Bringing care closer to home:

Improving palliative care in remote, rural and island communities

Acknowledgements

This report was funded via a grant from Aspire Pharma. Hospice UK would like to thank Aspire Pharma for their generous support for this project.

We also thank St. James' Place Charitable Foundation for the generous funding of Hospice UK's remote and rural grants programme for hospices.

We would like to give particular thanks to the members of our steering group for their generous time, advice and support:

Julie Bishop, St Barnabas Hospice, Lincoln

Julie Clayton, Eden Valley Hospice and Jigsaw Children's Hospice

Ben Dellow, Together for Short Lives

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Emma Saysell, St David's Hospice Care

Ellie Wagstaff, Marie Curie

We thank everyone who shared their experiences and expertise through our focus groups, interviews, surveys and workshops.

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How to cite this document

Hospice UK. Bringing care closer to home: improving palliative care in remote, rural and island communities London: Hospice UK; 2025.

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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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Contents

Foreword

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

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:

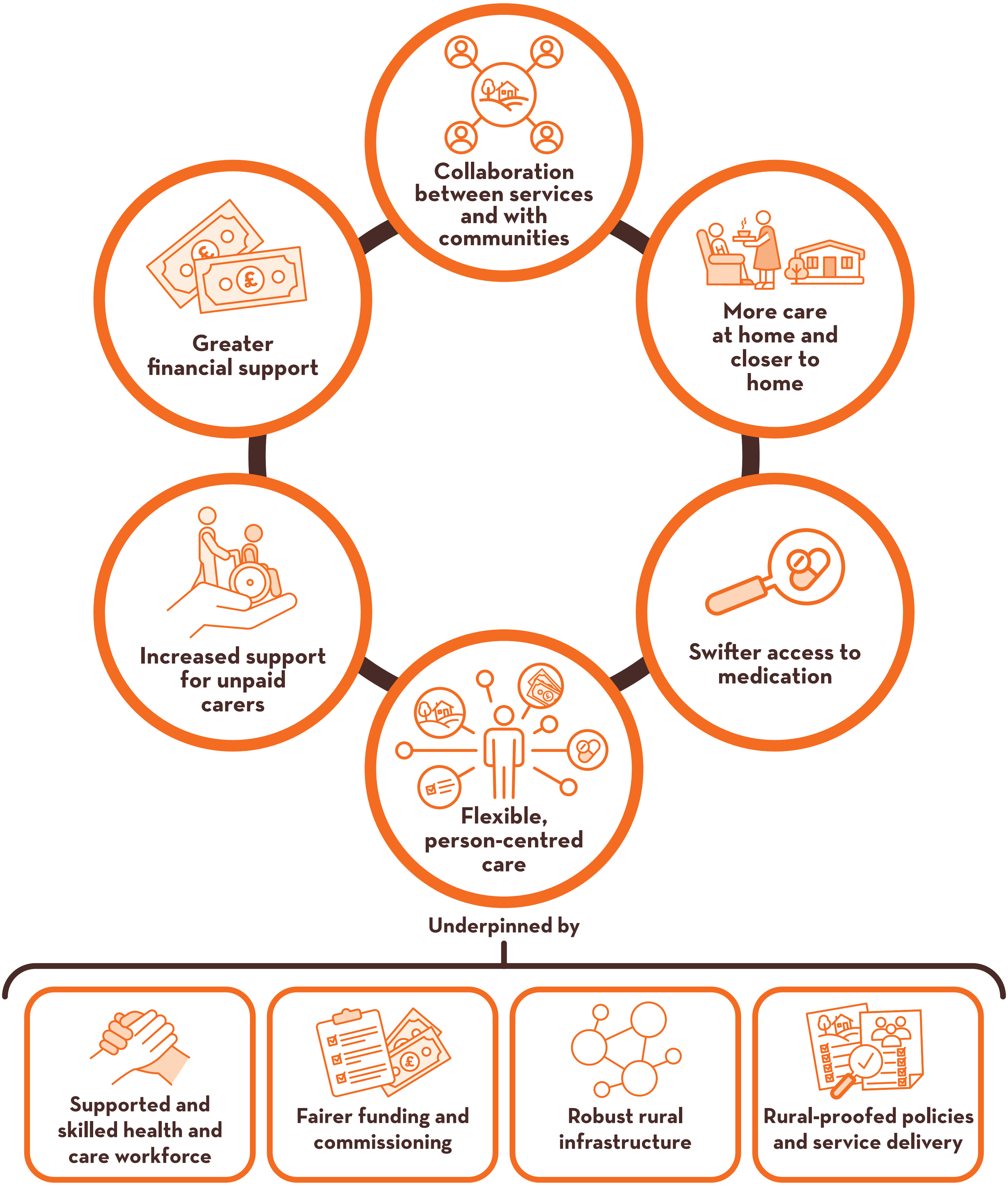
- Nearly two thirds of people living rurally said that they or the person they cared for with a life-limiting condition did not receive the care and support they needed.
- Two thirds of rural health and care staff said there are not enough staff with the right skills to support people with life-limiting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



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:

- Local health and care systems[i], 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.

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[i] '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.

Introduction

Across the UK, there is a higher proportion of older people living in rural communities than in towns and cities[1]. With many people leaving cities before they reach older age, our rural populations are ageing at a faster rate than in urban areas. By 2039, nearly half of households in rural areas are estimated to include people aged 65 or over[2].

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

Many people living in rural communities face long distances to travel to access healthcare services, particularly those living in remote areas or on islands. There is a shortage of health and care staff, and working-age people more generally, to meet the growing health and care needs in rural communities. People living in rural communities already experience ingrained and hidden health inequities[3]. In some rural areas, a lack of services means that people's human rights, including their right to health, are not being met[4].

Access to palliative care services is patchy in rural communities. Hospices and specialist palliative care services, like other specialist care, are typically based in towns and cities. Research has shown that people living rurally have less access to hospice care services[5,6]. Finding ways to equitably deliver palliative care across the UK's myriad of remote, rural and island communities is a challenge.

The need for palliative care in the UK is predicted to increase by 25% over the next 25 years (2023-2048)[7]. As people are living longer, more people are living with multiple conditions and require more complex care as they approach the end of their lives. With a faster ageing population, the need for palliative care in rural communities is likely to be even higher.

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. There are a wide range of life-limiting and life-threatening conditions affecting children and young people. Their condition might be stable for a time, suddenly deteriorate, gradually decline or vary up and down. Understanding and addressing the unique needs of children, young people and their families living rurally is essential.

The number of children and young people with a life-limiting condition has risen significantly and rapidly in recent years, and more children are living into adulthood[8,9,10]. While there is no specific data on the number of children with life-limiting conditions in rural communities, the overall increase across the UK suggests that rural communities will also be experiencing a rise.

Children with life-limiting conditions, and their families, already experience many barriers and challenges in accessing care and support[11]. Living in a remote, rural or island 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[12].

There has been a lack of focus on rural needs in health and care policy and service design[13], including the delivery of palliative care. There is also lot to learn from how rural communities and services work together locally to support people at the end of life. This report is the first comprehensive piece of policy work looking at how we can meet people's palliative care needs in remote, rural and island communities across the UK, now and into the future.

Our approach

This report aims to:

- Increase understanding of the experiences of people with life-limiting conditions in remote, rural and island communities and their families, and the issues that are important to them.
- Explore the challenges and opportunities in delivering palliative care in remote, rural and island communities, and share learning and examples of innovative approaches.
- Make recommendations to national policy-makers, local systems, health and care services and the hospice care sector to improve the care and support for people with life-limiting conditions and their families in remote, rural and island communities.

The report explores the needs of people of all ages with life-limiting conditions in rural communities, including children and young people. It looks across all four nations of the UK.

To inform the project, Hospice UK heard directly from people in remote, rural and island communities about their experience of care, through focus groups, interviews and surveys. We also gathered views from health and care staff delivering palliative care in rural communities via surveys, interviews and workshops, and reviewed existing published research. Our methodology is set out in Annex 1.

What do we mean by rural and remote?

There is no single definition of 'rural' and definitions vary across the UK. In England and Wales, rural is typically defined as settlements of less than 10,000 residents[14]. In Northern Ireland, it is fewer than 5,000 residents[15] and in Scotland, fewer than 3,000 residents. Scotland defines 'remote' as an area of more than 30 minutes' drive from a settlement of more than 10,000 residents[16]. Northern Ireland has similar classifications based on being within a 20 or 30 minute drive.

Rural areas in the UK are incredibly diverse. From rural coastal areas, to farming communities, to small rural towns and villages, to remote hamlets and island communities. This report looks across all different rural communities. In some parts of the report we have separated out island and remote communities because of the additional considerations needed to deliver care to these communities.

What do we mean by palliative care?

Palliative care aims to improve the quality of life and wellbeing of adults, children and young people who have a terminal illness or a long-term condition that cannot be cured, also known as a life-limiting condition. It can include symptom management, and social, practical, emotional and spiritual support. It helps people live as fully and as well as they can to the end of their lives, however long that may be. It can be provided in a hospice, hospital, at home or in a community setting.

The majority of palliative care in rural communities is delivered by GPs, community nurses, social care staff and community pharmacists. Families and unpaid carers also provide a significant amount of care and support, along with informal support from local communities. Some people may need specialist palliative care to manage complex symptoms and provide more emotional, social and spiritual support. Specialist palliative care is delivered in partnership with generalist staff by multidisciplinary teams including palliative care consultants, specialist palliative care nurses, allied health professionals, social workers and therapists. Hospice care organisations provide specialist and generalist palliative care, as well as expertise, education and leadership across the health and care system.

Report structure

The report is split into three sections:

- People's experiences of death, dying and bereavement in remote, rural and island communities.
- How can we improve support for people with life-limiting conditions and their families?
- What is needed to deliver this?

People's stories are highlighted throughout the report. These have been gathered from our focus groups and interviews, in people's own words. We have also featured innovative case studies from services and community organisations throughout the report.

The issues explored in the main body of text in each section apply to both adults and children. Additional issues that relate specifically to children and young people with life-limiting conditions and their families are highlighted in separate boxes.

1

People's experiences of death, dying and bereavement in remote, rural and island communities

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Travel and transport

Distances to travel

People in rural communities told us how long distances to travel make it harder for them to access health and care services, including palliative care. This is particularly the case for people living on islands who have to take ferries or fly to the mainland. Travelling long distances to appointments and services when you are very unwell is difficult. If patient transport is available, it is often unreliable, inflexible and takes a long time. It is not comfortable or suitable for people with palliative care needs.

Having to drive long distances puts a significant toll on unpaid carers, at an already challenging time. It also makes it more difficult for families and friends to visit loved ones staying in a hospital, hospice or care home.

Staff in rural areas spend a long time travelling to see patients, which limits the number of visits they can carry out and the number of people they can support. It can also take many hours for healthcare staff to reach someone's house, for example to provide pain relief in the middle of the night.

Travel infrastructure

Rural communities often have a fragile travel infrastructure. Bus and rail services are limited, expensive and not suitable for someone who is unwell. Travelling to a hospital or hospice can take multiple buses and some hospices are not on a bus route. Public transport rarely runs in the evenings and overnight.

In bad weather roads can close, cutting people off or meaning delays and diversions of many hours. People told us they would avoid accessing services if they had to travel over difficult or mountainous roads, especially in winter. Ferries to islands are routinely cancelled in poor weather meaning people can't access services on the mainland, health and care staff can't reach the island, and deliveries of medication are delayed.

Cost of travel

The cost of fuel and public transport is high. Ferries are expensive. In many rural areas, people have to rely on expensive taxis because there is no public transport available. Covering staff travel costs is a significant expense for services delivering palliative care in remote, rural and island communities, that services in urban areas do not have to meet.

Maggie's story

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.

Names have been changed

Children and young people

Where specialist paediatric services exist, they are typically in larger towns and cities. Some rural families have to travel hundreds of miles to access services for their child. Some also make regular trips by air ambulance for urgent care. Parents are not always able to travel with their child if they have a lot of equipment.

The type of transport that is most suitable for an individual child depends on the specific condition they have, and their positioning and posturing needs. Some rural families said they had difficulties accessing appropriate car seats or wheelchair accessible vehicles to transport their child safely. Some parents do not feel confident driving alone with their child for long periods, in case they need to provide suction or another intervention. Transport services might not take children who are on oxygen, need regular resuscitation or are prone to stopping breathing.

Transitioning from one form of transport to another can be difficult. This can make it very hard for families who have to take multiple buses or when the bus stop is far from where they are travelling to. Rural roads often do not have pavements suitable for wheelchairs.

Rural families also need to drive long distances to a nursery or school that is able to support their child, or to access respite services or other activities. Families stressed that their children are not just 'palliative', they are children who want and need to live their lives and enjoy their childhood. They felt that professionals could sometimes be risk-averse and not understand their and their child's need to get out and about. This also impacts siblings.

Rafferty's story

Living remotely had always been a dream of ours, both as individuals and as parents. What we did not anticipate was our third-born arriving unexpectedly with a muscular condition, requiring extensive support; including a ventilator, feeding pump and a humbling amount of hospital and community input. Rafferty is perhaps best pictured as a quadriplegic, who will likely always depend on his wheelchair, a situation totally unsuited to our small cottage on a hillside in east Cumbria.

Even prior to Rafferty's birth, life could be a challenge due to our location, but was offset by the beautiful views and different way of life. However, the problems of raising a profoundly disabled child out here, is now almost insurmountable. Alder Hey Children's Hospital is two and half hours away, with our nearest hospital at Lancaster over an hour; something that is always in the back of our minds when Rafferty is unwell.

We have been fortunate enough to be awarded a continuing care budget, but finding carers here has been very hard. Whilst we are amazed that the NHS caters for us so remotely, it can be difficult for visitors to reach us, especially in the winter where some roads can be impassable. In fact, probably one of the biggest challenges we have faced in the past 18 months is a landslip that has resulted in the absolute closure of our main route out of the dale. What was 20 minutes to our nearest large village (where Rafferty's carer lives, we work and our older children go to nursery), is now 45 minutes via single track, gated roads. This has amounted to an additional 10-15 hours in the car each week, something that we can not only ill afford, but also increases Rafferty's risk of aspiration and other complications.

In stark contrast to the difficulties of landslips, relentless appointments and hospital admissions; the help from Jigsaw children's hospice in Carlisle is probably the single best thing that has happened to us. Although an hour and half away, they represent so much more than respite. The staff are incredible in every way; compassionate, kind, enthusiastic and knowledgeable. Practically, they are just as wonderful, trying to get us in on cancellations, offering us accommodation and family days, whilst being just as superb and inclusive with our two older children. Rafferty is supported and viewed as part of a family and not as a single patient, the power of which is almost impossible to describe in words.

Care and support

Experiences of palliative care

Nearly two thirds (60%) of people living rurally who completed our lived experience survey, said that they or the person being cared for with a life-limiting condition did not receive the care and support they needed. This contrasts with our professional survey, where the majority of staff (63%) felt that people with a life-limiting condition could access the care and support they needed in the rural area they worked in. This difference could be explained by people being more likely to share feedback if they had a poor experience of care. Or it could reveal a difference in the perceptions of staff and the care being provided, compared to the care that people actually want and need.

There was a breadth of experiences across the people we spoke to. Some people said their loved one experienced very good palliative and end of life care. People living in more accessible rural areas, with good transport links to a city or within a reasonable drive to a hospice, found it easier to access palliative care services.

There were many examples of individual staff in rural communities going 'above and beyond' to support patients and families. People felt that the support could be very personal and that a benefit of being in a rural community is that health and care staff know each other, and the patient and family, well.

> *“When we lost our son so suddenly, we had to rely on the kindness and bravery of our funeral director to drive his body to the hospice for us to spend the weekend with him. It was during a terrible storm and we really didn’t think she should attempt it. She did, bless her, and we got our weekend. But had she not dared take the 4 hour round drive along mountain roads then our very last chance to see our boy and spend some time with him would’ve been lost.”*
>
> *Bereaved parent*

Jenny’s story

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.

However, when the time came, my husband said he couldn’t do it at home. “I can’t. I need you to be you, to be my wife, not my carer.” So, we decided to spend his last four days in the local hospice. Again, we were very lucky with the support from the hospice team. I was able to stay with him the entire time, and nothing was too much trouble.

After his passing, I received six months of intense and important bereavement counselling. 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. I have no anger about what happened; everything was as perfect as you could possibly wish for. We were truly fortunate.

Names have been changed

However, many people we spoke to had a poor experience. Bereaved carers were angry and upset that their loved one was unable to get the support they needed. They felt strongly that there was an inequity of palliative care services in rural areas compared to urban areas. There was a lack of hospital or hospice beds close to them providing specialist palliative care. These could be several hours’ drive away over rural roads, or a trip to the mainland by ferry. People also said there was a lack of suitable care home places for people who need nursing care. In some areas, community hospitals had closed, further cutting local support. The lack of services meant some people had to make difficult decisions to be cared for out of their local area, far from their family, friends and support network.

Sarah’s story

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 [city] centric. There’s three hospitals in [the city] 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.

Names have been changed

> ***"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*

There was a tension between the views of some professionals that we spoke to, and the views of people receiving care and their families. Some staff felt that people had made the choice to live in a rural community and that they understood this meant they would have less access to services. However, the people we spoke to in rural communities told us that they shouldn't have to choose between 'place vs care'.

Care at home

One of the biggest challenges identified by staff and people living in rural communities was the lack of care available to support people to stay at home. In particular, the lack of social care.

> ***"No one was helpful. I felt I was banging on closed doors. I had to argue for everything. No one was in a hurry to help. My uncle had little time left and I felt I was spending more time trying to get help, equipment and carers than spending valuable precious time with my dying uncle."***
> *Bereaved carer*

People found it difficult to find carers to deliver packages of social care. In some rural communities, no care agencies operate because the travel times, higher costs and lack of available staff don't make it viable. Available carers don't always have the skills needed to care for someone with palliative care needs. This is distressing for patients, families and staff. Carer visits being restricted to 15 minutes also meant there is not enough time to provide the care needed. Some people had positive experiences of using direct payments to employ flexible, personalised support from people within their local community. However, others still found it hard to find carers or services locally.

Healthcare services are under significant pressure in rural communities. It can be hard for people to get appointments with their GP and GPs are unable to do many home visits. District and community nurses have to cover large geographical areas, which means it can take a long time to visit patients at home. It can also take a long time for healthcare staff to reach a person's home to verify a death. Staffing and funding challenges limit the services that hospice care organisations can provide to people's homes in rural communities.

Many families want to deliver care themselves but do not have the resources or support they need to do this. People struggled to get the equipment they needed or be trained to use it. It could take a long time to get equipment adjusted or for equipment to be taken away after it was no longer needed.

Out of hours care

Lack of care in the evening, overnight and at weekends was another of the biggest challenges reported by staff and families. Insufficient support overnight can make the difference between someone being able to be cared for at home and them having to go into a hospital or care home. Family members felt frightened and unsupported in the middle of the night having to wait hours for healthcare staff to visit to give pain medication.

> ***"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*

In some rural areas there are no district nursing or GP out of hours services. Out of hours teams are typically overstretched and have large geographical areas to cover, often with poor roads and limited mobile phone reception. This causes delays to people receiving care. Difficulties in accessing GP appointments and services during the day also has a knock on effect with more people needing to access services out of hours.

Access to medication

Swift access to medication and pain relief is challenging in remote, rural and island communities. Family members have to drive long distances, sometime to multiple pharmacies, to find medication in stock. Finding a pharmacy open outside of normal working hours is hard. This is stressful for family members, especially when they have to leave the person they are caring for alone, or for parents who have to take their unwell child with them.

Community pharmacies, pharmacy professionals and primary care staff are under a lot of pressure, which can lead to delays in getting medication. Family members felt anxious waiting for staff to arrive or having to make decisions themselves about giving medication without proper training. One family member said that their *Just in Case* box, which contains medicines prescribed in advance to quickly manage symptoms, wasn't fully stocked.

Co-ordination of care

Two thirds (64%) of rural health and care staff we surveyed said that the planning and co-ordination of services for people with life-limiting conditions and unpaid carers was not effective. People with a life-limiting condition, and those caring for them, found it hard to know what services and support are available locally and how to access them. Family members felt they were having to co-ordinate everything and be an advocate for the person they were caring for, which was difficult and draining.

People felt that their loved one could have benefitted from being able to access palliative care earlier and hospice care staff said they often received referrals very late from other services. This reflects wider issues, not specific to rural areas, where healthcare professionals may not recognise that someone could benefit from palliative care or feel uncomfortable having these important conversations with patients and families. Research also suggests that long distances to travel might mean older people living rurally delay or avoid accessing specialist care, which may impact their prognosis[17].

Sometimes the service closest to where someone lives is in a different local authority area, healthcare system or even nation. Having to access services across boundaries and borders can cause issues. Some people said they were not allowed to access services that are geographically closer to them because they do not live in that area. People living on the Welsh-English border reported issues with cross-border financing, staff not understanding what services they were allowed to access, and accessing certain medications.

> *"I shouldn't have to inform ambulances and medical staff that I pay my tax to England."*
> Carer

Staff working in rural communities felt that there was little focus on commissioning health and social care services to work well and flexibly across different areas. Island health boards in Scotland have complex service level agreements with health boards on the mainland for different services. This means people may have to travel to different health boards on the mainland to receive care.

At a local level, there were examples of good joined up care, for example co-ordinating joint visits. Local staff know each other well and have strong working relationships across different teams. Some individuals felt very supported by different services coming together to plan care and support. Individual staff often went to great lengths to be flexible and supportive. People living in Northern Ireland particularly praised the support that undertakers in rural communities gave in co-ordinating care and support after someone's death.

Children and young people

Many of the parents we spoke to had very challenging experiences accessing care and support for their child. They felt they were fighting against a system that didn't understand or support children with life-limiting conditions. This reflects wider systemic issues that impact families living right across the UK, not just in rural areas.

Children with life-limiting conditions may receive palliative care for many years before they need end of life care. Families we spoke to said they didn't have enough practical help and support at home. Recent research by the Disabled Children's Partnership has found significant failings in the provision of social care for disabled children[18]. A review by the Law Commission has shown the legal frameworks for children's social care in England are outdated, fragmented and do not meet the needs of disabled children[19].

These failures particularly impact families in rural communities where long travelling times and a lack of services already make daily life a challenge. Services in rural areas are more typically geared towards the needs of older adults, with few services suitable for children with complex needs. There might be care agencies that provide care services for older people, but none that provide care for children. Some rural areas have no provisions for young adults with complex care needs so they have to move out of their local area to access the support they need.

> ***"They couldn't find anybody from children's services, so they put out a call to adult services."***
>
> *Parent*

A recent report by Together for Short Lives reveals major gaps in the provision of 24/7 end of life care at home for children and young people across the UK, including in many rural areas[20]. Staff we spoke to said it was challenging to provide 24/7 care at home in a timely and equitable way to families living rurally. They felt that having more support out of hours and better outreach services would mean rural families would be more likely to choose end of life care at home for their child.

Over three quarters of rural health and care staff we surveyed, who provide care to children, felt there was ineffective planning and co-ordination of care. Families said care felt disjointed. They often have to travel between multiple hospitals to access care for different aspects of their child's condition. Local community hospitals typically provide limited or no care for children. One family living on a Scottish island had to travel to respiratory and cardiology specialists in one hospital on the mainland, and neurology specialists in a different hospital in another city, because of different contracting arrangements for specialist services.

Local staff in rural areas may be much less familiar with supporting children with complex needs because of the low numbers of children with life-limiting conditions living there. Parents felt unsupported and that they had to 'pave the way' with services in their local area. Families were particularly concerned about what would happen if their child needed to transition to adult services.

> ***"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 [that] taught us what to do for the best. It meant a really unclear and unsuccessful path for our son."***
>
> *Bereaved parent*

Health and care workforce

Staff shortages and skills gaps

Two thirds (65%) of rural health and care staff we surveyed said there were not enough staff with the right skills to support people with life-limiting conditions in the rural community they worked in. In Wales and Northern Ireland this was even higher.

The most consistent workforce shortages highlighted were a lack of social care staff and community nurses, particularly out of hours. Recruiting staff with appropriate palliative care skills was also challenging. District nurses said that they were sometimes unable to recruit into positions, so had to employ less qualified staff.

Staff also reported shortages of GPs and community pharmacists, and shortages in specialist palliative care, including consultants and medical staff, nurses, healthcare assistants, allied health professionals, psychologists, social workers and therapists. Some hospices found it harder to recruit volunteers in the more rural parts of their catchment. Staff were also concerned about the high proportion of people delivering palliative care who are approaching retirement age. Across the UK, over a third of the hospice clinical workforce is aged over 55. In Wales it is even higher, at nearly half[21].

There are fewer NHS staff per head of population in rural areas compared to urban areas[22] and staffing shortages are reported to be higher in rural areas[23]. The proportion of working-age people in rural and coastal areas, who are able to provide care, is reducing at the same time that demand for health and care services is growing[24].

Rural areas struggle to attract healthcare staff because of a perceived or real lack of opportunities and amenities compared to better connected urban areas. Retaining staff can be difficult due to limited opportunities for skills and career development, and fewer professional support networks. A lack of affordable housing and higher cost of living make it harder for health and care staff to afford to live in rural areas. Coastal, island and certain rural areas also have issues with 'seasonal' staffing where tourism or other seasonal industry pays better during certain months. This ebb and flow of staff particularly affects lower paid staff, such as social care staff and healthcare assistants, who play a crucial role in providing palliative care.

> ***"Where we live, there's so much tourism. Even if there were services, they can't be staffed because tourism pay so well."***
> *Parent*

Impact of shortages and skills gap

Staff reported instances of poor care because there were not enough staff on shift to visit all palliative patients or there were long delays reaching them. Staff sometimes did not have the right skills to support patients with palliative care needs.

> ***"It is extremely stressful for relatives when they are caring for their loved one and clinical teams visit that often don't have the right skills and expertise to help. Particularly out of hours because it takes such a long time for clinical teams to get [there]."***
> *Bereaved carer*

Shortages in community and social care staff mean that patients and unpaid carers have less support at home. They are more likely to reach crisis point and need unplanned care and emergency admissions to hospital. It can also take longer to make appropriate care arrangements to allow them to come home after being in hospital.

> ***"A neighbour passed away before help could be arranged due to [their] home being very isolated"***
> *Healthcare assistant*

Staffing shortages have a greater impact in rural and island communities than in urban areas. With fewer staff available to cover large geographical areas, particularly out of hours, there is less flexibility to ensure enough staff are available to deliver care. Staffing pressures on one service have a significant knock-on effect on other services. Staff may experience stress and burnout, leaving services further understaffed. Staff retiring can also have a big impact on the delivery of palliative care services in rural areas[25].

> ***"In one of my teams there is often only one RGN [registered general nurse] on duty to cover a large rural area, meaning it is sometimes impossible to visit our palliative patients"***
> *District nurse*

Some rural services delivering palliative care need to rely on bank or locum staff. This can make it harder to provide adequate staff cover at weekends, overnight and holiday periods. It also makes it harder for patients to build relationships with staff. Strong relationships are especially important in palliative care to build trust and ensure care is person-centred.

Working in a rural area

Providing palliative care in a remote, rural or island community is a different experience to working in a big town or city. The lower number of people living in rural communities means that demand for palliative care services is unpredictable and can vary day to day. This makes it difficult to plan what staff are needed to cover an area.

> *"Work load is unpredictable as there are times when staff have no work and times when there are too many patients for the number of staff available."*
>
> *Hospice care at home nurse*

Lone working can be hard, especially in areas with poor roads, bad weather and no mobile reception. Staff need to be adaptable and comfortable 'working in the grey' in order to navigate complex, potentially challenging, situations in people's homes with limited support. Rural staff said they are more likely to work at the top of or sometimes beyond their scope of practice in a rural community. Some professionals felt working rurally was less suitable for newly qualified staff.

Staff also felt that there were lots of positives about working in rural areas and had a lot of job satisfaction when supported to work in a way that allowed them to meet the needs of people living rurally. This requires staff to be appropriately trained, with governance structures that recognise and support the different levels of risk involved in providing care to rural communities.

In some rural areas, such as on islands, staff live in and are part of the community they work in. This can be positive, bringing strong relationships and understanding of the local community. However, it can make it harder to maintain the privacy of patients and maintain professional boundaries. Staff travelling into a small rural community to carry out home visits are also easily recognisable.

Children and young people

Nearly three quarters of health and care staff surveyed who provide care to children with life-limiting conditions in rural communities felt that there were not enough staff with the right skills. This is higher than for staff providing care to adults.

Community children's nurses (CCNs) provide the bedrock of children's palliative care in communities[26]. However, there is a severe shortage of CCNs across the UK, including in rural areas. There is also a shortage of specialist consultants in paediatric medicine. This means in many parts of the country, access to specialist advice is not possible. These staff shortages have a bigger impact in rural communities where staff have to cover very large areas. The relatively low numbers of children with life-limiting conditions living rurally also mean there is less flexibility to provide more staffing if additional families need support or if a child's condition deteriorates.

Families emphasised that it's not just about clinical staff. They wanted more staff in wider roles who can support their child and family, including social care staff, family support staff, social workers and allied health professionals.

Families said that health and care staff in rural areas often did not have the skills or confidence to support their child because they had not encountered a child with such complex needs before.

> *"Nobody in our rural area was familiar with or trained in severely disabled children. Even stays in our local hospital meant we were showing staff how to use tubes for feeding"*
>
> *Parent*

Some local staff felt that specialists based in urban areas did not always understand the needs of families in rural communities and were unwilling to adapt how they offered services, for example making more visits or offering virtual support.

Family and unpaid carers

About two thirds (62%) of the carers who responded to our lived experience survey said they did not receive the support they needed when caring for someone with a life-limiting condition. A lack of support impacts carers' physical and mental wellbeing[27]. They are more likely to reach crisis point and be unable to care for their loved one. This could lead to the person they are caring for being admitted to a hospital or care home far from where they live.

> ***"If the family all break, that is way more expensive to society."***
> *Parent*

Carers told us they weren't trained in giving medication or using equipment. They had to make difficult decisions alone about whether to give medication or call an ambulance if the person they were caring for deteriorated. They wanted the reassurance of being able to speak to someone on the phone quickly when they needed support or advice, but this often wasn't available. They were frightened having to wait hours for staff to arrive in the middle of the night. This weight of responsibility took an emotional and physical toll.

This aligns with wider research showing many carers in rural communities caring for someone with a life-limiting condition feel unsupported and unprepared in their caregiving role[28]. Some rural carers we spoke to felt that there was an expectation from professionals that they would take on the bulk of the caring role and an assumption that people in rural communities didn't need support.

Carers wanted practical help with daily tasks such as collecting medication and food shopping. They needed access to respite, whether in someone's home for a few hours during the day or overnight, day care services or short breaks. However, there are limited and patchy respite services in rural areas, or these are several hours drive away, which defeats the point of using them.

> ***"When social workers come and sit with you, they will give you all the talk. Yes, we'll have a MDT [multi-disciplinary team] meeting. We'll organise services. But the reality is there's nobody's to deliver that service. So it's all lip service. Giving us that respite is not going to happen."***
>
> Carer

People in rural communities can face significant social isolation, particularly after experiencing a bereavement. Carers talked about the importance of having emotional support during their caring role and into bereavement, through peer groups, their local community, online support and bereavement services such as counselling. After their loved one died, some carers said the support and contact from professionals stopped overnight. They were left struggling with a loss of identity with the end of their caring role. This can have a lasting impact and lead to complex grief, especially if their loved one didn't have the kind of death they wanted. Bereavement support is hugely important but it is patchy and inconsistent in rural areas.

Diane's story

My father was never actually admitted to hospital. It was his GP who said he's not going to recover. He had prostate cancer and it progressed into his bones. I didn't find support from carers whatsoever. So it was really me, my sisters and my mum who looked after Dad.

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 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.

Names have been changed

Children and young people

Caring for a child with a life-limiting condition has a huge impact on families and carers. Families struggle to get the support they need and are left to plug this gap themselves. Although Section 17 of the Children Act 1989 places a duty on local authorities in England to promote the welfare of children in need, many parents of children with life-limiting conditions said they struggled to access adequate support due to inconsistent application of the law, limited resources, and a lack of tailored support for children with complex care needs. Some parents we spoke to were driven to desperate lengths by a system that was not set up to support them.

> ***"I nearly actually gave both of my children up for adoption. Because that's how bad stuff got."***
>
> *Parent*

This lack of support has a greater impact on families in rural communities because there are so few services for children with complex needs. Rural families struggle to find carers. Some felt that there was an expectation from professionals that they could rely on informal support from their local community and wider family. There was also a general assumption that, as parents, they would provide 24/7 care to their child.

> ***"There is no overnight or short stay care in our area. To get a sitter for 2 hours a month took 2 years to find. In 13 years with our disabled child, we never had carers at any point in our home as it was too difficult to source people."***
>
> *Parent*

There are a lack of suitable respite services in rural communities. If respite is offered, it could be too far away, too rigid or not what the family actually needs. Families wanted more flexible, person-centred support to fit around what they and their child did need. The support and social connections they made when visiting children's hospices were highly valued. However, for some, these were very far away which limited the support they could receive.

Some rurally-based parents were upset that they had to take on roles that they had told staff they were uncomfortable doing, such as carrying out medical interventions and giving medication to their child, because of a lack of formal services and long delays in staff reaching them.

Living in a rural community

Community support

Being part of a close-knit rural community has strong benefits. Friends and neighbours can provide practical and emotional support. Local community groups can offer support to someone throughout their caring role and into bereavement. Informal links can help people find local carers to employ.

> ***"My neighbours are extremely good. We get things delivered to the quay and my neighbours bring them up for me. So on my front porch I often find parcels and things brought up during the day. I've come to the best place for a community. In London it's everyone for themselves. Here it's completely different."***
>
> *Individual with a life-limiting condition*

Tourism and the rise of holiday homes can impact rural communities and mean that long-term residents lose their local support networks. Some people who move into to a rural community, for example during retirement, may be seen as a 'newcomer' for years or decades and not have the same support networks. Some people living rurally are very socially isolated, especially if they live alone.

Some people felt that professionals assumed that because they live rurally, they are 'very independent' or would have lots of support from their local community, so wouldn't need more formal support. However, this expectation sometimes created gaps in care, particularly for those who did not have a strong local support network. Some people felt strongly that having community support was not a replacement for actual paid services.

> ***“Rural people are very much: we’ll just get on with it, we’ll just do it ourselves. We’ll just sort everything out ourselves. But I know when it comes to situations like this, you can’t sort it out yourself. We need that expert help.”***
> *Carer*

Connection to place

People we spoke to who had grown up or lived a long time in their rural community, had a deep-rooted connection to where they lived and wanted to maintain this connection at the end of life. People spoke about the positive benefits of being close to nature. The familiarity and emotional ties to where they lived provided a sense of comfort and stability, and offered moments of peace and reflection at a difficult time.

This connection to place meant people often want to stay in their own home or within their local community at the end of life. People spoke of having to make difficult decisions about whether to stay in their local community or move far away to be closer to healthcare facilities, where families and friends would not be able to visit often. This was particularly the case for people living in island communities. Some people felt that their loved one’s condition deteriorated more quickly when they had to move away from their local community.

> ***“A lot of people in rural communities want to die at home, in their own place. But we find it more difficult to get carers to do that. So people through no fault of their own then end up somewhere in the middle of a built up area in a town where they’re not used to and, actually, they deteriorate a lot more and a lot quicker. Because they’re not with their family.”***
> *Bereaved carer*

Culture and tradition

Many rural communities, for example Scottish island communities, have a unique culture and strong local traditions surrounding death, dying, and bereavement[29]. Faith can play an important role. Some islanders are reluctant to ask for help or seek healthcare on a Sunday. Some people felt there was not enough faith-based and culturally sensitive support for communities.

In farming communities, death is seen as a natural part of life. But farming communities can be reluctant to seek care and support, and to talk about their needs at the end of life. This could be due to a strong attachment to the land and worries about what will happen to the farm. It can also be because they assume that family members will provide the necessary care.

People we spoke to in Northern Ireland said that Irish people are often perceived as being ‘good at death’. They felt that this was true after someone had died, where rural communities have strong local support systems and the wake is an important cultural practice. However, they did not feel there was the same level of support before someone died and that people were uncomfortable talking about dying and planning ahead.

People also talked about stigma in some rural communities surrounding certain types of death, such as death from suicide. This affected the support available to grieving families and can further complicate the bereavement process.

Catherine's story

When my grandmother died, she had to be repatriated and to do that, we had to use [service] in order to pass her body from [place] onto the boat and then her body was lifted into the coffin hold, which is built into all the ferries to repatriate people.

And then when it came to bringing her body off, they took all the tourists off first and the other traffic. It's out of respect. So people from the island would all come to the pier to meet the person coming off the boat. Because you see, everybody knows everyone and is interrelated and so they would know that the body was coming over on the boat. And then the crew, they take off their hard hats and they stand and bow their heads as the hearse reverses on and then the coffin is moved and then the family come off behind. And then the community often fall in behind and walk or drive behind the hearse back to the home where the body then is placed in a coffin in the house for a time. Usually just a few hours, rather than a few days.

The coffin then goes onto trestle tables outside the house and the service is there. I remember the whole community coming across. They all just kind of came as, almost like a cloud of black, to come and stand with us as we had the funeral. And then proceeded to the graveside to be buried in a family grave, with members of the family who have been buried there for over 300 years.

Names have been changed

Language

An estimated 538,000 Welsh speakers live in Wales, 18% of the population[30]. Gaelic is spoken by over 57,000 people in Scotland, including about half the population in Eilean Siar (the Western Isles)[31]. Nearly 6,000 people in Northern Ireland have the Irish language as their main language, with 44,000 speaking Irish daily[32].

Welsh-speaking people in our focus groups said it was '50-50' that Welsh-speaking staff were available. They felt that staff having even a few phrases of Welsh could help with communication and creating a rapport. They also talked about the importance of having resources, such as care planning forms, available in Welsh. In Scotland, some people felt there was a lack of Gaelic speaking staff providing palliative care. For example, there are only two palliative care consultants who are native Gaelic speakers.

People are more likely to revert to their first language in later life, especially if they have dementia. Studies have shown that caring for people with dementia in their preferred language, such as Welsh, improves their wellbeing[33]. Not doing this results in communication barriers, which could lead to inappropriate care and social isolation. Migration and the resettlement of refugees mean that rural communities have a diverse range of languages and cultures, that need to be considered.

Cost of living

The cost of living in rural and island communities is significantly higher compared to urban areas[34]. Bills are higher for utilities, council tax, travel, petrol and food. These increased costs exacerbate the financial strain that individuals and families are already dealing with when someone is dying[35,36]. Families caring for someone at home at the end of life have high energy bills because of running medical equipment, using the washing machine and dryer more often, and having the heating on. Some rural homes are not on the gas grid and use alternative fuels for heating, such as oil or coal. These households are more likely to experience extreme levels of fuel poverty, because their homes are not energy efficient[37]. In Northern Ireland, two thirds of households use oil boilers as their main source of heating[38].

> ***"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 so that if your child is on palliative and hospice care, that you can apply for an electricity discount, or grant?"***
>
> *Parent*

Rural deprivation can be severe and is often hidden. Some people said professionals assumed, wrongly, that they were wealthy because they lived in a bigger house. Some deprived rural areas have low levels of car ownership, so people are more reliant on expensive public transport. Family members may have to give up work to provide care, especially parents of a child with a life-limiting condition.

> ***"There is a gulf between those living in remote and rural areas with a strong network and finances and those that may be living in deprivation without strong networks – they may be the last member of their family, they may have rarely used health services before and don't seek help early enough or at all. It is not a level playing field at all."***
> *Hospice staff*

In farming communities, it may not be possible to stop working on the farm. This places a greater burden on family members, puts the farm at risk and can lead to complications around inheritance. Owning assets, such as a farm, may mean people are not eligible for financial support but they are still living hand to mouth.

The complexity of the welfare system can make it exhausting and overwhelming to apply for support[39]. A lack of information on social security and financial support often leads to people being unaware of what they are entitled to. And when people are aware, they often have to fight to receive it. Research has found that the UK welfare system is poorly adapted to meet the needs of people living in rural areas[40]. There are lower rates of people claiming benefits in rural areas. It's hard to access advice about what to claim particularly in areas with poor internet or phone coverage. People also have to travel for longer to get to medical assessments. There can be higher levels of stigma about claiming benefits in rural areas and some people do not want to seek support locally, for example from food banks, in case they are seen by members of their community.

Housing

There is a lack of suitable and affordable housing both for people living in rural communities, and for health and care staff working there. There is a particular shortage of bungalows, level access and adapted housing[41]. It can be expensive for people with life-limiting conditions to maintain and repair their homes. They can also experience difficulties and long delays getting adaptations to their homes to make them suitable as their care needs progress. People said there were advantages and disadvantages to living rurally. For example, having a larger home and more space to accommodate medical equipment, that wouldn't be possible if they were living in a small city flat. However, the running costs are higher.

The shortage of housing makes it expensive for health and care staff to live and work in rural communities, particularly combined with high travel costs to get to work. This makes it harder to recruit staff to the area and impacts the delivery of palliative care, especially from lower paid staff such as social care staff and healthcare assistants.

Children and young people

Many parents spoke about how invaluable the practical and emotional support they received from local friends and neighbours was. For example, helping with school runs for their other children. However, some parents had more complex feelings. They were uncomfortable accepting help as they did not want to feel indebted when they couldn't return the favour. They felt limited in what they could ask, as other people wouldn't have the skills needed to look after their child, and they also wanted to maintain their privacy.

Having peer support and making connections with people who understand their experience is incredibly important. However, in rural communities, there are often no other families with children with similar needs. Parents felt isolated and alienated. They did not feel comfortable going to local parent groups where other people wouldn't understand their situation.

> ***"I can't communicate with those other mums because the moment I say anything, I kill the conversation. I'm a social pariah."***
>
> *Parent*

Families with children with life-limiting conditions are particularly impacted financially. Parents often have to stop working and give up their careers. This has a huge impact while trying to care for their child at a time when energy costs and other bills are substantially higher. It also has long-term implications, for example if they are unable to pay into pensions. It can be difficult getting back into work after their child has died because they lack confidence and because of the lack of local employment opportunities rurally. Parents stressed the importance of being able to access proper financial advice.

> ***"We were £30k in debt by the time [our child] died."***
>
> *Parent*

2

How can we improve support for people with life-limiting conditions and their families?

Collaboration between services in partnership with local communities

In rural communities, resources are stretched thin across large geographical areas. Staff need to work creatively and flexibly across services, and build on what is already available within local communities.

Collaboration between generalist and specialist palliative care

GPs, district and community nurses, social care staff and community pharmacists provide the backbone of palliative care in rural communities. These generalist staff typically have a deep understanding of the local area and the needs of their local communities.

Research shows that models of palliative care delivered by generalist staff, with leadership from a specialist palliative care team, can improve the provision of services for patients and their families in rural areas[42]. By collaborating with local health and care teams, specialist palliative care staff can tap into local knowledge and establish strong community links. Staff can work together to provide integrated care, with specialist palliative care staff providing expertise, leadership and training in palliative care.

> ***"It is important to understand the community and I have found having local community children's nurses on board really helpful in understanding the needs of rural families."***
> *Consultant in children's palliative medicine*

Local health and care staff must be able to access specialist palliative care advice and support whenever they need it. This could be through local arrangements such as locally staffed palliative care advice lines, or contracted arrangements with services further afield, for example island health boards in Scotland having service level agreements to access specialist advice from health boards on the mainland.

There are a range of ways generalist and specialist staff can work more closely together in rural communities. These include regular multi-disciplinary team meetings between GPs, district nurses, pharmacists, hospice care staff and others to identify patients with palliative care needs and co-ordinate care; hospice-run outreach clinics at rural GP practices; palliative care link nurses in GP practices and community hospitals; joint initiatives with ambulance services; and shared posts and integrated teams. The enhanced skills of advanced nurse practitioners, advanced clinical practitioners and non-medical prescribers also have an important role in rural communities.

Education and training

Hospice care teams are ideally placed to provide palliative care education and training to wider health and care staff in rural communities. Highland Hospice, for example, runs a Rural Fellows ECHO programme on palliative and end of life care for GPs working in rural areas and a non-medical prescribing ECHO in adult palliative care[43]. Some hospice care organisations support and provide palliative care training to care homes and to social care staff delivering domiciliary/home care. This is particularly valuable given the key role of social care staff and the skills gaps identified in rural areas.

Paramedics play an important role in rural communities. In some areas they may be the only service that can reach people. The Scottish Ambulance Service and Macmillan have run a successful joint education initiative where specialist palliative care staff work with paramedics to improve confidence, knowledge and skills around end of life care. This has had a positive impact for people in rural communities[44]. The Welsh Ambulance Service has had palliative care paramedics for a number of years and has recently been piloting a new rapid response service[45].

Working in partnership with local communities

Engaging with local communities allows hospice care organisations and other services to better understand what is important to people living there. It can help staff to understand local cultural practices around death, dying and bereavement and unpick local dynamics, for example, where people in a local area are likely to travel to access services. This helps shape services to suit the local culture and context. Building trust and creating strong relationships takes time.

Working in partnership with local communities helps raise awareness and understanding of hospice and palliative care, and address misconceptions. Because hospices are typically based in urban areas, rural communities can have less exposure to and knowledge of hospice care[46]. Hospice care staff being visible at local community centres, cattle markets and libraries, can encourage conversations and greater openness around death, dying and bereavement. This is particularly important in rural communities, where there can be a reticence to discuss end of life plans and where it can take a long time to put care arrangements in place.

Rural areas can have a rich network of community resources, such as local community hubs, volunteer groups and activities. Key individuals and community groups can help services make local connections. Recruiting rural hospice care volunteers who could act as local connectors was seen as an 'untapped resource'. By identifying and building on what is already available in a community, services can build links between informal support and professional services. These community networks should complement, not replace trained professionals and formal services. They should be valued and appropriately resourced.

> ***"Local community groups are where relationships are built and social connections made. These are the communities who will provide the majority of the support (practical and emotional) for people as they become more poorly or are bereaved. We need to ensure they are as well prepared and able to recognise the value of their input."***
>
> *Hospice care staff*

There are a growing number of compassionate community and community development initiatives that support palliative care, for example Compassionate Inverclyde[47]. Some hospice care organisations have partnered with local community groups to provide information and training to people in rural communities. Some have taken services and resources to farming communities, community centres and local events. Building strong partnerships can have a lasting impact. For example, the South West Peninsula Palliative Care Research Partnership brought together universities, hospices, voluntary and community organisations, health research agencies, and individuals to identify community-based support needs for underserved rural and coastal populations in Cornwall, Devon, and Somerset[48].

Case study:
Compassionate Communities Northern Ireland

Accessing palliative care in rural Northern Ireland presents significant challenges that affect the quality and timeliness of support for individuals with life-limiting illnesses and their families. Services are often stretched over vast areas, and the centralisation of treatment centres in cities compounds these issues, leading to accessibility difficulties, financial strain, and added stress due to long travel distances.

Compassionate Communities NI is dedicated to enhancing health beyond the formal healthcare system through active social support. By fostering community-based initiatives, they work to increase death preparedness through Plan Ahead workshops and promote compassionate responses via the Compassion in Action programme.

In the sparsely populated southern sector of the Western Health and Social Care Trust, there is growing concern for older people with palliative care needs, many of whom live alone. To address this, Compassionate Communities NI is part of a coalition called Co-creating Hope, which brings together cross-sector professionals dedicated to redesigning the system through collaborative approaches. This coalition strives to meet the unique needs of the ageing rural population by leveraging collective expertise and building partnerships.

Through Co-creating Hope, the aim is to develop sustainable solutions that bridge the gaps in palliative care and ensure compassionate, accessible support for rural communities, ensuring that no one faces these challenges alone.

Case study:
The Farming Community Network partnership with Macmillan Cancer Support

The Farming Community Network (FCN) are involved in a UK-wide partnership with Macmillan Cancer Support to help improve the support available to those living with cancer in farming communities and rural areas.

Farmers, farm workers and people living in rural communities can have lower access to cancer services and support due to the nature of their work and rural life in often isolated areas. Farmers can be particularly at-risk of certain types of cancer – such as skin cancer, prostate cancer, or cancers caused by exposure to carcinogens.

Cancer can impact a family business that may employ many people and can have significant impacts on an individual and their families, including their housing and extended family situation, or immediate welfare issues for livestock.

The partnership aims to raise awareness in rural communities of the signs and symptoms of cancer and build referral bridges to and from Macmillan Cancer Support's services. FCN run a confidential helpline where people can talk to volunteers who understand rural and farming life. They have also developed resources as part of their 'Nip it in the Bud' campaign.

Local strategic partnerships

Local health and care systems are responsible for commissioning and delivering palliative care services that meet the needs of adults and children living rurally in their area. They must specifically consider their needs in local strategies and delivery plans for palliative care, and ensure that rural communities have access to funded specialist palliative care that is co-ordinated with generalist care.

Local strategic partnerships should drive robust strategic planning and collaboration across all relevant partners, including commissioners, community health and social care services, hospice care providers and local community organisations. Partners should work together to understand what people, of all ages, in rural communities want and need, and what good care looks like to them. They should assess what palliative care is available locally, how people are using services in rural areas and their experiences of care. They can then identify where there are gaps and pressure points in the system, and work together to develop local solutions to address these, building on existing resources. Analysing local service data and using Hospice UK's population needs assessment tool, PopNAT[49], can help inform this. Partners should also work towards having joined up IT systems so that data and information can be shared across services.

Case study:
End of Life Care Together partnership, Highland

At the end of life most people would prefer to be cared for at home. However, in Highland 75% of annual identifiable end-of-life care expenditure (£45m) is spent on hospital care and individuals in their last year of life account for:

- ▷ 1 in 5 emergency ambulance conveyances
- ▷ 1 in 4 unscheduled attendances to hospital
- ▷ 1 in 3 occupied unscheduled beds in hospital.

End of Life Care Together is a partnership of Highland organisations with the aim of improving palliative and end of life care for people when it matters most. Led by NHS Highland and Highland Hospice, other partners include Macmillan Cancer Support, Connecting Carers, Marie Curie, Highland Senior Citizens Network and Scottish Care.

Through the collaborative partnership they are delivering value and better care for the population. By working together, increasing identification of those needing palliative care, co-ordinating care and providing rapid response to care at home, the partnership is reducing admissions to hospital and reducing delayed discharges. This is especially important to meet the differing needs of this population, given the remote and rural nature of Highland Health board and the variation in how services are delivered across its disparate geography.

Two key components of the End of Life Care Together partnership are paving the way for this transformation: the 24/7 Palliative Care Helpline and the Palliative Care Response Service fast track social care.

The 24/7 Palliative Care Helpline supports the public, primary care, ambulance service and care homes. Individuals benefitting from the helpline (970 between May 2023 and September 2024) spent on average four fewer days in hospital toward the end of life. In Highland this equates to £3.8m in savings.

The Palliative Care Response Service provides rapid access to care at home, utilising the social care tariff. This results in an average of 20 fewer hospital bed days per client, delivers net savings of £18,900 for every individual supported and provides the care people want.

Case study:
Collaborative approach, North Cumbria

Eden Valley Hospice is based in a city but serves a vast community covering 2,614 square miles in a county which is home to the Lake District and many mountains. It can take more than two hours to get from one corner of the county to another.

The community of professionals supporting people at end of life is wide and varied. After COVID-19, local partners developed a collaborative day of learning to bring people together face to face. This was led by hospices, the main trust, primary care and commissioners and gave an opportunity for learning, networking and the chance to hear from Dr Kathryn Mannix.

There were planned opportunities to identify the things that helped a good death and where the gaps in the system are. Bringing people together in this way meant there was representation from a range of organisations, areas of the county and sectors of work and those involved were able to learn more about the wider support that could be accessed when everyone went back to base.

This galvanised people into action around improvements for patients and supplied evidence about the gaps that needed to be tackled. Building on existing work and relationships, partners were able to demonstrate energy for improvement which the Integrated Care Board has formalised into a workstream which the hospices chair. This work is bringing people together to see what can be done better together for the community. Strong relationships built across services are now influencing system leaders to support a more collaborative approach.

Children and young people

Local health and care systems need to understand the full range of support that families need in order for their child to live well with a life limiting condition in a rural area, and how this varies depending on age, level of need and complexity.

It is harder to plan and deliver sustainable children's palliative care services because of the small number of children living with complex needs in sparsely populated rural areas, compared to more densely populated urban areas. It is therefore even more important that services work flexibly and creatively together, based around what is available locally. This relies on strong collaboration and partnership working between services and with families. There also needs to be strong relationships between children's and adult services, especially to support the transition to adulthood.

Recommendations:

- Local health and care systems, 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.
- Local health and care systems, 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 understand what is important to people with life-limiting conditions of all ages living rurally, address gaps in palliative care in rural communities and improve palliative care education and training.
- 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 should ensure that IT systems are joined up, and data and information can be shared across services.

Deliver more palliative care at home and closer to home

People in remote, rural and island communities urgently need more community-based palliative care. This would allow people to maintain their connection to where they live, prevent long and expensive journeys to access care, and help stop people ending up in hospital unnecessarily, far from their home and local support network.

> ***"In rural communities we need to bring support to the people."***
>
> *Hospice care manager*

Delivering more care in the community is a key policy aim across the UK's four nations. The experiences of people in remote, rural and island communities will be a key measure of success of how well this policy aim has been achieved. It's also an opportunity to learn from the positive approaches and collaboration happening in rural communities and how this could be applied elsewhere.

Yet, currently, there has been limited progress and shift in resources to drive more care in the community. Expanding palliative care services at home, and closer to home, is only possible with appropriate funding and investment in community health and social care services, including hospice care. Hospice care organisations are key providers of palliative care in the community and have the potential to do so much more. However, they can only innovate and expand their services to meet growing demand in rural communities, if they are sustainably funded. Currently hospice care organisations rely on charitable funds for the majority of their income and the limited statutory funding they receive hasn't kept pace with rapidly rising costs and growing demand.

Delivering palliative care at home

Delivering more palliative care in remote, rural and island communities, requires creativity and flexibility. What works best will depend on the local context and how palliative care services can adapt around existing local support. Types of care that hospice care organisations are delivering to people in their own homes in rural communities include:

- **Flexible, intensive support:** Some hospice care organisations have developed very localised, intensive support delivered in someone's home in a remote or island community, in partnership with local services, for a period of time at the end of life. Staff travel from further afield and stay locally for a few days at a time, for example in local NHS accommodation. These staff support local carers, and rotate through a shift pattern to support the person at the end of life.

Case study:

Marie Curie Hospice Care at Home in island communities

Marie Curie Hospice Care at Home provides clinical and emotional support to patients in their own homes. Referrals are prioritised using a bespoke prioritisation tool which helps determine need. Patients are supported by teams of healthcare assistants and registered nurses, who in urban areas usually live within 25 miles of the patient's home. In more rural locations, a more flexible approach is needed, with staff prepared to change rota working patterns to meet patient need and travel logistics.

A patient living on a Scottish island was referred to Marie Curie and was assessed as needing a registered nurse to manage their complex symptoms. There were no nurses on the island or within 25 miles of the ferry terminal able to travel. Marie Curie's Clinical Nurse Manager contacted nurses across North and West Scotland who agreed to change their rostered shifts to accommodate travel times for the ferry. A nurse (who was three hours' drive from the ferry) supported the patient for three consecutive nights and stayed in NHS accommodation. This met patient need and made the best use of travel time.

The following week the patient continued to require care every night. This involved collaborative planning between the community nurse, GP, Marie Curie and other health care professionals. The Clinical Nurse Manger again reached out to the wider nursing team across all of North and West Scotland asking if anyone was able to travel. For some nurses, flights from Glasgow could be closer and quicker than driving to a ferry. One nurse from outside Glasgow agreed to attend and again the rota was adjusted to accommodate travel and support the wider care team's plans for cover. Once the nurse arrived on the island they were able to use an NHS car to get to the accommodation and to travel to and from the patient's home.

Key Learning:

- Partnership working is key when co-ordinating planned care provision.
- Marie Curie has an important role to support end of life care in rural and island communities.
- There needs to be a flexible, responsive and adaptable model that benefits the patient and family, and the wider health care system.

- **Hospice care at home:** Hospice care organisations deliver a range of specialist and generalist palliative care to rural patients at home. The type of service depends on where they have identified a need or gap locally. For example, providing more visits in the evenings and overnight or having hospice care nurses step in to support local rural teams at times of high demand. Visits might provide specialist care focused on symptom control, or more generalist care such as respite, night sitting services and wellbeing services such as complementary therapy. Some hospice care organisations have introduced virtual wards where patients are supported at home and reviewed daily by a specialist multi-disciplinary team. Others have introduced rapid response or crisis teams to quickly put in support for a patient whose condition deteriorates.

Case study:

St David's Hospice Care overnight Hospice at Home service, Powys

St David's Hospice Care has extended an overnight Hospice at Home service to help support patients and families in rural Powys. Powys is a rural, agricultural county without a district hospital or an out-of-hours district nursing service. Nursing home and care service provision are also very limited.

St David's decided to expand their Hospice at Home services, to better meet the needs of patients and carers in the community. They employed two dedicated part-time nurses to support patients to remain at home for as long as they wish, by helping with pain management, symptom control and reassuring patients and their families. The service has been really valuable to patients and families:

"Such an amazing service; dedicated and caring nurses. Allowed mum to stay at home."

"You provided a service that the NHS does not (but should) provide."

Given that those in rural communities often have a close relationship with their district nurses, St David's works with the local district nursing teams and other primary care providers, to raise awareness of the Hospice at Home service and encourage referrals.

Key learning:

- Partner with other services to meet local demand.
- Think about the area you cover – you might need to expand your catchment area to make sure there is enough demand.

- **Providing social care:** Some hospice care organisations are filling gaps where there is a lack of care workers to provide packages of social care in rural communities. They provide domiciliary/home care services from their own staff trained in palliative care, or train teams of carers in palliative care led by a district nurse or specialist palliative care lead. Some hospice care organisations provide an agreed amount of domiciliary/home care support to make existing care packages more resilient. Some hospice care organisations in England have been accessing Continuing Health Care funding to provide services.

Case study:

Supporting complex care packages, Eden Valley Hospice

In remote and rural areas it can prove hard to find care workers to support complex packages in a way which is resilient. If someone is living with a degenerative and palliative condition in a non-metropolitan area it may mean that their ability to live at home with a decent quality of life can be challenging.

Adam was diagnosed with Motor Neurone Disease and lived in a small village. While his family were able to find excellent carers, the package was fragile because they couldn't find enough to cover the hours without breaking the European Working Time Directive. The extent of the care needed meant it was difficult to make it manageable for carers, Adam or his family without the imminent risk of package breakdown.

The hospice was funded to provide one week in four for the last 18 months of his life which stabilised the package and ensured Adam received the consistency of care he needed. It also meant he built strong relationships with the team and was confident in his preferred place of care and death at the end of life.

There were no care homes locally that could meet his needs, and it is likely he could only have found that support out of county, much sooner and at much greater cost to the system and his family life. Fragile continuing health care cannot be commissioned as the package needs to be safe and resilient to meet the requirement for funding.

This approach enabled him to have much more control over his care. The specialist level of care hospices can provide can make a real difference to health and care systems when those systems are already under pressure.

Names have been changed

- **Single point of access palliative care helpline:** Palliative care helplines provide advice, support and reassurance to patients and families at home, as well as specialist palliative care advice to other health and care staff. Some also provide a single point of access to palliative care in a local area, triaging and referring people on to other services if needed. The importance of them is stressed across national policy and guidance, and by the recent Commission on Palliative and End of Life Care[50]. However recent research shows that these services are patchy, particularly at evening, overnight and at weekends[51].

  Palliative care helplines are particularly important for people in remote, rural and island communities where people are more isolated, there are fewer staff available and people face long waits for staff to arrive. Helplines can help people living rurally to stay at home, and avoid emergency care and unnecessary stays in hospital. The Goldline telephone hub in Airedale, for example, provides a 24/7 telephone contact point for patients with palliative care needs and their families. Specialist nurses answer the calls, and a palliative care consultant is available to the hub team at all times[52]. In some areas, these services are being integrated into the 111 system.

Case study:

Highland palliative care helpline

When Ian's pain and agitation increased through the night his partner and carer, Sarah, called the 24/7 Palliative Care Helpline (PCH) for advice. The helpline provides support for individuals in the last year of life, their families, carers and professionals. Sarah had been unable to contact their GP or district nurse and was worried that she couldn't cope with Ian's escalating needs through the night.

Angela, a senior nurse on the helpline, provided guidance on pain management and discussed Sarah's concerns. Sarah made clear Ian's wish to remain at home and that she didn't want him to be admitted to hospital if his symptoms could be managed at home. The PCH team co-ordinated with the local social work team to arrange a package of care to help support Ian at home.

Sarah and Angela also discussed the Marie Curie nursing service and agreed to make a referral. Angela co-ordinated a follow-up from Highland Hospice's Rehabilitation and Wellbeing team to asses Ian's mobility and therapy needs.

Angela referred to the hospice co-ordinator Lynne who created a care plan, arranged the necessary referrals, applied for end of life funding and sourced private home care. She also compiled a report to share with Ian's GP and district nursing team. Once the plan was in place, Angela called Sarah to confirm the arrangements and offer further resources. Thanks to the helpline's support, Ian received the care he needed to remain at home and Sarah felt reassured knowing help was always available.

Names have been changed

Some of the approaches hospice care organisations have used to staff services in rural communities include:

- **Flexible staffing models:** Having staff cover services across rural and urban areas can help manage the unpredictable demand and workload in rural areas. Different contract options for staff, including honorary contracts with local teams, can give greater flexibility. Joint working between hospice care and statutory services allows teams to cover a wider area. There are also examples of jointly funded posts. Some areas have a virtual team of people who can be called on from their substantive roles to provide a 24/7 response when needed.
- **Staff based locally:** Community staff being based from their own homes, instead of a hospice building, can cut down travel times. Basing staff in local health centres and community hospitals helps build strong relationships with these services and improves local knowledge. Recruiting staff who live locally can also bring a strong understanding of the local community, as well as reducing travel. However, some hospice care organisations have found it hard to recruit staff locally and have also found managing confidentiality in small communities challenging. It's important to have strong leadership and good communication to make sure staff working across different locations still feel part of a team.

- **Reviewing staffing models:** Reviewing staff roles and skill mix in community teams can help to better meet the needs of patients and families. For example, bringing in occupational therapists, physiotherapists and support workers in teams traditionally made up of clinical nurse specialists. Teams in rural communities might also need greater flexibility to follow different pathways and protocols from those used in urban areas.
- **Supporting staff and ensuring their safety:** Having a lone worker policy is essential to support community staff working in rural communities. Some ways hospice care organisations support staff working alone in rural areas include: having a clear support system overnight if problems occur; having an emergency kit in the car in case staff get stranded; using a lone worker protection system, such as 'PeopleSafe', which has 24/7 emergency assistance; using 'what3words' to help find addresses; asking families to meet staff in a more recognisable location; and having detailed handovers including about the state of the roads. In bad weather, staff could also be offered accommodation close to the patient so they don't have to travel.

Delivering palliative care closer to home

Not all services can be delivered at home. Hospice care providers have been exploring ways to deliver their services more equitably across the more rural parts of their catchment. Some have established satellite services and clinics in community hospitals, rural GP practices and local health centres. Others have developed community hubs and outreach services in partnership with local community organisations. For example, a day therapy service delivered at a local community centre. Some organisations have been exploring mobile units with equipment that staff can drive to different rural locations to offer services.

Delivering more services in rural communities helps builds stronger relationships with local health and care staff, and with local community organisations and groups. It reduces travel time for people receiving care and helps them to maintain important local connections, while also raising awareness of hospice and palliative care within rural communities.

> *"Our children's hospice supports those living with life limiting conditions across the county, many facing long journeys to visit with lots of equipment. We are moving family support days around the county to help make it easier for families to connect with our teams and enjoy support closer to home."*
>
> *Children's Hospice Chief Executive*

Case study:

Ayrshire Hospice Living Well Service Community Hubs

The Living Well Service at the Ayrshire Hospice provides a community-based hub across the three council areas of Ayrshire. This eases access to the hospice's services and reduces the anxiety that can come with an introduction to hospice care. The Hubs are positioned in rural spaces to maximise the opportunity for people in those areas, as the hospice has learnt that it can be difficult to attend a central urban town. The hospice further supports attendance through its volunteer transport service for those who need it.

The model is like a "Welcome mat" to hospice services and signposts to other local information and services. The Hubs are based in buildings which do not have a clinical feel, such as a community centre, to make it more familiar and welcoming. This also provides an opportunity to integrate with other community groups running from the same buildings, potentially expanding community links for the patients.

"I feel so lucky that this is on my doorstep."

The hospice invites self-referral, giving people choice, and taking away one barrier to accessing the support they are looking for. Once they arrive at one of the Hubs, they receive a warm welcome from other patients and families, hospice volunteers and staff. The programme runs once a week for two hours. The first half hour is dedicated to information and discussion on enablement topics people have said are important to them. This is followed by therapeutic activities, such as art, quizzes, games or a space to chat.

Connection is a core wellbeing element of the Hubs whether in the Hub itself or reconnecting people with their own rural communities and all of their assets.

"I have found such a lot of benefit from attending Hubs- given confidence to attend other community activities, made connections with others, enjoy the time at the Hub, enjoy laughing."

Interaction with people at earlier stages of their illness within their own community, allows for earlier interventions, an increased support network and the tools enabling them to live well for longer.

Digital health and virtual services

People living rurally told us they saw the value in digital services and would appreciate having this as an option. However, they did not want this to be the only way services are delivered or for it to replace in-person care. For people in very remote and smaller island communities, digital services offer essential connections to services that might otherwise be unavailable.

> *"We need to use digital technology more to improve access to support for those in the home in a rural setting. Monitoring of symptoms and virtual care could support people to stay in their own homes."*
>
> *Hospice Chief Executive*

Digital health technology offers innovative ways to improve palliative care in rural communities[53]. It allows patients to access specialist care from the comfort of their own home, without making long, tiring journeys. Types of services include:

- Remote consultations with healthcare staff and virtual care co-ordination
- Remote monitoring through virtual wards to allow continuous care and timely interventions
- Virtual wellbeing services to help patients manage symptoms and improve their quality of life
- Online prescribing of medication
- Online peer support to give a sense of community and connection that people may not be able to access locally in-person
- Virtual bereavement support
- A growing focus on the use of artificial intelligence in palliative care
- Developing apps to help with providing staffing cover in rural communities.

However, many people in remote, rural and island communities have poor broadband and mobile signal. Not everyone has access to computers or smartphones, and some may need support to use digital tools confidently. Healthcare staff need equipment, training and support to deliver virtual care effectively. Hospice UK has published a report on digital technology in palliative care and different approaches hospices are using to encourage digital inclusion[54].

Case study:

Frailty Virtual Ward (Hospital at home) Hull and East Riding; Humber and North Yorkshire ICB

The Frailty Virtual Ward (Hospital at home) Hull and East Riding team have introduced tech-enablement into their Virtual Ward. In partnership with leading providers of digital health they can now use:

- Health questionnaires for patient reported concerns (Inhealthcare)
- Remote monitoring of clinical observations (Biobeat)
- Remote examination utilising digital stethoscopes (Tytocare)
- AI scribing to improve efficiency of clinical interactions (Heidi Healthcare)

This initiative, which operates across a region of 1000 sq. miles between Hull and East Riding, aims to reduce pressure on hospital beds and improve patient outcomes by using tech-enabled care in community settings. Not all patients require digital services but the options are available to all patients admitted onto the virtual ward regardless of geographical location.

This technology enablement allows patients living with frailty and an acute illness to leave hospital sooner, receive care at home, avoid unnecessary admissions, have more choice in their care and improve patient flow through the wider health and care system. The team can support up to 45 Virtual Ward beds through a combination of high intensity (usually daily review) and low intensity (infrequent review) activity. This model is particularly valuable for small teams having to cover large geographies and working in remote and rural areas.

Children and young people

Some examples of services and initiatives that support more care at home or closer to home for children and their families living rurally include:

- Collaborative working between hospices and NHS services to provide 24/7 support for end of life care at home for children living rurally. For example:
  - An innovative partnership between Tŷ Gobaith Children's Hospice and Betsi Cadwaladr University Health Board, including jointly funding a new lead consultant in paediatric palliative care – a first for North Wales[55].
  - Children's palliative care staff working with district nurses and out of hours GPs to support end of life care at home for children in Grampian.
- Jigsaw Children's Hospice serves as a hub for face-to-face multidisciplinary team meetings, bringing together staff from the specialist team in Newcastle and children in Cumbria. This reduces a six- hour round trip to two hours for some families, lets them be in a familiar and comfortable environment with access to appropriate changing facilities, and helps other staff to connect in more easily.
- A nurse-led paediatric palliative care team in Cumbria with cover from paediatricians, palliative care consultants and GPs, which mirrors the services provided by the Children's Holistic Integrated Palliative Care Service team in Newcastle.
- Partnering with Macmillan nursing staff who are already present and understand rurality in order to deliver more robust family and child support.
- A partnership between Children's Hospices Across Scotland (CHAS) and Loganair, which provides free flights to CHAS@home nurses who are supporting families in remote island communities.
- Using honorary contracts for hospice nursing staff to support local teams in rural areas in times of exceptional need to deliver end of life care at home.
- Providing temporary accommodation for small teams of nursing staff in very remote areas so someone can be close at hand for families if needed. Families often don't want the 'intrusion' of having staff in the home 24/7 but want the security of having someone able to respond quickly if needed.
- Providing hospice outreach services to families who cannot travel easily from rural areas.
- Family link workers who work with families to assess their holistic needs, help them navigate the complex system and link them into personalised support.

Case study:

Supporting end of life care at home in children's palliative care, Grampian

A 15 year old child was living in a remote area with complex health conditions, including cerebral palsy, seizures, dystonia and significant feed intolerance. The nearest community hospital was 10 minutes from the family home however this only provides a short stay service for children. The nearest paediatric hospital was 1.5hrs away. The local community nursing service has 1 x 0.8 whole time equivalent nurse responsible for an outreach service for the whole of the Moray catchment, an area of 2238 km2.

The child hated hospital and the family had always been clear that home was their preferred place of death for their child. Given the rural location and limited specialist paediatric support available, it was essential to plan what services might be able to provide support, what skills were needed and what each sector would need to feel safe to deliver the support.

A multi-disciplinary team meeting was arranged with the family's GP, out of hours community nursing team, Diana Children's Nurse (DCN), palliative care consultant, gastro team lead, local community paediatrician, social work, school and respite team lead. The meeting agreed roles and responsibilities, and plans for when the child's symptoms escalated.

They agreed the DCN would be the co-ordinator, providing daily contact with the family Monday-Friday updating the community nursing team lead, and providing telephone advice as needed. Advance care and symptom management plans were shared across teams. The respite service agreed to transfer overnight support to the home to allow the parents to rest. School continued to support attendance until the last week of life. The community nursing team agreed to provide support with syringe driver changes as well as administering medication to manage breakthrough pain. The Children's Hospices Across Scotland CHAS@home team agreed to provide additional support to the rota for symptom management alongside the community nursing teams. The GP agreed to complete any prescription changes with guidance from gastro lead and palliative care consultant on call. The community paediatrician agreed to complete the certification of death when needed.

When the child's symptoms escalated, the pre-agreed plan was carried out and professionals met twice a week on Teams to check in and update. During the final 10 days of the child's life the family spent quality time together. The child's mum continued to lead in the care until her child's death. She was also supported to take care of their body after death allowing them to continue to be at home until the funeral.

Following on from supporting this family, engagement with adult community services has been formalised. There is an agreement to provide general awareness of paediatric palliative care sessions for teams and additional child-specific sessions to teams when a child is dying within their locality. An end of life care algorithm has also been developed.

Case study:

Family Link Worker, Forget Me Not Children's Hospice, West Yorkshire

Families told the hospice they need support earlier, ideally from before diagnosis, so they can access the help each family member needs. Building on this learning, the hospice is piloting a new Family Link Worker role. Family Link Workers will support families when they most need it: from awaiting or receiving a diagnosis (or referral), through the child's illness, and for two years after their death.

Over three years, the hospice's aim is for two Family Link Workers to support 150 families across West Yorkshire. The link workers will first meet each referred family to undertake a holistic assessment. They'll use person-centred tools to understand the family's strengths and needs across five domains:

1. home and family
2. health and wellbeing
3. education and employment
4. housing and income
5. community integration and support.

They'll then help families develop and implement a personalised action plan, and navigate complex systems, so they get the support they need. Support will be tailored to each family, but might include the following:

- Acting as an advocate, liaising with NHS and hospice medical professionals.
- Linking families to Forget Me Not services, e.g. short breaks, counselling and peer support groups.
- Working alongside the hospice's Clinical Educator to increase parent/carer's skills to care for their child at home.
- Accessing activities to help siblings cope and making referrals to services like Young Carers.
- Arranging help from partners including Kirklees Citizens Advice & Law Centre to apply for benefits/other entitlements.

Family Link Worker referrals have increased to 28 since the role started, offering two types of support to families: Engagement (Check-Ins) to explore family needs and provide signposting opportunities, and ongoing consistent contact from Forget Me Not Hospice for families accessing limited active care or clinical support. The other strand involves a more in-depth holistic assessment and planned support. In some cases, what initially began as check-ins have quickly evolved into more comprehensive assessments.

In addition, the hospice is planning to recruit 20 volunteers to create a supportive community network around families. These volunteers will help with everyday chores, including ironing, cooking, and gardening so families can focus on what truly matters: caring for the child and each other.

Recommendations:

- 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, hospice care providers, GPs, community nursing teams, community pharmacists, social care staff, out of hours teams and other staff should work together, in partnership with local communities, to improve the provision of palliative care delivered at home and in community settings in rural areas, particularly out of hours.
- 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 should ensure patients and families receive swift access to equipment needed to care for someone at home and are trained in how to use it.
- Hospice care providers should explore ways digital and virtual services could better support people in rural parts of their catchment.
- Hospice care providers should identify opportunities to improve training and education of health and social care staff delivering palliative care in people's homes and community settings in rural areas.

Improve access to end of life care medication

Not having timely access to end of life care medication is distressing for patients and carers, and can lead to unnecessary and costly unplanned emergency service use and hospital admissions. There are a range of approaches that can help patients in rural communities access medication more quickly and easily, when they need it. This is especially important out of hours.

Anticipatory prescribing

Anticipatory prescribing is where medication is prescribed in advance for patients who have palliative care needs or are under specialist care. A Just in Case box contains medicines prescribed for the patient 'just in case', along with needles and syringes, a sharps disposal box and a prescription and administration record.

Increasing the use of anticipatory prescribing and Just in Case boxes can help patients in rural communities have quicker access to medication. Local areas are exploring ways of doing this through training, education and partnership working. For example, a joint initiative by the Scottish Ambulance Service and Macmillan showed an increase in end of life care medication being administered by paramedics, providing quicker symptom relief and improved patient care[56]. Advanced Nurse Practitioners and non-medical prescribers can also help increase the use of anticipatory prescribing and access to medications in rural communities. Research from Australia suggests dispensing kits containing syringe drivers to rural doctors, in collaboration with community pharmacies, so that patients can receive end of life care medication faster[57].

Community pharmacies

Community pharmacies have a key role in rural communities, not just for dispensing medication but also providing advice and connections in their local community. However, they are under growing financial pressure and an increasing number of community pharmacies are closing[58]. This has a significant impact in rural communities. There needs to be more support for rural community pharmacies, including support to allow them to open outside of normal working hours.

There is a lot of variation in how community pharmacy palliative care services are commissioned locally. Having a national standard for community pharmacy palliative care service would help make services more consistent and make it clearer what patients, families and other professionals can expect. Pharmacists should be embedded in multi-disciplinary palliative care teams in rural communities and have access to shared care plans and health records.

There are opportunities to strengthen education and training in palliative care and bereavement support for rural pharmacists. For example, using Marie Curie and the Royal Pharmaceutical Society's Daffodil Standards for Community Pharmacy[59]. Having a palliative care specialist pharmacist contact in each local health and care system would help assist with training and advice.

Sourcing and accessing medication needs to be streamlined. Electronic prescribing can reduce delays and minimise travel. There need to be locally agreed services to support community pharmacies to hold stock of essential palliative care medicines. Having simple processes in place so that patients, carers and healthcare staff are able to see what medication is in stock would help reduce unnecessary travel. Having a funded delivery service would also help cut long journeys for rural patients and carers.

Training family members and unpaid carers

Some areas have introduced training for family members and unpaid carers to deliver end of life care medication, for example the CARiAD initiative in Wales. This can help people receive medication more quickly in rural communities where it may take a long time for healthcare staff to arrive.

Training can help carers feel empowered and supported. However, it's important that staff have honest conversations with carers about what is involved and what they are comfortable doing. For example, thinking about how they would feel if they were to give the final dose of medication before someone died. There is also learning from the COVID-19 pandemic about supporting unpaid carers with administering medication[60].

Case study:
CARiAD (CARer ADministration) package project, Wales

In the UK, most seriously ill people wish for their dying days to be at home. One way of making this happen is to empower willing lay carers (i.e. family members or friends) of a dying person to help manage symptoms at home. They are trained to give as-needed medicines using 'no-needle' injections when their loved one is too weak to swallow. This means not having to wait for a doctor or nurse to arrive to give such medicines. The practice has been successfully used in Australia for many years, but is new to most of the UK.

The North Wales-based team of researchers and clinicians led UK research on the practice, developed All-Wales policy for it, and put the CARiAD (CARer ADministration) package into clinical use in 2020. The work is helping to spread this practice across the UK, also through a national network (or 'Community of Practice') of clinicians which was set up in 2021.

The outcomes of the innovation in North Wales are excellent: dying people's symptoms are treated much quicker, with waits down from 105 to 10 minutes, meaning patients can be more sure that they can stay at home where they wished to be. Family and friends feel well-supported and empowered: they value the opportunity to support a loved one this way. This evidence-based approach is responding to changing priorities and needs within society, supporting choice at the very end of life.

Medication in care homes

Anticipatory prescribing is common practice in care homes. However, prescribing and storing controlled drugs on an individual basis for a large number of residents in care homes is time consuming, impractical due to limited storage space and wasteful due to unused medicines. Care homes that provide nursing care can hold a small stock of controlled drugs under a licence from the Home Office that any resident can be given (following an assessment and individualised prescription). This can help care home residents in rural areas receive end of life care medication more swiftly. However, the process for obtaining the licence from the Home Office is complex and expensive. This process could be simplified and the cost reduced. The eligibility criteria could also potentially be widened out to include residential care homes, if appropriate. Staff working in care homes also need support, training and education in palliative care, to feel confident administering medication.

Children and young people

Children with life-limiting conditions sometimes need less commonly used medication. The process for families to order and access these can be very complicated and time consuming, especially when they need to make multiple trips to their GP or pharmacy, or travel long distances. Having a more streamlined process, via local GPs and pharmacies, for accessing rare, complex and off-label drugs in the community, would help relieve some of the burden for families.

Families should receive greater support around how to administer their child's medication, if they wish. Approaches similar to the CARiAD project are done informally with some parents of children with life-limiting condition. This method could be made more accessible to families living rurally.

Recommendations:

- Local health and care systems, pharmacists, GPs, hospice care providers and other staff should develop local approaches to encourage greater anticipatory prescribing and timely access to medication for people in rural communities.
- Local health and care systems, pharmacies and GPs should streamline processes to supply and access medication in rural areas, and to allow patients, families and staff to see what medications are in stock.
- Local health and care systems should provide a consistent provision of community pharmacy palliative care services in rural communities based on a nationally agreed standard.
- Local health and care systems should ensure that local pharmacists are embedded in multi-disciplinary palliative care teams in rural communities, and that they are able to access shared care plans, advice from a palliative care specialist pharmacist, and training in palliative care and bereavement support.
- Governments across the UK should provide more support for rural community pharmacies, including to enable them to open outside of normal working hours.
- Local health and care systems should ensure there are funded delivery services to deliver palliative care medication to people in rural communities.
- Hospice and palliative care services should provide support and training for unpaid carers in rural areas to administer medication, if they wish to do so.
- The Home Office should simplify and reduce the cost for care homes to obtain a licence to hold a stock of controlled drugs.

Enable flexible, person-centred and culturally-sensitive care

In rural communities, limited services mean that care needs to be flexible, innovative and person-centred. Individuals need to be supported to maintain meaningful connections within their local community and culture, if this is important to them.

Direct payments and personal budgets

Adults and children with life-limiting conditions in rural communities need to have the flexibility, choice and control to arrange care and support locally to meet their needs. Across the UK there have been moves to make social care services more personalised and give people greater control and choice over how to arrange their own care through direct payments, personal budgets and self-directed support. In England, people can be eligible for personal health budgets. Direct payments for NHS Continuing Healthcare will also soon be introduced in Wales. Direct payments and personal budgets can give people in rural communities important flexibility, for example to employ someone from their local community to provide care.

However, there needs to be more effective implementation of the legislation intended to support the personalisation of care in rural communities. Direct payments are not always routinely offered as an option to people with a life-limiting condition and the process can be long and complicated to set up. Being offered direct payments can't just be a tick box exercise. For it to work in a rural setting, there need to be carers and services available locally that people can access. People using direct payments must be able to cover the higher cost of employing staff in rural areas. There also needs to be more flexibility in the system, for example to allow people to use direct payments to pay family members to provide care.

People also need support to understand how they might best spend the money to meet their needs. There are good examples of hospice care and voluntary sector services supporting people to make use of direct payments and personal budgets[61].

Huw's story

My wife lived for 12 years with a genetic form of frontal temporal dementia and Progressive Supranuclear Palsy. We managed with the help of a network of health professionals and some very good carers, the local nursing home, as well as the hospice. We managed to keep her at home for the whole 12 years.

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? Whatever help that we can give you, you want to use the direct payment because you'll be able to do the finding".

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.

I was also very fortunate again when we needed people like the district nurse and then the clinical psychologist, social worker, a dietician, a physio and the GP, and a continence nurse later on. They were all excellent. The district nurse was brought up in the same village as my wife. And the GP had known the family for years as well. So in terms of a network of support, I was very well supported.

Names have been changed

Advance care planning

In rural areas, where accessing services is more challenging and care arrangements often take longer to co-ordinate, advance/future care planning is essential to ensure individuals receive timely, well-organised support. Proactively anticipating people's needs allows practical steps to be taken in advance and helps to communicate a person's wishes across services. This is particularly important for people who wish to remain in their own homes at the end of life.

People living in rural communities may be less willing to engage in conversations about planning ahead and have limited awareness of hospice and palliative care services. By working in partnership with local community groups and networks, hospice care providers can become more visible and approachable in rural communities. This can encourage more openness around death and dying and support people to think about the care and support they want at the end of life.

Culturally-sensitive care

Care needs to be culturally-sensitive and respect local traditions around death, dying and bereavement. People in rural communities should be supported to maintain their connection to where they live and their local culture and community, if this is important to them. This could be through attending local community activities and day centres that let people connect to their rural heritage and language[62]. Palliative care volunteers can help rural patients and families learn how to live with their condition, and provide important connections to friends, activities and hobbies[63]. It could also be about making sure people are able to look out at views of where they live or have access to a rough terrain wheelchair so they can still get out and about. Being open, proactive and having a less risk-averse approach to personalising care can help people stay connected and get the most out of where they live.

People should receive care in their preferred language where possible. Wider challenges in recruiting health and care staff mean it can be hard to recruit staff who speak Welsh, Gaelic, Irish or other languages. Staff learning a few simple phrases can help foster connection and communication. Working in partnership with local communities can help make links with people and activities in that language. In areas where Welsh, Gaelic and Irish are more widely spoken, formal language plans by public bodies should make sure that hospice care staff are included in opportunities and resources available for health and care staff in public services.

Children and young people

Having a direct payment or personal budget gives families the flexibility to tailor care to the specific needs of their child. This might include personal care provided at home, short breaks that allow their child to participate in local activities while their parent or carer has respite, adaptations to the home, or other essential services. This flexibility is especially important in rural areas, where there are fewer services and opportunities available for children with complex needs.

There needs to be a greater focus by local health and care systems, local authorities, and government bodies on improving how social care direct payments and personal health budgets can be used to better support children with life-limiting conditions and their families, particularly in rural areas. For example, many of these children do not meet the strict eligibility criteria for NHS Continuing Care, which would allow access to personal health budgets, but they also face barriers in accessing social care direct payments, leaving families without the support and flexibility they need.

Direct payments and personal budgets must be underpinned by individual, person-centred plans that focus on maximising the child's quality of life. These plans should support them to 'be a child', so they can play, learn and participate in their local community.

Recommendations:

- 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.
- Governments, local health and care systems, and local authorities should review and improve how families of children with life-limiting conditions can access direct payments and personal budgets for health and social care.
- Hospice and palliative care staff should work with local communities to better understand and enable local culture and traditions around death, dying and bereavement and ensure care plans support individuals to maintain cultural links to their local community.
- Public bodies in areas where Welsh, Gaelic and Irish (and other relevant languages) are more widely spoken should ensure local language plans consider the needs of people at the end of life and include hospice care staff in opportunities and resources.

Increase support for unpaid carers

Unpaid carers in rural areas need more targeted support. Health and social care professionals must be equipped to identify and assist carers, including encouraging carer assessments and signposting to local services. Training programmes like the Carer Aware scheme in Wales can help professionals better understand carers' needs[64].

There is a pressing need for more funded respite options for carers in rural communities, including overnight care at home, day centres and short stays. Strengthening local networks through compassionate community initiatives can also offer informal respite and practical help with tasks like shopping, housework and collecting medication. These are also areas where direct payments and personal budgets can make a difference.

Carers struggle to find information and co-ordinate care. A single point of access palliative care helpline would provide reassurance, timely advice and reduce the burden of having to navigate multiple services. Carers also need clear routes to welfare advice and financial support.

Rural carers need to be equipped with the skills and confidence to carry out their role. This includes training in using equipment, administering medication and other procedures, if they are comfortable with this. Some hospice and palliative care staff are delivering joint training with community organisations in rural communities, which help carers feel more supported. International examples show how virtual support, such as video visits from palliative care nurses, along with follow-up calls or texts, can provide ongoing guidance and reassurance[65].

Finally, carers need better access to emotional and mental health support. This includes counselling, peer support groups, and bereavement services. This is especially important in rural areas where social isolation is common. Online and phone-based options, alongside local community-based organisations and resources, can help support carers living rurally.

Case study:
End of Life Aid Skills for Everyone (EASE)

End of Life Aid Skills for Everyone (EASE) is a free course for people in Scotland who want to be better equipped to help friends or family who are caring, dying, or grieving. It was developed by the Scottish Partnership for Palliative Care.

EASE welcomes adults of all ages, experiences and walks of life. The course takes approximately 8-12 hours to complete over a period of four weeks. Through activities, short films and group discussion participants explore a range of issues that can arise when someone is approaching the end of life, and some practical ways a friend or family member can offer support.

Volunteers can train to run EASE courses within their own communities, meaning the number of EASE course facilitators is gradually growing in areas such as Grampian and Highland with significant remote and rural populations. The first EASE course was recently delivered on the Isle of Mull. The course can also be delivered online, increasing its accessibility for those living in remote and island populations.

More than 500 people have completed the EASE course, and feedback shows that people leave the course feeling more confident and knowledgeable in providing support around death, dying and bereavement.

> ***"...one of the best courses I've done in ages. Wish I'd done this before my Dad died. It's been hugely supportive. I've met a wonderful community...Learned and relearned so much."***
>
> Participant on the EASE course

Children and young people

Improving palliative care services for children with life-limiting conditions in rural communities and having more options for flexible, tailored support for, as detailed earlier in this report, will help support parents and families. Along with addressing the wider systemic issues that prevent families, particularly those in rural areas, accessing the support they need.

Providing more opportunities for social connection and peer support can help families living rurally feel less isolated. For example, running outreach activities so rural families have shorter distances to travel, funded transport to access support, and more options for virtual support. Support groups, counselling and therapy sessions need to be run by staff with appropriate expertise and there need to be enough sessions to effectively build relationships and trust.

Families also value activities to do at home with their child and any siblings. For example, activity packs that can be sent in the post and online activities for when in-person is not an option. However, families stressed that these should complement and not be a substitute for actual services on the ground and in-person support.

Recommendations:

- Local health and care systems, and local authorities, in partnership with local communities and health and care services, should review how well carers are being identified in rural communities, identify what is important to them, assess the support available, including respite and bereavement support, and develop plans to address gaps and increase support.
- Hospice and palliative care services, in partnership with local community groups and local services, should develop resources and training for unpaid carers looking after someone with a life-limiting condition at home in a rural community.
- Hospice care organisations, in partnership with local community groups, should explore the use of volunteers and compassionate community initiatives to provide practical help and increase peer support for carers living rurally.

Support people with the financial cost of living rurally at the end of life

Deprivation is commonly viewed as an urban challenge because this is where it is most visible. Part of the challenge of addressing rural deprivation is that it is often hidden. People living rurally with a life-limiting condition are facing a double financial burden. The high financial impact associated with death and dying, alongside the higher cost of living in a remote, rural or island community.

Rural patients and carers need financial support to cover the cost of travelling to services, so that they are not left out of pocket. Policies around reimbursing travel costs vary depending on where you live and whether you receive benefits. People are not always aware of reimbursement schemes, they may not meet the eligibility criteria and the cost of carers travelling with someone might not be included. These policies need to be reviewed and consistently implemented. There also needs to be financial support to pay for accommodation, or suitable places made available to stay overnight, when people have to travel long distances to access healthcare services.

There needs to be more funded patient transport services in rural areas that are suitable for someone with palliative care needs to use. Some hospice care providers are setting up their own community transport services to help rural patients and families access their services more easily and comfortably.

Financial and welfare support is highly valued by people with a life-limiting condition and their families. But support is patchy and reliant on stretched voluntary sector services[66]. A minimum standard of welfare advice must be consistently available to people in remote, rural and island communities. Longer-term, the welfare system needs to be 'rural proofed'[67] to ensure that people living rurally are not disadvantaged when it comes to accessing financial support they are entitled to. There also needs to be more support for people with their energy bills through an energy social tariff.

Children and young people

Families speak very highly of free accommodation that families travelling long distances can stay in, close to, or within, specialist children's hospitals, for example the Ronald McDonald Houses. However these can only support a limited number of families. Together for Short Lives has an energy adviser service that can support families who are struggling financially to afford energy bills[68].

Recommendations:

- 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.
- 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 financial support they are entitled to.
- The Department for Energy Security & Net Zero should introduce an energy social tariff to reduce the energy bills of vulnerable and low income households.

3

What is needed to deliver this?

A supported and skilled health and social care workforce

We must plan for the workforce we need, and support the workforce we already have. The number of people needing palliative care is increasing rapidly in rural communities. But we have fewer health and social care staff to care for them. It is not enough to rely on the goodwill of staff to go above and beyond.

We urgently need a plan to make sure we have enough health and social care staff with the right skills to support the growing number of adults and children who need palliative care in remote, rural and island communities. Staff need to be valued and supported, and not be priced out of living in the rural communities they work in.

National workforce planning

Governments across the UK have introduced various initiatives to try and attract and retain health and social care staff in remote, rural and island communities. These include financial incentives, support for training and development, and targeted recruitment campaigns. However, the feedback we gathered shows there are still significant shortages of staff delivering palliative care in rural communities. There needs to be a more concerted push by governments across the UK to recruit and retain staff rurally.

National workforce planning must focus on meeting the growing need for palliative care and delivering more community-based care. It must address the workforce shortages and skills gaps in adult and children's palliative care in rural communities. This includes specialist and generalist staff across health and social care.

Education and training

Healthcare staff commonly stay in the area that they train in. Developing 'rural friendly' approaches to recruitment and training, can help attract people from rural communities. There are various training collaborations between universities and local NHS organisations to support rural pathways for healthcare staff. In Scotland, there are rural training fellowships for GPs and a Scottish rural medicine collaborative. There are also specific post-graduate courses for rural staff. For example, the University of the Highlands and Islands offers an online masters in rural advanced practice for nurses and allied health professionals, which includes a focus on palliative and end of life care.

Given the growing need for palliative care in rural communities, training and education for rural health and care staff must include a focus on palliative care. Staff must have protected time for training and professional development. National organisations with a remit to support the rural health and care workforce should include a focus on the delivery of palliative care in their workplans. For example, the National Centre for Rural Health and Care in England, the National Centre for Remote and Rural Health and Care in Scotland, and Rural Health and Care Wales.

Likewise, palliative care training and education must also focus on the needs of rural communities, for both specialist and generalist staff. Including rural placements as part of palliative care education can help staff become more familiar with working in rural communities. Palliative care training should also focus on emerging opportunities to support rural communities, such as the use of digital technology.

Local approaches

At a local level, hospice care organisations are trying various approaches to address workforce challenges in rural communities:

- Training up their own local workforce. Developing a pipeline of skilled local palliative care staff through local recruitment and training initiatives. For example, training healthcare assistants to become nursing associates and then nursing staff.
- Recent retirees who have moved to rural communities can be a highly skilled pool of people to try and recruit from e.g. nursing staff, carers or volunteers.
- Tapping into informal community networks in rural communities to recruit staff, such as care assistants, from local communities.
- Establishing strong connections with other services and institutions in the region, for example research partnerships, to make roles more attractive and providing more training, career opportunities and support networks.
- Investing in supervision for staff working in rural areas.
- Working collaboratively to rotate staff across different services to maintain skills in different settings.
- Sourcing virtual medical cover, such as Supportive Care UK, to cover gaps in consultant cover.
- Paying rural employees for travel time and mileage, and at a slightly higher rate of pay.

> ***"We have a demographic of highly skilled and experienced people in [rural area]. Lots of newly retired people new to the area and looking for purpose and to make connections. We have recently been able to recruit very highly experienced and motivated nursing staff."***
> *Hospice at home manager*

Children and young people

Workforce planning must improve the provision of palliative and end of life care for children and young people who live rurally. It needs to be informed by a clear understanding of the holistic care and support that children and families need, and the full range of services and staff needed to support them.

As part of this, workforce plans must include how to address the shortages of community children's nurses (CCNs) and paediatric palliative care consultants. Expanding the CCN workforce will be critical in ensuring that children in rural areas can consistently access the care and support they need at home. More specialist consultants are needed to ensure that there is access to specialist advice, to support rural families at all times. This is especially important given that local health and care staff in rural areas are often unfamiliar with the complexity and rareness of the conditions these children live with. Specialist staff can also support more education and training for local staff in rural areas.

Recommendations:

- Governments across the UK should publish, implement and monitor national workforce plans to improve the recruitment and retention of health and social care staff in rural communities and invest in initiatives to support the recruitment, retention and training of staff.
- Governments across the UK should ensure that national workforce planning addresses the growing need for palliative care in rural communities, and addresses skills gaps and workforce shortages in palliative care across health and social care staff. This must include staff delivering specialist and generalist palliative care, for adults and children.
- Local health and care systems, and local authorities, should ensure that health and social care staff in rural areas have protected time to access education and training in palliative care.
- Education and training providers should ensure that there is a focus on the needs of rural communities, including opportunities for rural placements and a focus on digital services, in palliative care education and training.
- National centres for rural health and care should include a focus on the delivery of palliative care in their workplans.

Fairer funding and commissioning

It costs more to deliver health and care services in rural areas[69]. While there are some adjustments made for rural areas, funding formulas to local health and care systems across the UK do not adequately reflect the particular circumstances of rural communities or the increased cost of service provision[70]. There is also a lack of transparency in how they are calculated.

The commissioning of services, such as hospice care, does not take into account the higher cost of delivering these services in rural communities. Commissioning processes are commonly focused on 'reach' i.e. the number of people that the service provides care too. This does not reflect that people are more geographically spread out in rural areas and it costs more to deliver care to fewer people. This is particularly problematic given that the commissioning of hospice care more widely is already underfunded, making rural services even less sustainable.

> ***"It is difficult to convey to commissioners the need for relatively high numbers of staff (per unit population) in rural areas in order to establish any kind of sustainable service."***
>
> *Consultant in children's palliative medicine*

Some contracts for social care may factor in rurality, but the extent to which this is considered varies widely between regions. Some local authorities have looked at different tariffs based on rurality for social care services.

Funding allocations, commissioning processes and contracts need to accurately reflect the higher cost of delivering care, including palliative care, in rural communities. Hospice care organisations and social care providers need to be adequately resourced to cover the extra costs of delivering care in rural communities.

There also needs to be more flexible and clearer commissioning where palliative care services operate across boundaries and borders. More regional approaches to commissioning may be helpful in some rural areas.

Case study:

The Palliative Care Co-ordination Centre (PCCC) and contracting care agencies, Lincolnshire

The Palliative Care Co-ordination Centre (PCCC) was commissioned to source domiciliary packages of care for patients in receipt of Fast Track funding in Lincolnshire. Prior to April 2023, the PCCC had sourced these packages on a 'Spot Purchase' basis from care agencies who were approved by Continuing Healthcare (CHC).

Due to the distance and rurality of some patients, it wasn't financially viable for agencies to offer on these requests. This led to lengthy delays (sometimes weeks) to sourcing care for patients at end of life with some patients dying in hospital before care could be sourced, or families struggling trying to support their loved one at home. The Integrated Care Board (ICB) asked the PCCC to collate extensive data highlighting the postcodes where there were delays and tracking timelines to care.

In April 2023, the ICB informed the PCCC that they had divided Lincolnshire into seven zones and had contracted four care agencies to deliver the care after a formal tendering process. There were three hourly rates for the agencies depending on the location of the patient (identified by postcode), Urban, Rural and Isolated.

18 months into this process, there were minimal delays in care with the vast majority of packages being sourced within 48 hours or less, supporting patients to remain at home and expediting palliative discharges. There were some 'teething problems', which were addressed as they arose, and the service met with the ICB contracting team bi-weekly.

Key learning:

- ▷ Greater collaboration, with the PCCC being more fully involved in discussions and implementation would be beneficial if this were to be replicated elsewhere.
- ▷ The PCCC received some reports of poor quality care. There is an opportunity for hospices to educate and train carers delivering care packages.
- ▷ Some aspects of personalisation and choice are impacted as the PCCC could only approach the four contracted agencies unless the patient had a care provider in place already that would accept the zone rates.
- ▷ Devolved responsibility was vital. This allowed hospice senior clinical managers to approve urgent funding out of hours. They could approve up to 28 hours daycare and 4 nights, or individual urgent nights if needed. This supported patients to remain at home and was used regularly. The condition of approval is that the referring clinician completes the fast-track documentation the next working day.

Children and young people

There is significant variation in how children's palliative care is planned, funded and provided[71]. The low number of children with life-limiting conditions in rural communities makes it harder to provide sufficient staffing and deliver sustainable services. Local health and care systems should explore whether more regional approaches to planning and delivering children's palliative care would allow for greater flexibility and best use of limited resources in rural areas. Longer term, the UK Government should review how children's palliative care is planned and funded, including whether commissioning at a national or regional level would better meet the needs of rural families.

Case study:

East of England Regional Advice and Facilitation Team

The East of England Regional Advice and Facilitation Team (RAaFT) was established in 2022 in response to growing numbers of babies, children and young people in the East of England with life-limiting and life-threatening conditions, following additional funding by NHS England.

RAaFT is spearheaded by Cambridge University Hospitals NHS Foundation Trust (CUH). The Regional service is delivered in partnership with other palliative care providers, East Anglia's Children's Hospices (EACH), Keech Hospice and Little Havens Hospice; as well as with the primary and secondary statutory health care organisations.

This regional service supports improved symptom management, advance care planning and end of life care for babies, children and young people and their families needing support 24 hours a day seven days a week by working in partnership with those organisations and professionals operating in the East of England Children and Young People's Palliative and End of Life Care Managed Clinical Network (MCN).

In addition, the Consultant Clinical Psychologist provides consultation, supervision, debriefing and teaching for the complex multiagency and multidisciplinary network of professionals around children with palliative care needs and their families and the Play Specialist co-ordinates a programme of study days for play specialists across the region working with life-limited children.

The Children's Hospice Services provide 24/7 specialist nursing care face to face for all who need it with specialist clinical oversight and support coming from RAaFT during office hours and specialist telephone support from the MCN consultants out of hours. RAaFT also has an education and research role.

The highly specialist multi-disciplinary team consists of: Nurse Consultant (Clinical Lead 0.8 WTE); Consultant in Paediatric with Special Interest in PPM (0.2 WTE); Consultant in Paediatric Palliative Medicine (maternity leave 0.5 WTE); Clinical Nurse Specialist (1.8 WTE); Consultant Clinical Psychologist (0.5 WTE); Senior Paediatric Pharmacist (0.5 WTE); and Play Specialist (0.2 WTE).

The RAaFT service provides a critical component of the MCN which extends across hospitals, children's hospices and community services in Cambridgeshire, Peterborough, Norfolk, Suffolk, and Essex and reaching into Bedfordshire, Hertfordshire, Luton and Milton Keynes.

Recommendations:

- 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.
- Governments across the UK should ensure that funding allocations to local health and care systems accurately reflect the higher cost of delivering care in rural communities.
- Local health and care systems should introduce clearer, more flexible approaches to commissioning palliative care across borders and boundaries.
- Local health and care systems should explore whether regional approaches to planning and delivering children's palliative care would allow for greater flexibility and better use of resources to deliver care in rural areas.
- 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.

Robust rural infrastructure

Improving care to people in remote, rural and island communities relies on having the infrastructure to underpin it. While there are ongoing initiatives to improve infrastructure, more needs to be done to improve broadband and mobile reception, transport infrastructure, and available housing in rural communities. Without this it will be difficult to meet the growing needs of rural communities in the future.

There needs to be more reliable and affordable public transport in rural communities. Journeys to hospices need to be factored in when planning local bus routes. There needs to be affordable housing stock for staff working in rural communities to live in. There also needs to be more affordable and appropriate housing for people with palliative care needs, for example more accessible and single storey housing. People need quicker and easier access to housing adaptations as their needs change.

Recommendations:

- Governments across the UK should invest in improving the digital, communications, transport and housing infrastructure in remote, rural and island communities.
- Governments and local authorities should implement plans to address the lack of affordable and appropriate housing stock in rural communities.
- Local authorities should factor in travel to hospices, when planning patient transport needs in their area.

Rural-proofed policies, strategies and service delivery

National and local strategies for palliative care, and the design of services, must consider the specific needs of adults and children in rural, remote and island communities and what is important to them. They must address how to meet the growing need for palliative care in rural communities and how to deliver more care at home and closer to home. Policies around housing, transport and social security must also be 'rural-proofed' to ensure that people with life-limiting conditions in rural communities are not disadvantaged.

Policy development and service delivery should be informed by local knowledge and practice from rural areas. New initiatives should be piloted in rural localities and there should be a process of continuous learning and refinement. Resources such as Rural England's Rural Proofing for Health Toolkit[72] and Northern Ireland's Rural Needs Toolkit for Health and Social Care[73] can help local health and care systems think about how to address the rural needs of their local population. Marie Curie and KPMG has also developed a toolkit to help Integrated Care Boards assess how they are meeting their duties under the Health and Care Act[74].

National governments, local health and care systems, and local authorities, need to be held to account for delivering existing policy frameworks relating to palliative care for adults and children, and children's services. There should be ongoing monitoring and reporting of how these have been implemented in rural communities and how well the needs of people in rural communities are being met.

There also needs to be further research into different approaches for delivering palliative care in remote, rural and island communities in the UK. There is a particular lack of research into the delivery of children's palliative care in rural communities. Local service evaluation is also important as so much of delivering care in rural communities depends on local context.

Recommendations:

- Governments across the UK should include the specific needs of adults and children in rural communities in national strategies and delivery plans related to palliative care, and monitor and report on how their needs are being met. This should include how to meet growing demand for palliative care in rural communities and how to deliver more care at home and closer to home.
- Local health and care systems, and local authorities, should implement existing policy frameworks relating to palliative care for adults and children in rural areas and ensure local strategies and delivery plans include the specific needs of people in rural communities. They should monitor how well their needs are being met and take action to address gaps.
- Hospice care organisations should carry out a needs assessment across the whole geographic area they serve and include plans to address the current and future needs of their rural communities within their organisational strategy.
- Research funders should prioritise and invest in research on the delivery of palliative care in rural areas, for both adults and children.

Conclusion

People in remote, rural and island communities deserve the best possible care until the end of their lives. This report highlights the urgent need to plan ahead and respond to the growing demand for palliative care in these communities. While the challenges are complex and deeply interconnected, we can begin to make progress by acting now.

Local health and care systems can take immediate steps to better understand how well current services meet the needs of adults and children in rural communities. By working closely with local communities and services, including hospice care organisations, they can identify gaps in care, strengthen collaboration and build on existing community strengths. Creative, flexible approaches, rooted in local knowledge, can start to drive meaningful change.

At the same time, we need long-term, strategic action. National and local policies must prioritise rural communities, ensuring the workforce, funding and infrastructure are in place to meet the growing demand for high-quality, community-based palliative care.

The voices in this report remind us what's at stake. We cannot delay. Everyone, regardless of where they live, must have compassionate, dignified care at the end of life.

Annex 1: Methodology

To inform the project we carried out:

- Five online focus groups for people living with or caring for someone with a life-limiting condition in a rural community. One focus group was for people living in England, one for Scotland, one for Wales and one for Northern Ireland. One focus group was for parents or carers of a child with a life-limiting condition. We also carried out 1-to-1 interviews with individuals who preferred participating that way.
- A short online survey for people with lived experience in rural communities to share their views (49 respondents).
- A detailed online survey for health and care staff from any discipline who provide care and support to people with life-limiting conditions in rural communities (235 responses; 55% of respondents work in England, 19% in Scotland, 15% in Wales and 11% in Northern Ireland; 19% of respondents provide care and support to children and young people with life-limiting conditions).
- Interviews with staff from 11 hospices who received a Hospice UK remote and rural grant, funded by the St James Place Charitable Foundation, to share learning from their grant project.
- Key stakeholder interviews with hospice and palliative care staff, GPs, district nurses, pharmacists and commissioners in rural communities.
- A literature review of published research.
- Gathering of case studies of initiatives, services and staffing models.
- A workshop with wider workforce leads and representatives from professional bodies, including ambulance staff, pharmacists, community nursing, allied health professionals, social care, specialist palliative care and bereavement support, to discuss the key themes from the evidence gathered and the focus of draft recommendations.

The project was overseen by a small steering group consisting of people with lived experience and professionals from across the UK. The steering group gave advice and direction on the key themes, recommendations and drafting of the report.

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