Marie Curie Submission to the Health Social Care and Sport Committee: Healthcare in remote and rural areas

Call for Evidence

What are the most important issues that the Health, Social Care and Sport Committee should look at in its inquiry into healthcare in rural and remote areas?

Marie Curie strongly urges the Committee to consider access and delivery of palliative and end of life care in rural and remote areas.

Key challenges

Challenges in palliative care access and delivery can be evidenced through four 'As'[1]:

1. **Availability**; of resources for palliative and end of life care providers, including specialist palliative care teams, social care workforce and carers, to meet the needs of terminally ill people. Challenges with resources include workforce recruitment and retention, equipment and technology in care homes, hospices, hospitals and at home

2. **Accessibility**; challenges terminally ill people, their families and carers face accessing palliative and end of life care, including access to medicines pharmacy support. Intersectional transport issues are at the heart of this.

3. **Accommodation;** how palliative care providers meet terminally ill people's preferences and needs; of greatest concern are 1) existing out of hours of operations in rural and remote areas, e.g. how phone calls are handled, by whom and how they are actioned, and 2) a patient's ability to receive palliative care without prior appointments (including emergency admissions).[13]

   Accommodation also relates to the condition of terminally ill people's own homes, and challenges with ensuring homes are fit for purpose to receive palliative and end of life care, and to die there, if that is their wish.

4. **Affordability**; of living in rural and remote areas. The "rural premium" means those living in rural and remote areas face significantly higher costs in housing, energy and food among others. This is before additional costs associated with terminal illness which Marie Curie projects costs an individual between £12-16,000 per year.

   Affordability also centres around sustainability of palliative care funding in rural and remote areas. Urban centric models are usually transferred, ineffectively, to rural and remote areas because they do not reflect rural and remote challenges as above.

These unique challenges highlight palliative and end of life care access and delivery in remote and rural areas as an inequity worthy of exploration by the Committee.

[1] Access to Care: Remembering Old Lessons; Wyszewianski, Lhttps://www.ncbi.nlm.nih.gov/pmc/articles/PMC1464050/

What is palliative care and where are people dying in Scotland?

Palliative and end of life care supports people who have a terminal illness. By terminal illness, we mean a disease or condition which will likely result in the person's death. Someone can live for years, months, weeks or days with a terminal illness following their diagnosis. Palliative care can be provided in different settings, including in a person's own home, hospital, a hospice, care or nursing homes.

> **Many terminally ill people prefer to receive palliative care and die at home where that is possible, indeed in 2021–22, almost 90% of the last six months of life of those who died was spent in community settings[2].**

Palliative care aims to support a person to have a good quality of life – this includes being as well and active as possible in the time they have left. It can involve:

- Managing physical symptoms such as pain
- Emotional, spiritual and psychological support
- Social care, including help with things like washing, dressing or eating
- Support for family and friends
- Maintaining independence at home for as long as possible

A higher proportion of older people live in rural Scotland, particularly in remote and rural areas, and Scotland has an ageing population more generally.

> **Marie Curie research has found that by 2040, the biggest increase in palliative care demand will be in over 85s[3], meaning a large proportion of future palliative care need is likely to be in rural and remote areas.**
>
> **However, while rural elderly populations are increasing, there is lower demand and accessibility to specialist healthcare, including palliative and end of life care, and terminally ill patients living in rural and remote areas are at significant risk of being hidden and forgotten[3]**

Exploring the challenges of palliative care access and delivery and rural and remote areas

Availability

Availability reflects challenges with resources for palliative and end of life care providers, including specialist palliative care teams, social care workforce and carers, to meet the needs of terminally ill people.

Issues with workforce recruitment and retention are particularly acute for specialist palliative care teams, as well as generalist teams, and the social care workforce. This places increased physical, emotional and financial burdens on carers of terminally ill people, who experience challenges with access to respite, self-care, emotional burdens , management of medications, isolation and loneliness, and grief.

> **Workforces are ageing, and this challenge is felt acutely in rural and remote communities, and compounded by domestic migration of the working age population away from rural areas, particularly young people[4].**
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> **In the context of terminal illness, this can be the difference between someone getting the support they at end of life, or not.**

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[2] Public Health Scotland: percentage of end of life spent at home or in community settings https://publichealthscotland.scot/publications/percentage-of-end-of-life-spent-at-home-or-in-a-community-setting/percentage-of-end-of-life-spent-at-home-or-in-a-community-setting-financial-years-ending-31-march-2013-to-2022/#:~:text=In%202021%2F22%2C%20there%20were,remaining%2010.2%25%20spent%20in%20hospital.

[3] https://spcare.bmj.com/content/3/1/129

[4] Jamieson, L & Groves, L 2008, Drivers of Youth Out-Migration from Rural Scotland: Key Issues and Annotated Bibliography. Scottish Government.

Workforces which do serve rural and remote communities are also more likely to care for someone they know because of smaller population sizes. The impact this has on patients as well as social care staff has not been widely captured, but must be considered.

As well as workforce challenges in the delivery of community palliative care, acute settings such as rural hospitals often don't have access to the same specialisms as urban hospitals, including space, some equipment and digital connectivity. There often leads to an increased reliance on generalist care teams, including care homes, who usually do not have much, if any, palliative care training.

> **This lack of availability of resources in rural and remote areas makes accommodating end of life choices very difficult, and in many cases impossible altogether**.

Accessibility and accommodation

This relates to challenges terminally ill people, their families and carers face accessing palliative and end of life care, including access to medicines pharmacy support.

Geographic accessibility is a significant determinant on how easily terminally ill people, families and carers can physically reach a palliative care provider's location.

> **Research has shown geographical access to inpatient palliative care is associated with where people die, and patients living more than 10 minutes from inpatient care are less likely to die there.[5]**
>
> **More broadly, people living in rural areas are less likely to live within 15 minutes' drive of key public services, particularly those in remote rural areas.[6]**

More people in rural areas will be dying at home, whether or not that is their preferred place of care and death because they cannot reach different care settings such as care homes, hospital or hospices. This places increased demand on community palliative care providers, including the social care workforce, and carers who already face significant challenges delivering palliative care in rural and remote settings.

It is therefore even more important that rural homes can also reflect access and installation of home adaptations to ensure a terminally ill person's home is fit for purpose to receive palliative support, and to die there, if that is their wish.

> **However, demand for accessible properties and home adaptations currently outweighs supply across Scotland, which is more acute in rural and remote localities. This generates further implications for bereaved families in remote and rural areas facing eviction from their property after the terminally ill person has died**.

There are also intersectional transportation issues which restrict accessibility to palliative care including poor road conditions, lack of public transport, lack of volunteer drivers and lack of accessible vehicles. This can leave people reliant on expensive public transport.

> **These costs are exacerbated by the nature of living with a terminal illness. People may have multiple appointments, spread across several locations and dates with different specialists.**

Choice at the end of life is further limited by poor access as palliative and end of life care needs cannot be as person-centred in rural areas, instead needs are shaped by reduced access and limited availability of palliative care services.

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[5] Chukwusa, Emeka; Verne, Julia ; Polato, Giovanna ; Taylor, Ros ; J Higginson, Irene ; Gao, Wei *Urban and rural differences in geographical accessibility to inpatient palliative and end of life care facilities and place of death: a national population-based study in England*

[6] Evidence from NHS Highland and University Highlands and Islands to UK Government Inquiry into Cost of Living in Rural Communities 2023

These challenges result in significantly reduced opportunities for early palliative care interventions and poorer pain management for rural patients, resulting in a poorer quality end of life experience than someone in a more accessible part of Scotland could expect.

Affordability

There is a clear "Rural Premium" associated with living in rural and remote areas. NHS Highland and the University of the Highlands and Islands described this inequity in a submission to the UK Government Inquiry into Cost of Living in Rural Communities:

> **"…the budget that households need to achieve a reasonable living standard in remote rural Scotland are typically 10-40 % higher than elsewhere in the UK.**
>
> **"For households living in the most remote island locations additional costs can be even greater. There were three principal sources of this premium: higher prices paid for food, clothes and household goods; much higher fuel bills; and cost of travel to access work and services."[7]**

Marie Curie research has found that 8,200 people die in poverty every year in Scotland, equating to one in four working age people and one in eight pensioners[8]. A "double burden" of increased costs is caused by terminal illness including excess energy, housing and transport costs and lost income from carers having to give up work to provide care.

> **Across the UK, Marie Curie estimates the average yearly cost of living with a terminal illness is between £12,000 and £16,000.[9] This is likely to be higher for those in rural and remote areas who already face the "Rural Premium" excess costs for energy, housing and transport.**

These challenges together create a unique inequity facing people at the end of life in rural and remote areas. It is incumbent on the committee, government and organisations working in palliative care to ensure everyone facing dying, death and bereavement has access to best end of life experience no matter where they live.

Key questions Marie Curie urges the Committee to consider:

Access to palliative care

- How can we ensure that people in rural and remote communities know what palliative care is and how to access it?
- How can we ensure that palliative care is delivered to meet the needs of people in rural communities and afford them the same end of life choices that are available to people in urban settings?

Carers

- How can we ensure rural carers are supported to provide the care a person with a terminal illness requires at the end of life?
- How can we ensure rural carers are supported with opportunities for respite and self care both before and after a bereavement?

Workforce

- How can we support recruitment and retention of specialist, generalist, social care workforces to deliver palliative care to rural and remote areas?
- What could the role of communities be in supporting palliative care delivery in rural and remote areas?

[7] Evidence from NHS Highland and University Highlands and Islands to UK Government Inquiry into Cost of Living in Rural Communities 2023

[8] https://www.mariecurie.org.uk/globalassets/media/documents/policy/dying-in-poverty/h420-dying-in-poverty-scotland-4th-pp.pdf

[9] Marie Curie: Dying in Poverty, Exploring Poverty at the end of life in the UK, 2022

About Marie Curie in Scotland

About Marie Curie Marie Curie is here for people living with any terminal illness, their families and carers. We offer expert care and guidance through our two Hospices in Edinburgh and Glasgow, and Marie Curie Nursing Service in 31 out of 32 Local Authorities.

Our volunteer-led Helper service provides companionship and support to those affected by terminal illness and has a presence across all 32 Local Authorities, as well as our Information and Support lines, including dedicated bereavement line, which provide emotional support and practical and clinical information about terminal illness.

Marie Curie is also the biggest charitable funder of palliative care research across the UK. In 2021-22, Marie Curie Scotland cared for 8,660 people at the end of life. With more and more people dying in the community throughout the pandemic, demand for our community nursing services has remained extremely high.

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Marie Curie
Care and support through terminal illness