

60 YEARS

 carers NI



Caring in Northern Ireland

The reality and hopes of unpaid carers

Carers NI

Carers NI is part of Carers UK. It is Northern Ireland's membership organisation 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.

Acknowledgements

Carers NI would like to thank every carer who took the time to tell us their story, gave us an insight into their lives and told us of their hopes for the future.

Foreword

Kellie Armstrong MLA

Thank you to Carers NI for bringing forward this timely and important reflection on the realities and hopes of unpaid carers in Northern Ireland.

In addition to my role as an MLA, I am a carer myself. I was a sibling carer for my late brother Michael until his passing in 2022, and I now support my octogenarian father, who has limited mobility. Like many others, I find being a carer both rewarding and challenging.

As a member of this Assembly, I fully recognise that carers save the government substantial resources by providing essential care and support to loved ones within the community. Yet, this invaluable contribution is often overlooked. I firmly believe that carers deserve greater recognition, which is why I fully support the Carers' Rights Charter.

I am actively working to secure paid carer's leave, fair and appropriate respite to provide carers with much-needed breaks, and the establishment of a Carers Register to ensure that no carer in Northern Ireland is left behind.

Carers are the backbone of our society. Every day, we provide both physical and emotional support to those we care for. It is, therefore, imperative that the role of carers is formally recognised. Our health and wellbeing must be supported, and we must be provided with appropriate assistance to enable us to continue this vital work.

Without the 220,000 unpaid carers in Northern Ireland, our health service would collapse. The government simply could not afford to replace the billions of pounds' worth of care that carers provide each day.

For far too long, successive governments have taken carers for granted, relying on their compassion, commitment, and sacrifices. It is time for this to change. It is time to recognise, respect, and invest in caring and carers.

Kellie Armstrong



Introduction

Helen Walker, Chief Executive, Carers UK

2025 is Carers UK's 60th anniversary year. As we reach this milestone it is important to take some time to reflect - to look at the challenges and the successes. It is vital that we look forward and plan for the future focussing on our theme for our anniversary year – *Equality: today and tomorrow*. A future where life is better for unpaid carers.

In 1965 Reverend Mary Webster, a carer herself, founded the first ever carers' organisation – The Council for the Single Woman and Her Dependents and the carers movement was formed becoming Carers UK in 1988.

In the intervening 60 years there have been significant changes. Many steps have been made in policy and in legislation and yet there remains a gender imbalance in caring, a lack of understanding and value of unpaid carers and substantial gaps in service provision and support.

The numbers of unpaid carers across Northern Ireland has grown massively over recent decades and this trend is likely to continue as our population ages and people live longer with more complex illnesses. This coupled with a social care system that

is on its knees has increased the pressure on unpaid carers.

Unpaid carers are the backbone of the health and social care system, providing care worth £5.8 billion a year and yet for many, providing this care comes at significant personal cost in employment opportunities, finances, and their own health and wellbeing.

The last few years have been particularly challenging. The Covid-19 pandemic hit carers hard with increased pressure from lockdown and shielding, closure of services and the financial impacts of a cost-of-living crisis. The aftermath of the pandemic still remains with many services and support not fully resumed.

Carers UK wants to see a society that recognises, values and supports carers. However, we can see from the experiences carers have shared with us in this book the huge challenges they currently face in their everyday lives. As a society we must work together to change this. We need to value the unpaid care that hundreds of thousands of people in Northern Ireland are providing and support them, not just in their caring role but also in achieving a balance



where caring is not at the expense of their own opportunities and health and wellbeing.

Helen Walker

Caring in Northern Ireland

Unpaid care

1 in 8 

There are over **220,000 people** providing **unpaid care** in Northern Ireland, **1 in 8** of the **population**. **1 in 15** people in the **UK** become an unpaid carer every year.¹

1 in 7 

Over **1 in 7** of all **working age adults** in Northern Ireland are providing unpaid care.

Gender

60% 

Nearly **60%** of unpaid carers are **women**.

Hours

50+ 

The number of hours of care provided every week varies but nearly **1 in 3** unpaid carers (31%) are providing care for more than **50+ hours**.

Economic value

£5.8bn 

The economic value of the care provided by unpaid carers in Northern Ireland is **£5.8 billion**. This has increased by **42%** since 2011 and is the equivalent of around **85%** of the Department of Health's budget for 2021/2022.²

Unless otherwise stated the statistics on this page are from NI Statistics and Research Agency, Census 2021

1 Carers UK & The Centre for Care. Cycles of caring: transitions in and out of unpaid care. 2022

2 Carers NI & The Centre for Care. Valuing Carers 2021. November 2023



Carers' stories project

The theme for Carers UK's 60th anniversary year is Equality: today and tomorrow. Equality should mean that unpaid carers are not disadvantaged by taking on a caring role, can participate fully in society and have access to the same opportunities as everyone else.

As part of this anniversary year Carers NI wanted to amplify the voices of carers, enabling them to share their experiences of caring, both good and bad, and their hopes for the future.

Everyone's caring journey is different but through volunteers from our Carer Policy Forum and Carers NI's membership we have presented seven stories which illustrate different situations and challenges faced by unpaid carers.

These carers have given us an insight into their daily lives and outlined what they feel would make life better. We are grateful for their candour.

Carers responding to our 2024 State of Caring survey were also asked how they would like to see the future for carers. We have outlined the main themes from these responses in the form of quotes from individual carers.

We hope that those in our society who have the power to make policy and legislative changes read this booklet carefully, take time to reflect and work together to make change happen – to make life better for carers.

Helen's story

I became an unpaid carer when my son was diagnosed with type 1 diabetes – he was four.

I was working full time and studying part-time for my Postgraduate Diploma. I shared the overnight care, the medical decisions, the hospital appointments etc with my husband.

Then my husband was diagnosed with an incurable and life limiting form of brain cancer, with related epilepsy. The tumour, and his treatment contributed to him developing severe acquired brain injury. At 35 I found myself a carer for two people, and a solo parent.

Caring massively impacted me. My husband and I had shared the caring responsibilities for our son, and we managed – we had each other. However, his diagnosis with brain cancer was devastating and changed everything. His behaviour became incredibly erratic and difficult to deal with. I look back at photos of myself during this time, and I know it's me, but I know how much effort it took to put a smile on my face. I was exhausted. I survived on very little sleep, and I lived at a constant heightened level of anxiety.

Being an unpaid carer is very lonely and isolating and my life revolved around caring.

I had no social life, I couldn't go out after work, and any downtime I had was spent on caring or household admin. My mental and physical health declined, but there was minimal support for me; the support focused on the person I was caring for.

My relationship with my son changed too – we stopped going on adventures, and life very much revolved around caring for my husband and his needs.

Professionally, my career stalled. It was put on hold when my son was diagnosed with diabetes, and then my husband's cancer and severe acquired brain injury meant giving up a job I loved completely to care for him.

I went beyond breaking point so many times and was simply expected to carry on. Unpaid carers need more practical support.



NI SURVEY

Nearly

1 in 3

**carers felt lonely
always or often**

Carers NI State of Caring 2023



Ian's story

I have always been a carer. My brother has Downs syndrome so I was always helping him up until I went to university in Scotland.

He is now in supported living and I act as his appointee looking after all his monetary needs and buying his food and clothes.

My cousin has schizophrenia. Every week I visit him and look after all his needs as well and make phone calls on his behalf.

Then I have my two elderly parents I care for all the time at home. I run the household as they both are not fit to do that now. I have my own health problems, but I keep going. Family is the most important thing. You somehow find the strength daily to get work done and keep all healthy.

I think the mental illness is the hardest one to deal with and with no professional help or guidance for non-paid carers it makes it very challenging. All I can do is try my best and keep searching for help.

There is very little care for carers out there and when there is it is usually limited funding and does not last beyond a few days a year.

Getting a break is a challenge but it is important as a carer to take one at least to talk to others and help you relax. Singing I find is the best. I am in a local community choir once a week for rehearsals and it makes all the difference. My advice to other carers is to take up a hobby. Even if it is only for an hour a week it will help. Carers NI do a great job and are always there at the end of a phone or email for support.

Carers need more information and guidance to help them in their caring role, especially when dealing with mental illness.

NI SURVEY

1 in 3

carers said that they have **put off health treatment** for themselves because of their caring role

Carers NI State of Caring 2023

Deborah's story

You could say I've grown up a carer. I had four younger siblings by the time I was six and I became a single parent when my children were young.

So I've got many years of experience in that sense. I developed many skills along the way, and it was no surprise that I became a nurse. My career spanned 36 years, the last 25 of which were spent in palliative care.

I previously cared for my stepfather who had dementia for 10 years and my dad who lived for three years with a disability from a stroke. Both died in my arms. During this time, I was also caring for my daughter who has complex mental health needs and who I still care for. I also now care for my 80-year-old mum who has been diagnosed with dementia.

As a direct result of caring 24 hours a day, I became mentally and physically unwell.

I now have several conditions including compassion fatigue, PTSD, (as a result of caring), and physical pain. I had to give up my job as a nurse which was a shock, as I thought I could carry on doing what I was passionate about forever.

This broke my heart! Without my job my income now is a little pension.

I feel that when health professionals know there is someone caring for a relative, even if they have their own health problems, they just leave the carer to get on with it.

Their support is needed for someone who has nobody. My other daughter who is a doctor, says, "it's sad that in the NHS today, support has now become a luxury." This is true - the only dementia support my mum and I get is from the Alzheimer's Society. Thank goodness for charities, like them, and Carers NI, Cause, AMH, and the carers support groups within the trust - they are a lifeline for carers.

I would tell carers to get formally recognised as a carer and seek all the support you can. Meeting other carers has been invaluable for me. Although I find my caring role very tough, I honestly can't imagine what it's like for elderly or disabled carers, or those with no experience.

I do it because I love my mum and daughter. Carers do an amazing job - often for free.



NI SURVEY

More than

1 in 2

carers felt their physical health had suffered due to caring

Carers NI State of Caring 2023



NI SURVEY

1 in 3

women who provided unpaid care reported **giving up employment** to care

Carers NI State of Caring 2023

Heather's story

My husband has suffered from ill health for over 30 years. He has multiple sclerosis and a lung condition which means he has recurring infections.

His health has been impacted since our two children were born, so we have always had to compromise with family life but we were a self-contained happy family unit muddling through.

However, my husband's health has gradually worsened over the years and I have struggled to acknowledge my transition from wife to full-time carer. The balance of responsibility for our household has slowly shifted from a 50/50 split to me having 100% responsibility for every decision. Like many wives it is natural to accept the practical domestic duties, but I have found it much harder to deal with the more traditional male roles like the car and DIY tasks.

Caring can be very isolating. I found it hard to find peer support in my forties, as most seemed to be aimed at older carers or parents caring for children. I had no time for relaxing or hobbies.

I was working 32 hours a week until the pandemic as I was the sole breadwinner and so had to juggle many demands.

When I had to leave my job the sudden jolt to full-time carer and the loss of my identity as an employee was unexpected and difficult.

Although I am content that this was the right decision, at times I have struggled to accept it.

My work was the balance to my role as a carer. I wish that enough support and protection could be provided to allow carers to maintain some employment.

Acknowledging that I need help and then actually finding it has been a challenge. I have grieved for the loss of the life we had planned, but I am accepting of the circumstances we find ourselves in, and grateful for the small things that we can still enjoy such as a cup of coffee. I have learned that I need my sleep, and everything is more difficult when I am tired. I am also learning that it's ok to take time for myself and not to feel guilty.

Other people's attitudes to disability can be very confronting and I often wish people had more empathy.

Natasha's story

I became a carer in my twenties when two of my children were born with multiple and severe disabilities, including severe learning disabilities.

It was recognised early on that my son had some additional needs; however, he wasn't properly diagnosed until he was five and by that time my daughter was born. Never did I imagine that she would also have disabilities, but I have since learned this is very common. They are now young adults, aged 25 and 21 and I have been caring for so long that I can't imagine my life without care responsibilities.

For me caring is 365 days a year and I find balancing high intensity care for two dependents adults, whilst maintaining full-time employment incredibly hard. Every day, I am exhausted and stressed and some days it is tough to just simply exist. I often describe myself as one person, leading three people's lives.

Given the demands of caring, it's unsurprising that it adversely impacts on my own life, especially my employment opportunities, progression and earnings, my health and well-being, and socialising with friends.

Policy makers need to start valuing the work carers do and enable us to have the same opportunities as others to fully participate in society.

We are a strong family unit - I'm never lonely and I live in a house where comedic instances are the norm, which certainly keeps colleagues, friends and family entertained! In our house (also known as the party house), we celebrate everything in a big way because it brings so much joy to my children. For me, I'm one of the lucky parents because I still get to create magical atmospheres and savour moments way beyond the childhood years.

Caring has many challenges, but it has also been very rewarding and has given me many valuable skills.

Beyond the celebrations and exemplary party planning I am an excellent multitasker, I'm great at following instructions, and I can keep good routines whilst being flexible and adaptable to change. My children have also taught me acceptance, humility, compassion in addition to the importance of valuing others and treating everyone as an individual - for that, I am very thankful.



NI SURVEY

1 in 4

carers live in poverty.
The inability to balance employment with caring is a key driver of this

Carer Poverty Commission 2023



Nicola's story

I care for my husband and my two children. The children have been diabetic since they were two years old. My husband has also been a diabetic since the age of 10.

I need to monitor their blood sugar levels day and night and count carbohydrates for each of their meals. This allows me to calculate the correct amount of insulin for each of them.

New technology means that I can monitor glucose levels in my children and husband remotely whilst they are at school or work, but I must remain close by in case their levels drop, and I need to intervene. This limits what I can do and where I can go.

Night times are especially challenging. Any severe rise or lowering of blood glucose levels triggers an alarm on my phone. I must then get out of bed, check the blood glucose and either give them more insulin to bring the blood glucose down or give them some fast acting carbs to bring their glucose levels up. This can happen multiple times a night meaning I get little sleep.

As a carer and a mother, I have found it challenging to enrol the children in after school activities.

Group leaders are unable or unwilling to accept the challenges presented by a diabetic child needing insulin. This means the children miss out on extra-curricular activities and I have no time to take a break. I am fortunate that the children can visit their grandfather as this allows me some rest.

Going away on holiday or even just for the weekend is not easy. While on holiday I can never fully relax. I'm always wondering – "Did I calculate the carbohydrate right for the food they just ate? Did I give the right amount of insulin? What are we doing later – does the dose need adjusted?"

I'm always thinking what if... What if I got sick and ended up in hospital, how would my husband cope? I can never switch off fully.

Being a carer means my life isn't on the straight and narrow like everyone else it's more of a roller coaster and I have to take the good with the bad.

Caring in this manner is extremely important but also exhausting. There needs to be support for carers to be able to take a break away.

NI SURVEY

**Less than
2 in 3**
carers reported
having a **break**
from caring in the
last 12 months

Carers NI State of Caring 2023

Daphne's story

My caring journey began in 2022 when my 92-year-old totally independent mother was severely disabled by a stroke.

After weeks in hospital, we were told that further recovery was unlikely. Mum was transferred to a nursing home for two weeks "rehabilitation". Within a week she was begging me to take her home – her care needs were not being met.

We got a care package in place and a bed, air mattress and hoist in our spare room. As a retired nurse with 40 years experience I thought I could cope with the help of carers and the community stroke team.

My optimism was misplaced. Our lives were turned upside down. Active retirement swiftly turned into busy jobs for both my husband and myself. I now work 12 to 13 hours a day, on-call at night and get no days off or sick days. If it was a paid job these conditions would be illegal.

I didn't volunteer for this (I felt I had no choice) and no one asks how I'm doing.

Our home is no longer a private space. It feels as if we're living in a public building.

Within six months I was exhausted, anxious, depressed, despairing. I felt (and still feel) angry, frustrated, resentful and isolated. I feel guilty that I'm not doing enough and not coping. I asked for Mum's care to be reviewed, and the paid carer hours were cut, not increased. My request for physiotherapy was denied. I believe that, with professional support, my mother might have regained some functionality and dignity. Caring for her might have been made easier.

The expectation is that the "family" will do everything, irrespective of their age, physical fitness or wider family support. To survive I have had to accept that Mum's care is sometimes good, sometimes barely adequate and I can only do my best. Sometimes I'm overwhelmed by grief, knowing that at the end of this journey my mother is no longer with us.

Discharge planning from hospital needs to be much better and our paid care workforce need better training and enough time to do the job properly.

Care managers need to adequately support unpaid carers and politicians need to realise how broken the system is and fix it urgently.



NI SURVEY



The number of people performing the **most intense caring roles** has increased significantly during the last 20 years

NISRA Census 2021

Unpaid carers responding to Carers NI's State of Caring survey 2024 were asked about their vision and hopes for the future. Some of their responses are shown below.

“I want to see a future for carers where...

they can be something more than just a carer.”

they are less tired and have time to enjoy life as well as supporting loved ones.”

they can lead lives with the same choices as everyone else.”

they can have peace of mind and not fear death because they don't know where loved ones will be placed.”

Carers have **choice**

“I want to see a future for carers where...

they don't have to fight for everything.”

they do not feel isolated and left alone to deal with loved ones.”

they are recognised as crucial partners in the health service and treated as such.”

they are quickly identified and supported in knowing how to care for their loved one.”

Carers are **recognised**

“I want to see a future for carers where...

**they don't have to
plead to get help.”**

**they are valued
and supported.”**

**they are appreciated for the
unpaid work they do and the
benefits they bring to an
overburdened social care system.”**

they have a life too.”

Carers are **valued**

“I want to see a future for carers where...

they are supported with advice, one to one support and guidance.”

carers get adequate breaks - where they are not suffering burn out and mental health problems.”

no carer ever feels they are on their own.”

they don't struggle financially and are supported in the workplace.”

Carers are **supported**

The Carers' Rights Charter

In the summer of 2024 Carers NI launched a **Carers' Rights Charter**³, which outlines the rights which should be afforded to all unpaid carers in Northern Ireland.

The charter lists 14 specific rights and was informed by the contributions of unpaid carers, carer groups, community and voluntary sector organisations and other expert stakeholders from across Northern Ireland.

The charter includes the right to:

- 1.** choose to be an unpaid carer or not
- 2.** be proactively recognised as a carer
- 3.** information and support
- 4.** maintain your own health and wellbeing
- 5.** a break from caring
- 6.** reliable, accessible, good quality social care for the cared for person
- 7.** an assessment of needs and for identified needs to be met
- 8.** financial support
- 9.** be treated as expert partners in care
- 10.** education and further education
- 11.** employment opportunities and career progression
- 12.** specific support at transition points
- 13.** a plan for the future
- 14.** equality of provision of support across Northern Ireland

³ Carers' Rights Charter, carersuk.org/media/bb0ho0ih/carers-rights-charter-ni.pdf

The stories in this booklet illustrate the scale of the challenges that carers face in their everyday lives. At Carers NI we actively campaign, lobby and influence decision and policy makers about strategies that impact the lives of Northern Ireland's carers. We also work with academics to create the evidence base for positive intervention and support across all areas of life.

We believe that carers deserve a better deal. They deserve to be acknowledged for all they do in propping up a struggling health service. They deserve better support and if the rights in the Charter were implemented in full, we know that carers would experience a better quality of life, now and into the future.



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