

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

Briefing for Wales, 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.

One in three people in Wales live in rural areas¹. 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 in Wales have aged more than twice as fast as urban areas². 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 across the UK is predicted to increase by 25% over the next 25 years (2023-2048)³. 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 Wales 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 areas of Wales vary widely. About half of people we heard from living rurally in Wales said that they or the person they cared for with a life-limiting condition *did not* receive the care and support they neededⁱ. A lack of support at home, especially overnight, and delays accessing medication are particular challenges.
- Nearly three quarters of rural health and care staff surveyed in Wales said there are not enough staff with the right skills to support people with life-limiting conditionsⁱⁱ. 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 living on the border of England and Wales said care was not joined up. They reported issues with cross-border financing, staff not understanding what services they were allowed to access, and difficulties accessing certain medications.
- For Welsh speakers, receiving palliative care in their preferred language is vital for clear communication, connection and effective care planning. This is especially important for people with dementia, who may revert to their first language, but it also matters across age groups. People described access to Welsh-speaking staff as inconsistent, though they said that even having a few phrases in Welsh helped foster communication and rapport.
- 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.

ⁱ 21 people in Wales participated in Hospice UK's lived experience survey or focus groups. 7 out of 14 Welsh survey respondents stated they or the person they cared for with a life-limiting condition did not receive the care and support they needed.

ⁱⁱ 36 out of 235 rural health and care staff who responded to Hospice UK's professional survey worked in Wales. 26 out of 36 Welsh respondents said there were insufficient staff to meet people's needs.

People's experiences

"My husband was diagnosed 10 years ago with prostate and bladder cancer. He was fiercely independent about it all. He insisted on driving himself. It was an hour and a half drive. And then he'd have to have his chemotherapy and then come home and be sick. Towards the end, I was driving him, which just became a necessity. But it was such a long way. It was quite gruelling. I was told there was transport and I tried to book the hospital transport but one time they didn't show up and the other time they were so late that I had to just drive him anyway. It's things like that that were really frustrating on top of looking after somebody.

I can remember an occasion when I went to pick up his medication and none of the chemists in our nearest town had the oxycodone, so I ended up driving all round [the area] trying to find a chemist that had some stock. It's little things like that that make it so hard. I wish on that day there had been somebody or someone I could have got in touch with to say this is the situation. He's in terrible pain and I'm going to have to travel around [the area] looking for a chemist that's got the stock. Things like that would have been so helpful."

Bereaved carer, Wales

"Because we live in a rural area, we still know most of the people around here. It's quite a close-knit community. About half a mile down the road a senior manager of Social Services lives and I happened to see her one day when I was going for a walk. She stopped and said "I saw your wife in the front garden a few days ago and you need to get in touch with us now. I was quite surprised about the change in her."

I knew nothing about social services, virtually nothing about their role. So I took her advice and she said, "do you want to go down the direct payment route?"...I happened to know one carer who had retired. And luckily again, being in this close-knit group of villages, there were a couple of other carers retired from the local authority and they came to help. I was so lucky with the carers. I even had a nurse in training as a carer because she was the daughter-in-law of one of the carers. I was very, very lucky because good care is few and far between."

Bereaved carer, Wales

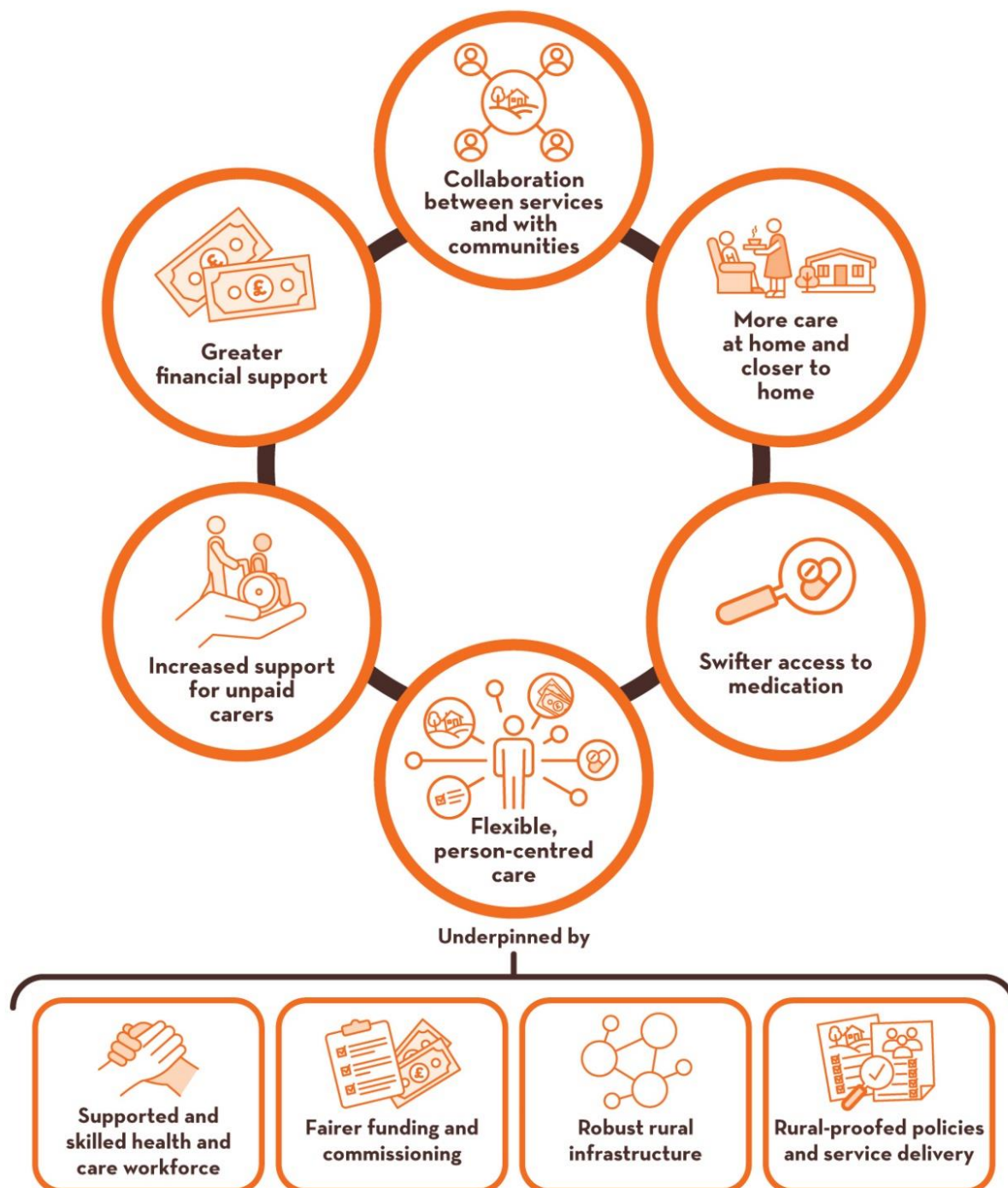
"Honestly, we said to our local team a lot that it felt like they were hoping young children with severe disabilities either moved away or died before teenage years or adulthood because they were so under equipped to deal with them. It's sad but we seemed to pave the way every step at a time when we really could've done with a system to have taught us what to do for the best. It meant a really unclear and unsuccessful path for our son."

Parent of a child with a life-limiting condition, Wales

"We deserve the services as much as people in cities, who within a 4 hour drive could've reached maybe half a dozen hospices."

Bereaved carer, Wales

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



Key recommendations

What can be done now:

- 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 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 boards and local authorities, 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.
- Welsh Government and the National Palliative and End of Life Care Programme should ensure that the National Service Specification for Palliative and End-of-Life Care and National Commissioning Framework for Hospices include the specific needs of people in rural communities.

Priorities for service development and investment:

- Welsh Government should commit funding and resources to enable a shift to more palliative care delivered in the community.
- Health boards 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 boards 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 boards 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.
- Welsh Government and health boards 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.
- Health boards and local authorities should ensure Welsh language plans consider the needs of people at the end of life and include hospice care staff in opportunities and resources.
- Health boards and Regional Partnership Boards in Wales, along with Integrated Care Boards in England, should introduce clearer, more flexible approaches to commissioning palliative care across borders and boundaries.

Long-term priorities:

- NHS Wales Performance and Improvement, and Health Education and Improvement Wales (HEIW), should develop a palliative and end of life care workforce plan that addresses the growing need for palliative care in rural communities.
- Welsh Government 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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References

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 - ² Intergenerational Foundation. No country for young people: The problems of accelerating rural-urban age segregation. [Policy report] [London]: Intergenerational Foundation; 2023.
 - 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 Fraser L, Bedendo A, Jarvis S. Children with a life-limiting or life-threatening condition in Wales: trends in prevalence and complexity. [York]: [University of York]; 2023
 - 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.