

Marie Curie Briefing

Cost of Living Crisis and Scottish Budget, December 2022

This is Melanie's story.

Melanie Finlay, 48, was diagnosed with terminal metastatic bone cancer in March 2021. She lives in the Highlands with her husband and her seven-year-old son.

"I've got a really aggressive form of cancer and we just can't control it. So, **there is the likelihood that we're not going to be able to do this winter what we did last winter. I've already started stockpiling winter blankets and hot water bottles.** That's probably the only thing that's going to keep us going. I can't even rely on things like electric blankets because the electricity's going through the roof as well.

"We're going to just have to rough it.

"As soon my bones get cold, they hurt. It's very painful. We have to keep the house warm. But with the energy prices going up we can't do that. **There's no way we're going to be able to afford it."**



The 'double burden' of income loss and increased cost of living expenditure brought on by a terminal illness, such as higher energy bills and home adaptations, can leave people struggling to make ends meet, and force those who were already on the threshold below the poverty line.

It is vital that the right physical, emotional and financial support can be accessed to help those affected by dying, death and bereavement to die with dignity, without having to worry about their finances.

Marie Curie and Loughborough University research¹ into poverty at the end of life found:

- 1. Over 8,200 people in Scotland die in poverty every year;** equating to 1 in 4 working age people, and 1 in 8 pensioners
- 2. 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.
- 3. Working age people with dependent children are more likely to experience poverty at the end of life**
- 4. 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.

¹ Marie Curie and Loughborough University; [Dying in Poverty at the End of Life](#)

Marie Curie asks of Scottish Government's Budget to support terminally ill people, their families and carers:

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- 2. Commit to increasing the Child Payment beyond the standard rate for terminally ill claimants of working age with dependent children**
- 3. Extend the upcoming Scottish Carer's Assistance for up to six months after a person's caring role ends**
- 4. Reflect the financial needs of people affected by terminal illness in both its upcoming Palliative Care Strategy, and National Care Service**

Implications of the cost of living crisis for dying people, their families and carers

Fuel poverty at the end of life

By early 2023, **more than 70% of Scottish households are expected to be living in fuel poverty**, with some of the most rural areas across the country being the most affected². Rural communities can be particularly impacted.

Terminally ill people are already at a heightened risk of experiencing fuel poverty, as their symptoms will often make them feel colder and they will spend increasing amounts of time at home with the heating on as their condition deteriorates³.

Average energy bills have also been shown to almost double after a diagnosis of motor neurone disease⁴, for example, a condition that will affect many patients while they are of working age. This has worsened in recent months as energy prices have skyrocketed:

Entitling terminally ill people to access the financial, physical, emotional and spiritual support is crucial to reducing the risk of falling into poverty as a result of their condition.

Deprivation and poverty

The vicious cycle of poverty, deprivation and social exclusion affects thousands each year, and has deepened as a result of the pandemic with twice as many deaths from Covid-19 in the most socioeconomically deprived areas than in the least⁵.

There are clear links between areas of high deprivation in Scotland and poverty at the end of life across the country, but particularly in Glasgow, Dundee and West Dunbartonshire

Approximately **one third of working age people and one fifth of pensioners experience poverty at the end of life** in Glasgow, Dundee and West Dunbartonshire, and **almost one fifth in these three Local Authorities were claiming key working age benefits.**

This evidences deep rooted, systemic inequality in how terminally ill people, their families and carers are affected by unprecedented levels of financial hardship from decades of structural inequality, and how this is magnified through poverty at the end of life.

Families with dependent children

Families with dependent children are more likely than people who don't have children (or who don't have children living with them) to experience poverty. **In Scotland we already know that⁶:**

² [Fuel Poverty estimates for the UK; University of York](#)

³ Marie Curie (2020). The vicious cycle of fuel poverty and terminal illness

⁴ Demos (2017). MND costs: Exploring the financial impact of motor neurone disease

⁵ National Records of Scotland; Deaths from Coronavirus

⁶ Joseph Rowntree Foundation; Poverty in Scotland 2021

- Single adults (of all ages) and particularly single parent families (at 38%) experience higher levels of poverty than all people
- The poverty rate for people in minority ethnic families is more than double that of people in white families.
- Poverty rates for people in families that have part-time work are triple (at 30%) those of people in families where at least one person is in full-time work (at 10%).

Among people nearing the end of life across the four nations, Marie Curie and Loughborough University’s research has found that:

- People in families with children are the most vulnerable of all family types to experiencing poverty in the last five years of life.
- They are the group most likely to be ‘mostly in poverty’ during the last five years of life, and the most likely to be ‘moving in and out of poverty’ during this period
- Two out of three working age terminally ill people with children will experience poverty in their last five years of life.

Many working age parents affected by terminal illness who are unable to work will miss out on support with the costs of childcare despite being impacted by the additional costs of terminal illness, making childcare less affordable.

We recognise that the Scottish Government has doubled the Child Payment for low income families in 2022 and has extended to children under 16, and this is welcome.

However, there needs to be more done to support terminally ill people with dependent children who are already living in relative or persistent poverty, or at risk of moving into poverty because of a combination of childcare costs, other household bills such as energy and food, and end of life care costs.

Carers of terminally ill people

Carers have a crucial role in helping terminally ill people get the day-to-day support they need for a good quality of life. Yet 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.

“Friends couldn’t come to help in case they gave him Covid. They would have come to help but they couldn’t. It was just us. We were exhausted (Carer)”

I just wanted to scream. I thought oh my god have I got to deal with this? I found it so, so hard that we were left to do this on our own (Relative)⁷.

Unpaid care has historically, and disproportionately, impacted women. Marie Curie and Loughborough University’s research has found that (on a UK scale) women have a higher risk of poverty at the end of life than men, reflecting higher levels of poverty than men in the general population and persistent employment and income inequalities. But these are not new findings.

In Scotland existing research has shown that^{8, 9}:

- Less than 12% of women receive the full basic state pension based on their own contributions
- A woman’s average retirement income is 53% of men’s because they take time out to care
- The average woman working full-time is paid 15% less than a man

This highlights long-standing, structural inequality in the labour market, lower individual retirement income, and unpaid care responsibilities which significantly impact women disproportionately. These inequalities don’t lessen at the end of life, they magnify.

⁷ The Experiences of Informal Carers during the Covid-19 Pandemic: A Qualitative Systematic Review 2022; IJERPH; Bailey, C, Guo P, MacArtney, J, Finucane, A, Swan, S, Meade, R, Wagstaff, E

⁸ Engender: [Taking forward the Government Economic Strategy; a discussion paper on tackling poverty, inequality and deprivation in Scotland](#)

⁹ Public Health Scotland: [Child Poverty in Scotland; priority groups; lone parent families](#)

Marie Curie and Loughborough University's research has highlighted that (on a UK level):

- If women were to lose their job or give up work, nearly two-thirds of working age women have savings that would last a month or less while a third have savings that would last less than a week¹⁰
- Exiting the labour market is the single biggest risk factor for falling below the poverty line in the last years of life

The role of being a carer for someone who is terminally ill has a huge impact on the life of the person they are caring for, as well as the financial, physical and emotional wellbeing of the carer themselves.

Carers provide £10.9billion worth of care each year¹¹, yet support for carers themselves is often overlooked and needs to be more greatly recognised.

Costs for unpaid care are usually categorised into three main areas, and **have risen sharply during the pandemic, exacerbating the cost of living crisis for carers of terminally ill people¹²:**

1. **Work related** (e.g. changes in employment such as going part-time or giving up work entirely)
2. **Carer time costs** (related to time investment required by carers)
3. **'Out of pocket costs'** (direct outgoings including transport, food, medicines)

The financial burden of caring is currently recognised through the Carer's Allowance, and Carer's Allowance Supplement in Scotland, which some carers are eligible for. But once a caring role comes to an end it can have a significant impact on the carer's wellbeing, financial position, relationships and virtually every aspect of their life.

Much of the support provided to them while they were a carer is withdrawn following the death of the person they were caring for, putting them at risk of poverty and continuing in a cost of living crisis.

The public back action to support terminally ill people, their families and carers

Marie Curie recently commissioned a poll of the Scottish public to understand the extent to which people in Scotland:

- Would have a financial safety net of their own if diagnosed with a terminal illness
- If they would welcome further support
- Which groups they felt had the most responsibility to protect people against falling into poverty as the result of terminal illness

The results found on average:

- **94% are concerned about family or friends who are terminally ill** being able to keep their home warm over autumn and winter
- **75% would struggle to pay their energy bills** this autumn and winter if they were diagnosed with a terminal illness and unable to work. **Women in particular would struggle a lot (78%)**
- **80% agreed that Governments should take targeted action to support terminally ill people with the cost of living¹³**
- **70% believe Scottish Government has the most responsibility to protect people from falling into poverty as a result of terminal illness¹⁴**

¹⁰ Ibid

¹¹ [Carers Scotland : The Cost of Living Crisis for Unpaid Carers in Scotland 2022](#)

¹² Gardiner, C et al *Equity and the financial costs of informal care giving in palliative care: a critical debate* BMC Palliative Care 2020

¹³ 'Targeted Action' refers to support aimed at people with particular needs or vulnerabilities to rising costs, such as those who are terminally ill, in addition to support governments make available to everyone

¹⁴ This was followed by Local Government (45%), Employers (23%), Individuals and Family Members (15%), Charities (13%)

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- 8. Reflect the financial needs of people affected by terminal illness in both its upcoming Palliative Care Strategy, and National Care Service**

About Marie Curie

Marie Curie is here for people living with any terminal illness, their families and carers. We offer expert care and guidance through our two [Hospices](#) in Edinburgh and Glasgow, and [Marie Curie Nursing Service](#) in 31 out of 32 Local Authorities.

Our [volunteer-led Helper service](#) provides companionship and support to those affected by terminal illness and has a presence across all 32 Local Authorities, as well as our [Information and Support lines](#), including dedicated bereavement line, which provide emotional support and practical and clinical information about terminal illness. Marie Curie is also the biggest charitable funder of [palliative care research](#) across the UK.

In 2021-22, Marie Curie Scotland cared for 8,660 people at the end of life. With more and more people dying in the community throughout the pandemic, demand for our community nursing services has remained extremely high.

For further information

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