

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

Briefing for Scotland, 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.

People living in remote, rural and island communities face unique and significant challenges accessing health and care services. Rural Scotland accounts for 98% of the land area of Scotland but only 17% of its population, with people spread over vast distances and many island communities¹. 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. In some areas, a lack of services means that people's human rights, including their right to health, are not being met². For those at the end of life, these challenges are even greater.

There is a higher proportion of older people living in rural and island communities than in towns and cities, and rural populations are aging at a faster rate. At the same time, there are fewer working-age people living rurally who can provide care. The number of people living alone is increasing and people moving to rural and island communities in later life may not have the same support networks that people who have grown up there do.

This demographic crisis cannot be ignored. Demand for palliative care in Scotland is rising rapidly, with an additional 10,000 people a year predicted to need palliative care by 2048³. With a faster ageing population, this surge in demand will be most intense for remote, rural and island 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 Scotland has risen significantly and rapidly in recent years, and more children are living into adulthood⁴. Children with life-limiting conditions, and their families, already experience many barriers and challenges in accessing care and support⁵. 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 needs⁶.

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:

- People's experiences of palliative care in rural and island communities in Scotland varied widely. About half of people we heard from in Scotland said that they or the person they cared for with a life-limiting condition *did not* receive the care and support they needed¹. A lack of support at home, especially overnight, delays accessing medication and long, difficult journeys to access care are particular challenges.
- Over half of rural health and care staff surveyed in Scotland said there are not enough staff with the right skills to support people with life-limiting conditions². In particular, there is a lack of social care staff and community nurses.
- 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 maintain their connection to where they live, their local culture and community at the end of life.
- 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.
- Families of children with life-limiting conditions living in rural and island communities 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.
- People face a significant double financial burden: the higher cost of living in rural communities, combined with the added financial strain of caring for someone at home. This includes higher energy bills from running medical equipment, more frequent use of appliances like washing machines and dryers, keeping the heating on for longer periods, costly travel to reach health and care services, and often the loss of income due to giving up work to provide full-time care.

¹14 people in Scotland participated in Hospice UK's lived experience survey, focus groups or interviews. 4 out of 8 survey respondents stated they or the person they cared for with a life-limiting condition did not receive the care and support they needed.

² 45 out of 235 rural health and care staff who responded to Hospice UK's professional survey worked in Scotland. 25 out of 45 Scottish respondents said there were insufficient staff to meet people's needs.

People's experiences

"We need to get this right. It's too important to rely on the good will of the limited resources available. The impact on families is catastrophic."

Bereaved carer, Scotland

"He died bolt upright, extremely distressed, breathless, terrified but staring at his cattle through the window, which his son had moved around for him. Which was what he wanted. But I don't think he really chose place over palliation. I think if you'd have known that he'd have died so badly he wouldn't have chosen place. And I don't know why it has to be one or the other. I find that very distressing."

Bereaved family member, Scotland

"We're dependent on kindly neighbours to care for each other. The nearest hospices are 75 miles in each direction on country roads. There's no hospice nearby. It's the elderly loved one - how are they able to drive there every day? How are they able to afford the transport costs if the distance is a 3 hours round trip?"

Carer, Scotland

"My husband wanted to pass away at home, not in a hospice, so we made extensive plans for that. We were incredibly fortunate with the care and attention we received, allowing us time to prepare. We participated fully in the MDT [multi-disciplinary team] community discussions with the GP, practice and district nurses, and the palliative care team. It felt like we were the sole focus of these professionals, which was a very powerful feeling. ... I believe that the quality of care and support we received was second to none. It shapes your memories. I truly believe that none of that would have been quite as good as it was up here had I have still been down in [city] with that busy city life."

Bereaved carer, Scotland

"I found it extremely distressing and frightening. I was frightened because I didn't think we were meeting his needs because the district nurses during the night weren't able to get to him in time."

Bereaved carer, Scotland

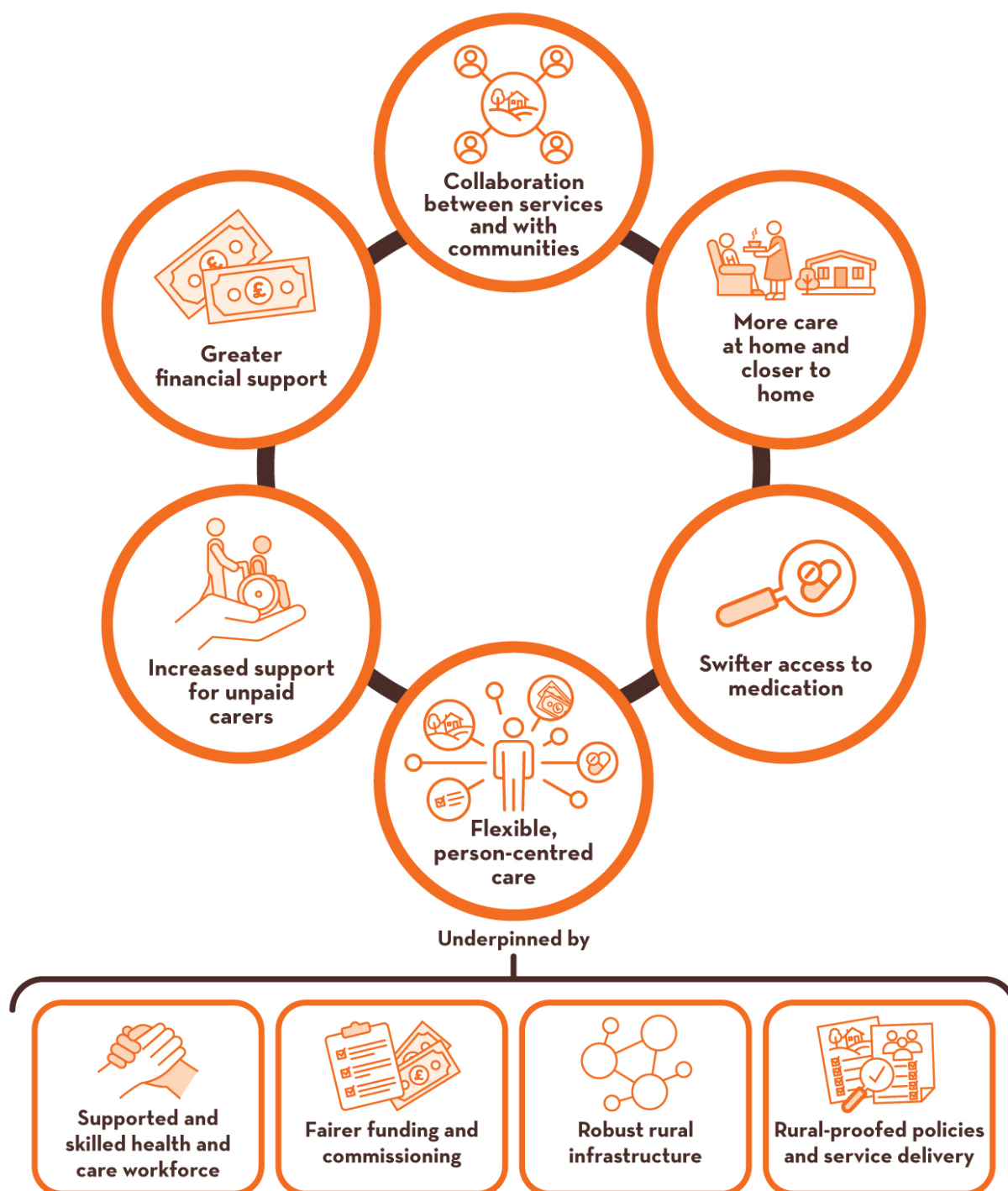
"Everything is far away and prohibitively expensive to travel to. There is no community, no support, and we are told this 'is the price of living in the beautiful isles.' It feels especially so because of it being a paediatric patient, means we aren't eligible for a lot of the carer support that is available if you are caring for an elderly parent or spouse. ... My electricity is over £700 a month due to running equipment. But of course, I am a full time carer. Why is there no grant that if your child is on palliative and hospice care, that you can apply for an electricity discount, or grant."

Parent of a child with a life-limiting condition, Scottish island

"I'm frankly terrified of my death. My husband has a heart condition. If something happens to him, I'm up the creek."

Individual living with a long-term condition, Scottish island

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



Key recommendations

What can be done now:

- Scottish Government should ensure that its new national strategy for palliative care, and accompanying delivery plan, considers the specific needs of adults and children in rural and island communities, including addressing the growing demand for palliative care in rural areas, support for delivering more care at home and closer to home, ensuring access to specialist advice, and improving access to medication. Progress must be monitored and reported on.
- Health and Social Care Partnerships, along with Health Boards and Local Authorities, 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 in rural and island communities 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 Partnerships and Local Authorities should ensure people living in rural and island communities are aware of and are supported to use direct payments, so they have greater flexibility and control to arrange care that meets their needs.
- Scottish Government and Health and Social Care Partnerships 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:

- Scottish Government should commit funding and resources to enable a shift to more palliative care delivered in the community.
- Health and Social Care Partnerships and Health Boards should 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 Partnerships and Local Authorities 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 Partnerships and Local Authorities 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.
- Scottish Government, Health Boards and Health and Social Care Partnerships 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:

- Scottish Government should publish, implement and monitor its Rural and Islands Workforce Recruitment Strategy, and ensure there are sufficient staff with the right skills to meet the growing need for palliative care for adults and children.
- The National Centre for Remote and Rural Health and Care should include a focus on the delivery of palliative care in their workplan.
- Scottish Government should 'rural proof' the welfare system, so that people living rurally are not disadvantaged and can access the financial support they are entitled to.
- Scottish Government should invest in improving the digital, communications, transport and housing infrastructure in remote, rural and island communities.

Full recommendations, detailed findings and innovative case studies are available in the [main report](#).

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References

¹ Scottish Government. Rural Scotland: key facts 2021. [Statistical compendium] [Edinburgh]: Scottish Government; 2021. Available from: <https://www.gov.scot/publications/rural-scotland-key-facts-2021/>

² Scottish Human Rights Commission. Economic, social and cultural rights in the Highlands and Islands. Edinburgh: Scottish Human Rights Commission; 2024. Available at: <https://www.scottishhumanrights.com/projects-and-programmes/spotlight-projects/economic-social-and-cultural-rights-in-the-highlands-and-islands/>

³ Marie Curie. How many people need palliative care? Updated estimates of palliative care need across the UK, 2017-2021. [Data and evidence briefing] [London]: Marie Curie; 2023

⁴ Public Health Scotland. Children in Scotland requiring Palliative Care (ChiSP) 3. Edinburgh: Children's Hospices Across Scotland; [2020]

⁵ Together for Short Lives. Built to last? The state of children's palliative care in 2025. Bristol: Together for Short Lives; 2025. Available at: <https://www.togetherforshortlives.org.uk/changing-lives/speaking-up-for-children/policy-advocacy/the-state-of-childrens-palliative-care-in-2025/>

⁶ Papworth A, Hackett J, Beresford B, Murtagh F, Weatherly H, Hinde S, et al. Regional perspectives on the coordination and delivery of paediatric end-of-life care in the UK: a qualitative study. BMC Palliat Care. 2023; 22(1):117. doi: 10.1186/s12904-023-01238-w.