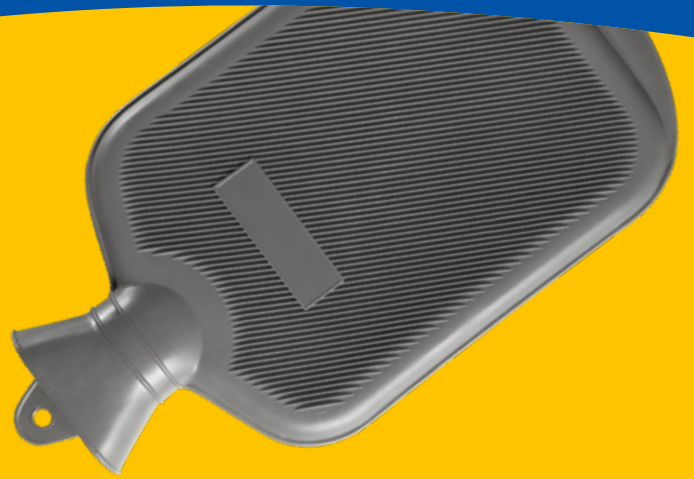


# Dying in Poverty in Scotland 2024





## Introduction

### Every year, 10,400 people with terminal illness in Scotland die in poverty.

New research undertaken by Marie Curie and Loughborough University Centre for Research and Social Policy has found **one in six people (17%) who die in Scotland, die in poverty at the end of life.**

### Key findings from Marie Curie and Loughborough University

- 1. one in six people (17%) people with a terminal illness in Scotland die in poverty. This equates to one in four (25%) working-age people, as well as one in six (17%) pensioners.** The number of pensioners has increased from one in eight in 2019.
- 2. One in five people in Scotland (20%) die in fuel poverty in their last year of life,** the majority of whom live in social rented housing (46% across the UK).
- 3. More working-age people of a minoritised ethnicity die in poverty in their last year of end of life,** including 47% of Black people, 43% of Asian people, and 37% of people who are mixed race or are of another ethnicity. This compares with 25% of white working-age people.
- 4. Working-age people with dependent children are at greater risk of poverty at the end of life, including 40% of working-age single parents – who are usually women.** A terminal illness comes with many additional financial burdens, including the need to pay for care, more childcare and more energy use. For working-age families, this comes on top of the massive financial impact of one of both parents having to give up work, meaning poverty not only affects the person at the end of their life, but leaves their children experiencing poverty at the beginning of theirs.

5. **Almost one third of women with a terminal illness (30%) die in poverty, compared to a quarter (25%) of men.**

Women's lifetime earnings are less than two-thirds of men's due longstanding,

structural inequity in the labour market, lower individual retirement income and disproportionate unpaid caring responsibilities.

### Marie Curie is calling for:

1. UK Government to guarantee a State Pension-level income for people of working age living with a terminal illness. One way to achieve this is to grant access to the State Pension for people living with terminal illness of working age with less than 12 months to live, based on their National Insurance Contributions (NICs). If a person living with a terminal illness has not made enough NICs to receive the full State Pension and receives Universal Credit, they could receive a Pension Credit Element within Universal Credit to top this up to a level equivalent to the State Pension.
2. Scottish Government must commit to and implement a Right to Palliative Care, which supports the financial wellbeing of people living with a terminal illness, their families and carers.
3. The UK and Scottish Governments must take action to tackle the barriers to women's labour market equality in order to eliminate gender inequality at the end of life. They must introduce mandatory gender pay gap action plans and hold employers accountable on these through the UK gender pay gap reporting regulations, and the Scottish-specific duties of the Public Sector Equality Duty. Scottish Government must also act to progressively realise a childcare system that is flexible, affordable and accessible, and to ensure its economic strategy is gender-sensitive and invests in women's work.
4. Scottish Government must ensure people living with a terminal illness have access to adequate income and financial support by committing to and implementing a Minimum Income Guarantee,<sup>1</sup> and automatically qualify terminally ill people for the Winter Heating Payment, and Scottish Child Payment for parents living with a terminal illness with dependent children under 16.
5. UK and Scottish Government must commit to and implement a Social Tariff, which delivers an equitable energy discount of 50% of the market rate or a price cap to terminally ill people's households.



## Margaret's story

**A**T the age of 64, Margaret's main worry as she neared the end of her life was ensuring her teenage daughter would be financially secure after her death. Margaret had been careful with money her whole life and had been self-sufficient from a young age, leaving home at 16 and being steadily employed.

**“Even though her whole world was ending, she was still a strong person, and you can still see the fight in her.”**

*Dying in the Margins*

She worked with the hospice social worker to check she had got all the benefits she was entitled to. She was upset when she found out she wouldn't be able to access her pension which she had worked so hard for:

**“I've never claimed unemployment benefits, ever. Talking about national insurance stamps, I'm fully booked up. I'm going to lose my old-age pension which I never, ever received.”**

Margaret



## Max's story

**M**AX, 65, wanted to remain in his local community at the end of his life, and to be with his friends and dog, Lily. He was an army veteran with prior experience of homelessness and trauma, and he felt trapped by institutions:

**“I prefer being at home. No one wants to be in a hospital. I want to do my own thing.”**

But being at home was not always easy. There were four flights of stairs to manage, plus his front steps. This meant he was essentially housebound and not able to get outside:

**“You see about the stairs, right, the stairs are a big, big problem.”**



© Margaret Mitchell for *Dying in the Margins*

The bath was also a problem as he couldn't get in and out of it to take a shower. His local housing association didn't appear to prioritise the adaptations he needed or the maintenance issues he experienced in his final few months. Max wasn't well enough to keep things clean or tidy and it's possible that carers visiting him at home would have judged his environment "unsuitable".

Each time Max's cancer symptoms became too severe, or his carers could no longer manage, he was admitted to the hospice. Max was supported at home until the final week of his life, when he asked to be moved into the hospice because his symptoms were worsening. This provided some relief for his friends who had been caring for him.

# The case for a right to palliative care in Scotland

**A** DDRESSING lack of palliative care need, including the financial needs at the end of life, underpins Marie Curie's proposal for a Right to Palliative Care in Scotland. By 2040, up to 10,000 more people will need palliative and end of life care each year. This growing demand comes as the cost of living with a terminal illness is increasing and the costs of delivering palliative care are also rising rapidly.<sup>3</sup>

Too many people are dying without some or all the palliative care and support they need, despite the fact 90% of people who die in Scotland each year would benefit from it.<sup>4</sup>

When people miss out on care this leads to significantly poorer physical and mental health, as well as worse financial outcomes for people living with a terminal illness people, their families and carers. This means many die in poverty.

As a society, the support we provide at the end of life is as important as what comes before. A Right to Palliative Care provides a clear legal underpinning of this principle. Support shouldn't depend on your age, where you live, your income, your housing situation, or your diagnosis.

*Dying in the Margins*<sup>5</sup> evidences the impact of financial hardship and deprivation of people living with a terminal illness wanting to die at home, as highlighted by the experiences of Margaret (page 4), Max (page 5), Marie (page 14) and Amandeep (page 16).

These stories lay bare the experiences of those who are often left behind, but who often require the highest level of physical, emotional, spiritual or financial support at the end of life.

Marie Curie and Loughborough University's research shows that the number of experiences like Margaret's, Max's, Marie's and Amandeep's are rising rapidly in Scotland, reaching almost 10,500 every year.

A right to palliative care has the potential to eliminate inequality and inequity at the end of life as an integrated element of system change to improve outcomes for people living with a terminal illness, their families and carers.

The Right to Palliative Care should work alongside proposed mechanisms to build greater financial security, such as the Minimum Income Guarantee,<sup>6</sup> and a Social Tariff to support vulnerable groups with their energy bills, which increase significantly after a terminal diagnosis.

## Recommendation

The Scottish Government must commit to and implement a Right to Palliative Care, which supports the financial wellbeing of people living with a terminal illness, their families and carers.

# 1. Prevalence of poverty for people in the last year of life in Scotland

Local Authority	Age 20+		Age 20-64		Age 65+	
	Number in poverty	Percentage in poverty	Number in poverty	Percentage in poverty	Number in poverty	Percentage in poverty
Glasgow City	1,542	23.8	456	34.3	1,086	21.1
West Dunbartonshire	230	19.8	58	30.2	172	17.8
Dundee City	345	19.8	86	30.2	259	17.7
North Ayrshire	374	19.3	86	29.8	288	17.4
Inverclyde	220	19.2	52	29.	169	17.4
Clackmannanshire	124	18.8	27	29.4	97	17.1
North Lanarkshire	705	18.1	188	28.1	517	16.0
East Ayrshire	288	17.3	67	27.5	220	15.6
Renfrewshire	367	17.0	91	27.0	276	15.2
South Lanarkshire	627	16.3	155	26.1	472	14.5
Shetland Islands	36	15.5	7	25.8	30	14.2
West Lothian	284	15.6	70	25.4	214	13.9
Aberdeen City	352	15.5	84	25.3	267	13.8
Highland	455	15.3	98	25.3	357	13.8
Fife	708	15.3	152	25.3	556	13.8
Na h-Eileanan Siar	67	15.1	13	25.3	54	13.8
City of Edinburgh	745	15.5	182	25.3	563	13.8
South Ayrshire	251	14.7	47	24.8	204	13.4
Falkirk	299	15.	74	24.8	225	13.4
Dumfries and Galloway	326	14.7	65	24.7	262	13.3
Argyll and Bute	174	14.5	36	24.4	138	13.1
Midlothian	148	14.3	33	24.0	115	12.8
Scottish Borders	215	14.0	42	23.8	173	12.7
Angus	211	13.8	41	23.6	170	12.5
Moray	155	13.3	27	23.2	128	12.2
Orkney	37	13.2	7	22.9	31	12.0
East Lothian	166	13.2	33	22.9	133	12.0
Perth and Kinross	259	13.2	54	22.8	205	11.9
Stirling	137	13.1	31	22.5	106	11.7
East Renfrewshire	112	12.1	18	21.7	94	11.1
Aberdeenshire	322	12.1	69	21.3	253	10.9
East Dunbartonshire	146	11.3	26	20.5	120	10.3



## 2. Key research findings and recommendations to eliminate poverty at the end of life in Scotland

### Key research headlines

1. **One in six people (17%) living with a terminal illness in Scotland die in poverty.** This equates to:
  - **One in four (25%) working-age people**, and **one in three in Local Authorities which experience the most acute socioeconomic deprivation** such as Glasgow, West Dunbartonshire and Dundee
  - **One in six (17%) pensioners.** The number of pensioners has increased from one in eight in 2019. It's unclear what has driven the increase for pensioners, although potential factors could include greater numbers of people renting into retirement. Further research is required to better understand this.
2. **One in five people in Scotland (20%) die in fuel poverty in their last year of life**, the majority of whom live in social rented housing (46% across the UK).
3. **More working-age people of a minoritised ethnicity die in poverty in their last year of end of life**, including 47% of Black people, 43% of Asian people, and 37% of people who are mixed race or are of another ethnicity. This compares with 25% of white working-age people.
4. **Working-age people with dependent children are at greater risk of poverty at the end of life, including 40% of working-age single parents – who are usually women.** A terminal illness comes with many additional financial burdens, including the need to pay for

care, more childcare and more energy use. For working-age families, this comes on top of the massive financial impact of one of both parents having to give up work, meaning poverty not only affects the person at the end of their life, but leaves their children experiencing poverty at the beginning of theirs.

5. **Almost one third of women with a terminal illness (30%) die in poverty, compared to a quarter (25%) of men.** Women's lifetime earnings are less than two-thirds of men's due to longstanding, structural inequity in the labour market which leads to lower individual retirement income, and disproportionate unpaid caring responsibilities.

### Differences in poverty at the end of life by age group

**The risk of being in poverty at the end of life has increased since our last report in 2022, especially for people of pension age.**

In Scotland we already know that:<sup>7,8</sup>

- There is an average 24-year gap in healthy life expectancy between the most and least deprived communities.<sup>9</sup>
- One fifth of Scotland's population lives in poverty, which has hardly changed in 20 years.
- Over 10% of workers in Scotland are locked in persistent low pay; 72% of them are women.
- Workers in families of a minoritised ethnicity where everyone works full time are twice as likely to experience in work poverty than white workers.

- While also seeing worse labour market outcomes such as low pay, over half of all families where no-one is working have someone in the family who is living with a disability.
- Single parents who manage to secure work struggle to earn a decent income from it, while single-parent families also make up 20% of the people in poverty where no one is working.

Marie Curie and Loughborough University's research furthers this evidence of poverty by showing that people living with terminal conditions also experience significant loss of income. This is the result of reduced hours or needing to leave work altogether, coupled with increased costs associated with terminal illness, such as increased energy, housing and childcare costs.

This effect might not only be felt by the person living with a terminal illness, but also by others in their household if they must take on caring responsibilities and reduce or give up their own work altogether. This is more likely to affect working-age people, and the combination of exiting the labour market and being diagnosed with a new health condition greatly increases the risk of moving into poverty – higher than people who were already out of the labour market.

There was an even stronger association across Marie Curie and Loughborough University's research between people who exit the labour market and those diagnosed with a new health condition, which further suggests that needing to leave work because of a terminal condition may be an important driver of poverty at the end of life. Differences in the availability of support through the social security system for people of working and pension age are also likely to play a part.

Finally, the cost of childcare is more likely to affect people of working age than of pension age, due the greater likelihood of working-age people being primary carers for children.

## Recommendation

UK Government must grant access to the State Pension for working-age people living with a terminal illness with less than 12 months to live based on their National Insurance Contributions (NICs). If someone is living with a terminal illness and has not made enough NICs to receive the full State Pension and receives Universal Credit, they should receive a Pension Credit Element within Universal Credit to top this up to a level equivalent of the State Pension.

## Differences in poverty at the end of life by ethnicity

People from minoritised ethnic backgrounds are more likely to be in poverty throughout their lives. This reflects disadvantages in wider society, including education, health and social care, and employment. We already know that the poverty rate for minoritised ethnic families is more than double that of white families in Scotland.<sup>10</sup>

For some minoritised ethnic groups, poverty rates are extremely high – **poverty among UK Bangladeshi households, for example, is estimated to be as high as 53%**. This is likely to be related in part 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's unsurprising that people from minoritised ethnic backgrounds are more likely to die in poverty than white people. Due to data limitations, the research has not able to provide a full breakdown of estimates of dying in poverty by ethnicity and/or individual nations, but even based on broad categories, there is a clearly disproportionate impact across the UK:

**25% of working-age white people aged between 20-64 who died did so**

**in poverty, compared to a shocking 47% of Black people, 43% of Asian people, and 37% of people who are mixed race or have another ethnicity.**

From what we know about poverty rates among different ethnic groups in the general population, it's almost certain that similar and similar-sized disparities exist among particular ethnicities dying in poverty.

### Recommendation

Scottish Government must collect disaggregated data to better understand local population needs as part of a public health approach to the end of life, in order to identify those most at risk of poverty.

Marie Curie recommends initiatives such as Connected Bradford, which are whole-system data linkage accelerators that link health, education, social care, environmental and other local government data (including housing and economy) for effective population health management.<sup>11</sup>

### Differences in poverty at the end of life by gender

**In 2023, 30% of working-age women who died did so in poverty, compared to 25.4% of men.**

This represents a change compared to 2022. Since then, women of this age have become more likely to die in poverty, whereas men have become slightly less likely to. The increase in the relative risk of being in poverty at the end of life is also greater for women than it is for men. There are likely to be many reasons underlying this difference. In Scotland we already know that:<sup>12</sup>

- Women are the majority of low-paid workers in Scotland, and are more likely than men to be underemployed and in insecure work.<sup>13</sup>

- Women are more likely than men to live in poverty, particularly in-work poverty, and experience worse levels of poverty than men, and for longer.<sup>14</sup>
- Women working full-time earn 7.9% less than men working full-time, an increase of 1.3% from 2021. Women working part-time earned 26.3% less than men working full-time. The part-time pay gap illustrates the systemic undervaluation of “women’s work”, which continues to be concentrated in low-paid, part-time jobs.
- 73% of part-time workers in Scotland are women, and are three times as likely to work part-time than men (38.3% of women compared to 13.4% of men).

As a result, women’s lifetime earnings are significantly less than men’s, creating disproportionate pressure on women affected by terminal illness when they must give up work, whether fully or part-time.

Women are also less likely to have savings than men – which combined with lower income, means they’re more likely to rely on social security. **In Scotland women are twice as likely to be reliant on social security.**<sup>15</sup>

Women are also more likely to have responsibility for childcare, and/or care for someone who living with a terminal illness or disability, which further limits earnings and progression, and adds an inescapable cost at the end of life. In Scotland, carers – 60–70% of whom are women in Scotland – are twice as likely to suffer from ill-health; and women are twice as likely to give up work to carry out unpaid care.<sup>16</sup>

The gender pay gap is an indicator of ongoing workplace inequality that contributes to women’s poverty. A persistent lack of access to flexible and part-time work in well-paid jobs, bias in recruitment and promotion practices, and sexist and sexual harassment means employers are not taking the required steps to address gender inequality in their workplaces. This keeps women’s wages

low and poverty rates high compared to men's.

Another potential explanation for higher rates of poverty at the end of life in women, particularly for pension-age women, is their increased life expectancy compared to men, which in part drives their greater likelihood to live alone.

It's less clear what has driven the more recent change since our [last report in 2022](#), but one possibility is the greater reliance on the social security system among women. Although benefits were uprated in line with inflation between 2019-2023, this comes with a lag, and earnings growth was high over the same period.

A similar disparity exists among pension-age people, although poverty rates are lower. This is likely to be a combination of private savings, and the remaining 'State Pension gap' between men and women.

Eliminating poverty at the end of life at the root cause for women needs an equitable approach, recognising that different resources and action are required.

## Recommendation

The UK and Scottish Governments must take action to tackle the barriers to women's labour market equality in order to eliminate gender inequality at the end of life. They must introduce mandatory gender pay gap action plans and hold employers accountable on these through the UK gender pay gap reporting regulations, and the Scottish-specific duties of the Public Sector Equality Duty. Scottish Government must also act to progressively realise a childcare system that is flexible, affordable and accessible, and to ensure its economic strategy is gender-sensitive and invests in women's work.

## Differences in poverty at the end of life by family type

### Working-age people with dependent children experience increased poverty at the end of life.

This is a result of childcare costs and the impact of one or both parents potentially having to leave work. The impact of sliding into poverty on these families won't only affect the person at the end of their life, but leave their children experiencing poverty at the beginning of theirs.

Childcare is an inescapable cost for most working parents, who must find a way to meet the costs of paid help to look after their children, even if they're living with a terminal illness. Childcare costs in the UK are high compared to other countries, with some couples spending up to a quarter of their wages on childcare on average.

Given these costs, it's not surprising that families with children are at particular risk of poverty as they approach the end of life.

### Less than half of households with children are never in poverty in the last five years of their lives, making them the family type at the second-greatest risk of experiencing poverty currently, after working-age single households.

Families with children are also the most likely family type to move into poverty for the two years before a member living with a terminal illness dies, having not been in poverty previously. This could be due to a combination of the reduced income following a terminal diagnosis, higher costs associated with children, and the unavailability of the full 30-hour entitlement for younger children that working families receive.

Women are also more likely to have dependent children than men, making up the majority of lone-parent families across the UK in 2023: 85% or 2.7m, with lone fathers now accounting for 15%, or 477,000.



Lone-mother families also tend to have lower savings and be more in debt than dual couple households with children, and have seen the fastest rise in poverty, with 40% of working-age single parents now in poverty.

Scottish Government has committed to eradicating child poverty in Scotland, and the findings in this report are clear; children of terminally ill working age parent(s) are often living in poverty as a result of terminal illness within their family.

### **Recommendation**

Scottish Government must ensure people living with a terminal illness have access to adequate income and financial support. This includes Government taking the necessary steps needed to deliver a Minimum Income Guarantee.<sup>17</sup>

### **Recommendation**

Scottish Government must automatically qualify parents living with a terminal illness with dependent children under 16 for the Scottish Child Payment on presentation of a BASRiS.<sup>18</sup>

## Marie's story

**M**ARIE was a very calm, positive, and resilient woman. She managed to escape her own childhood experiences of severe hardship and homelessness and gave her kids a different start in life. She was proud of being self-sufficient and of what she had achieved. Marie was living with a rare form of cancer, but despite her symptoms and the uncertainty she experienced, she always tried to make the best of things. As a single parent, she made ends meet, partly through support she received from the Welfare Rights team at the Council

who helped maximise her entitlement to state support. Marie didn't like being dependent on state support, but she wasn't able to work:

**“Sometimes it feels like begging for money as I have always been fiercely independent with money and never ask anyone for handouts, but my needs now mean I must swallow my pride and apply.”**



Taxis were the biggest expense for Marie; getting to and from hospital appointments could be up to £100 per week:

**“I’m unable to walk and wait on a bus. I feel a combination of dizziness and weak legs, so going to a bus stop and waiting, then the bus journey itself amongst people during a pandemic is too much for me.”**

Other costs Marie had to meet included heating, electricity, and the cost of clothes because her weight fluctuated dramatically as a result of her illness. This meant there was very little left for anything else, limiting Marie’s opportunity to make memories with her daughter.

## Amandeep's story

**“Things are changing hour by hour; one day I can be okay and then the next minute I can be not so well... it's scary because I don't know what's going to happen.”**

Amandeep, 22, lives with his mum and two of his siblings in a three-bedroom flat. He has lived with the symptoms of Duchenne

muscular dystrophy for much of life. His mum is his full-time carer. Amandeep feels a great deal of uncertainty about his future in terms of how they will both manage. Months on end spent shielding from Covid has made him more reliant on his mum than ever. His world has been his bedroom.

A shortage of professional carers and an inability to leave his house has meant his mobility has taken a serious dip.



© Margaret Mitchell for *Dying in the Margins*





Photo: Amandeep's photo-voice

Amandeep feels that he has had to fight for many of the supports he has in place, and for the equipment and technology which are his lifeline. He relies heavily on electronic medical devices like his wheelchair, hoist and ventilator to stay at home.

Amandeep wants to stay at home, but that means paying considerable heating costs,

and the costs of running all his equipment – up to £400 a month. These have spiralled recently, causing significant financial strain for the family.

**“Do we heat our house up or do we eat food? It’s very much getting to that point now.”**

## 3. Fuel poverty for people in the last year of life in Scotland

**Table 1: Prevalence of fuel poverty at the end of life in Scotland**

Local Authority	Age 20-64		Age 65+	
	Number in fuel poverty	Percentage in fuel poverty	Number in fuel poverty	Percentage in fuel poverty
Glasgow City	219	26.5%	1,113	23.2%
Dundee City	44	25.1%	297	21.8%
West Dunbartonshire	29	24.2%	189	20.9%
North Ayrshire	42	23.5%	311	20.2%
Inverclyde	25	23.4%	182	20.0%
East Ayrshire	35	23.0%	259	19.6%
North Lanarkshire	93	22.4%	573	19.0%
Clackmannanshire	13	22.3%	100	18.9%
Dumfries and Galloway	36	22.0%	340	18.6%
Scottish Borders	23	21.2%	228	17.9%
Fife	79	21.2%	670	17.8%
Midlothian	18	20.9%	147	17.6%
South Ayrshire	25	20.9%	249	17.6%
Angus	22	20.8%	221	17.4%
Aberdeen City	43	20.6%	312	17.3%
West Lothian	35	20.6%	248	17.2%
Falkirk	38	20.6%	271	17.2%
Argyll and Bute	19	20.5%	168	17.2%
Renfrewshire	43	20.5%	290	17.1%
East Lothian	18	20.4%	177	17.1%
South Lanarkshire	75	20.3%	516	17.0%
City of Edinburgh	90	20.2%	641	16.8%
Highland	48	20.0%	403	16.7%
Moray	14	20.0%	162	16.7%
Perth and Kinross	29	19.9%	266	16.6%
Stirling	17	19.8%	140	16.5%
Na h-Eileanan Siar	6	18.8%	56	15.5%
Orkney Islands	3	18.3%	36	15.0%
Shetland Islands	3	18.1%	29	14.8%
Aberdeenshire	36	17.7%	315	14.5%
East Dunbartonshire	13	16.5%	146	13.4%
East Renfrewshire	8	15.6%	100	12.6%

## The cause and consequence of fuel poverty at the end of life

**An average of one in five people with a terminal illness in Scotland will die in fuel poverty, with fuel poverty more generally affecting 850,000 households.**<sup>19</sup>

As fuel poverty is based on spending on fuel, not necessarily need for fuel, it's likely that Marie Curie and Loughborough's research is an underestimate of the number of people in energy difficulty. This analysis can't capture if someone is not in fuel poverty under our measure because they're not spending what they should in order to have a decent level of warmth and standard of living. However, looking at fuel spending confirms an impact of being at the end of life.

Energy costs are one of the biggest costs that can increase when someone is at the end of their life. This can be in relation to needing to run medical devices, needing to maintain a particular body temperature, or simply spending more time at home.

Marie Curie's previous work has highlighted [the inconsistency and unavailability of rebate schemes for medical devices](#), which can place additional financial strain on people living with a terminal illness.

**Marie Curie and Loughborough University has found that more than two in three people across the UK are seeking emergency support to top up a prepayment meter have a critical need for energy, which can include needs caused by terminal illness.**

Being unable to afford energy also causes financial stress and the discomfort of living in a cold or dark home. It can also directly affect health, resulting in higher rates of admission to hospital, as well as readmissions if someone is discharged into a cold home and their recovery slows or stalls as a result.

Scottish Government has committed to preventing and tackling health inequalities in its Programme for Government and

proposed new National Performance Framework.<sup>20</sup> This approach must embed wider public health factors, such as fuel poverty at the end of life and housing quality, which contribute to high levels of delayed discharge, hospital admissions and readmissions because support needs at the end of life remain unmet.

As with deaths in poverty, this picture was not identical among different groups. But unlike deaths in poverty, there was relatively little difference between the fuel poverty rate for working-age people aged 20-64 compared to pension-age people, which could be due to higher fuel usage among older people compensating for higher income.

Table 2 on page 20 shows fuel poverty rates at the end of life by age and selected demographics across the UK.

Due to sample sizes, this analysis is not able to provide as detailed a breakdown between different types of conditions, ethnic groups or nations, but these findings underscore the need to understand and address these disparities.

The increased risk of fuel poverty among minoritised ethnic households compared to white households at the end of life is not as stark as the increased risk of poverty, but still represents a considerable increase.

Given the over-representation of minoritised ethnic groups among social and private rented tenants, the rates of fuel poverty at the end of life among these groups is particularly concerning.

One of the most shocking findings relates to people living in social rented housing being most susceptible to fuel poverty at the end of life. This is likely caused by multiple issues, primarily social housing not being fit for purpose as a result of older and/or cheaper appliances which are not energy efficient and cost more to use.

As with poverty at the end of life, there is also an increased rate of fuel poverty

**Table 2: Differences in fuel poverty at the end of life: age, ethnicity and housing tenure**

<b>Working-age</b>		Men	22.2%
		Women	20.5%
		Cancer diagnosis	19.5%
		No cancer diagnosis	22.3%
<b>Pension-age</b>		Men	18%
		Women	22.3%
		Cancer diagnosis	18.2%
		No cancer diagnosis	21%
<b>All ages</b>	<b>Ethnicity</b>	White	19.4%
		Minoritised ethnic groups	26.5%
	<b>Housing tenure</b>	Own property outright	11%
		Own with a mortgage	13.7%
		Social rented	46.1%
		Privately rented	31.7%

among people at the end of life with a non-cancer diagnosis compared to people with a cancer diagnosis.

There was also an increase in spending across fuel types, again with a significant increase for people at the end of life who use oil for heating. This is particularly concerning given the prevalence of this fuel type among rural and island communities in Scotland, which exacerbates the “rural premium” of the cost of living and dying that they experience more generally.

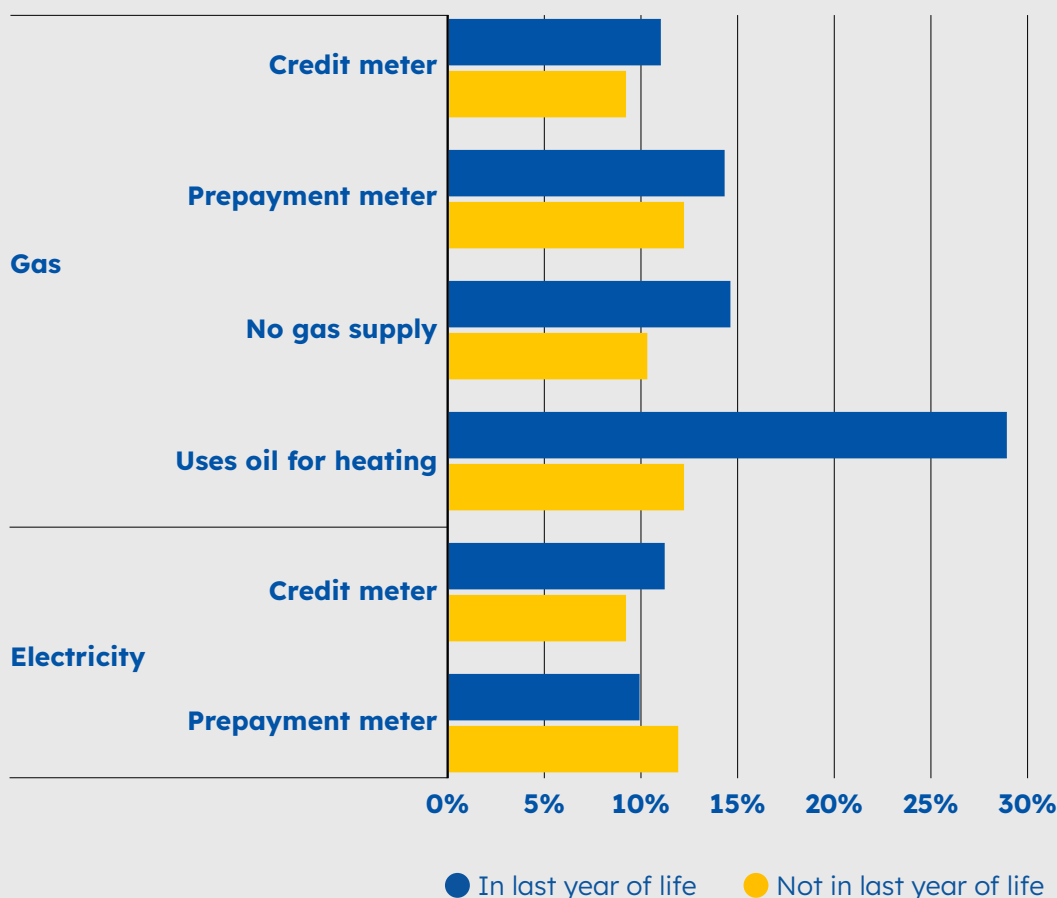
Perhaps counterintuitively, people in the last year of life with an electricity prepayment meter saw their electricity

spending rise less than households not at the end of life (Figure 1, page 21). One possibility here is that households with electricity prepayment meters were choosing to top up their electricity meter less in order to prioritise their spending on gas (typically cooking and heating).

The risk of underconsumption of energy exists regardless of payment type. But it's greater for prepayment meter or heating oil customers, as this can be forced (by the meter having no credit or the supply of oil having run out), whereas a credit customer is not constrained in this way.



**Figure 1: Change in spending by fuel type between 2021-22**



### A social tariff

Across the UK, a **social tariff** which provided a 50% discount on energy bills based on Age UK’s model, **could lift 54,000 people out of fuel poverty at the end of life**, and close to halving rates of fuel poverty among pensioners.

### Recommendation

Until a social tariff is introduced, Scottish Government must include people living with a terminal illness in eligibility in its Winter Heating Payment, and forthcoming Pension Age Winter Heating Payment.<sup>22</sup>

### Recommendation

UK and Scottish Governments must implement a social tariff and include people living with a terminal illness in eligibility for a 50% reduction. A social tariff should also be mandatory for all energy suppliers and automatically enrol eligible households, while providing equitable benefit to those on prepayment meters and using alternative fuels.<sup>21</sup>

## 4. What needs to happen next?

**T**HE stark reality in Scotland today is that the things affecting peoples' health during their lives are both a cause and a consequence of poverty. And these things continue to affect people when they're dying. Since our last report in 2022, the number of people dying in poverty has increased – and we now know the shockingly high number of people dying in fuel poverty, struggling to heat their homes and run vital medical equipment even in their final months, weeks, and days.

There are steps local, national, and UK government should take now to reduce the financial strain that the end of life can bring, and ensure everyone is able to live as well as possible for as long as possible.

### The key steps that would make the biggest difference to people living with a terminal illness are:

1. **UK Government should guarantee a State Pension-level income for people living with a terminal illness of working age.** One way to achieve this is to grant access to the State Pension for people living with a terminal illness of working age with less than 12 months to live based on their National Insurance Contributions (NICs). If a person living with a terminal illness has not made enough NICs to receive the full State Pension and receives Universal Credit, they could receive a Pension Credit Element within Universal Credit to top this up to a level equivalent to the State Pension.
2. **Scottish Government must commit to and implement a Right to Palliative Care,** which supports the financial wellbeing of people living with a terminal illness, their families and carers.
3. **The UK and Scottish Governments must take action to tackle the barriers to women's labour market equality in order to eliminate gender inequality at the end of life.** They must introduce mandatory gender pay gap action plans and hold employers accountable on these through the UK gender pay gap reporting regulations, and the Scottish-specific duties of the Public Sector Equality Duty. Scottish Government must also act to progressively realise a childcare system that is flexible, affordable and accessible, and to ensure its economic strategy is gender-sensitive and invests in women's work.
4. Scottish Government must ensure people living with a terminal illness have access to **adequate income and financial support** by committing to and implementing a **Minimum Income Guarantee**,<sup>23</sup> and automatically qualifying terminally ill people for the **Winter Heating Payment**, and **Scottish Child Payment** for parents living with a terminal illness with dependent children under 16.
5. UK and Scottish Government must commit to and implement a **Social Tariff**, which delivers an **equitable energy discount of 50% of the market rate or a price cap to terminally ill people's households.**

These would provide meaningful, direct support, and help to substantially reduce the additional uncertainty, stress and health impacts of poverty at the end of life.

The end of life will always bring challenges. But neither poverty, nor fuel poverty, need to be among them. With almost 10,500 people dying in poverty every year in Scotland, there is no time to lose.

# Annex 1

## 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 still some limitations to this definition, but it's 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.

There is no single universal definition of poverty, and consequently no single way to measure of poverty.

## What is fuel poverty?

As with poverty, there is no single definition of fuel poverty. Scotland uses the following measure:

- 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 the analysis of deaths in fuel poverty across the UK, the Centre for Research in Social Policy used the definition of fuel poverty that is used in Scotland. This is because:

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

In the analysis, the only way to identify who has fuel costs necessary to maintain a satisfactory heating regime of over 10% of their income was to look at who spends that much. That means **this measure of fuel 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. Therefore, the figures in this section are lower bounds for the numbers of people who die in fuel poverty.

## Annex 2: Winter Heating Payment projected costings

Our estimate is that **1,654** working-age people in Scotland might receive Personal Independence Payment (PIP)/ADP under SRTI but might not be eligible for the WHP. Extending the WHP to them would cost **£97,175** this year.

**Approximate costing for Scottish Government to extend the Winter Heating Payment (WHP) to people living with a terminal illness receiving Adult Disability Payment (ADP) under the Special Rules for Terminal Illness**

England and Wales							
Total number of PIP recipients	Who also receive UC	Who also receive ir-ESA	Who also receive JSA	Who also receive Income Support	Who also receive Pension Credit	Who also receive SMI	Who receive none
2,706,392	1,060,649 39%	677,014 25%	5,180 0%	22,715 1%	N/A	N/A	940,834 35%
<b>Total number of PIP recipients under SRTI</b>				<b>As a proportion of PIP recipients</b>			
29,361				1.08%			
Scotland							
Total number of PIP/ADP claimants							
PIP	ADP (as of 31st Oct 2023)		Total				
190,178	137,490		327,668				
Total number receiving under SRTI							
PIP	ADP (as of 31st Oct 2023)		Total		As a proportion of PIP/ADP claimants		
898 0.47%	3,860 2.81%		4,758		1.45%		
Number of SRTI PIP/ADP claimants estimated not to qualify for WHP				Potential cost of extending WHP			
1,654				£97,175			

**Value of WHP:** £58.75

**Data sources:** Stat-Xplore (for data except ADP) and <https://www.gov.scot/publications/adult-disability-payment-high-level-statistics-to-31-october-2023/>

All data as of November 2023 unless otherwise stated



It's important to note that these costs are very approximate due to limited data in Scotland and DWP.

A few limitations to this:

- We have assumed that the proportion of PIP recipients in England who also receive a relevant benefit is the same for PIP/ADP recipients in Scotland.
- DWP's Benefit Combination data lets you look at who receives PIP alongside other benefits, but not the subset of PIP recipients who receive it under SRTI.
  - We have assumed the proportion of PIP claimants who receive it under SRTI rules vs normal rules is same across benefit combinations.
- To be eligible for the WHP, it's not enough just to receive Universal Credit. For example, a person would also need to meet one of a number of criteria (e.g. receiving LCW/LCWRA element or having a child under five).
  - It's possible that some SRTI PIP claimants who get a relevant benefit would not currently get the WHP if they don't also meet one of these criteria. We have assumed that everyone who receives PIP under SRTI and receives a relevant benefit would be eligible for WHP. This might **underestimate** the number of people who currently miss out on WHP.
- One of the relevant benefits is income-related JSA. Stat-Xplore does not allow you to just look at people who receive income-related JSA specifically. The numbers are small so we don't think this will make a significant difference, but it might **underestimate** the number of people who currently miss out on WHP.
- One of the relevant benefits is Pension Credit. Because PIP is a working-age benefit, we haven't included this in the projections, although some people whose PIP claim started shortly before they reached pension age might be receiving PIP and PC. So, this might **overestimate** the number of people who currently miss out on WHP.
- One of the relevant benefits is Support for Mortgage Interest. We don't know where data for this are held, so have not included it. However, the numbers are expected to be small. This might **overestimate** the number of people who currently miss out on WHP.

# References

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3. AM Finucane et al. (2020). *How many people will need palliative care in Scotland by 2040? A mixed-method study of projected palliative care need and recommendations for service delivery*. <https://www.doi.org/10.1136/bmjopen-2020-041317>
4. Ibid.
5. Ibid. (University of Glasgow and Marie Curie)
6. Ibid. (The Poverty Alliance)
7. Joseph Rowntree Foundation, *Poverty in 2023*
8. [National Records of Scotland: Healthy Life Expectancy in Scotland 2019-2021](#)
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13. [Close the Gap: Women, Work, and Poverty in Scotland](#)
14. Close the Gap briefing for Members' Business: Challenge Poverty Week 2024
15. Ibid.
16. [Engender briefing on Women's Health Inequalities](#)
17. The Poverty Alliance: [Policy Briefing 3: A Scotland where we all have enough to live a decent and dignified life - The Poverty Alliance](#)
18. BASRIS stands for [Benefits Assessment for Special Rules in Scotland](#), and is a form that can be used by people living with a terminal illness to claim fast-tracked disability benefits under the Special Rules for Terminal Illness (SRTI). SRTI use a clinical judgement definition of terminal illness whereby a doctor or a nurse can declare someone has a terminal diagnosis without having to project how long they have to live.
19. [The Scottish Fuel Poverty Advisory Panel](#)
20. Scottish Government Programme for Government 2024-25
21. Estimated costing for extending the state pension to people living with a terminal illness of working age can be found here: <https://www.mariecurie.org.uk/policy/poverty>
22. Estimated costs for extending the Winter Heating Payment can be found in Annex 2 on page 24
23. Ibid. (The Poverty Alliance)

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For the full report and recommendations visit:



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