Bringing care closer to home: Improving palliative care in remote, rural and island communities

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Background

Remote, rural and island communities in the UK face deep-rooted barriers to accessing health and care services[1]. Rural populations are ageing faster than urban populations and have fewer people of working-age able to provide care[2]. This means that the increasing demand for palliative care, being experienced across the UK, will have the greatest impact on rural communities.

Aim

In 2024 - 2025, Hospice UK carried out a policy research project to:

- Increase understanding of people's experiences of death, dying and bereavement in remote, rural and island communities across the UK.
- Explore the challenges and opportunities in delivering palliative care, and share learning.
- Make recommendations to national policy-makers, local systems and services.

Methods

A qualitative study, with due ethical/safeguarding processes in place, consisting of:

- Five lived experience online focus groups, one in each UK nation and one for parents of children with life-limiting conditions, with supplementary one-to-one interviews where preferred (22 participants).
- Two online surveys: one for adults with lived experience (49 responses) and one for health and care staff (235 responses).
- A series of stakeholder interviews and a professional workshop, including hospice and palliative care staff, commissioners, service planners, education leads, district nurses, GPs and pharmacists.
- A literature review and collection of case studies.

Results

- Nearly two thirds of people living rurally said they did not receive the care and support they needed. In particular, they identified a lack of care and support at home, especially out of hours, and delays accessing medication.
- Two thirds of health and care staff who support people with life-limiting conditions living rurally said there are not enough staff with the right skills, particularly in social care.
- People are being forced to choose between where they live and the care they receive at the end of life. Some people face moving hours away from family and friends to access care.
- Families of children with life-limiting conditions living rurally face significant additional barriers, with rural services more tailored to older adults and staff lacking paediatric expertise.
- People face a double financial burden: the high cost of living rurally, combined with the financial impact of caring for someone at the end of life.
- Rural areas require a creative, community-driven approach. People need the flexibility to arrange care around what they need, drawing on existing community strengths and support.

Conclusion

Remote, rural and island communities face deep structural inequities in access to palliative care. Urgent policy reform and service redesign are needed to address this. Local systems must work with services and local communities to identify and address gaps in care, strengthen collaboration and build on existing community strengths. National policies must be 'rural-proofed' to ensure the workforce, funding and infrastructure are in place to meet rising demand for community-based palliative care.

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References

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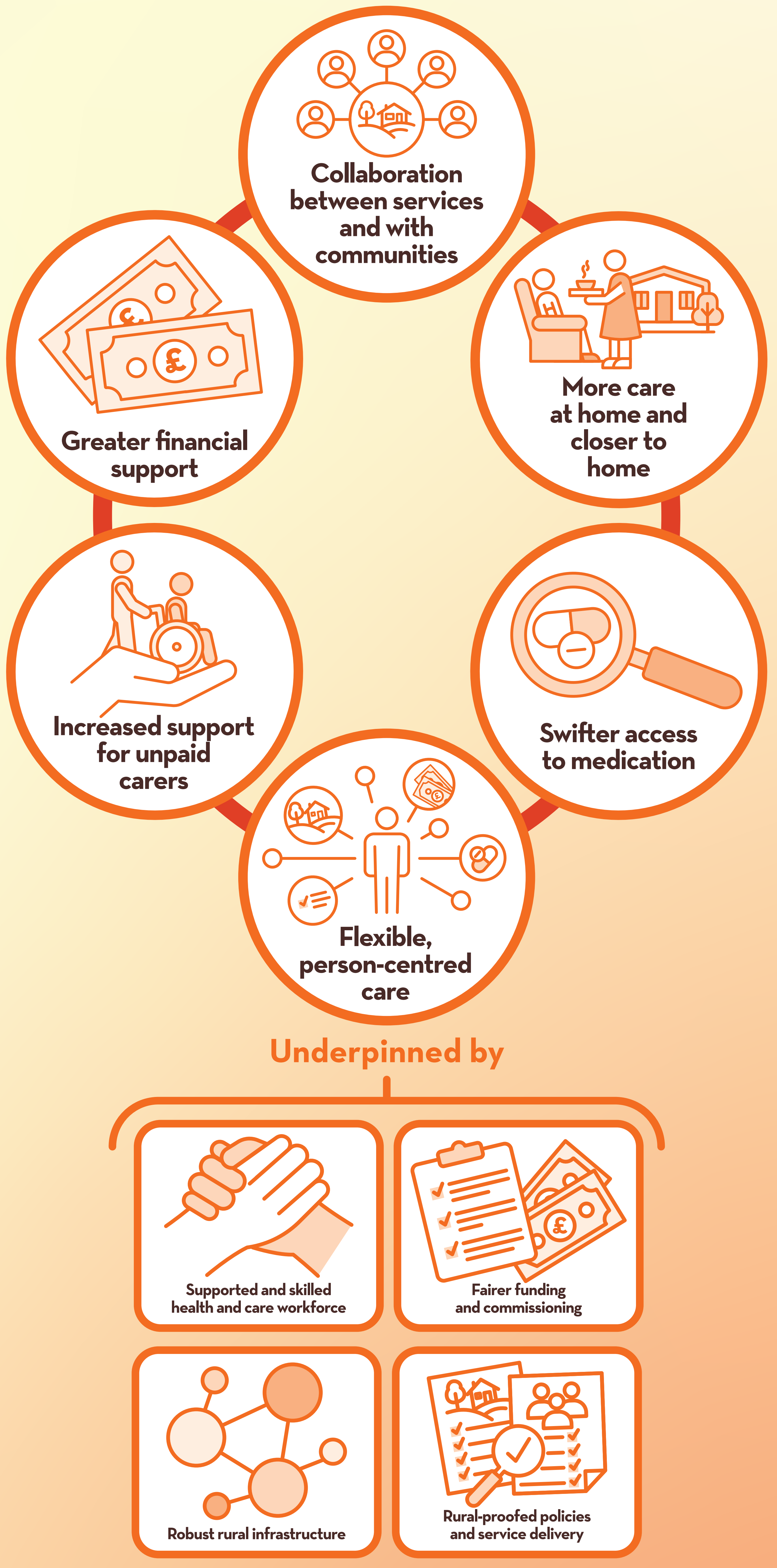
2. Whitty C. Chief Medical Officer's annual report 2023: health in an ageing society. London: Department of Health and Social Care; 2023. Available at: www.gov.uk/government/publications/chief-medical-officers-annual-report-2023-health-in-anageing-society

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

To download the full report and nation-specific briefings, please scan the QR code.

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