

**What does the Rural and Islands Housing Action Plan need to achieve to ensure people in rural, remote and islands communities can die in a place of their choosing?**

- 1. More accessible houses built in rural, remote and island communities.**
- 2. Adaptations made to rural, remote and island properties as quickly as possible for terminally ill people.**
- 3. Adequate housing for social care and nursing staff to allow them to live and work in rural, remote and islands communities.**

**Marie Curie is the largest third sector provider of palliative and end of life care services in Scotland for adults. In 2022-23, Marie Curie supported over 8,100 people in Scotland.**

**We serve rural and islands communities across Scotland and campaign for the best possible end of life experience for all.**

### Where are people dying in Scotland?

Many terminally ill people prefer to receive palliative care and die at home where that is possible. In 2021–22, almost 90% of the last six months of life of those who died was spent in community settings, including people's own homes and care homes.<sup>1</sup>

Research has shown geographical access to inpatient palliative care is associated with where people die, and patients living more than 10 minutes away from inpatient care are less likely to die there, irrespective of whether or not that is their wish.<sup>2</sup>

**Thus in remote and rural areas, people are more likely to die in their own home.**

Scotland's ageing population means more people will be dying in the years to come. Marie Curie research has found by 2040<sup>3</sup>:

- 60,000 people will die with palliative care needs, 10,000 more per year than currently.
- People dying with multi-morbidities (more than one terminal condition) will have increased by over 80%.
- Two thirds of all deaths in Scotland will be in community settings such as people's

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<sup>1</sup> Public Health Scotland: percentage of last six months of life spent in community settings 2021-22

<sup>2</sup> 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

<sup>3</sup> Finucane, A.M., Bone, A.E., Evans, C.J. et al. The impact of population ageing on end-of-life care in Scotland: projections of place of death and recommendations for future service provision. BMC Palliative Care 18, 112 (2019)

own homes, care homes and hospices.

**The demand for housing for terminally ill people living with multi-morbidities will increase significantly.**

Scotland has an ageing population, and particularly high elderly populations in rural, remote and island communities. Marie Curie research estimates by 2040 the biggest increase in palliative care demand will be in over 85s.<sup>4</sup>

**A disproportionately large amount of future palliative care need is likely to be in rural, remote and island communities.**

### Accessible Housing

As the number of people ageing with multiple terminal illnesses increases, demand for accessible homes will increase too. In rural, remote and island areas we know that demand already exceeds supply for standard properties, let alone accessible properties.<sup>5</sup>

The Rural and Islands Housing Action Plan describes a development on the Isle of Arran that included wheelchair liveable homes being built for social rent by North Ayrshire Council, partly funded by the Scottish Government. This is welcome, however it is the only example in the action plan that cites any kind of accessible homes being built in remote, rural or island communities.

According to MND Scotland 23% of the local authorities who responded to their enquiries regarding how they defined an accessible home told them they “did not have any agreed upon and council wide definition of accessible or stated that they did not hold this information”.<sup>6</sup>

The lack of an agreed definition for accessible homes has been noted as an issue by The Association of Local Authority Chief Housing Officers (ALACHO). Which they stated in their response to the Citizen Participation and Public Petitions Committee investigation into PE1956.<sup>7</sup> Marie Curie supports ALACHO's calls for this single definition of what an accessible home is, to enable implementation by local authorities, and social and private housing providers.

We welcome the intent of the Scottish Government's new Housing and Scottish Accessible Homes Standard to provide clarity in this area. However, the definition of accessible housing must reflect the needs people living with multi-morbidities (more than one terminal condition).

Once a definition is agreed we support calls from MND Scotland for the building of a minimum percentage target of accessible housing, to be enshrined into legislation, with a minimum of 10% of all new homes built to this guidance.<sup>8</sup>

***“I recently visited a lady who had advanced COPD and was approaching end of life. When we arrived, we found her sitting on an office chair in the kitchen.*”**

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<sup>4</sup> Finucane, A.M., Bone, A.E., Evans, C.J. et al. The impact of population ageing on end-of-life care in Scotland: projections of place of death and recommendations for future service provision. BMC Palliative Care 18, 112 (2019)

<sup>5</sup> [https://www.heraldscotland.com/business\\_hq/23342555.highlands-islands-housing-crisis-hampering-economic-growth/](https://www.heraldscotland.com/business_hq/23342555.highlands-islands-housing-crisis-hampering-economic-growth/)

<sup>6</sup> MND Scotland, No Time to Lose: Addressing the Housing Needs of People with MND, 2022

<sup>7</sup> ALACHO, Submission to Citizen Participation and Public Petitions Committee enquiry on PE1956: Increase the provision of wheelchair accessible homes, 2023

<sup>8</sup> MND Scotland, No Time to Lose: Addressing the Housing Needs of People with MND, 2022

***“It seems she has been sitting on this chair for three months and eats and sleeps on it as she was no longer able to get upstairs to her bedroom and the settee and chairs in the sitting room were too low for her to get up unaided.”***

- Marie Curie Hospice Care at Home team

## **Housing Adaptations**

While building more accessible homes would be welcome and is necessary, the first preference of many terminally ill people living in unsuitable accommodation is that their current home is adapted to suit their needs to enable them to die at home if that is their wish. It is important that any new homes built are constructed in a way that considers that there may be need for further adaptations to the property in the future.

Long waiting periods for adaptations are common for people living with terminal illness, and many who are living in unsuitable accommodation would prefer for their current home to be adapted to suit their needs, but not all existing grants cover these costs and even subsidized adaptations can prove too costly at the end of life. A common complaint of terminally ill people and their carers who have been deemed to require adaptations to their property is the waiting time for these adaptations to take place:

***“A man who is an amputee was told by an Occupational Therapist that he would be unable to get adaptations to his home in the first instance so should be putting his name onto the housing list for sheltered accommodation. Whilst this was happening he had then gone back into hospital.”***

- Marie Curie Hospice Care at Home team

Marie Curie Hospice at Home staff working across Scotland reported to our internal 2021 survey that they regularly visited terminally ill people who use a wheelchair, but who are living in homes with doors too small for them to fit through.

Evidence suggests that there is a greater importance placed on the role of community networks in supporting people through the end of life experience in rural communities. So it is important where we can, to keep people in the same rural, remote and island communities where their extended network live.

**Every effort must be made to ensure people can stay in their own homes with adaptations, at the end of life if that is their wish.**

## **Housing the Rural Workforce**

Marie Curie urges parliament to consider wider public health aspects in the context of the Rural and Islands Housing Action Plan.

The lack of available accommodation for workforces in rural and remote areas, particularly island communities impact workforces ability to deliver palliative care, as well as recruitment and retention.

**This forces providers of palliative care in island, remote and rural settings to often rely on bank staff which is costly, and unsustainable in the long term.**

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**About Marie Curie Scotland**

Marie Curie is the largest third sector provider of palliative and end of life care services in Scotland for adults. In 2022-23, Marie Curie supported over 8,100 people in Scotland.

Marie Curie have two Hospices in Scotland, one Glasgow and one in Edinburgh. As well our inpatient services, the hospices offer outpatient services for terminally ill people and in some cases their bereaved loved ones delivered by clinical staff, allied health professionals and counsellors. Clinicians from both hospices also offer expert palliative support to generalist and community health and social care staff.

Marie Curie's Hospice Care at Home service is active in 31 of Scotland's 32 local authority areas. The exact Hospice Care at Home service Marie Curie provides differs by area but the key services we provide are:

- A "Managed Care" service where a clinical coordinator manages all aspects of a patients care to make sure they are fully supported at the end of life.
- A "Urgent Hospice Care at Home" service where a nurse or a social care assistant will respond to urgent calls for assistance.
- A "Sitting Service" where a nurse or a social care assistant will go to a terminally ill persons home and spend a block of time with them (often through the night) to provide care and provide respite for carers.
- A "Fasttrack" service where Marie Curie will provide comprehensive health and social care support to allow a terminally ill person to leave hospital without a care package from their local authority in place.

The Marie Curie [Information and Support](#) line can be called from anywhere in Scotland for practical or clinical information, and emotional support for someone living with a terminal illness, their carer or someone who has experienced a bereavement. Marie Curie's Companion volunteer [service](#) supports facing terminal illness in coping with social isolation feel after a diagnosis.

Marie Curie is also the biggest charitable funder of palliative care research across the UK.

