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# Bringing care closer to home:

Improving palliative care in remote,  
rural and island communities

Executive Summary

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## About Hospice UK

Hospice care eases the physical and emotional pain of death and dying. Letting people focus on living, right until the end. But too many people miss out on this essential care. Hospice UK fights for hospice care for all who need it, for now and forever.

St  
James's  
Place

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P H A R M A



# Foreword

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**Caring effectively for the needs of people with life limiting and end of life conditions is central to good medicine. Not all of those nearing the end of life require formal palliative care but a high proportion do. Some will require hospice care, including community care by palliative specialists, and an even wider number, including family members, informal carers and medical, nursing and care teams will require professional support and advice.**

Palliative care may be needed for people at any age in life, but in the UK a disproportionately large proportion of the elderly population who are the most likely to need palliative care live in rural, remote or coastal areas having moved there at an earlier stage of their lives, often from cities. Meanwhile specialist services including hospices and palliative care teams tend to be based in cities and large towns.

Meeting the palliative care needs of people living in rural, remote, coastal and island communities provides additional challenges including difficulties of transport and providing clinical and social care at a distance on top of those seen in urban areas. This important report by Hospice UK addresses this major issue of providing palliative and wider end of life care for those with life limiting conditions in rural areas.

Professor Chris Whitty  
Chief Medical Officer for England



# Executive summary

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**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. 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 rural areas, a lack of services means that people's basic human rights, including their right to health, are not being met. For those at the end of life, these challenges are even greater.

Populations in rural areas are growing and ageing at a faster rate than in urban areas. Over the next 15 years, nearly half of rural households will include people aged 65 or over. At the same time, there are fewer working-age people living rurally who can provide care.

This demographic crisis cannot be ignored. Already we are seeing the need for palliative care rising rapidly across the UK. Almost a million more people will die over the next 10 years than in the previous decade. And as many as 90% of them would benefit from palliative care. With a faster ageing population, this surge in demand will be most intense for rural communities.

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:

- ▶ Nearly two thirds of people living rurally said that they or the person they cared for with a life-limiting condition did not receive the care and support they needed.
- ▶ Two thirds of rural health and care staff said there are not enough staff with the right skills to support people with life-limiting conditions. 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. Too many people 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.
- ▶ 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.

***“When we needed care, it wasn’t there for us. I feel very let down. Do people in cities experience this? No, they don’t.”***

*Bereaved carer*

***“We need to get this right. It’s too important to rely on the goodwill of the limited resources available. The impact on families is catastrophic.”***

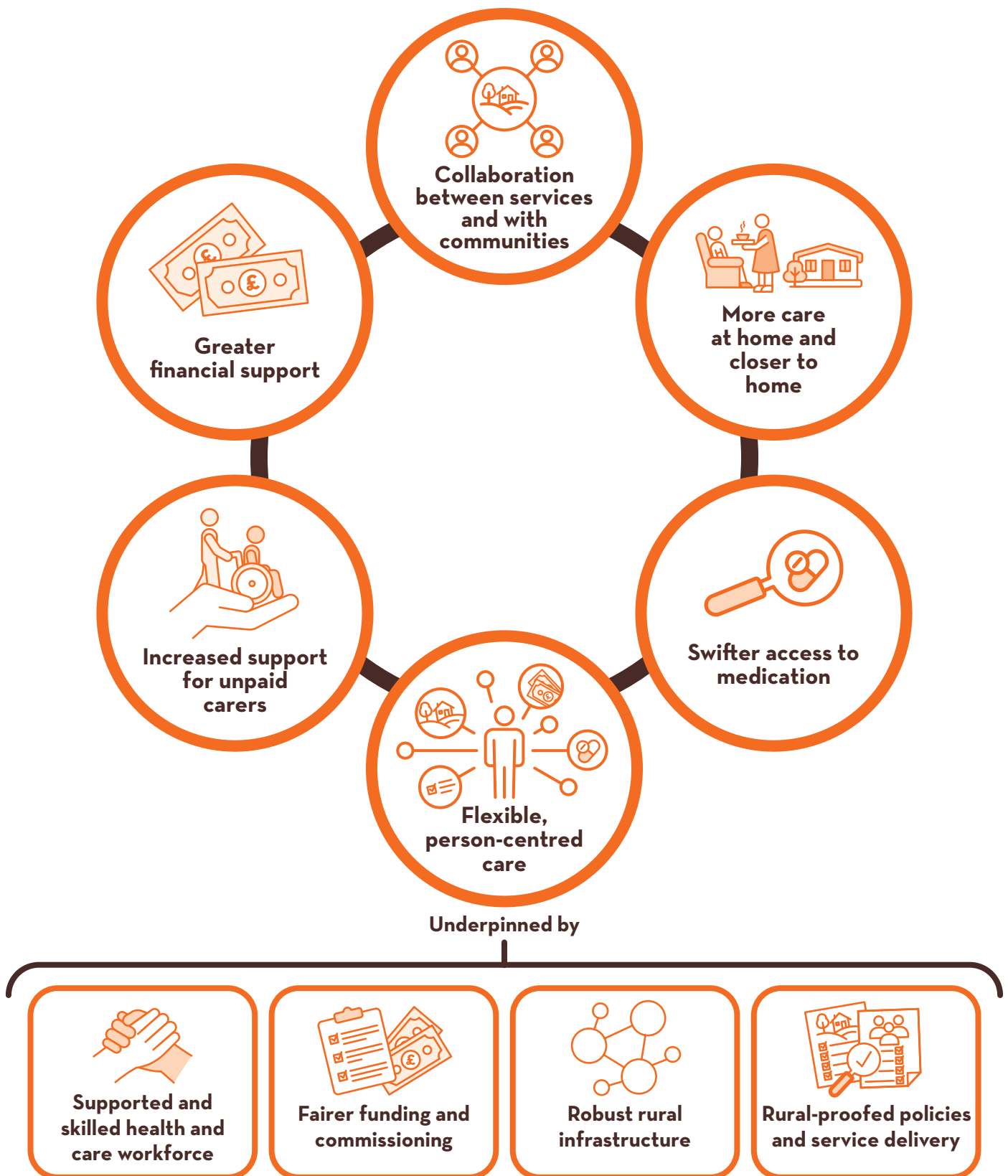
*Bereaved carer*

***“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.’”***

*Parent*



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



# Key recommendations

## What can be done now:

- ▶ Local health and care systems<sup>i</sup>, along with 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.
- ▶ Local health and care systems, and local authorities, should ensure people living rurally are aware of and are supported to use direct payments and personal budgets so they have greater flexibility and control to arrange care that meets their needs.
- ▶ Local health and care systems 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:

- ▶ Governments across the UK should commit funding and resources to enable a shift to more palliative care delivered in the community.
- ▶ Local health and care systems 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.
- ▶ Local health and care systems, 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.
- ▶ Local health and care systems 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.
- ▶ Governments and local health and care systems 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:

- ▶ Governments across the UK 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 Department for Work and Pensions, the Scottish Government and 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.
- ▶ Governments across the UK should invest in improving the digital, communications, transport and housing infrastructure in remote, rural and island communities.
- ▶ The UK Government should review whether commissioning children's palliative care at a regional or national level would better meet the needs of rural families.

<sup>i</sup> 'Local health and care systems' refer to Integrated Care Boards in England; Health Boards and Integration Joint Boards in Scotland; Health Boards and Regional Partnership Boards in Wales; and the Strategic Planning and Partnership Group and Area Integrated Partnership Boards (as they are established) in Northern Ireland.



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