

Marie Curie Scotland Briefing

Dying in Poverty in Scotland 2025

Marie Curie is a campaigning and social justice organisation with a mission to close the gap in end of life care. We are the largest provider of specialist adult palliative care outside of the NHS in Scotland. Taken from research carried out by Loughborough University and Marie Curie, findings from "Dying in Poverty in Scotland" evidences the extent of end of life poverty and fuel poverty in 2025.

"Mum didn't like to admit to me that she didn't have money for food, but I went to do a shop for her one day and she had to tell me she didn't have the money to pay for it.

"I didn't tell my mum, because she had enough to worry about, but I actually had to take out a bank loan to be able to afford to stop working to care for her. I had bills coming in for my own house. I just didn't want to put any more pressure on her than she already had." – Gillian, South Scotland.

Research overview:

- Over 6,500 people living with terminal illness die in end-of-life poverty each year in Scotland, and 7,700 die in fuel poverty, according to findings from research by Loughborough University and Marie Curie.
- End of life poverty has stagnated and has not improved between 2019-2024, despite some policy efforts. In some areas, it has worsened.

Findings from Marie Curie and Loughborough University indicate:

1. Prevalence of End-of-Life Poverty in Scotland 2025

- 1 in 4 working-age people (26.1%) and 1 in 6 pensioners (15.8%) with terminal illness die in end of life poverty each year.
- 1 in 5 people (20.7%) die in end-of-life fuel poverty, driven by high energy costs and medical device use.
- End of life poverty most severely impacts people in their last year of life.

Policy recommendation: UK Government must guarantee people of working age living with a terminal illness to be guaranteed a State Pension-level of income. As part of this, the UK Pensions Commission should explore how access to the State Pension can be provided to people of working age who are living with a terminal illness.

2. Impact on Families

- Terminally ill working-age parents with dependent children continue to be disproportionately impacted by end of life poverty.
- The double burden of income loss and increased costs associated with terminal illness, including additional childcare, housing and energy, is plunging families below the poverty line.
- This not only affects the parent(s) living with terminal illness, but also perpetuates and deepens child poverty in Scotland.

Policy recommendation: Scottish Government and Social Security Scotland must maximise uptake of disability and childcare benefits using a values-first approach to remove stigmatisation.

Policy recommendation: All public, independent, and third sector bodies responsible for delivering palliative care must empower all health and social professionals with knowledge about BASRiS to support fast-tracked access to Scottish disability benefits for terminally ill people.

3. Ethnic Disparities

- Minoritised ethnic groups are disproportionately affected by end of life poverty in the UK: nearly half of working-age Black (46%) and Asian (45%) people die in end-of-life poverty, compared to 25% of white people.
- For pension-age groups, the disparity persists (e.g. 39% of Black pensioners vs. 15% of white pensioners).
- These disparities are likely a result of unequal earnings and employment opportunities experienced by minoritised ethnic groups. For example, Bangladeshi households rely on benefits (excluding State Pension) for 20% of their income on average, compared to 7% of white households.
- Due to data limitations, the research was not able to provide a full breakdown of estimates of dying in poverty by ethnicity for Scotland, but even based on broad categories, there is a clearly disproportionate impact across the UK.

Policy recommendation: Scottish Government must commit to addressing specific barriers faced by minoritised ethnic communities when accessing support after a terminal diagnosis.

Policy recommendation: Scottish Government must commit to working with minoritised ethnic groups and palliative care providers to better understand and take action to address wider inequalities which persist into the last year of life among people from minoritised ethnic communities.

4. Geographical Inequality

- Glasgow City, West Dunbartonshire, Dundee City, North Ayrshire, and Inverclyde have been most adversely impacted by end of life poverty over the five year period (2019-2024) Marie Curie and Loughborough University have been monitoring this.
- The average for people dying in end of life poverty for these Local Authorities increases to 1 in 3 working age people (compared to a Scotland average of 1 in 4), similarly increasing for pension-age people to 1 in 5 (from 1 in 6).
- Socio-economic deprivation is closely linked to higher rates of end-of-life poverty.
- While we recognise the financial pressures which both national and local government is under, councils do have the powers to take action on improving the financial situation of people dying in poverty.
- One preventative option would be to introduce council tax relief for terminally ill people.
- For example, Manchester City Council has one of the highest rates of deaths in poverty among working-age people in the UK, with more than 40% of working age people who die doing so in poverty.
- Manchester's change to its Discretionary Council Tax Support Scheme means that any household containing someone with a terminal illness – whether or not they are the billpayer – will have their council tax reduced to zero upon presentation of an SR1 form.
- This support will not immediately stop upon the person's death, but will continue until the end of the financial year in which they die.

Policy recommendation: Scottish Government, Local Authorities and COSLA must work together to exempt terminally ill people from council tax using BASRiS.¹

¹ BASRiS stands for Benefits Assessment for Special Rules in Scotland and is used to claim fast-tracked disability benefits in Scotland under the Special Rules for Terminal Illness. BASRiS forms are completed by clinicians and confirm that someone has a terminal illness that is expected to get worse over time and cause death.

“Stacey was in such a state that she needed to choose between paying for the heating or paying for a taxi the next morning to go to the hospital for chemo. She chose chemo, and one night she woke up and her glass of water was frozen on the nightstand. It was that cold.” – Joost

5. Fuel Poverty at the end of life

- Around 7,700 people with terminal illness experience fuel poverty in their last year of life, equating to 1 in 5 people.
- Crippling costs associated with terminal illness, such as high energy bills and heating or mains powered medical devices, rapidly increase at the end of life as many spend more time at home with the heating on because of their terminal condition.
- Medical devices are essential for the safety of the patient, or their ability to maintain some independence and dignity. While a person may be provided with the device itself by the NHS, they are often left to pay for the running costs themselves. This can reach up to £10,000 per year in severe cases, such a late stage Motor Neurone Disease.
- In some cases, people might not use their medical devices to the extent that they should because of cost, risking their safety, comfort, or dignity.
- This means they might instead have to receive treatment or care in hospital rather than at home – adding costs to the NHS, and perhaps going against their preference for location of care or treatment, simply due to cost.
- Previous research by Marie Curie and Nuffield Trust showed £2.3 billion is spent in public expenditure on people in their final year of life in Scotland. Of that £2.3bn, only £512,000 is spent on social security, £1.1bn was for care in hospital, including 59% on emergency hospital care, and only 14% on community care.
- Scotland's rural and island communities can experience higher energy bills as a result of different and more costly fuel types for heating. Yet, these communities do not receive any additional support to mitigate the impact of the “rural premium” on life's essentials, including higher energy, housing, travel and food costs.

Policy Recommendation: UK Government should introduce a social tariff for energy, or equivalent direct bill support. That should provide at least a 50% reduction on bills, and be available to people with a terminal illness, to help them meet the extra costs of terminal illness at a time when their income is likely to have fallen. A comparable scheme should be developed for households relying on alternative fuels, if they cannot be included in the ‘main’ support scheme.

Conclusion

- There is no single solution to ending deaths in poverty or fuel poverty.
- A whole-system, public health approach is a preventative measure to stop end of life poverty from taking hold in the first place.
- The recommendations in this briefing provide a blueprint for a Scotland where people with terminal illness can live focusing on making memories rather than making ends meet.

For further information

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