only there isn’t an option of ‘sink or swim’ – someone is depending on you now, so you just have to figure it out. But the anxiety and stress that causes is debilitating sometimes.”

“There is no help to teach you how to lift them in a way that supports my back. I’ve asked so many times for this training, but the health workers are under so much strain and have such a high turnover.”

Even those who had been caring for years highlighted a lack of accessible information and advice on the support services available to them and where they could go for help. Many said they had come to rely on information and signposting from other carers, and sometimes charities, because provision from the statutory sector was so inconsistent.

“It is overwhelming. No one has any real answers to help you. You’re just left at breaking point.”

“I’ve had to find out what support was available over the years, mainly by word of mouth from friends. Advice on how to be a carer, and what support is available, is poor.”

A particular issue raised here was the regular turnover and difficulty accessing social workers, which left many carers with nowhere to go for the information and advice they needed.

“They don’t contact you. It’s up to you to contact them. When you try to, the key people are often unavailable or have moved onto another role. So, you’re leaving messages, which mostly aren’t returned. The support is so inconsistent.”



Co-designed carer recommendations:

- Health bodies and charitable providers should develop a central library of information and signposting on all of the services and supports available to unpaid carers in the place they live. This could be hosted by the Department of Health or Public Health Agency.
- The Department of Health should maintain a regional Carers’ Register, with all HSC staff, and other relevant public sector workers, trained to identify carers and add them to the Register. This should include training for those working in education to identify young carers. All carers on the Register would then be sent high-quality information and advice to help them in their caring role; prompts to access the information library above; and access to regular training on the different elements involved in providing unpaid care – including on how to safely carry out physical caring tasks like lifting and bathing.
- Outside the cared-for person’s social worker, all unpaid carers should be assigned a Key Support Worker to carry out a monthly check-in call and provide information, advice and training opportunities.

Treating carers as expert partners

Unpaid carers are genuine experts by experience. In many cases, there are none who better understand the needs of a sick or disabled person than the family members or friends supporting them every day, but too often, these voices are excluded from decision-making and care planning.

Carers recounted experiences of being ignored by HSC professionals – diminishing the irreplaceable role they play and ignoring an expert voice when decisions are made.

“ *I should be treated as an equal partner, instead of being made to feel that I know nothing and that they [HSC professionals] are the only experts.”*

“ *There should be recognition that many carers are the experts in the individual they support and should play a fundamental role in deciding the correct services. We can support staff to understand the individual, to ensure a person-centred approach to the right care. Otherwise, it becomes a staff or Trust-centred approach, and possibly the wrong care.”*

Co-designed carer recommendation:

- A duty on Health and Social Care bodies to treat unpaid carers as expert partners in the care of the person they look after.



Maintaining carers' health and wellbeing

Unpaid caring is a massive driver of ill-health. In Carers NI's 2022 State of Caring survey, around 1 in 5 carers described their physical health as bad or very bad, and over a quarter said the same about their mental wellbeing.³



The above is hardly surprising. Many carers told us that they're caring around the clock – carrying out demanding roles with little sleep, opportunity for a break, a life of their own or even the chance to eat properly or undertake exercise. They're languishing on long waiting lists for healthcare services that don't have the capacity to meet demand, with all of this leaving them worn out and in ever-deteriorating health.

“It's exhausting. I'm in survival mode and dread every day.”

“It has been so difficult. I am either working or caring. Every day is so stressful and then I have to put my face on for work and try to concentrate, when I am breaking inside.”

Support to keep carers well

What was perhaps most striking is that so many of the carers we spoke to said they received absolutely no help, support or services to look after their own health and wellbeing while caring. As one put it bluntly when asked about the support they receive:

“Nothing. Nil. Zero. None.”

Carers described getting a phone call from their GP or community nurse once a year, at most, to ask if they were okay – but largely being left to struggle alone the rest of the time.

“Help is non-existent. I just have to try and keep going.”

“It’s just assumed we are ok and will get on with it, whilst we drown in our own health – picking up the pieces from a system that ignores us.”

“I’m running on empty and nobody cares.”

They talked about the difficulty getting help from under-resourced and overstretched health services – including community mental health, physiotherapy and General Practice – and highlighted an over-reliance on medicating their mental ill-health, when a preventative approach would have been better.

“I have looked after my son, who has Down Syndrome, for 40 years. Due to a lack of care from anyone else, I have suffered extreme mental health issues.”

“I have a sore back from lifting my son, who is non-ambulant [ie unable to move unassisted]. I was given exercises by my GP in the form of a printout because waiting lists are far too long for physio.”

Elsewhere, carers also described the loneliness and isolation of caring, which – mixed with the lack of help in their caring role and declining health – was leaving some feeling hopeless and without a future to look forward to.

“I’m stuck here till I ‘go out’ [ie die].”

More broadly, some carers said the demands of their caring roles and inadequate support from the Health and Social Care system was leaving them little time, if any, to even think about themselves and their own wellbeing. They put their own health last and sacrifice themselves to ensure the cared for person’s needs are met.

“I am physically and mentally exhausted. People say I should be sure to look after myself, but there are days when I hardly have time to get washed and dressed. I don’t know what looking after myself would look like in our circumstances.”

“Time off to look after myself is non-existent. I can’t even make a doctor’s appointment for myself. It took me four months to get to an eye test.”

While a Carer’s Assessment is supposed to be the gateway to accessing the help carers need, many had been left deeply frustrated by long delays to getting an assessment and the lack of follow-through once their needs were identified.

“You wait ages for a Carer’s Assessment, spend so much time going through it, and then what changes afterwards? Absolutely nothing. The whole process is a joke.”

“Got a Carer’s Assessment, then rarely heard from services after that.”

Co-designed carer recommendations:

- Annual medical MOTs for all unpaid carers, including an annual offer of counselling. This should be offered to all carers regardless of their age, including child and young adult carers.
- Priority access to GP appointments and other community health and wellbeing services.
- Discounted or free access to gyms and other leisure services to allow more carers to take part in exercise.
- Greater opportunities for peer support sessions with other carers, facilitated and organised by their Health Trust.
- Entitlement to meaningful outcomes and support following the identification of need in a Carer’s Assessment.

Access to meaningful breaks and respite

If there was one issue that was near universal in impacting the carers who contributed to this report, it was difficulty accessing regular breaks and respite. Nearly half of carers identified more breaks as among their top needs as a carer in Carers NI's last State of Caring survey,³ but the barriers to accessing them are often insurmountable.

Due to statutory staff and funding shortages, as well as oversubscription, many carers are waiting months, in a lot of cases even years, for the opportunity for a proper break that meets their needs – leaving them burnt out and running on empty.

“ I went on holidays last year after three years with no break and I spent most of the time sleeping, as I was too exhausted to even enjoy it. How sad is that? It is only when you actually get a break that you realise how tired and exhausted you are. You just keep going as you have no other choice.”

“ My child has been referred for overnight respite, but there is no availability, so I don't get a break from caring. I haven't had a full night's sleep in 12 years.”

“ Never feel I get a break. I thought I understood the caring role of friends before I became a carer, then you really have your eyes opened. The responsibility weighs incredibly heavily on me. I fell a couple of months ago and as I was sailing through the air, desperately trying to regain my balance before hitting the tarmac, my first thought was: 'who's going to look after mum if I'm injured?'. I don't even feel I can get away for a night.”

“ I have only just availed of respite care for the first time in 15 years of caring.”

Some carers suggested that their need for a break was only taken seriously by their Health Trust if they could demonstrate that they had reached some sort of crisis point.

“ Always being told there isn't any help out there. I feel like unless I say I can't look after my daughter and put her in care, no one will give me a real break.”

“ You get less support if you aren't yet having a breakdown or until you are in crisis.”



Carers highlighted that the provision of respite and short break opportunities are patchy in different parts of Northern Ireland – with some rural communities especially poorly served. And in many cases, even when respite is offered, it is done at very short notice – making it difficult for the carer to plan a meaningful break or opportunity to properly recharge their batteries.

“I can’t book respite for my Mum in advance. When I need a break, I have to wait and see what respite beds are available, which means I only have a few days to arrange my own holiday.”

“I planned a trip last September. Started the process of organising respite, only to be informed that I would not know until a week before we were scheduled to travel whether the bed would be available. I understand the pressures on the system, but this approach isn’t good enough when trying to get a break away for the first time in six years.”

With such poor statutory provision, the only chance for many carers to have a break is when family members are able to help out. Being able to use the time for a meaningful rest or social activities, however, is still dependent on being able to afford it, which many carers can’t due to the financial pressures of caring (see page 14).

“I get Income Support and Carer’s Allowance, which is pitiful for the 24/7 care duties that I do. I have no other income. I cannot pay my bills on this amount of money, let alone afford to take a break. I can’t even afford a bus or train fare to the next town just to get out for an hour.”

“Once household bills are paid, oil, electricity, there is little in the way of finance to take a break.”

While access to breaks and respite was a struggle for carers before March 2020, many highlighted that the situation had seriously deteriorated since the beginning of the COVID-19 pandemic. Respite and day services were severely disrupted at the onset of the pandemic and, in many cases, are yet to return to full pre-pandemic capacity.

“It’s worse since Covid. Practically non-existent before, but now it is even worse!”

“Inability to return to normal daycare, along with transport and respite [since the pandemic] have all had a huge impact on my wellbeing. I feel like I’ve aged 10 years in the last three.”

Child and young adult carers similarly struggle to access regular breaks, robbing them of some of the life opportunities enjoyed by their peers.

“I’m a young carer for my older brother. It’s really hard. Everything revolves around him. My parents try, but it’s hard. There is so much we don’t get to do that other people take for granted. It would be good if we got more help and support.”

Co-designed carer recommendations:

- Legislation to enshrine a legal right to regular breaks for unpaid carers – as proposed elsewhere, eg in Scotland’s National Care Service Bill.⁴
- Funding packages to support carer breaks, including holiday and hotel vouchers.
- Urgent restoration and expansion in the provision of community care packages, respite and day service provision in every Health Trust.
- Greater forward planning and communication around respite and break availability, to allow carers to utilise the opportunities in a meaningful way.
- Greater provision of respite and community activities in rural areas of Northern Ireland.

Addressing carer poverty and financial hardship

As well as being physically and mentally exhausting, being an unpaid carer in Northern Ireland is also often very expensive.

Even before the price of daily essentials began to rise so steeply, many local carers already faced inescapable higher household bills linked to caring – 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 health appointments.

As the cost of living crisis has continued to bite, these pressures have only been compounded, and meeting them is doubly-hard when carers are forced out of work due to the demands of caring.

Meeting the high costs of caring

The financial despair carers are facing was palpable when we spoke to them. They talked about being unable to afford the very basics, cutting back on essentials so their family doesn’t go without, and having to sacrifice their own wellbeing and any sort of quality of life to ensure they could meet the cost of caring.

“My child’s life is dependent on 16 pieces of equipment which need electricity. With the enormous cost of living increase, we feel the pressures times ten. I deny myself full price food products, buy only sale or used things to make sure my child has the life-saving equipment she needs. There is very little I can cut back on and will probably have to rely on charities to survive.”

“I’m very careful towards heating and electricity bills. I cancelled extra TV bills and go to bed very early to reduce heating use.”



“It is very difficult being a full-time caregiver. The stress and anxiety are difficult enough without having to decide to eat or pay bills.”

“We cut corners everywhere to make ends meet. We have few luxuries. Our car was made in 1998.”

Social security support

In the context of such a difficult financial environment, carers expressed major disillusionment with the support provided by Carer's Allowance – the main carer social security benefit. There was a widespread consensus that the system is unfit for purpose and in need of urgent reform.

Common issues raised included the low value of Carer's Allowance payments, which represents pennies per hour for those caring around the clock;⁵ the exclusion of young carers and those receiving State Pension; the single payment provided to those who care for more than one person; and the strict earnings threshold, where one penny earned over the cap means losing the entire Carer's Allowance payment.

These issues combined to leave many carers struggling in poverty, feeling entirely unvalued and deeply frustrated that they are expected to get by on so little – especially when many could be bringing in a much greater income through paid work if they weren't providing unpaid care (see page 16).

“ I receive £69.70 per week [in Carer's Allowance]. How on earth does the government expect anyone to live on this?”

“ All I receive is the Carer's Allowance each week. If it was paid at a reasonable rate it would help make life easier. Just making ends meet is impossible at the moment.”

“ Financial help is non-existent. I am retired and as soon as I got the pension, the Carer's Allowance was stopped. This is grossly unfair. My husband needs more and more care and I get no support.”

“ I have reduced my hours to 15 hours a week to look after Mum. I receive below the minimum wage now but I'm still over the limit for Carers Allowance. I am drowning in debt and despair.”

Co-designed carer recommendations:

- A review of the value of Carer's Allowance.
- Delivery of additional in-year payments for those receiving Carer's Allowance, like the Carers Allowance Supplement scheme in Scotland.
- Reform of overlapping benefit rules to allow more older people to receive Carer's Allowance alongside their State Pension.
- An increase in the Carer's Allowance earnings threshold, to allow people to work more while keeping their payments.⁶
- Multiple Carer's Allowance payments to recognise the higher costs of caring for more than one person.
- Welfare support for child and young adult carers – eg, the Young Carer Grant in Scotland.
- Development of a central and comprehensive bank of information on the financial help available to carers – to be offered from day one of someone becoming an unpaid carer.
- Inclusion of unpaid caring as a qualifying criteria under the Rates Relief scheme.
- Discounted public transport for unpaid carers, including child and young adult carers.
- Financial support schemes to help unpaid carers afford dentistry, optician appointments and other paid-for healthcare.

Making it easier to juggle work and unpaid caring

The pressures associated with an unpaid caring role are an enormous barrier to the labour market. In 2019, nearly 130,000 people in Northern Ireland either reduced their hours, or left work entirely, due to the demands of a caring role.⁷

There is a gendered element to this issue – with women making up over 60% of the local carer population⁸ and evidence suggesting they are more likely to be pushed out of the labour market due to those caring responsibilities.⁹

Carers told us about the financial impact of these barriers to work – particularly in the context of the cost of living crisis – as well as the significant emotional and mental toll.

“I can’t juggle my paid employment with caring, so have had to come to the decision to leave a thirty year career in nursing and teaching to be with him. It is just heartbreaking. I can’t leave him, and don’t want to, but I also don’t want to leave a rewarding career that is of value and is the other half of my identity.”

“I had to give up work eight years before retiring to care for my husband. We live on a shoestring to make ends meet.”

Informal workplace support

One issue is a lack of support from employers, with a number of carers sharing experiences of receiving poor support and a lack of understanding or leeway from their employers when trying to manage the day to day demands of their caring role.

“I had dreadful experiences trying to juggle paid employment. My bosses were terrible and did not care at all, so much so that my mental health was affected terribly. I had to leave in the end as I felt no one cared or were willing to help. It was a really bad experience.”



Co-designed carer recommendation:

- Employers should foster carer-friendly workplace cultures, providing peer support, understanding the unpredictable nature of caring, and help to make juggling work and caring easier, including the option to work from home where feasible.

Legal entitlements for working carers

While these more informal approaches can make a big difference, carers also talked about the importance of greater employment rights and protections. For example, barriers to flexible working were raised repeatedly, with some carers having to turn down paid work because of the long qualifying period before they could request flexible working. Others were forced to accept being under-employed, in roles they were over-qualified for, because they couldn't secure the required flexibility anywhere else.

Elsewhere, many carers also talked about the additional stress and burnout when they have to use holiday leave, sickness absence or unpaid days off work to take their loved one to hospital appointments or manage the other demands of being a carer.

“The use of annual leave to take my looked-after person to all their appointments means that the time everyone else is able to use for their own rest and recovery is being used in my caring role.”

Co-designed carer recommendations:

- Legislation to make flexible working requests a day one right for working carers.
- The introduction of statutory paid carer's leave.

Like so much in the world of unpaid caring, this conversation links back to the inadequate provision of community support services – which give carers little time or space to do anything else, including going to work. Some carers highlighted the particular challenges here since the COVID-19 pandemic began.

“I have had to give up a part-time job because day care services have not resumed since lockdown. This little job was very good for my mental health.”

More widely, working carers with children are also suffering from the lack of affordable childcare that is affecting so many families across Northern Ireland and acting as such a major barrier to going to work.

Co-designed carer recommendations:

- Health Trusts should urgently restore and expand the provision of community care packages, respite and day services.
- The Department for Education should deliver a fit-for-purpose and affordable childcare system and the long-promised Childcare Strategy for Northern Ireland.

In some cases, circumstances may change that allow carers to think about returning to the labour market, but doing so can be difficult – especially if they've been out of work for a while. They told us that gaps in their CV, skills or qualifications often put them on the back foot, and many also lack the confidence to pursue the opportunities they want after being out of work for so long.

“We need real opportunities to work. So many of us left the workforce because we had no choice. Now our skills are lagging, and no one will hire us.”

Co-designed carer recommendation:

- The Executive, working with employers and education institutions, should develop a bespoke work placement and employability programme for unpaid carers – offering work opportunities and coaching to help carers return to work if/when they want to.

All of these policies are likely to bring business and economic benefits along with making life easier for working carers. Evidence suggests that the impact of staff turnover, absence and stress as a result of juggling work and caring unsupported could be costing UK businesses over £3.5bn every year.¹⁰

Meeting the housing needs of unpaid carers and those they support

The overwhelming message we heard from carers about housing in Northern Ireland is that the systems are broken, and families impacted by disability or ill-health are being badly let down.



Social housing and supported living provision

Carers talked about spending years – sometimes a decade or more – on waiting lists for suitable social housing or supported living. Access to wheelchair accessible properties and bungalows was raised as a particular problem.

For some carers, this situation means living in dangerous housing environments while they wait. For others, it means the person they care for being forced to stay in hospital or another care institution when they don't need to be there because there is no suitable alternative.

“After contacting all parties involved in social housing, I was advised that to get a house we would need to be on a list, wait for plot becoming available and then several years for a house to be built. Many families do not have those years and are left living in substandard, dangerous conditions.”

And for others, it means putting their own health in jeopardy as they perform physical caring roles in an unsuitable housing environment.

“I hurt from lifting and the unsuitable house [we live in]. I lift my daughter in her wheelchair into the house every day. I've given up on myself now. I just make sure she is ok.”

Some carers argued that provision is especially lacking in rural areas.

Another specific challenge was identified for young carers, who may face an additional barrier to education when the housing offered for their family is a long distance away from their school.

Co-designed carer recommendations:

- Major reform and funding to deliver the levels of accessible and suitable social housing and support living facilities required by those with disabilities/ill-health and their carers, in every part of Northern Ireland.
- Reform of the NI Housing Executive points system to award extra points to those with unpaid caring roles who are applying for social housing.

Timely and accessible housing adaptations

Many of those carers we spoke to who didn't want or need to move house but had tried to secure necessary adaptations to their existing property, had also experienced significant challenges.

Flaws in the Disabled Facilities Grant (DFG) process were raised frequently, with many carers finding even the initial application for a DFG to be incredibly complex.

“ [We need] better joined up thinking to explain the entire process of applying for a Disabled Facilities Grant. No one understands it. The process is a minefield.”

Waiting times for applications to be processed, and adaptations carried out, were then insurmountable – leaving many carers forced to pay for expensive work out of their own pocket to ensure the cared-for person could have their basic needs met and enjoy a good quality of life.

“ NIHE are operating a broken system. If you were in any way financially vulnerable, you could not undertake the adaptations process without a serious risk of putting yourself in debt.”

“ The lack of financial support to do the disabled extension has left me worse off. Savings for university for my children had to be used to fund it.”

**Co-designed carer recommendation:**

A significant policy overhaul and funding injection to speed up the Disabled Facilities Grant system.

Delivering a New Deal for unpaid carers: Summary of recommendations

This report sets out a programme of recommendations co-designed with over 240 unpaid carers in Northern Ireland to give them the support they need in the spheres of health and social care, social security, employment, housing and more. Forming the outline of a desperately needed New Deal for unpaid carers here, this suite of measures is summarised below.

These recommendations should be delivered for all carers who need support – from child and young adult carers through to pensioner carers, and everyone in between. And they should be pursued on a cross-departmental basis, with an approach that recognises organisations in the community and voluntary sector as strategic delivery partners.



To better support them through the Health and Social Care system, unpaid carers called for:

- Expansions and greater flexibility in the provision of community care packages.
- Reform of adult social care to:
 - » Ensure greater consistency in high-quality service provision across the whole of Northern Ireland.
 - » Improve the pay and terms and conditions of social care workers.
- Expansion of the Self-Directed Support navigator roles in each Health Trust.
- A central library of information and signposting on all of the services and support available to unpaid carers in the place they live.
- A regional Carers' Register and training for all HSC and other relevant public sector staff (eg education) on identifying carers and adding them to the register.
- New Key Support Workers to provide information, advice and training opportunities to unpaid carers.
- A duty on Health and Social Care bodies to treat unpaid carers as expert partners in the care of the person they look after.

To help better maintain their health and wellbeing, unpaid carers called for:

- Annual medical MOTs for all unpaid carers, including an offer of counselling.
- Priority access to GP appointments and other community health and wellbeing services.
- Discounted or free access to gyms and other leisure services.
- Greater opportunities for peer support sessions with other carers, facilitated and organised by their Health Trust.
- Entitlement to meaningful outcomes and support following the identification of need in a Carer's Assessment.
- Legislation to enshrine a legal right to regular breaks for unpaid carers.
- Funding packages for carer breaks, including holiday and hotel vouchers.
- Urgent restoration and expansion in the provision of community care packages, respite and day services in every Health Trust.
- Greater forward planning and communication around respite and break availability.
- Greater provision of respite and community activities in rural areas of Northern Ireland.

To address the poverty and financial hardship they face, unpaid carers called for:

- A review of the value of Carer's Allowance.
- Delivery of additional in-year payments for those receiving Carer's Allowance – eg, the Carers Allowance Supplement scheme in Scotland.
- Reform of overlapping benefit rules to allow more older people to receive Carer's Allowance alongside their State Pension.
- An increase in the Carer's Allowance earnings threshold.
- Multiple Carer's Allowance payments to recognise the higher costs of caring for more than one person.
- Welfare support for child and young adult carers – eg, the Young Carer Grant in Scotland.

- Development of a central and comprehensive source of information on the financial help available to carers.
- Inclusion of unpaid caring as a qualifying criteria under the Rates Relief scheme.
- Discounted public transport for unpaid carers, including child and young adult carers.
- Financial support schemes to help unpaid carers afford dentistry, optician appointments and other paid-for healthcare.

To make it easier for them to juggle work and caring, unpaid carers called for:

- Carer-friendly workplace cultures from employers.
- Legislation to make flexible working requests a day one right for working carers.
- Introduction of statutory paid carer's leave.
- Urgent restoration and expansion of community care packages, respite and day services across Health Trusts.
- Delivery of a fit for purpose and affordable childcare system and Northern Ireland childcare strategy.
- Development of a bespoke work placement programme for unpaid carers – including work opportunities and coaching.

To better meet their housing needs, unpaid carers called for:

- Major reform and funding to deliver the levels of accessible and suitable social housing and support living facilities required by those with disabilities/ill-health and their carers, in every part of Northern Ireland.
- Reform of the NI Housing Executive points system to award extra points to those with unpaid caring roles who are applying for social housing.
- A significant policy overhaul and funding injection to significantly speed up the Disabled Facilities Grant system.

Further reading

The following resources from members of the Coalition of Carers Organisations provide further information and insight into the challenges and lives of different groups of unpaid carers in Northern Ireland.

Action for Children (2023). Young carers' education research.

https://media.actionforchildren.org.uk/documents/Young_Carers_in_Education_Report_2023.pdf

Age NI (2021). Lived experience 2021: What matters to older people in Northern Ireland

<https://www.ageuk.org.uk/globalassets/age-ni/media/lived-experience-2021.pdf>

Barnardo's (2022). The voice of young adults making sense of their caring childhoods: Demonstrating resilience through adversity.

<https://www.tandfonline.com/doi/full/10.1080/13676261.2022.2101357>

Carers NI (2022). State of Caring 2022: A snapshot of unpaid caring in Northern Ireland.

<https://www.carersuk.org/media/xjzfw4x/cni-soc22web.pdf>

Carers UK (2019). Juggling work and unpaid care: A growing issue.

<https://www.employersforcarers.org/media/p0ccp5di/juggling-work-and-unpaid-care-report.pdf>

Consortium for the Regional Support for Women in Disadvantaged and Rural Areas (2022). Reform of adult social care consultation response.

<https://www.womensregionalconsortiumni.org.uk/wp-content/uploads/2022/07/Womens-Regional-Consortium-NI-response-to-Adult-Social-Care-Consultation-Final.pdf>

Marie Curie (2022). Experiences of loneliness among people at the end of life and their carers in Northern Ireland.

<https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2022/experiences-of-loneliness-among-people-at-the-end-of-life-and-their-carers-in-northern-ireland.pdf>

Marie Curie (2022). Dying in poverty: Examining poverty at end of life – Implications for Northern Ireland.

<https://www.mariecurie.org.uk/globalassets/media/documents/policy/dying-in-poverty/h420-dying-in-poverty-ni-3rd-pp.pdf>

Marie Curie (2018). Lost retirement: The impact on older people of caring for someone with a terminal illness.

<https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/lost-retirement-the-impact-on-older-people-of-caring-for-someone-with-a-terminal-illness.pdf>

Parkinson's UK NI (2020). Policy statement: Carers' support.

<https://www.parkinsons.org.uk/sites/default/files/2018-03/Carers%27%20support%20policy%20statement%20%202018%20%28PDF%2C%20321KB%29.pdf>

Stroke Association (2019). Lived experience of stroke – Chapter 3: Caring for a stroke survivor.

<https://www.stroke.org.uk/lived-experience-of-stroke-report/chapter-3-caring-for-a-stroke-survivor>

Endnotes

1. Census 2021.
2. Kelly, D and Kennedy, J (2017). Power to People: Proposals to reboot adult social care and support in NI.
3. Carers NI (2022). State of Caring 2022: A snapshot of unpaid caring in Northern Ireland.
4. National Care Service (Scotland) Bill: Explanatory notes. See: <https://www.parliament.scot/-/media/files/legislation/bills/s6-bills/national-care-service-scotland-bill/introduced/explanatory-notes-accessible.pdf>
5. Carer's Allowance was previously worth £69.70 per week, rising to £76.75 from April 2023.
6. Carers NI recommends matching the earnings threshold to the equivalent of 21 hours per week at the National Living Wage.
7. Carers UK (2019). Juggling work and unpaid caring: A growing issue.
8. Department for Communities (2022). Family Resources Survey report 2020-2021.
9. Department for Communities (2020). Gender Equality Strategy Expert Advisor Panel report: Research thematic areas, key findings and recommendations.
10. Carers UK (2020). Carers UK's response to the BEIS consultation on Carer's Leave.



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