

Dying in Poverty: Improving financial support for terminally ill people with the cost of living



Care and support
through terminal illness

Marie Curie Budget 2022 briefing

The cost of living crisis is hitting people living with terminal illness and their families particularly hard. Between April and September 2022, nearly one in five calls to Marie Curie's Support Line were from people affected by terminal illness who were concerned about their finances – up by 38% on the same period last year.

Even before recent rises in the cost of living, the financial impact of terminal illness, from lost income to increased costs, was causing many families significant hardship. Our research has shown that 90,000 people die in poverty each year. At a time when they should be able to focus on making memories with their loved ones, many terminally ill people are instead spending the last stage of their lives worrying about how to make ends meet.

Recent changes to the benefits system, as part of the Social Security (Special Rules for End of Life) Act are welcome – they will make it easier for many terminally ill people to claim benefits they are entitled to. However, these changes alone will not be enough to address the cost of living pressures many terminally ill people and their families are facing or to prevent them from falling below the poverty line in the aftermath of a terminal diagnosis.

The Medium-Term Fiscal Plan planned for 31 October is an important and urgent opportunity for the UK Government to take action to protect people living with a terminal illness and their families from the rising cost of living and to prevent dying people falling into poverty as a result of their illness.

We are calling on the government to:

1. **Give all dying people access to their State Pension, no matter their age**
2. **Protect dying people from soaring energy bills**
3. **Support dying parents with childcare costs**

More than **135,000 people** have already signed Marie Curie's petition in support of these changes and **75%** of UK adults supported them in a recent poll conducted on behalf of Marie Curie by Opinium.

We also believe it is vital that the government commits to **uprating benefits by inflation** this year.

Summary of key points:

- **90,000** people die in poverty in the UK each year
- **1 in 4** people who dies in working age is in poverty at the end of life
- **2 in 3** working age parents with a terminal illness face poverty in the last five years of life
- Terminally ill people are **particularly vulnerable** to rises in energy prices
- **Two-thirds** of terminally ill people rely on benefits as their main source of income; our research has shown that for working age people these benefits are **not sufficient** to prevent a fall below the poverty line
- Giving working age terminally ill people access to their State Pension could **almost halve** the rate of poverty among them, lifting more than **8,600** out of poverty at the end of life every year
- The DWP could deliver this change in policy for **£114.4 million** per year – just **0.1%** of the State Pension bill
- **72%** of people polled by Marie Curie believe the government has a responsibility to protect terminally ill people from falling into poverty
- **Three-quarters** of the public back the policy proposals Marie Curie is calling for
- **1 in 6** UK adults would have no safety net other than benefits if they became terminally ill

Dying in Poverty: the facts

Nobody should die in poverty.

For too many people in the UK, however, the last stage of their lives is spent worrying about how to make ends meet, forced to make impossible choices about whether to heat their homes or feed their families, struggling to pay bills and incurring debts that will be passed onto their loved ones when they are gone.

In 2021 Marie Curie commissioned Loughborough University to examine the number of people who die in poverty in the UK each year, and how the risk of being in poverty at the end of life varies for different groups of the population¹.

This research reveals, for the first time, the extent of poverty and financial insecurity among people living with terminal illness and at the end of life in the UK. The full report can be read at www.mariecurie.org.uk/poverty.

The facts are striking:

- **90,000 people** die in poverty every year in the UK
- **1 in 4** people who die in working age are in poverty in their last year of life
- **2 in 3** working age parents who die experience poverty in the last five years of life
- **Women and people from minority ethnic groups** are more likely to die in poverty

The added costs brought on by terminal illness – travelling to appointments, paying for medications and higher energy bills – often come just as people are forced to reduce or stop working. For many, this ‘double squeeze’ on household finances directly leads to a fall below the poverty line. Working age people living with a terminal illness are a third more likely to be in poverty than other working age people.

For those who die in working age the risks are even higher. Without the fixed income provided by the State Pension and other lifetime savings to rely on, people who die in working age are more than twice as likely to experience poverty at the end of life as those who die in pension age.

Working age families with children are particularly vulnerable to falling into poverty when hit by terminal illness. Childcare costs cannot be avoided and the impact of one or both parents leaving the workforce means that these families are more likely than any other group to fall below the poverty line when one parent is terminally ill.

Women and people from minority ethnic groups are more likely to be in poverty at the end of life than men and people from white ethnic groups. Terminal illness effectively ‘locks in’ the lifelong inequalities faced by women and people from minority ethnic groups in employment, income, and wealth throughout their lives, contributing to a significantly higher risk of falling into poverty, or deeper into poverty, at the end of life.



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If Simon gets too cold he stiffens up and can't use his hands. He's in debt now because of rising energy prices. I've brought him some reflective blankets like the ones you get inside cool boxes to try to keep him warm. It's like going back to the dark ages, really.

¹ Our research uses the Social Metrics Commission's definition of poverty. This measure better captures so-called 'inescapable costs,' such as disability and childcare, which some households face and which make them more likely to experience poverty. More information about the definition can be found at www.socialmetricscommission.org.uk

This pattern is repeated across every nation and region of the UK. While the risk of poverty at the end of life in different parts of the country reflects differences in the general risk of poverty between the UK's nations and local authority areas, those at the end of life everywhere see a substantial increase in their risk of falling below the poverty line.

What needs to happen?

Our social security system should provide a safeguard against poverty, but for too many terminally ill people it is failing to do so.

Working age benefits have been devalued in real terms relative to wages and the State Pension. Too much financial support is either unavailable to many terminally ill people, or insufficient to meet the costs they face.

Working age terminally ill people cannot, for example, claim the Winter Fuel Payment and are not automatically entitled to the Warm Home Discount to help with the cost of energy, while a single person on Universal Credit receives around half as much as a person receiving the State Pension.

Marie Curie welcomes changes to the benefits system that will make it easier for terminally ill people to access support quickly – the scrapping of the 'six-month rule' for fast-track access to benefits is a significant step forward. However, this change alone will not be enough to prevent people at the end of life from falling into poverty.

Uprating all benefits in line with inflation

Improving access to benefits does not make the level of financial support people receive from the benefits system more generous. We are greatly concerned that the real terms value of working age benefits has fallen in recent years – and the high inflation the UK is experiencing this year means benefits will be worth even less in real terms if they are uprated by less than inflation.

Two-thirds of terminally ill people rely on benefits as their main or only form of income. It is vital that all benefits – including disability benefits like Personal Independence Payments and means-tested benefits like Universal Credit – are **uprated in line with inflation** to ensure terminally ill people do not find their income falling further behind.

Simply uprating disability benefits in line with inflation but allowing means-tested benefits to fall behind will not be sufficient – people living with disabilities and ill-health, including the terminally ill, are likely to be reliant on benefits unrelated to their disability as well. When the government adopted a similar approach in 2013 (uprating disability benefits in line with inflation but means-tested benefits below inflation), its own impact assessment found that those living with disability would still be more likely to be affected by the real-terms cut than other groups². **The government must use the Medium-Term Fiscal Plan to uprate all benefits in line with inflation.**



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Before I had a full-time job, a company car and a decent salary. But I got made redundant – I didn't think they were allowed to do that, with me being terminally ill. If I had the energy I would fight it in court.'

² <https://www.gov.uk/government/publications/welfare-benefits-up-rating-bill-impact-assessment>

Marie Curie's Dying in Poverty campaign calls on the UK Government to:

1. Give all dying people access to their State Pension, no matter their age

The stark difference in the risk of poverty at the end of life between working age people and pensioners is shocking, and underlines the ineffectiveness of the working age benefits system as a means to prevent poverty compared to the State Pension.

Two-thirds of terminally ill people rely on benefits as their main or only source of income. While the value of the State Pension has been protected by the triple lock, the value of working age benefits has fallen behind inflation – meaning working age people are less protected against the financial impact of terminal illness, from lost income to increased costs.

It cannot be right that terminally ill people are denied support from a system they have paid into all their lives simply because their lives are cut short before they are 'old enough' to receive it. The State Pension should be there for all of us at the end of our lives – whenever that time comes.

2. Protect dying people from soaring energy bills

Even before the recent cost of living crisis, terminally ill people faced higher energy costs than the average household. The symptoms of many terminal conditions make people feel the cold more or cause them pain if they do not stay warm, while others require medical equipment in the home such as respirators, dialysis machines or monitors which cannot be turned off.

These higher energy needs and the inability to easily ration energy use mean that terminally ill people are particularly vulnerable to fuel poverty. In the aftermath of a diagnosis of some conditions like motor neurone disease, a person's energy bill can rise as much as 75% from before they were diagnosed.

Measures such as the planned energy price cap freeze will ease the impact of rising energy prices on households with average energy needs until April 2023. The decision to scale back support after April will increase the uncertainty terminally ill people are facing, however – given the high energy needs terminally ill people have, it is vital that targeted support is made available and they are supported after April 2023.

We urge the government to make all terminally ill people, regardless of age, eligible for automatic support from the Winter Fuel Payment and Warm Home Discount Scheme this winter, to ensure terminally ill people are automatically on their energy provider's Priority Services Register and to prioritise them for interventions to improve the energy efficiency of their homes under the Energy Company Obligation.

3. Support dying parents with childcare costs

No matter their circumstances, parents have to find a way to meet the costs of looking after their children. Working age people with children are likely to be paying a significant proportion of their income in childcare costs – the financial impact of terminal illness hits these families particularly hard and they are more likely than anybody else to fall into poverty after a terminal diagnosis.

Much government support with childcare costs – such as the 30 Hours Free Childcare for 3-4 year olds and Tax-Free Childcare for children aged up to 11 – is often unavailable if one parent is not working. While in most cases a parent who is not working can take care of childcare, the symptoms of many terminal illnesses mean that terminally ill parents will need support with childcare.

Making financial support with the cost of childcare available to all terminally ill parents who cannot work due to terminal illness (and parents who are carers of terminally ill partners) would be a lifeline for these families, reducing the significant financial strain they face and helping them – and their children – avoid poverty.

Making the State Pension available to all terminally ill people

The State Pension is the single most effective safeguard against poverty in our social security system. By extending that safeguard to working age people living with terminal illness, we can prevent thousands of people and their dependents from falling into poverty at the end of their lives.

It simply isn't right that so many people miss out on this safeguard – in most cases after having contributed to the system all their lives through National Insurance contributions – and find themselves in poverty in the aftermath of a diagnosis of terminal illness, simply because they reach the end of their lives before they are 'old enough.'

In June 2022 Marie Curie asked Loughborough University to model the cost and benefits of extending access to the State Pension to anybody who meets the new definition of terminal illness in the UK benefits system introduced by the DWP in the Social Security (Special Rules for End of Life) Act 2022, namely that their death can be "reasonably expected within 12 months."

What would terminally ill people be entitled to?

Under our proposal, terminally ill people in working age would first be **entitled to claim the amount of New State Pension indicated by their National Insurance contribution (NICs) record.**

If a person living with terminal illness had made the full 35 years of qualifying NICs they would therefore receive the full New State Pension amount (£185.15 per week in 2022/23); if they had made fewer contributions, they would receive a lower level of State Pension.

While more than 90% of working age people (those aged 20-64) in the last year of life have made some qualifying NICs, only around 25% have made the full 35 years of contributions. The majority have made between 5-35 years of contributions, with older people typically having made more.

Therefore, if the household's income after the terminally ill person was entitled to claim their State Pension still fell below the Pension Credit Guarantee threshold (£182.60 for a single person and £278.70 for a couple in 2022/23) and they were otherwise eligible to claim Pension Credit (i.e. they did not have significant savings), then the terminally ill person would **be entitled to claim Pension Credit to top their income up to this level.**

This approach would entitle people who become terminally ill in working age to benefit from the NICs they have made throughout their working lives and receive their State Pension, and ensure that those most likely to fall below the poverty line in the aftermath of a terminal diagnosis – those with a lower NICs record (typically younger people and women who have taken time out of the workforce) and those without significant savings or assets to rely upon, who would be reliant on benefits as their sole or main source of income – would have a guaranteed minimum income.

How many people would be lifted out of poverty at the end of life?

According to our analysis, adopting this policy would lift around **8,600** people in working age out of poverty in their last year of life each year, and reduce the poverty rate among working age people with a terminal illness from 26% to just 14% - in line with the rate of end of life poverty among pensioners (see table 1 below).

This policy would eliminate the additional risk of poverty at the end of life currently experienced by terminally ill people in working age.

Table 1: Cost/benefit analysis of extending State Pension to people aged 20-64 in the last 12 months of life³

	No intervention (current policy)	Proposed policy
Poverty rate for those in last year of life (%)	26.0	14.1
Number in poverty (thousands)	18.9	10.3
Number lifted out of poverty (thousands)	-	8.6
Weekly cost to the state (£millions)	-	2.2

Source: Loughborough University analysis conducted on behalf of Marie Curie

How much would this cost the UK Government?

As indicated in the table above, according to Loughborough University’s analysis the cost of extending the State Pension to working age people with a terminal illness as described would be £2.2 million per week – or **£114.4 million per year**.

To put this figure into context, in 2021-22 the total UK State Pension bill was £104.7 billion; extending the State Pension to terminally ill people in working age and lifting 8,600 people out of poverty at the end of life would therefore cost the UK Government an additional **0.1% of the annual State Pension bill**.

Just 6.8% of terminally ill people aged 20-64 have made no NICs during their working lives and more than a quarter have contributed the 35 years necessary to be eligible for the full New State Pension; on average they have accrued 24 years of NICs by the time they reach the last year of life.

Even among the younger age group (those aged 20-44), on average terminally ill people have made 17.8 years of qualifying NICs by the time they reach the last year of life – more than half of the contributions necessary to receive the full New State Pension.

This policy would therefore extend to terminally ill people in working age support which they have **paid into the system for** and which they **would already be entitled to**, if they had not become terminally ill before they reached State Pension age, at a **minimal cost to the state**.



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My partner has had to reduce his work hours to look after me and my son, which means a reduction in his salary. There's a lot of focus on the person who's ill, but nobody thinks about the knock-on effect on your family.

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

In August 2022 Marie Curie commissioned Opinium to conduct a poll of the UK public to understand the degree of support for the key recommendations of our Dying in Poverty campaign and the extent to which people in the UK would have a financial safety net of their own if diagnosed with a terminal illness.

Opinium polled a nationally representative sample of 2,000 UK adults between 31 August and 5 September. To better understand and compare public perceptions in each of the UK’s nations, Opinium polled a further sample

³ Analysis restricted to subset causes of death, i.e. excluding those people who died in working age where their cause of death is unlikely to be from a terminal illness.

of UK adults between 6 September and 13 September to bring the overall sample size to 2,000 adults in England, 1,000 adults in Scotland, 750 adults in Wales and 500 in Northern Ireland.

The public believe government has a responsibility to act

We asked the public which three groups they felt had the most responsibility to protect people against falling into poverty as the result of terminal illness. Across the UK **72%** of adults believe the UK Government has the most responsibility to do so.

Similar proportions of respondents in the devolved nations felt the UK’s devolved governments also have a responsibility and a substantial minority across the UK felt that local government also has a responsibility to protect local residents from falling below the poverty line if they are terminally ill.

Top 5 groups/individuals UK adults feel have most responsibility to protect terminally ill people from falling into poverty:

- 1. UK Government – 72%
- 2. Scottish/Welsh/Northern Irish Government – 69/61/57%
- 3. Local Government – 44%
- 4. Employers – 28%
- 5. Individuals themselves – 26%

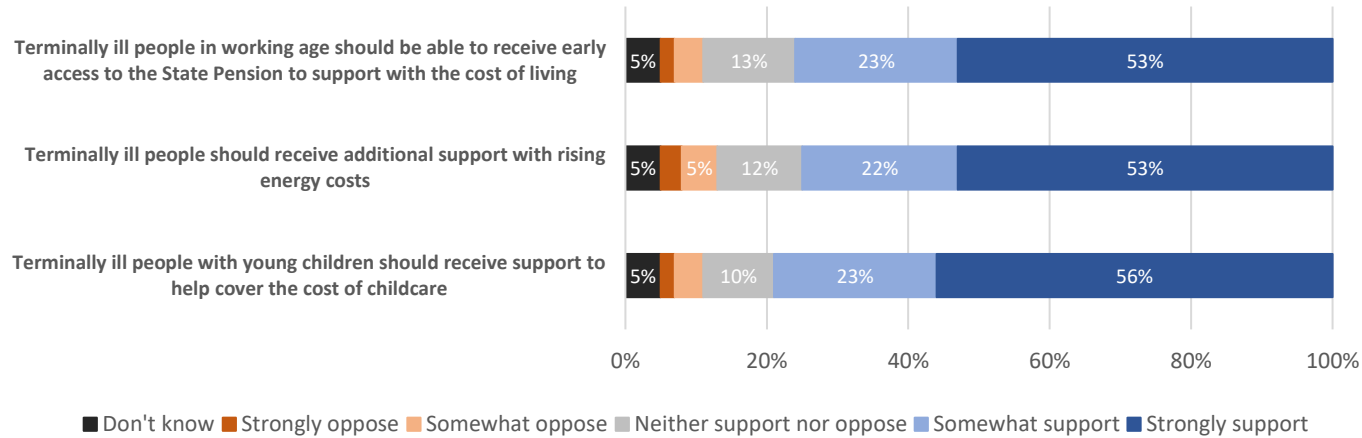
We also asked respondents whether they agreed government should take targeted action to support those most at risk, such as the terminally ill, with the cost of living – in addition to support that the government may make available to everybody. Overall, **73%** of the public support targeted action to support terminally ill people, with 44% saying they strongly agree with this. Only 6% of the public disagree with targeted support being given to terminally ill people.

The public back the recommendations of Marie Curie’s Dying in Poverty campaign

We asked the public the extent to which they support the key policy proposals in our Dying in Poverty campaign - enabling working age terminally ill people to access their State Pension, more support for dying people with the rising cost of energy and support for dying parents with childcare costs.

There is overwhelming public support from the UK public for all three policy proposals with minimal opposition – at least **75%** of respondents supported each measure, with more than half strongly supporting them.

Fig 1. Extent of support or opposition for policies in Marie Curie’s Dying in Poverty campaign⁴



⁴ % under 5% not shown

Public support for these measures is remarkably consistent, with no notable difference in support between respondents of different age groups, in different regions, by employment status or by income – and net support for each policy across all of these categories.

One in six UK adults would have no safety net other than benefits if they became terminally ill

We asked respondents three questions to determine what types of safety net the UK public would have in the event they became terminally ill and unable to work.

Firstly, we asked respondents to list up to three forms of income or support they would be most reliant on if they became terminally ill and unable to work:

- **30%** said they would rely on benefits
- **74%** of those over the age of 65 would rely on the State Pension and **38%** on private pensions
- **41%** said they would rely on existing savings and investments – typically those who were older or with a higher household income
- **22%** would be reliant on their partner's salary
- **9%** said they would need to borrow money to cover their costs
- **16%** of the public said they would have no form of safety net other than benefits

That so many respondents would be reliant on benefits as their main income in the event of terminal illness, and that one in six would have no safety net other than benefits, is a cause for concern. As outlined earlier in this briefing, the working age benefits system has been devalued in real terms, leaving it increasingly ineffective as a safeguard against poverty for people living with terminal illness.

Secondly, we asked respondents the extent to which they would struggle to pay their own energy bills this winter if they became terminally ill and unable to work. **61%** of the UK public would struggle to pay their bills, with those on lower incomes and women particularly likely to say they would struggle a lot.

Finally, we asked respondents who said they had a friend or family member who was terminally ill how concerned they were, if at all, that this person would be able to keep their home warm this winter. **93%** of those who know somebody living with terminal illness are concerned about this, with two-fifths (43%) very concerned.

These concerns underline the importance of taking **urgent, targeted action** to support terminally ill people with the cost of living.

The public believe the Government has a **responsibility** to act and **would support action** to protect terminally ill people from rising energy prices, to support dying parents with the cost of childcare, and to ensure everybody has access to the State Pension at the end of life.

For more information on the issues covered in this briefing please contact Mark Jackson, Senior Policy & Research Manager, via parliament@mariecurie.org.uk

Marie Curie is the leader in end of life experience in the UK. We work hard to provide a better life for people living with a terminal illness and their families. We offer expert care across the UK in people's own homes and in our nine hospices. Last year, we supported more than 50,000 people across the UK at the end of their lives.

Our free information and support services give expert care, guidance and support to families so they can have something that really matters to them – time to create special moments together.

We are the largest charitable funder of palliative and end of life care research in the UK and campaign inside and outside Parliament for the policy changes needed to deliver the best possible end of life experience for all.

