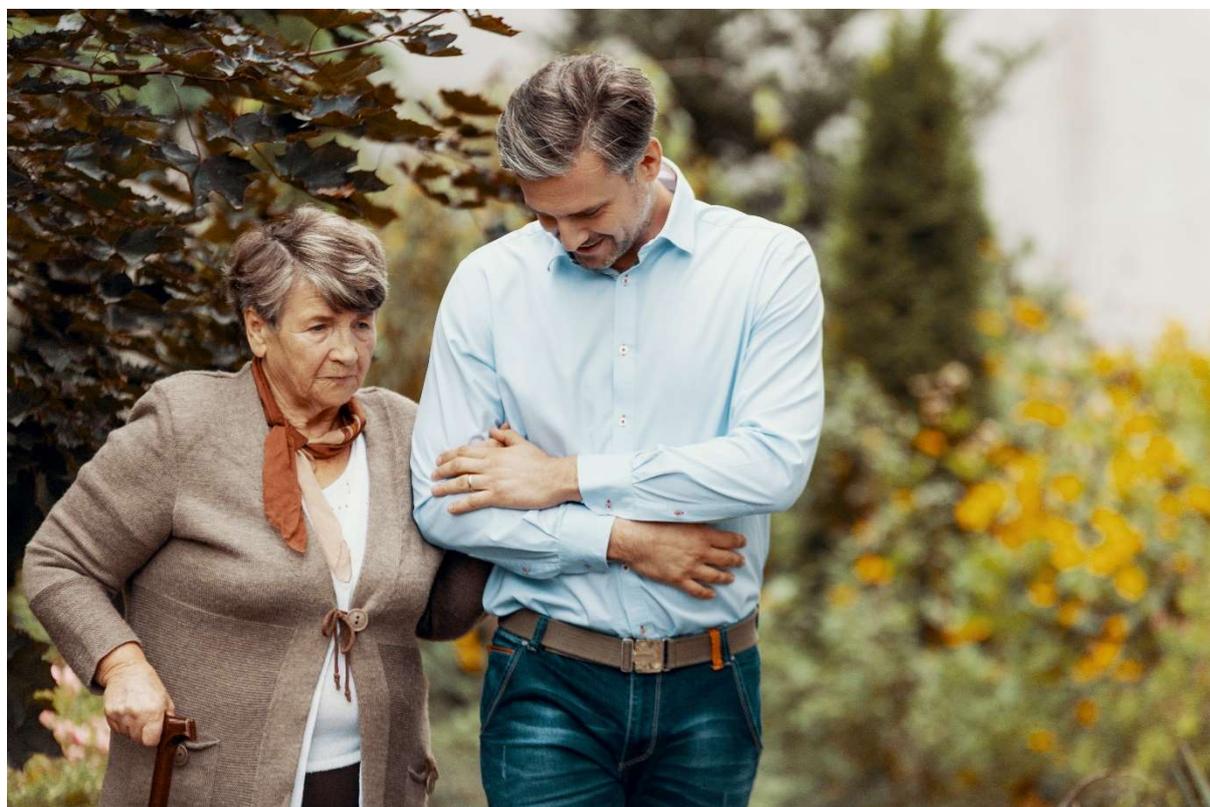


# Social care in rural areas

## A carer's perspective

September 2024



### **Acknowledgments**

Carers NI would like to thank IMPACT for the opportunity to lead the local Network and for their ongoing support. We are grateful to everyone who took part in the Network, especially the unpaid carers who gave up their time to tell us about their experiences and co-design solutions.

Produced by Angela Phillips, Senior Policy & Engagement Officer, Carers NI on behalf of the local IMPACT Network.

# Summary

- More than a third of the population of Northern Ireland live in a rural area.
- Over a third (39%) of unpaid carers live in a rural area.
- Unpaid carers in rural areas face unique challenges due to their location which exacerbate challenges that are common to all carers.
- Carers in rural areas are affected in two ways by the care system. Firstly, by the provision and accessibility of social care services for the person they care for. Secondly, by the provision and accessibility of support, for themselves as unpaid carers, to enable them to maintain their own health and wellbeing whilst providing care.
- Currently, carers within rural areas are experiencing long waiting times for care packages and unavailability of some care packages (eg packages needing two care workers), long waiting times for accessing multidisciplinary support, a lack of choice of providers, and inconsistent quality and poor reliability of packages. This is due to several root causes, such as a lack of capacity within the social care workforce, poor transport infrastructure and poor digital connectivity. The root causes often interact, increasing the negative effect.
- Carers who live in rural areas can face additional challenges to those who live in urban areas in accessing support to maintain their own physical and mental wellbeing. These include a lack of information, poor co-ordination of care and support, difficulty accessing healthcare professionals and increased travelling distance and time.
- Adequate consideration must be given within the current reform of adult social care to the needs and particular issues of carers and those they care for in rural communities.



**39% of unpaid carers  
in Northern Ireland  
live in a rural area**

# Introduction

The delivery of adult social care and support for unpaid carers in rural communities can present challenges which are unique to those communities, or which exacerbate existing difficulties within the care system. When planning service delivery, it is important to fully understand the issues affecting people who live and work in these communities.

## Definition of an unpaid carer

An unpaid carer is anyone who cares for someone who is ill, disabled, or older, and is not paid to do so.<sup>1</sup>

## Definition of a rural area

The Northern Ireland Statistics and Research Agency developed settlement classifications in 2015. These use a population threshold of 5,000 to differentiate between urban and rural areas and also take into account access to a range of key services (eg doctors, schools, supermarkets) through measures of distances to settlements with a population of 10,000 or more.

## Geographical features of Northern Ireland

More than 80% of the land mass is rural and more than a third (36%) of the population live in a rural area.<sup>2</sup> The rate of population growth is higher in rural areas than in urban areas. Between 2001 and 2020 the population of rural areas rose by 20% compared to 7% in urban areas.<sup>2</sup>

## Demography of carers in Northern Ireland

Over 222,000 people provide unpaid care, 1 in 8 of the population. The majority are aged between 16 and 65 years old (83%), although there is also a significant number of carers (16%) aged over 65. The number of hours of care provided varies but nearly 1 in 3 (31%) provide care for more than 50+ hours per week. Over a third (39%) of carers live in a non-urban area.<sup>3</sup>

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<sup>1</sup> Carers UK. August 2024. <https://www.carersuk.org/wales/for-professionals/carers-aware/resources/who-are-unpaid-carers>

<sup>2</sup> The Department of Agriculture, Environment and Rural Affairs. Key Rural Issues 2023. <https://www.daera-ni.gov.uk/news/key-rural-issues-2023-publication>

<sup>3</sup> NISRA. Flexible table builder. August 2024. <https://www.nisra.gov.uk/statistics/2021-census/results/flexible-table-builder>

# Our project

In 2024, Carers NI co-ordinated a local **IMPACT Network** to examine social care in rural areas from the perspective of unpaid carers. IMPACT is a UK-wide centre focused on implementing evidence in adult social care. The Network in Northern Ireland includes health and social care providers, community partners who regularly engage with rural unpaid carers, and those with lived experience of providing unpaid care in a rural setting.

This report summarises the discussions held during the Network.

## Social care in rural areas

Unpaid carers in rural communities are affected in two ways by the care system. By:

- the provision and accessibility of social care services for the person they care for
- the provision and accessibility of support for unpaid carers themselves to enable carers to maintain their own health and wellbeing whilst providing care.



The two are interlinked with one often impacting on the other. For example, a lack of social care provision in rural areas will increase the amount of caring an unpaid carer has to provide to bridge the gap in service provision. This can result in carers being unable to take up opportunities to maintain their own health and wellbeing due to a lack of time and access to replacement care.

The Network examined both areas in more detail.

# Provision and accessibility of social care in rural areas

The provision of social care across the whole of Northern Ireland is currently very challenging, with long waiting lists for care packages and concerns over the quality of care.<sup>4</sup>

However, those living in rural areas are often hardest hit, with the shortage of care packages disproportionately affecting these areas.<sup>5</sup>

These problems are not unique to Northern Ireland but are a challenge faced across the whole of the UK.<sup>6</sup>

The Network members raised the following concerns with regards to social care provision in rural areas:

- Long waiting times for the provision of care packages and unavailability of some care packages (eg packages needing two care workers)
- Long waiting times for accessing multidisciplinary support eg occupational therapy and physiotherapy
- A lack of choice of providers
- Inconsistent quality
- Poor reliability.

Several root causes, which often interacted, were felt to be responsible for these.

## Transport

Rural areas often have a lack of timely, reliable public transport with infrequent bus services and the transport infrastructure can be poor. The weather can exacerbate the road conditions with roads in rural areas potentially being prone to flooding or icy and ungritted conditions in winter months. Distance between homes can be substantial.

Consequently, social care providers need access to a car and can experience long travel times between clients which may be seen as uncompensated time.

Medical and multidisciplinary services are often based in larger hubs and the time taken to travel to appointments from rural communities can be substantial.

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<sup>4</sup> Department of Health. Reform of Adult Social Care NI. August 2024. <https://www.health-ni.gov.uk/sites/default/files/consultations/health/doh-rasc-consultation-document.pdf>

<sup>5</sup> BBC News. June 2024. <https://www.bbc.co.uk/news/articles/c722qd900v4o>

<sup>6</sup> The Health Foundation. Major challenges facing health and care across England. November 2023. <https://www.health.org.uk/publications/long-reads/nine-major-challenges-facing-health-and-care-in-england>

Network members noted a reduction in transport services provided by the community and voluntary sector in recent years due to funding cuts and a decrease in transport provided by Trusts to access services such as day centres or respite.

“ My [parent] took ill one night and the roads were flooded. It was so hard to get to the house. There are other occasions when the roads aren't even gritted. I know there is very little money in the pot but simple things like having roads fit to drive on would help.”

“ Literally where we live there is no public transport at all. It is non-existent except for school buses at certain times of the day.”

### Social care workforce

Recruitment and retention problems within the social care workforce are well documented.<sup>7</sup> Network members felt the inadequate numbers of social care staff are due to poor terms and conditions, including low pay and short-term contracts, concerns over the rights of social care workers who are non-UK nationals, and a lack of career progression. Social care is often not seen as a good career choice for school leavers.

“ I think the issue really stems from the workforce – it is not a job people strive to be involved in and then if you offer them a job in [a rural area] – with the state of the roads and length of journeys they are going to pick a town every time.”

“ Have you ever heard of any career advisor in school talking about working in the care industry? There are care assistants who tell us they get better wages going to supermarkets.”

These problems are not solely found in rural areas. However, when linked with other factors, such as long uncompensated travel times between clients and the need for care workers to have access to a car, it can mean if a company has a choice to deliver a service in an urban area or a rural area, they will choose the urban area.

<sup>7</sup> Department of Health. Reform of Adult Social Care NI. August 2024. <https://www.health-ni.gov.uk/sites/default/files/consultations/health/doh-rasc-consultation-document.pdf>

“ I think it costs more to run a rural care package. If their [care providers] clients are 10 minutes apart that's great for the budget but if it is 40 minutes between clients that is costing money in terms of fuel to get there with no income for that time. If you were a business owner, it would make sense to stay in larger towns or urban areas.”

### **Incomplete transformation of health and social care services**

Current strategic direction advocates a closure of smaller hospitals with the delivery of many services in large secondary care centres. However, to support this approach primary care in rural areas needs to be strong. Unpaid carers in our Network noted that General Practitioners (GPs) act as gatekeeper to services, but accessing GPs in rural areas is very difficult and often requires multiple phone calls at set times. This is very difficult when attending to caring responsibilities. An increasing number of general practices in rural areas have resigned their NHS contracts to provide GP services as they feel these contracts are unsustainable in the current climate. This has a subsequent impact on service provision.

The Department of Health has developed a new model for primary care multidisciplinary teams (MDTs). First contact physiotherapists, social workers and mental health practitioners with enhanced district nursing teams will focus on early intervention and maintaining the physical, mental and social wellbeing of communities. Network members felt the roll out of these MDTs across GP Federations was positive, but concern was noted that this is incomplete with no timescale for resumption due to lack of funding.

“ Multidisciplinary Teams in the [Trust] are emersed in the community and can respond flexibly to the needs of that community. We have rolled out some information hubs in rural areas linking in with the multidisciplinary teams and the partnership is working well, especially for carers who feel very isolated in these areas.”

“ You can be better off in terms of what you are getting [social care provision] in one part of Northern Ireland compared to another even though we are a small place. The fragmentation in the system beggars belief.”

## Housing

There can be a lack of suitable housing in rural areas when people reach the stage of needing care or adaptations. For example, there may not be many bungalows. This may reduce rural dwellers' ability to remain independent and increase their need for social care packages. A shortage of housing options in rural areas can also pose difficulties for unpaid carers who wish to move to the area to take on additional caring responsibilities.

“ There are less options if people need to move to different types of housing to suit their needs or if families need to move to offer support.”

## Transition points

Network members noted a large reduction in services and support when transitioning from child to adult social care. Whilst this is not unique to rural areas the travelling distance/time to services can result in this being felt particularly acutely in rural areas.

“ I am new to adult services, but I see a drastic change from children's disability services to adult services. People did warn me there is no help out there. No one knows anything.”

## Digital connectivity

Whilst overall digital connectivity has improved in rural communities over recent years it remains a challenge for some areas. This can limit options for the delivery of virtual services and appointments. Carers reported they could wait hours to talk to a service provider online and then, when they eventually get a virtual appointment, the connection “drops”. Additionally older generations, who are large users of social care services, may not find this approach easy or acceptable.

“ If you are caring for someone in a rural area trying to get away is nigh on impossible, so you are stuck waiting for calls. Where I live the internet conks out all the time. I might wait for a call and when it finally comes, I'm on for a few minutes and then it cuts out – that's normal everyday life here.”

## **Rural needs assessment**

The Rural Needs Act places a duty on Northern Ireland departments, district councils and the other public authorities to have due regard to rural needs when developing, adopting, implementing, or revising policies, strategies and plans. However, Network members who routinely work in rural communities felt that these assessments were inconsistent in quality and mitigations identified were often not implemented. The Act was not felt to deliver on its ethos to protect rural communities.

# Provision of support for unpaid carers in rural areas

Access to support for unpaid carers to maintain their own physical and mental health and wellbeing is critical. This is a challenge across Northern Ireland, and indeed, across the rest of the UK.<sup>8,9</sup>

Carers who live in rural areas can face additional issues in accessing support compared to those who live in urban areas.

Network members felt the following factors contributed to the difficulties unpaid carers are facing in accessing support in rural areas in Northern Ireland.

## Recognition of who is a carer

Carers often do not identify themselves as carers. Often, they feel they are simply a son or daughter (or other family member or friend) who is “helping out” a loved one. This means they do not proactively seek support for themselves.

“ I left my career to come and look after my parents. I never saw myself as a carer I just thought I was looking after my parents.”

“ When I was looking after my [partner] I didn't think of myself as a carer. They were just ill, and I needed to look after them. It was only when my [parent] moved in a few years ago so I could look after them too that I started thinking of myself as a carer.”

Network members who were providing unpaid care felt primary and secondary care services did not recognise carers or proactively offer them support or information about rights or available services.

“ I haven't a clue if I am registered as a carer in my GP practice. I've filled in forms all over the place and asked but no one has acknowledged me. I've no idea what benefit there would be if I was – is there any benefit?”

<sup>8</sup> Carers NI. State of caring 2023. The impact of caring on health. November 2023.

<https://www.carersuk.org/media/yfwjwk5g/the-impact-of-caring-on-health-in-northern-ireland.pdf>

<sup>9</sup> Carers UK. The impact of caring on: health. November 2023.

[https://www.carersuk.org/media/xgwlj0gn/soc23-health-report\\_web.pdf](https://www.carersuk.org/media/xgwlj0gn/soc23-health-report_web.pdf)

## Awareness and information on services

Unpaid carers within our Network reported a lack of information about what support was available and where and how to access it. This left them feeling unsupported.

“ I didn't have any knowledge of what I was entitled to. I needed to put a shower in and mobility aids for my [parent]. I put rails around the house. I did it all at my own expense. When they came out for the assessment, they told me I was entitled to have all that done. I had no idea. I had been to the doctor and told him about the problems, but no information was passed on to me or my [parent] at that stage.”

“ The electricity went off here one night. I had to stand on top of the garage with the phone in the air to get in touch with my [sibling]. My [sibling] contacted the electricity company and said I was caring for two vulnerable people. They put me on a list and my electricity came back on in half an hour, but those further down in the village didn't come back on all day. It would have been useful to know about that list before.”

The extent and type of support services available was noted to vary greatly across Northern Ireland and indeed across the UK and this made it difficult for unpaid carers and those they care for to understand what help was available in individual areas.

Network members highlighted that carers assessments are not always offered proactively and indeed several carers on the Network were unaware of carers assessments and had not been offered one.

## Traveling distance and time

Carer support services and information and advice services are often based in larger towns or hubs. This can mean carers, who are often already extremely pressed for time with their caring role, are unable to afford the time to access these services to support their own health and wellbeing.

“ I have two people in the house to care for and I can't just walk out and leave them. A hub - online or close by - would work for rural people. If there was a place you could call into if you could get five minutes away it would be brilliant.”

“ I don't have time to sit down and do things during the day [for my own health and wellbeing]. It is when my [partner] goes to bed that I sit down but those things [sessions to support carers own mental health and wellbeing] are not there at that time.”

The distance and time to travel anywhere in a rural area combined with difficulty accessing respite services can also impact on carers' ability to access services that support them in their caring role and to look after themselves.

“ In rural areas it is difficult for carers to get out and they can feel very lonely in their caring role. There is very little chance to get respite. It has such a big impact when carers don't get a break. It is 24/7 – they can't just walk away. It is totally affecting their mental health and wellbeing.”

Combined these can leave carers in rural areas feeling very lonely and isolated.

Similarly places of employment are often based in larger urban areas and the travelling time can mean carers give up employment as they cannot juggle employment, travelling time and their caring role. Employment can represent a source of social connections for carers and time spent away from their caring role, so this was also felt to negatively impact carers own health and wellbeing.

“ I came over from [another area] to look after my parents. I left my career. I didn't realise living in a rural area would mean I would become so isolated...from friends, relationships, work, everything.”

## Transport

As noted before, transport in rural areas can be very limited with infrequent services therefore carers without their own means of transport struggle to access larger towns or hubs where services are often located.

## Difficulty accessing healthcare professionals

Unpaid carers within the Network reported that healthcare professionals, such as GPs, social workers, physiotherapists and occupational therapists, were very difficult to contact when advice or support was needed. Having to make multiple phone calls and try to co-ordinate care services was very stressful. This negatively impacted on carers' own mental wellbeing but also on the time available for them to access support services for themselves. The carers within our Network felt this could be particularly stressful when trying to access services when there was an emergency or a deterioration. Carers felt they almost had to pre-empt deteriorations to ensure services were in place.

“ They brought something in for my [parent] to help access the toilet, but it didn't work – it was too high and my [parent] too small. I got in touch with the OT and was told it was a nine month wait for the OT to come out. There is nothing timely about that.”

“ You have to pre-empt everything. I could see my [parent's] mobility decreasing. I could see we were going to need a stairlift. It took nearly a year to get it in place. You have to act as the professional OT and see the need arising and then put your social worker hat on to arrange.”

“ At the moment I have my [partner] in a good routine. I don't know if am going to need help in the future, but it is a worry. If I need help, how will I get it quickly, in a timely fashion that is going to be meaningful for me to move forward. Help doesn't come overnight.”

### A lack of coordination of care and support

Network members felt that carers were often left to source information and services themselves and organise and co-ordinate care in addition to the caring role. This led to frustration and exhaustion.

“ We are not just unpaid carers, we are unpaid every discipline [referencing having to be OTs, physios, social workers, nurses, GPs]. We need one point of contact so we can go and say I can see this coming, tell them what I need and say can you sort that out for me. Currently I ring someone, and they say no you need to ring someone else and then they say no you need to contact this service. All those phone calls. You have to sit on hold for at least 20 minutes before someone talks to you and still carry on caring.”

“ My [parent] has multiple appointments. We need to look at how those appointments could be collated so people don't have to travel to multiple appointments over multiple days.”

### Digital connectivity

Online carer services may provide a way forward to engage with carers in rural areas and to provide services to help carers look after their own health and wellbeing. There is certainly precedence in providing services in this way from the covid pandemic. However, it must be recognised that, in some rural areas, digital connectivity remains an issue, limiting carers' ability to access such services. In addition, unpaid carers in our Network felt that these were not always a substitute for face-to-face contact and time away from the home.

“ A hub would be great. If I was able to get someone, even on the internet, to talk to, to sign post me to the right person without me having to do all the initiating.”

### Partnerships of care

Carers felt that health and social care providers often failed to recognise the role of unpaid carers and did not involve them in decisions such as discharge planning. This meant that adequate support was not always in place. Indeed, one carer described being “put under pressure” to take the cared for person home and provide support until an appropriate care package was in place, despite being unwell herself. This increases the stress, frustration and isolation carers often feel.

“ I had the social worker from the hospital ringing me to say my [parent] was medically fit for discharge. I explained to her that I was dreadfully unwell myself. It felt she was putting pressure onto me to take my [parent] home and wasn't listening that I had pneumonia and was very unwell. Thankfully I spoke to the community social worker who was amazing. She eventually managed to get a nursing home place but there was a five-day period where I was having to care for my [parent] even though I was so unwell.”

### Social care packages

A lack of social care provision in rural areas (including replacement care, respite, sitter services), is resulting in carers having to fill in the gaps themselves and provide increasing amounts of care, often for extended periods of time. This in turn, has a knock-on effect on carers who have reduced time to avail of services to look after their own health and wellbeing, employment and social activities.

“ Eight months ago, we applied for a care package. It had come to breaking point. My [parent] wasn't getting on well. I didn't know there was a problem getting a package in rural areas. When I reached out and asked for help it came as a shock because the care package wasn't there. Fortunately, we were able to get through but the impact on the carer...I have really struggled at times.”

“ The carers come in twice a day – a medication check. They are rushed off their feet – 10 minutes, 15 max. But this allows me and my sister to go to work in the morning without needing to call in on my [parent]. It makes a huge difference to us in terms of being able to hold down a job. It's also a huge reassurance. We know our [parent] has been seen by someone in the morning.”

“ We have actually put our house on the market to move [because of a lack of social care packages in the area]. Moving a 94 year old. I think it is an absolute disgrace in today’s society that we have to go to those lengths.”

Some members of our Network had experience of self-directed support. Some had found the process helpful whilst others found it very stressful acting as an employer. In general carers felt there was a lack of knowledge of this process.

“ The direct payment system was explained to me by the social worker. But to be honest, it was beyond me – it was like being an employer. I’ve always been an employee so to be interviewing people, taking people, who you need to trust, into your home – it was too much.”

“ I use direct payments. I am an employer. My biggest challenge is finding a member of staff. We have had over 20 people since Covid that wanted the job but when they find out it is in a rural area they just fall of the planet – don’t reply to your messages, don’t want to know.”

“ I have a positive experience of the direct payment system. We found a lady who has set up her own company. She does all the pay, holiday leave etc. I couldn’t take that on...working out tax .. it is just too much.”

# What would help?

The following pillars were felt to be essential in providing a social care service in rural areas that delivered quality, reliable services to the cared for person and supported carers to look after their own health and wellbeing.

- A local service
- A single point of contact
- A timely response to prevent a crisis developing
- Fit for purpose respite services
- Opportunities for carers to access local peer support and support for their own mental wellbeing
- An advocate at local level
- Equity of access to services across Northern Ireland and across the whole of the UK
- Services which have sustainable funding (including those run by the community and voluntary sector) in order to stop the start/stop approach often seen with short term funded projects and services
- Awareness raising to promote recognition by carers of their caring role
- Awareness raising to improve the recognition and identification of carers by HSC staff (primary and secondary care) and direct carers into an appropriate support system
- Comprehensive information given to carers at the start of their caring journey outlining rights and entitlements, benefits and available support services.

“ To be able to know where to go for things, to be able to know where to access things, would be great.”

“ Knowing what you can do, having relevant information, having someone you can contact if you need help, and being able to access information in a relevant and timely way would be great. Living in the country it is hard to get things done.”

“ A single point of contact is the way forward. I am toileting my [parent]; I am doing everything. I don't have the luxury of holding on a phone call or ringing someone else. Just someone who you can call and say – this is my problem – and that person says I will go and sort it and come back to you. WOW.”

“ Someone who can help you navigate the system, give you information, act as an advocate. Carers are exhausted – they don't have the energy to deal with the bureaucracy.”

# Conclusion

It was clear from the Network that social care provision and support for unpaid carers in rural communities is failing many carers and those they care for. Carers are being placed under relentless pressure filling in gaps in service provision without adequate support or appropriate breaks. This is often at the detriment of their own physical and mental health. Many carers are stressed, anxious, exhausted and burnt out.

Unpaid carers save the health and social care system in Northern Ireland £5.8 billion per year,<sup>10</sup> yet they feel unrecognised and unsupported. Rural carers, in particular, can feel very isolated.

Our Network felt recognition is needed from society of the contribution unpaid carers make. Support should be given to help them continue their caring role without sacrificing their own health and wellbeing, careers and social circles. If a carer becomes ill, burnt out and unable to continue caring then two people enter our health and social services requiring care – the cared for person and the carer themselves. Society should have a moral and economic imperative to support unpaid carers.

Caring in a rural community/location presents some unique challenges. In addition, existing issues facing the carer population can be exacerbated by other factors specific to rural areas.

We must ensure robust, quality, reliable social care provision is delivered in our rural areas and that unpaid carers, in these areas, are proactively identified and offered support.

Whilst the financial situation is challenging there are opportunities to be harnessed. The reformed Government will hopefully lead to greater stability and the ability to plan across multiple years. This will allow transformation of social care services ultimately delivering better social care provision across the province including in rural areas.

The development of multidisciplinary teams represents an opportunity to ensure that services such as social work, physiotherapy, occupational therapy, and pharmacy services are readily accessible to those in rural communities.

Improved delivery of information and support to unpaid carers via online or local hubs is an opportunity to better support carers in rural areas.

The reform of adult social care is being taken forward within the Social Care Collaborative Forum. This Forum examines many of the issues raised within the Network. It will be important to ensure the Forum considers the needs and particular issues of unpaid carers and those they care for in rural communities across Northern Ireland. We hope this work will inform that debate.

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<sup>10</sup> Carers NI and the Centre for Care. Valuing carers 2021. November 2023.  
<https://www.carersuk.org/reports/the-economic-value-of-unpaid-care-in-northern-ireland/>



Carers NI is Northern Ireland's membership body for unpaid carers. We're here to listen, to give carers expert information and tailored advice. We champion the rights of Northern Ireland's 220,000 carers and support them in finding new ways to manage at home, at work, or in their community. We're here to make life better for carers.

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