Bringing Care Closer to Home: Improving palliative care in remote, rural and island communities

Briefing for Northern Ireland, June 2025

Introduction

Everyone, no matter where they live, should receive the best possible care and support at the end of life. But the needs of people living rurally have been overlooked for too long.

Over a third of people in Northern Ireland live in rural areas[1]. People living in rural communities face unique and significant challenges accessing health and care services. Long distances to travel, poor public transport and a chronic shortage of health and care staff leave people struggling to get the care they need. For those at the end of life, these challenges are even greater.

There is a higher proportion of older people living in rural communities than in towns and cities. Rural populations age at a faster rate than urban areas and at the same time, there are fewer working-age people living rurally who can provide care.

People moving to rural communities in later life often do not have the same support networks that those living there their whole lives have. The number of people living alone in rural areas is also increasing.

This demographic crisis cannot be ignored. Demand for palliative care in Northern Ireland is predicted to increase by 32% over the next 25 years (2023-2048)[2]. With a faster ageing population, this surge in demand will be most intense for rural communities.

Palliative care is not just about end of life care. It is about supporting people to live well with a life-limiting condition, sometimes for many years. This is especially true for children and young people, whose needs and the care they require differ significantly from those of adults. The number of children and young people with a life-limiting condition in Northern Ireland is expected to rise significantly over the coming years, and more children are living into adulthood[3].

Children with life-limiting conditions, and their families, already experience many barriers and challenges in accessing care and support[4]. Living in a rural community brings additional challenges. Fewer specialist paediatric services are available, families have to travel longer distances, and rural health and care staff are less familiar with supporting children with complex needs[5].

Where you live shouldn't impact how you die. We need urgent action to tackle the ingrained inequities people living rurally face and to make sure all adults and children receive the best possible palliative care now and in the future.

Key findings

This report is the first comprehensive policy report addressing the palliative care needs of adults and children in remote, rural, and island communities across the UK. Based on extensive engagement with patients, carers and professionals, we found:

- About two thirds of people we heard from living rurally in Northern Ireland said that they or the person they cared for with a life-limiting condition *did not* receive the care and support they needed[1]. A lack of support at home, especially overnight, delays accessing medication and equipment, and a lack of training and support for unpaid carers are particular challenges.

- Four out of five rural health and care staff surveyed in Northern Ireland said there are not enough staff with the right skills to support people with life-limiting conditions[2]. This is higher than the UK as a whole. In particular, there is a lack of social care staff.

- People are being forced to choose between where they live and the care they receive. Those at the end of life face moving hours away from family and friends to access care. They need more support to stay at home and in their local community.

- People in farming communities found it particularly challenging to juggle caring for someone at the end of life with farming responsibilities. Some individuals with a life-limiting condition were reluctant to plan ahead and seek support because of worries about what would happen to the farm. Owning a farm may also mean that people are not eligible for financial assistance.

- Families of children with life-limiting conditions living rurally face significant additional barriers to accessing care and support. Rural services for children with complex needs are scarce, local staff often lack familiarity and confidence, and sustaining an equitable palliative care service is hard when there are few families spread across vast distances.

- In rural areas, stretched staff and limited resources require a creative, community-driven approach. People need the flexibility to arrange care around what they need, drawing on existing community strengths and support.

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[1] 12 people in Northern Ireland participated in Hospice UK's lived experience survey or focus groups. 4 out of 7 survey respondents stated they or the person they cared for with a life-limiting condition did not receive the care and support they needed. 4 out of 5 focus group participants reported poor experiences of care.
[2] 26 out of 235 rural health and care staff who responded to Hospice UK's professional survey worked in Northern Ireland. 21 out of 26 Northern Irish respondents said there were insufficient staff to meet people's needs.

People’s experiences

“I’m a dairy farmer. I looked after my mother in law for five years until she passed away. She had Alzheimer's. My husband says whenever you get married, if you marry a farmer, it says in the vows that you have to look after your mother and father-in-law. That's part of the deal. Because they live on the farm and are close to you. They have four daughters, but I'm the daughter-in-law. I ended up doing everything because I was here. A year ago, we just got to the end of our tether. My husband and me couldn't do it because we farm. The two of us are here. We have to do the work as well.”

Bereaved carer, Northern Ireland

“I lost my father a couple of years ago and the end of life care was not good. We're very rural, we're 25 miles or 30 miles from the nearest hospital. And we have no buses or anything, so people can't even get from [the area] to the hospitals.

With a small population, you're very, very limited on carers. We couldn't get carers. The last week before he went into hospital, I literally had six hours sleep the whole week because he used to keep getting out of the bed but he couldn't walk. We had no night support from [palliative care service]. They came once. They were brilliant the night they came, but that was it. It doesn't help us being so far from everywhere. We are very Belfast centric. There's three hospitals in Belfast and then the rest of us are left to fend for ourselves.

Because we were so far away from the hospital, when we got the phone call me and mum, we went straight away. But it took us an hour because it was rush hour traffic. And when we got there, my daddy had passed away while we were in the car park. So we never got to say goodbye.”

Bereaved carer, Northern Ireland

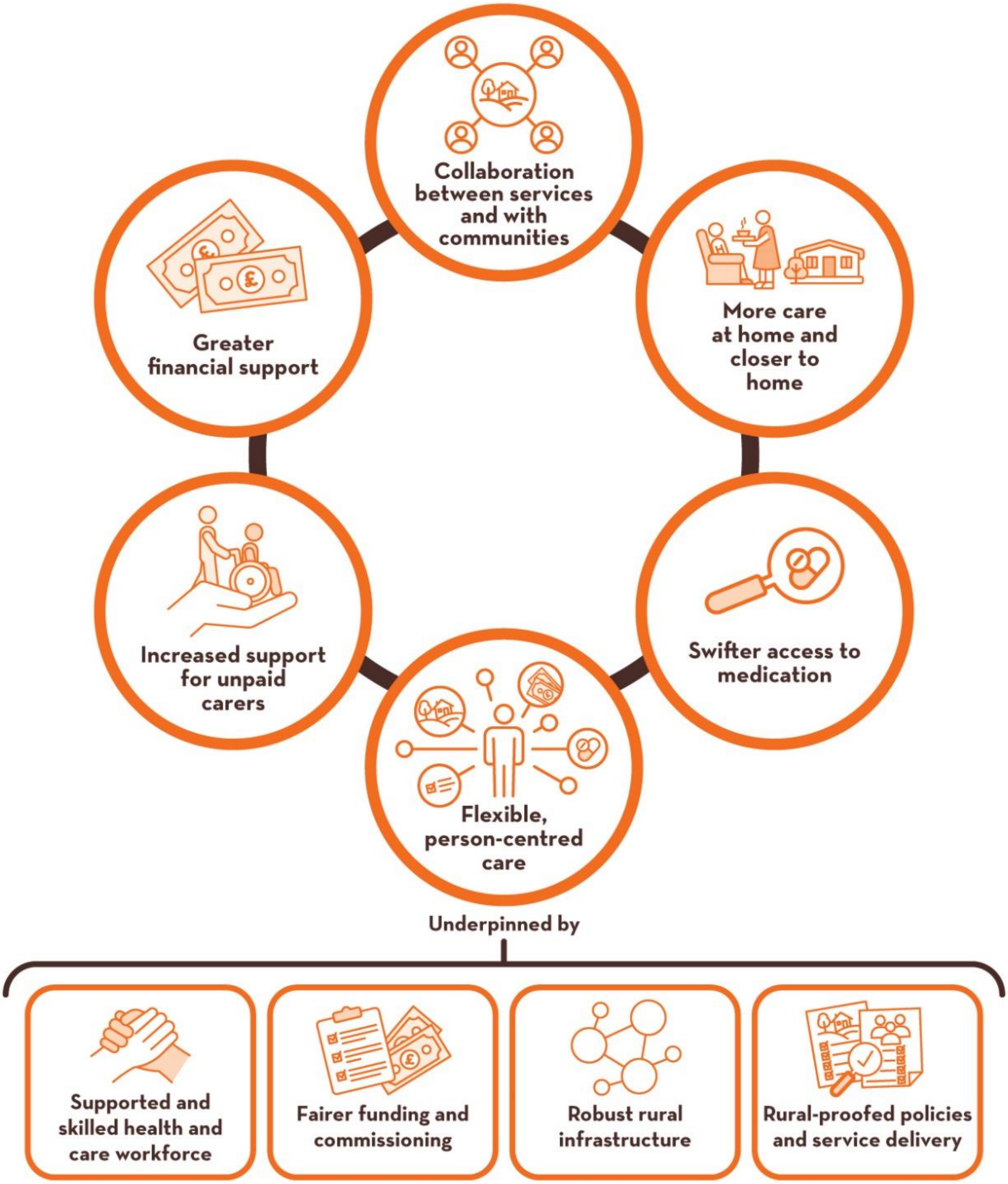
“I just felt that we seemed to be arguing all the time, trying to get a bed, trying to get a hoist, trying to get all of the equipment. And when you do eventually get the equipment, they don't show you how to use it. So the first time you see a hoist, I didn't know how to put Dad in it, and he's dying of bone cancer. He's in an awful lot of pain.

The district nurse would come, and only after several phone calls, and did not really take Dad seriously, telling us to give him paracetamol every four hours. Because my father is typical, you know, Irish. Polite man. If a doctor asked, he would always say “No, I'm OK”. You know, as a family that he wasn't OK.

And then when it comes to medication, we have these things called just in case box, which is delivered to everybody's home. But it wasn't fully stocked. And then they gave us the responsibility of administering morphine, a controlled drug. But not showing you how to do it and, apparently, I was supposed to be giving 5 mils, but I wasn't shown how to do it, and I used to think, what's going on here? Dad's still crying and in pain. But I was actually giving him 0.5 mils because I didn't really know how to how to use the thing.

It was traumatic for everybody. I just felt the whole time that we were arguing and fighting to get any service, to get the equipment, to get the training. Everybody gives you a little leaflet, and it's got all these things in it that the palliative care team will do. They didn’t do one single thing in that leaflet they were supposed to. They're supposed to ask you the questions, how you're feeling now. What do you need? Refer you maybe to counselling or refer you to all of these groups. There was none of that.” *Bereaved carer, Northern Ireland*

What would improve care and support for adults and children with life-limiting conditions living rurally?



Collaboration between services and with communities

More care at home and closer to home

Swifter access to medication

Flexible, person-centred care

Increased support for unpaid carers

Greater financial support

Underpinned by

- Supported and skilled health and care workforce
- Fairer funding and commissioning
- Robust rural infrastructure
- Rural-proofed policies and service delivery

Key recommendations

What can be done now:

- Health and Social Care Trusts should assess and be held accountable for the commissioning and delivery of palliative care and social care services that meet the needs of adults and children with life-limiting conditions living rurally.

- Hospice care providers, GPs, community nursing teams, community pharmacists, social care staff, out of hours teams and other staff should identify opportunities to work more closely together to address gaps in palliative care in rural communities, particularly care at home, improve palliative care education and training, and improve access to medication.

- Hospice care providers should work in partnership with local communities to better understand what adults and children with life-limiting conditions living rurally need; what community groups, networks and resources are already available; and how best to build on these, for example through compassionate community initiatives.

- Health and Social Care Trusts should ensure people living rurally are aware of and are supported to use direct payments so they have greater flexibility and control to arrange care that meets their needs.

- Health boards should ensure sustainable funding and fairer commissioning of hospice and palliative care services that reflect the higher cost of delivering services in rural areas.

Priorities for service development and investment:

- The Northern Ireland Executive should commit funding and resources to enable a shift to more palliative care delivered in the community.

- Health and Social Care Trusts should commission, fund and ensure the delivery of a 24/7 single point of access palliative care helpline for patients, unpaid carers, and health and care staff to access support and specialist advice.

- Health and Social Care Trusts should increase support, resources and training for unpaid carers who are caring for someone living rurally with a life-limiting condition, in partnership with local services and local communities.

- Health and Social Care Trusts should ensure the provision of a minimum standard of welfare and social security advice for people with a life-limiting condition and their carers in rural communities.

- The Northern Ireland Executive and Health and Social Care Trusts should review and implement consistent policies to reimburse travel and accommodation, and provide funded transport, for people with life-limiting conditions and their carers travelling to access services.

Long-term priorities:

- The Northern Ireland Executive should publish, implement and monitor national workforce plans that improve the recruitment and retention of health and social care staff in rural areas, and ensure there are sufficient staff with the right skills to meet the growing need for palliative care for adults and children.

- The Northern Ireland Executive should 'rural proof' the welfare system, so that people living rurally are not disadvantaged and can access the financial support they are entitled to.

- The Northern Ireland Executive should invest in improving the digital, communications, transport and housing infrastructure in rural communities.

Full recommendations, detailed findings and innovative case studies are available in the main report.

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