



# Marie Curie Briefing- SNP Conference

## Poverty at the end of life

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### **Impact of poverty and inequity on dying, death and bereavement in Scotland**

*Poverty, inequity in energy, housing and palliative and end of life care are just some of the challenges people experiencing dying, death and bereavement face.*

*What do we know about poverty at the end of life, and what needs to happen to ensure it doesn't impact end of life experience?*

### **What needs to happen to ensure poverty and related inequity does not impact end of life experience?**

1. Additional support to help terminally ill people cope over the winter period and beyond with their energy bills, by including terminally ill people in the eligibility for any increased support from the Warm Homes Discount this winter and working with energy companies to deliver a social tariff.
2. Local Government must use BASRiS forms to fast-track applications for housing adaptations for terminally ill people and increase funding and awareness of the scheme of assistance.
3. Scottish and UK Government to provide comprehensive social security support for terminally people and their carers. Longer term, Carers Support Payment should continue for six months after the person being cared for has died.

### **Marie Curie and Loughborough University research into poverty at the end of life found:**

- Over 8,200 people in Scotland die in poverty every year; equating to 1 in 4 working age people, and 1 in 8 pensioners
- Being terminally ill and reaching the end of life can substantially increase the risk of poverty, not just for the person who is terminally ill but also for carers and families who look after them.
- Working age people with dependent children are more likely to experience poverty at the end of life than any other group.
- Women are more likely to experience poverty than men due to long-standing, structural inequality in the labour market, lower individual retirement income, and disproportionate unpaid care responsibilities. These inequalities are significantly magnified at the end of life.

## Poverty

Where and when people die is greatly impacted by structural inequality. There is a 24 year gap in healthy life expectancy between the most and least deprived areas communities in Scotland.

**Two in three people living with a terminal illness are reliant on benefits as a main or sole source of income.**

This financial burden does not only fall on the person who is dying, it also falls on their families and carers. The excess costs of living with a terminal illness in the last year of life in the UK, including higher energy bills and housing adaptations, are estimated to cost a household between £12,000- £16,000.

**Much of the support provided to those carers eligible, while they are caring, is withdrawn following the death of the person they were caring for, putting them at risk of severe poverty.**

The burden of income loss caused by the person with the terminal illness and their carer having to give up work or reducing their working hours can be significant. It is amplified by and creates a 'double burden' along with the additional costs associated with terminal illness, such as significantly increased heating bills and home adaptations, and can leave people struggling to make ends meet.

## Energy

For the first time in 2022 average UK energy bills rose above £2000, a year later it has been estimated that 72% of Scottish households could be living in fuel poverty this winter.

**84% of Marie Curie Hospice Care at Home staff tell us that they have cared for patients struggling with energy costs.**

**In a poll Marie Curie previously commissioned of the Scottish public, 94% of respondents said they were concerned about family or friends who are terminally ill being able to keep their home warm over autumn and winter.**

Many terminal conditions can cause poor circulation and limit mobility, forcing people to have their heating on at a high level. This is often coupled with further costs from medical equipment such as nebulisers and ventilators and extra utilities, such as using washing and tumble drying machines multiple times a day.

### Amandeep's story

Dying in the Margins<sup>1</sup> highlights terminally ill people's experiences of financial hardship and deprivation for those wishing to die at home. Amandeep, a participant of the study, had to turn down his own home because of financial circumstances, also impacting his wider physical and mental health:

***"It's difficult because all my stuff is electrically powered and that uses a lot of electricity...I was getting offered my own place, but I turned it down...There's no way I'm going to afford them on my own, because everything, all my stuff runs on electricity, and you know the electricity prices, they sky rocketed"***

## Housing

From 2021 to 2022, people who were dying spent around 90% of the last six months of their lives at home.

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<sup>1</sup> Dying in the Margins is the first research study in Scotland, and UK to use visual methods to evidence circumstances of dying at home in financial hardship. The research was undertaken by University of Glasgow and Marie Curie, and funded by the Economic and Social Research Council (ESRC), part of UKRI (UK Research and Innovation)

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 subsidised adaptations can prove too costly at the end of life:

**“A man who is an amputee was told by an OT 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 Healthcare Assistant, Fife

### Unpaid Care

Carers have a crucial role in helping terminally ill people get the day-to-day support they need for a good quality of life. It would be difficult for anyone to die at home without the presence of a live in carer, but for people with some conditions such as dementia or multi morbidities, dying at home without a live a carer would be almost impossible. Pre-pandemic, Oxfam estimated the value of unpaid care work at £36 billion in Scotland.

**Despite their importance identifying carers can often be difficult, as many do not self-identify as carers or get picked up by formal services and therefore miss out on support, and benefits, they may be eligible for.**

### Rural and remote

Challenges in palliative care access and delivery can be evidenced through four 'As'<sup>2</sup>:

**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.

**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.

**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).<sup>13</sup>

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.

**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.

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<sup>2</sup> Access to Care: Remembering Old Lessons; Wyszewianski, [Lhttps://www.ncbi.nlm.nih.gov/pmc/articles/PMC1464050/](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1464050/)

## What needs to happen to ensure poverty and related inequity does not impact end of life experience?

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- 2. Local Government must use BASRiS forms to fast-track applications for housing adaptations for terminally ill people and increase funding and awareness of the scheme of assistance.**
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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 almost 8,000 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 Helper and companion volunteer [service](#) supports tackling the social isolation many terminally ill people feel after a diagnosis.

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

### [Further information:](#)

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