

# Bringing care closer to home

Lived experiences of palliative care in rural and island communities across the UK

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## Rural demand is rising

- ▶ Rural and island communities across the UK are ageing faster than cities<sup>1</sup>.
- ▶ The number of working-age people who can provide care is declining<sup>1</sup>.
- ▶ UK research is limited and tends to focus on older people or specific parts of the UK, leaving many voices unheard.

**“When we needed care, it wasn't there for us. I feel very let down.”**

Bereaved carer

## What we did

We explored people's experiences of death, dying and bereavement in rural and island communities across England, Wales, Scotland and Northern Ireland, including families of children with life-limiting conditions.

**22** people participated in lived experience focus groups or alternative 1-2-1 interviews.

**49** people shared additional lived experience insights through an online survey.

**235** rural health and care staff responded to an online survey.

**4** online focus groups in **England, Scotland, Wales** and **Northern Ireland** for people living with or caring for someone with a life-limiting condition in a rural or island community.

**1** online focus group for **parents of children** with life-limiting conditions living in a rural or island community.

- ▶ We also ran interviews and a workshop with health and care staff across a wide range of roles.
- ▶ Focus groups and interviews followed appropriate ethical and safeguarding procedures.

## What do rural communities need?

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

Carer

Urgent policy reform and service redesign is needed to 'rural-proof' palliative care. Scan the QR code to download our full report and nation-specific briefings, and read recommendations for:

- ▶ Health and care services
- ▶ Local health care systems
- ▶ National governments across the UK

### Acknowledgements

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### References

<sup>1</sup> Whitty C. Chief Medical Officer's annual report 2023: health in an ageing society. London: Department of Health and Social Care; 2023.

To read more please scan this QR code:



## What did we find out?

**“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

### There are major barriers to accessing palliative care



- ▶ Long distances to travel, poor public transport and costly journeys.
- ▶ Lack of support at home, especially out of hours and delays accessing medication and equipment.
- ▶ Staffing and skills shortages, particularly in social care.
- ▶ Care is fragmented across regional and national borders.

### Families with children face additional barriers



- ▶ Rural services are tailored to older adults.
- ▶ Staff lack confidence and skills to support children with complex needs.
- ▶ Families feel socially isolated.
- ▶ Few families spread across vast distances make delivering services hard.

### Living rurally can bring support - but also tensions

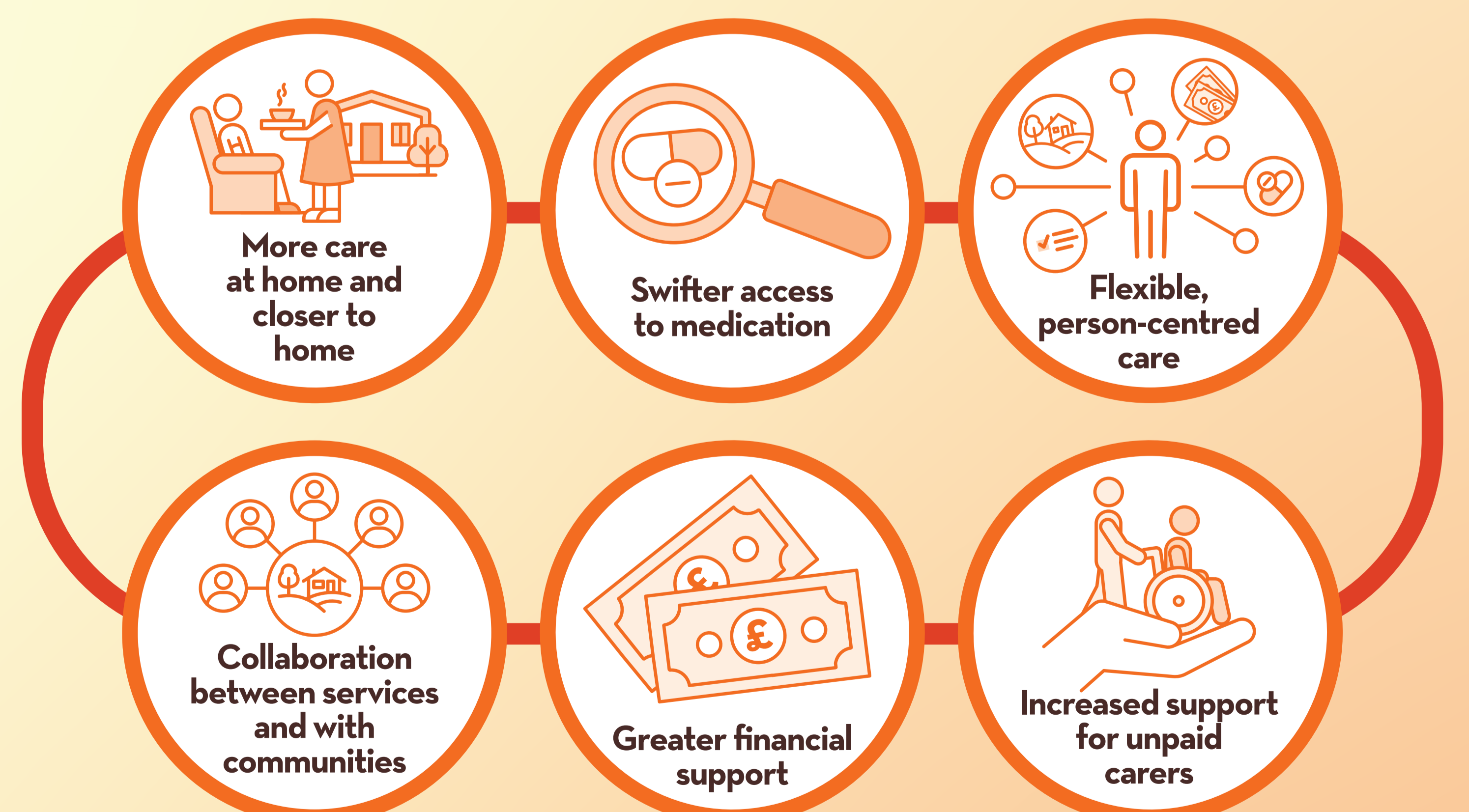


- ▶ Close-knit rural communities provide invaluable support.
- ▶ However, those without a strong support network face significant social isolation.
- ▶ Unpaid carers need more support. Farming families struggle to balance caring with farming duties.

### There is a lot to learn from rural communities



- ▶ Rural communities offer powerful examples of people coming together around death, dying, and bereavement, in creative community-led ways.
- ▶ Rural communities can help people maintain their cultural identity, language preferences and ties to land and place - which are central to care experiences.



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