

Dying in Poverty in Scotland 2025

November 2025



Introduction

Over 6,500 people living with terminal illness are dying in end of life poverty in Scotland, with 7,700 also dying in fuel poverty in the last year of life, according to the latest research by Loughborough University Centre for Research and Social Policy and Marie Curie.

End of life poverty has stagnated in Scotland and is not improving. Despite some measures aimed at reducing poverty, the situation is either unchanged or in some areas significantly worse over the five year period 2019-2024.

Gillian's story

Gillian lives in South Scotland. Her mum struggled with her finances while at the end of life living with lung cancer.

“She 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.

“The last thing that anyone needs when they know they’re dying is to be worrying about financial issues. People shouldn’t have to cope with that on top of everything that they’re already going through.”



Five key findings from Loughborough University and Marie Curie

1. One in four working age people (**26.1%**) and one in six pensioners (**15.8%**) living with terminal illness die in end of life poverty every year in Scotland.
2. One in five people (**20.7%**) die in end of life fuel poverty in Scotland as a result of increased energy costs, and heating or mains powered medical devices.
3. 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 we have been monitoring this, 2019–2024.
4. Minoritised ethnic groups are far more likely to experience end of life poverty as a result of unequal earnings and employment, with almost half of working age Black people (**46%**) and Asian people (**45%**) dying in end of life poverty compared to 25% of working age white people.
5. Working age parents with dependent children continue to be disproportionately impacted by end of life poverty as a result of the double burden of income loss and increased costs, including childcare.

Marie Curie Scotland is calling for:

1. 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. 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 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.
3. Scottish Government, Local Authorities and COSLA must work together to exempt terminally ill people from paying council tax using BASRiS¹.
4. Scottish Government and Social Security Scotland must maximise uptake of disability and childcare benefits for terminally ill people using a values-first approach to remove stigmatisation.
5. 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.

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.

Who is living in end of life poverty?

Working age people

Our previous reports found particularly high levels of deaths in poverty among working age people – and this analysis is no different. Someone of working age is almost twice as likely to die in poverty than someone of pension age:

- 26.1% (1 in 4) of working age people in Scotland living with terminal illness in their last year of life experience end of life poverty.
- 15.8% (1 in 6) of pension age people in Scotland living with terminal illness in their last year of life experience end of life poverty.

While both working age and pension age people are more likely to be in poverty in the last year of life compared to those not in the last year of life, this increase in risk is greater for working age people, especially those with dependent children. The double burden of income loss and increased costs associated with terminal illness, including childcare, plunge families below the poverty line.

The difference between working and pension age people is likely to be due to several factors. A key element could be the relative amounts provided under the different state benefit systems. People over pension age are more likely to be able to draw on larger private pension pots (and are more likely to have access to more generous Defined Benefit pensions).

The differences in the increased risk of poverty associated with being in the last year of life may be due to the income drop that comes from stopping working, which is more likely to affect people of working age.

Recommendation 1: Scottish Government and Social Security Scotland must maximise uptake of disability and childcare benefits using a values-first approach to remove stigmatisation.

Recommendation 2: 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.

Recommendation 3: 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.

Minoritised ethnic groups

People from minoritised ethnic groups are more likely to be in poverty throughout their lives. This reflects disadvantages in wider society, particularly relating to earnings and employment.

For some particular groups, these figures are extremely high. For example, poverty rates among Bangladeshi households are estimated to be as high as 56%. This is likely to be related to available sources of income. Bangladeshi households rely on benefits (excluding State Pension) for 20% of their income on average, compared to 7% of white households.

Given this starting point, it is therefore unsurprising that people from minoritised ethnic backgrounds are far more likely to die in poverty than white people.

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 as highlighted by Table 1.

Table 1: Rates of deaths in poverty and fuel poverty by ethnicity in the UK

Poverty at the end of life	Working age	White	25%
		Black	46%
		Asian	45%
		Mixed/other	40%
	Pension age	White	15%
		Black	39%
		Asian	27%
		Mixed/other	32%
Fuel poverty at the end of life	All ages	White	20%
		Minoritised ethnic groups	27%

Recommendation 1: Scottish Government must commit to addressing specific barriers faced by minoritised ethnic communities when accessing support after a terminal diagnosis.

Recommendation 2: 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.

Geography

Poverty rates are not the same across Scotland and so, unsurprisingly, rates of end of life poverty are not equal either.

These five Scottish local authorities have been consistently, adversely affected by end of life poverty over the five-year period 2019-2024:

1. Glasgow City (WA – 34.1%, PA – 20.1%)
2. West Dunbartonshire (WA – 30.5%, PA – 17.2%)
3. Inverclyde (WA – 30.3%, PA – 17.1%)
4. Dundee City (WA – 30.2%, PA – 17%)
5. North Ayrshire (WA – 30.2%, PA – 17%)

**** (WA = working age) (PA = pension age)**

The research shows a causal link between areas with existing socio-economic deprivation in Scotland and high levels of end of life poverty. For example, end of life poverty in working age people living with terminal illness increases to one in three (from one in four), similarly increasing for pension age end of life poverty to one in five (from one in six).

While we recognise the financial pressures which local government is under, councils do have the powers to take action on improving the financial situation of people dying in poverty.

More must be done on local levels to mitigate the impact of end of life poverty on communities.

Summary of Manchester City Council's council tax support for people living with terminal illness

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.

Its 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.

Recommendation: Scottish Government, Local Authorities and COSLA must work together to exempt terminally ill people from council tax using BASRiS.²

2. 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 and Joost's story

Stacey was on a zero hours contract, and was fired from her job as a result of not being able to work because of her terminal condition.

“Stacey would often take half a day off to have her chemo in the morning and then would work the second half, which was really, really brave. She did it for a few weeks, but then just couldn’t do it anymore...She soon got sacked from her job because they said she wasn’t working enough hours.

“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.



“She couldn’t pay for gas, couldn’t pay for heating, nothing. And then you think, but why did she have to choose between heating or going to chemo?”

– Joost

End of life fuel poverty in Scotland

Approximately 7,700 people living with terminal illness experience fuel poverty in their last year of life in Scotland, equating to one in five.

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 because of their terminal condition.

Measures to improve the general financial situation of people living with a terminal illness will also contribute to reducing fuel poverty. If people have more money available, they can more easily afford the energy that they need. However, it is also clear that there is a particular need for specific support to bring down energy bills at the end of life.

Improving energy efficiency of the UK's housing is often where policy attention lies. Marie Curie supports such measures and in the longer term they will help to reduce energy costs for people across the UK, including those at the end of life.

However, for people living with a terminal illness today, energy efficiency upgrades are often inappropriate and disruptive. They can take time to install, and/or for the financial benefits to be felt - time that people with a terminal illness do not have.

Energy efficiency measures also only help with heating costs. While heating costs can increase after a terminal diagnosis, for example due to some types of treatment, a need to maintain a certain body temperature, or simply spending more time at home and sedentary, it is electricity costs that often see the most significant rise.

For some conditions that cause difficulties with multiple parts of someone's life, such as Motor Neurone Disease, these can reach astronomical levels. For example, in some

cases, electricity costs can rise to £10,000 a year in the late stages of the condition.

Scotland also has many rural and island communities which use 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.

Another significant gap in support relates to the running costs of medical devices used at home. These devices are essential for the safety of the patient, or their ability to maintain some independence and dignity. Yet while the patient may be provided with the device itself by the NHS, they are often left to pay for the running costs themselves.

These costs can be substantial. Previous Marie Curie evidence across the UK found that a household that includes a person with a terminal illness may see an additional monthly energy cost equivalent to 6.9% over an average household if they have an electric bed, 15.8% if they are receiving at-home dialysis, 20.6% if they are on a ventilator and as much as an extra 37.8% more than the average household if they are receiving oxygen concentration. People needing multiple devices will see these extra costs stack up.

Struggling to pay these costs can have significant impacts. In some cases, people living with terminal illness will be unable to meet them. This could mean they go into debt causing further distress at the prospect of leaving their loved ones with unpaid bills. 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. In some cases, people might not use the devices to the extent that they should, risking their safety, comfort, or dignity.

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. In many cases, deaths in poverty are a continuation of lives in poverty. In others, that poverty stems from a financial crisis caused by the impact of a terminal diagnosis.

Yet while there is no single solution, there are key areas that matter, and practical steps Scottish, UK and Local Governments can take to reduce the prevalence of poverty at the end of life.

Most significantly, there is a pressing need to address the gap in guaranteed income between working age and pension age households in which someone has a terminal illness. There is no justification for this disparity.

Taken together, the recommendations in this report set out a blueprint for a Scotland in which people with a terminal illness can live their final months, weeks and days in financial security, able to focus on making memories, not on making ends meet.

Living in poverty is difficult. Dying in poverty is intolerable. We look forward to working with Scottish, UK and local governments and key decision-makers to begin to put an end to deaths in poverty.

We are calling for:

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2. 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.
3. Scottish Government, Local Authorities and COSLA must work together to exempt terminally ill people from paying council tax using BASRiS .
4. Scottish Government and Social Security Scotland must maximise uptake of disability and childcare benefits for terminally ill people using a values-first approach to remove stigmatisation.
5. 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.

Appendices

Background to this report

This report is the third produced by the Centre for Research in Social Policy at Loughborough University. In 2021, Marie Curie commissioned the Centre to examine the number and proportion of people who spend the last year of their lives in poverty in the UK. This led to Marie Curie's landmark report, *Dying in Poverty*, published in 2022, which set out the findings using data from 2019 and made a series of policy recommendations.

In 2024, we published the first of three planned updates to this research. This provided an update to the analysis of poverty using data from 2023, and for the first time provided estimates of fuel poverty at the end of life.

This second update uses figures from 2024 and provides deeper analysis in a number of areas.

What is poverty?

Most of the findings of the Centre for Research in Social Policy's studies, and consequently in this report, use the Social Metrics Commission's definition of poverty. There are some limitations to this definition. However, it is the most comprehensive definition currently available, and the most evidence-based way to account for the additional costs of disability and ill health on a person's financial situation, and therefore their risk of experiencing poverty.

What is fuel poverty?

Scotland defines fuel poverty as fuel costs to maintain a satisfactory heating regime are over 10% of the household's income after housing costs. And after housing, fuel, disability and childcare costs, the remaining income is less than 90% of the Minimum Income Standard (MIS).

In their analysis of deaths in fuel poverty the Loughborough Centre for Research in Social Policy based their definition on that used in Scotland. This is because:

- It does not require someone to live in an energy-inefficient household to be in fuel poverty.
- By considering the post-energy income, it avoids classifying high-use, high-income households as being in fuel poverty.

The definition used in this briefing differs from the technical definition used in Scotland in two ways. Firstly, it considers all energy usage, not just heating costs, which provides a more rounded view of someone's situation. This is particularly important in reflecting the spend on mains-powered medical devices. Secondly, it looks at actual spending, rather than modelling costs needed to reach a certain temperature.

That means **this measure of fuel poverty does not identify people who should be spending more than this, but go without** – either by simply not turning the heating on or “self-disconnecting” by not topping up their prepayment meter. Figures in this section are the lower bounds for the numbers of people who die in fuel poverty.

Unless otherwise stated, data in this report come from the Centre for Research in Social Policy's analysis.

Notes on terminology

Age

Due to some of the datasets used, the age breakdown used by the Centre for Research in Social Policy divides between 20-64 and 65+. In this report, although the State Pension Age was 66 in the years of analysis, we use the terms “working age” and “pension age” to describe these groups. The Centre for Research in Social Policy has

conducted further analysis that confirms that including a small number of people under State Pension Age in “pension age” figures makes a negligible impact on the overall results.

Ethnicity

We recognise that there are a range of ways to describe people not from white ethnic backgrounds, but use “minoritised ethnic groups” throughout this report for consistency. Where we refer to specific minoritised ethnic groups, these are based on answers selected by respondents to the Understanding Society survey, which uses the categories in the census.

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Full data breakdowns for end of life poverty and fuel poverty at the end of life are available on request.

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Marie Curie is the UK's leading end of life charity.
Whoever you are, whatever your illness,
we're with you to the end.

