

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 campaign for the best possible end of life experience for all. We are proud to be members of the Poverty Alliance and grateful for opportunity to brief MSPs on this important debate on Challenge Poverty Week.

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
- 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.

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.**
- 2. 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.**
- 3. Scottish Government and Integration Authorities must take a whole-system approach to developing a sustainable palliative care funding model which supports equitable access to palliative care, and reflects local population health needs across Scotland by working with all palliative care providers**

Poverty at the end of life

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 Margins¹ 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"

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.

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.

The 'State of Caring in Scotland – The financial impact of caring in 2023' report from Carers Scotland found that

¹ 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)

- More than a quarter of carers (28%) and 41% of carers on Carer's Allowance are struggling to make ends meet
- 44% of carers on Carer's Allowance are cutting back on food and heating
- One in six carers on Carer's Allowance are visiting foodbanks

Housing

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

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 Hospice Care at Home team

Rural, remote and island communities

People living in rural and remote communities face inequity at the end of life, not experienced by their urban counterparts.

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 a household £12-16,000.

Sustainability of palliative care funding in rural and remote areas is also vital to ensuring no-one dies in poverty. 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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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 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.