Marie Curie

Dying in Poverty 2025

Deaths in poverty and fuel poverty – and what needs to change

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Foreword

Nobody should die in poverty.

This is Marie Curie's third report into the prevalence of deaths in poverty across the UK. In this latest update, we found that more than 100,000 people died in poverty across the UK, and an even higher number – over 120,000 – died in fuel poverty.

As in our previous reports, working age people are far more likely to die in poverty than pension age people, in large part due to the continuing gap between the working age and pension age benefit systems. It cannot be right that someone with a terminal illness who is 64 receives hundreds of pounds less in support every month than someone who is two years older.

We have also again found shockingly high rates of poverty at the end of life among minoritised ethnic groups: almost half of Black working age people, and nearly 40% of Black pensioners, die in poverty. While this is often the legacy of wider inequalities in society, it only underscores the need for action.

These numbers are stark, but they must not take our attention from the real life experiences that underlie them: worrying about how to afford the travel to your next hospital appointment; sitting in the cold for fear of turning the heating on; or going hungry due to the cost of running at-home medical devices.

Such sobering findings demand decisive action. There are steps that governments across the UK, from Westminster, to devolved nations, to local authorities, can take to begin to tackle this crisis.

Firstly, government must improve the incomes of working age people at the end of life. The Pensions Commission, announced this summer, is a major opportunity to expand access to the State Pension to working age people diagnosed with a terminal condition – an issue that will be all the more important if it recommends an increase to the standard State Pension age. At the same time, the Department for Work and Pensions must increase rates of Universal Credit paid to people with a terminal illness, to ensure that those on the lowest incomes who have fewer years of National Insurance Contributions receive the same support.

Secondly, we need urgent action on energy bills. A social tariff would make a material difference to people living with terminal illness – as would a comprehensive system of up-front support for the running costs of medical devices provided by the NHS. People living with terminal illness today cannot wait for the promise of future reductions in bills through energy efficiency upgrades, or energy infrastructure changes.

These recommendations are the backbone of this report, but we urge political leaders and officials at all levels of government to consider the full package of recommendation here. Together they offer a blueprint for how we can build a society in which everyone has financial security at the end of life.

Matthew Reed,
Chief Executive, Marie Curie

Executive summary

Every year in the UK, more than 100,000 people die in poverty.

The end of life should be a time to focus on what really matters: making memories with friends and family, and living your final months, weeks, and days as well as possible.

Yet for more than one in six people who died in the UK in 2024, the last period of life was marked by financial difficulty. This is not just an abstract concept: in reality, it means additional stress and worry, cold homes, or social isolation at the worst possible time.

Fuel poverty is a particularly pernicious form of poverty at the end of life, given the way the need for heating or mains-powered medical devices at home can rocket after a terminal diagnosis. Over 120,000 people die in this form of poverty each year.

Poverty at the end of life affects all groups in society – but some more than others. People from minoritised ethnic groups are far more likely to die in poverty than white people, and working age households have a much higher rate of poverty than pensioners.

A key step in addressing poverty at the end of life is to ensure the working age benefits system provides protection against poverty, comparable to that provided to pension age households. The Pensions Commission is a critical opportunity to widen access to the State Pension, while government should also increase Universal Credit for households including a terminally ill person, to ensure working age low-income households with less State Pension entitlement are equally supported at the end of life.

The major changes needed to address fuel poverty at the end of life, meanwhile, are a social tariff for energy, and a comprehensive scheme to provide upfront support with the cost of running at-home medical devices.

These changes are far from impossible, but they need political will and leadership. The recent report from the All-Party Parliamentary Group for Hospice and End of Life Care on the additional costs of a terminal illness shows that this is an issue increasingly of interest to parliamentarians, which now needs to translate into real policy change.

There is no single fix to poverty at the end of life, but there is a need for urgent action. In the next year, 100,000 more people are counting on it.

About the analysis and definitions

The main analysis for this report has been conducted by academic researchers at Loughborough University's Centre for Research in Social Policy, using a combination of the longitudinal Understanding Society survey and mortality rates from national statistics agencies.

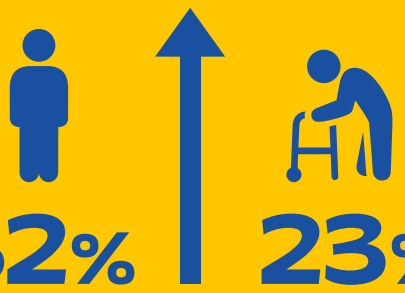
The report uses the Social Metrics Commission definition of poverty, which takes income after 'inescapable costs'have been deducted, such as housing, childcare and costs relating to disability. The definition of fuel poverty used here is based on that used in Scotland, which considers both spend on energy and income after energy costs have been met.

Key facts

More than **100,000 people** die in poverty every year in the UK

100,000+

Being in the last year of life is associated with a **32%** greater risk of poverty for working age people, and a **23%** greater risk for pensioners

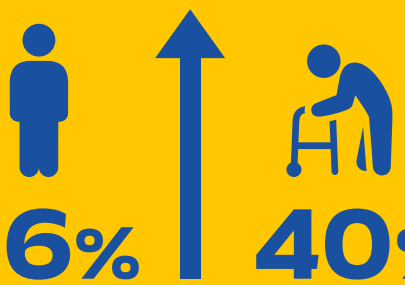


32% **23%**

A working age couple including someone with a terminal illness can receive nearly **£500 a month** less in benefits than a pension age couple

£500
a month

Almost half (**46%**) of working age Black people die in poverty, as do around **40%** of Black pensioners



46% **40%**

Over **120,000 people** a year die in fuel poverty

120,000+

Introduction

At any time of life, poverty causes challenges. But at the end of life, it represents an additional strain alongside the emotional, physical, and psychological challenges of dying.

More than one in five people in the UK – over 14 million people – live in poverty.[i] This is a stark statistic, and the fact that it has remained relatively stable in recent years should not blind us to that. The impact of poverty is also not felt equally across the population. The Joseph Rowntree Foundation has found that certain types of households have greater risk of poverty, including larger families, lone-parent families, many minoritised ethnic groups, households including disabled people, and social and private renters.[ii]

Definitions of poverty are based on financial resources, yet have an inextricable link to health. Having a disability or a long-term health condition (including terminal illnesses) is a significant 'risk factor' for poverty. This is partly because someone with such a condition is less likely to be in work[iii] – and if they are in work, they are likely to be paid less.[iv]

In the other direction, poverty also affects health. People in poverty are more likely to experience health inequalities throughout their lives: they are more likely to have long-term health conditions, face barriers to accessing healthcare services, and have lower overall life expectancy as well as lower health life expectancy. People struggling to heat their home are not just uncomfortable, but run a greater risk of developing or worsening serious health conditions.

This relationship between poverty and health persists even at the end of life. A terminal diagnosis can lead to significant financial pressures, alongside the medical, emotional and psychological impacts. Many costs can increase after a terminal diagnosis – including energy costs, which can soar by thousands of pounds, care costs, and transport to and from appointments. And of course, 'regular' costs like housing and other household bills remain.

Particularly for working people, these higher costs can come at a time when household income significantly drops. The person diagnosed with a terminal condition may need (or choose) to reduce or stop working due to their health, as might a partner in order to care for them.

Financial security is a vital component of a good death. That's why Marie Curie has again partnered with the Centre for Research in Social Policy at Loughborough University to understand the prevalence of deaths in poverty, and what changes are needed to ensure a future in which no one dies in poverty.

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, in 2022, which set out the findings using data from 2019 and made a series of policy recommendations.[v]

In 2024, we published the first of three planned updates to this research.[vi] 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?

There is no single universal definition of poverty, and consequently no single way to measure it. The Department for Work and Pensions (DWP), in its official poverty estimates for the United Kingdom, uses definitions of both 'relative' and 'absolute' poverty:

- A person is in relative poverty, or relative low income, if they live in a household with income below 60% of median household income in that year.
- A person is in absolute poverty, or absolute low income, if they live in a household with income below 60% of the 2010/11 median, uprated for inflation.

The relative poverty measure is typically used to compare inequality between low and middle-income households. The absolute poverty measure is typically used to consider how the living standards of low-income households change over time.

Both of these measures can be considered before housing costs have been deducted, or after. Because lower-income households typically spend a larger proportion of their income on housing costs, poverty rates are generally higher when incomes are measured after housing costs.

However, these measures only consider income and family size, meaning that they miss important costs that reduce the real resources available to a household. An alternative approach has been developed by the Social Metrics Commission, which aims to consider how well someone's resources meet their needs after housing costs.

Some of the main ways this measure differs from the main measures used by the DWP include:

- It estimates and deducts 'inescapable' costs, like those relating to childcare and disability, from a household's available resources.
- It considers all financial resources a household has, like savings, rather than just income.
- It includes some groups previously omitted from poverty statistics, such as people living on the streets, or those who are just above the low-income threshold but living in overcrowded housing.

In 2024, the DWP announced that it was developing the 'Below Average Resources' statistics to provide a new additional measure of poverty based on the approach proposed by the Social Metrics Commission.[vii] The latest release of these statistics, relating to 2023, shows a slightly higher proportion of people living in poverty than the official statistics.[viii]

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. 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?

As with poverty, there is no single definition of fuel poverty. Nations within the UK use different measures. These are summarised below:

- **England:** Lives in an energy-inefficient property and is in poverty after housing and energy costs.
- **Scotland:** 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.

- **Wales & Northern Ireland:** Fuel costs to maintain a satisfactory heating regime are more than 10% of their full household income.

In their analysis of deaths in fuel poverty the 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 analysis 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 – which 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. So, 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.

Sex/gender

We use the term 'sex' in this report for consistency with Understanding Society's survey data. This is also self-reported by survey respondents.

Peter's story

I was diagnosed with COPD roughly eight or nine years ago. I've stopped smoking and I manage the COPD very well but then in November 2021, I got diagnosed with chronic myeloid leukaemia. It's a blood cancer. When I was diagnosed, I was put on a medication, and I was told that I would last okay up to five years, maybe longer. The side effects come on now and again and they are not very nice, they're hard to describe. It's mainly a lot of tiredness and a lot of sickness. I've lost a lot of weight. I'm only seven stone now, but I've stayed at that and I've not lost anymore.

I've been renting private. It's a lot of money. It's just been going up since I've been here. It's gone up three times since I've been here, the rent.

I've got what's called a private landlord's meter. If I put £20 on it, it takes nearly £4 straight away in service charge. If I put £50, it takes £12-£15. I've got no gas at all, I'm all electric. Sometimes, I can put £50-£60 on my electric a week. I've only got little heaters because I can't afford to run the electric ones on the wall. I've got a nice one bedroom flat, but I've been living in one room for months and months now to try and keep warm, and I really do need to move.

I want to be out of this flat before next winter. I don't think I'll manage another. I'm here with lots of clothing on and a cover around me, I've got a heated blanket as well. I'm mainly cold most of the time. Once I get like that, it puts me off of eating. It puts you off of doing a lot of things.

I get PIP being on the sick, but other than my pension, I don't get other benefits. I don't know what other benefits I'm allowed. I tried to get a mobility scooter because I don't walk too far. I've got a bus pass, but apparently I'm not in the right criteria for a scooter. I don't know how that worked out, because I'm terminally ill.

It kills me sometimes. My granddaughter is 26, and she's just got married and she had a baby a couple of days ago. I've got a great grandchild, but at the moment I can't afford to buy him something, with the way things are.

The only thing I struggle with is this electric nonsense when I could be doing other things, like having a break somewhere. I was asked to go away for the weekend for a bit of rest, but it's just affording little things like that. I've been mostly housebound for quite a few months. I went out today on the bus, but I can't go out a lot, especially if it's cold. If it's cold, I don't go anywhere. It's nice and sunny today at the moment, and I'm lucky that I had got a shop just over the road from me so I'm okay for the little things. At the moment, for anything big my son helps me.

1. Who dies in poverty and fuel poverty?

In 2024, more than 100,000 people died in poverty in the UK – representing 18% of all people who died. An even larger number – 121,000 – died in fuel poverty. And of course, many people will have experienced both poverty and fuel poverty.

This 'headline' proportion of deaths in poverty is lower than the poverty rate for the general population. This is due to the fact that pensioners are less likely to be in poverty, but are more likely to die than working age people. Across all breakdowns of the data, people in the last year of life are more likely to be in poverty than the same population not in the last year of life.

The numbers of deaths in poverty and fuel poverty are slightly lower than in 2023. However, this is driven by a fall in the overall number of people dying – not in improved financial circumstances. The proportion of people dying in poverty and fuel poverty has remained the same as in 2023, and the raw number of people dying in poverty is still higher than in 2019.

Figure 1: Deaths in poverty by year

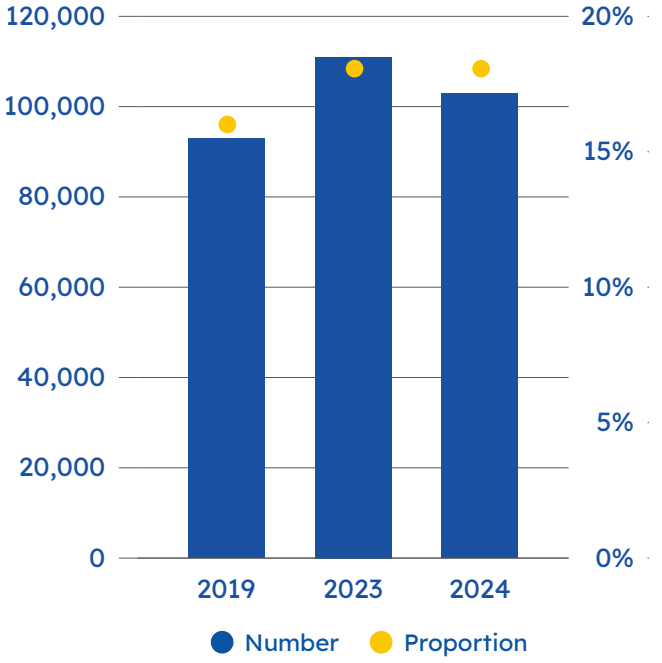
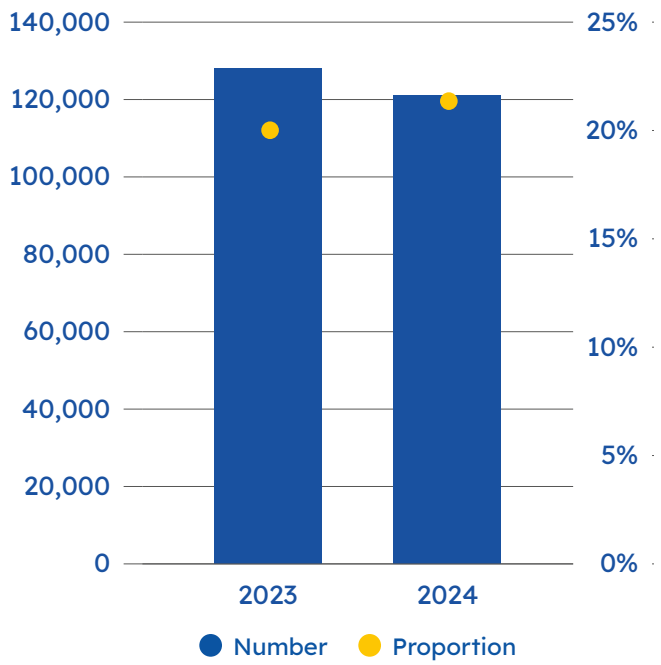


Figure 2: Deaths in fuel poverty by year



For the first time, this report shows that 23,000 people a year die in 'deep poverty' – with incomes 50% below the poverty line. Almost one in ten people of working age who die do so in deep poverty – compared to one in 33 people of pension age.

Just as poverty is not evenly distributed across the population, nor are deaths in poverty or fuel poverty, as explored below.

Age

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. 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.

This difference is due to several factors. A key element is likely to be the relative amounts provided under the different state benefit systems, which is explored further later in this report. People over pension age are, of course, older, and so more likely to be able to draw on larger private pension pots as well (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 well be due to the income drop that comes from stopping working, which is more likely to affect people of working than pension age.

Within people in the working age population who died in 2024, people in 'younger working age' (aged 20-44) had a higher rate of dying in poverty than those aged 45-64 (31% vs 28%).

In contrast to the findings for poverty, there is much less difference between rates of fuel poverty among working age and pension age households, as well as a lower additional risk of being in fuel poverty related to being in the last year of life.

Table 1: Deaths in poverty by age

	Proportion of deaths in poverty	Increased risk of poverty associated with being in the last year of life
Working age	29%	+7pp (32% increase)
Pension age	16%	+3pp (23% increase)

Table 2: Deaths in fuel poverty by age

	Proportion of deaths in fuel poverty	Increased risk of fuel poverty associated with being in the last year of life
Working age	21%	+2pp (11% increase)
Pension age	20%	+2pp (11% increase)

This difference between income-based poverty and fuel poverty findings by age could be explained by various factors, particularly energy usage. Older people typically use more energy than younger households, which might offset their typically higher income.

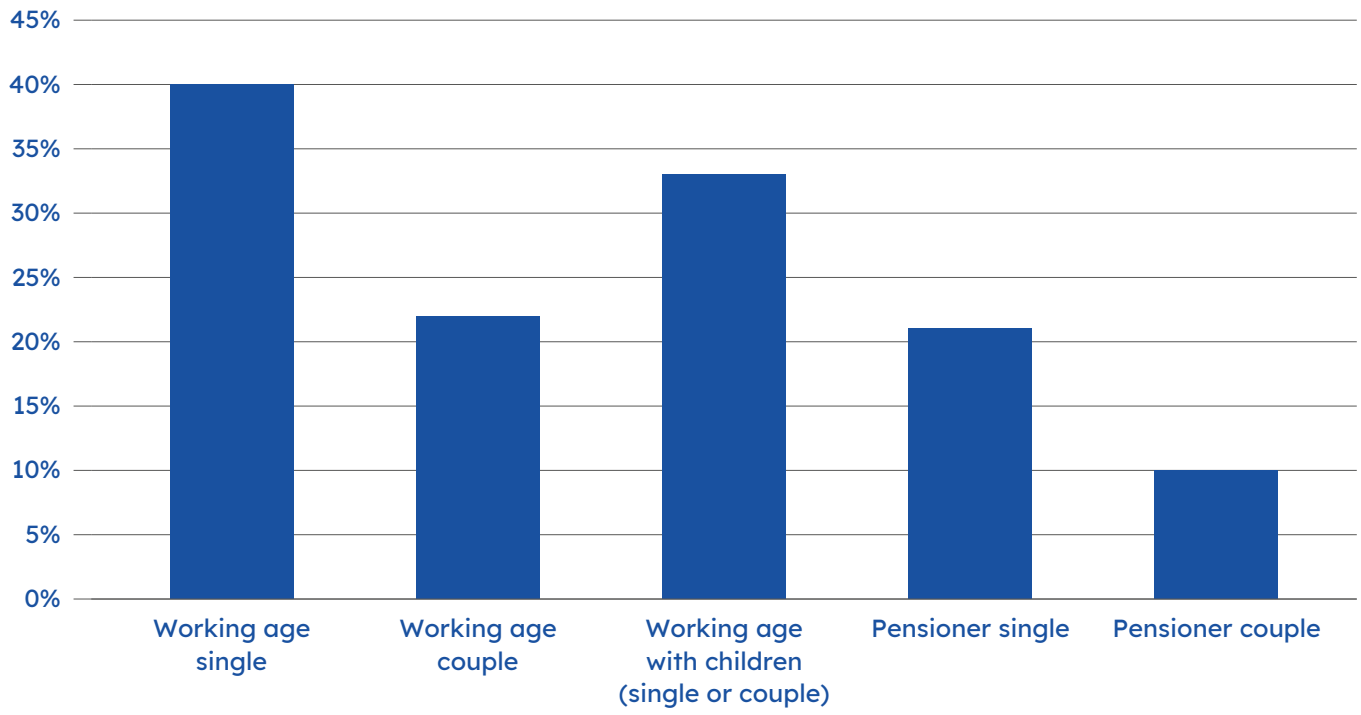
Household composition

Across both working age and pension age people, single-person households are particularly at risk of dying in poverty – around twice as likely as couples.

Previous work funded by Marie Curie has also found that rates of poverty among end of life household carers (who will often be the partner of the dying person) increases after their death. This suggests that measures to increase income among single people are vital to prevent poverty at the end of life.

While the total numbers are small, there is also a worrying rate of working age people with children dying in poverty. Overall, 33% of working age parents who die do so in poverty.

Figure 3: Poverty rates at end of life by household composition



Ethnicity

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.[x] For some particular groups, these figures are extremely high. For example, poverty rates among Bangladeshi households are estimated to be as high as 56%.[xi] 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 analysis conducted by the Centre for Research in Social Policy was not able to provide a full breakdown of estimates of dying in poverty by ethnicity, but even based on broad categories, there is a clearly disproportionate impact. 25% of working age white people who died did so in poverty, compared to a shocking 46% of Black people, 45% of Asian people and 37% of people who are mixed race or have another ethnicity. For pension age households, the findings are similar. 15% of white people over pension age die in poverty, compared to nearly 40% of Black people, over a quarter of Asian people, and nearly a third of people from other backgrounds.

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

The data around ethnicity for fuel poverty could not be broken down by the same categories, but there is a clear higher risk of dying in poverty for people from minoritised ethnic groups compared to white people.

Table 3: Rates of deaths in poverty and fuel poverty by ethnicity

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

National governments must take action to understand and address the wider inequalities that persist into the last year of life among people from minoritised ethnic communities, as well as specific barriers to accessing available support aftera terminal diagnosis.

Sex

In previous reports, women have been slightly more likely to die in poverty than men. In this latest report, however, that gap has closed.

When it comes to fuel poverty, the comparison is different depending on age. Working age men are more likely to die in fuel poverty than working age women, but pension age women are more likely to die in fuel poverty than pension age men.

Differences by geography

Poverty rates are not the same across the UK. Unsurprisingly, rates of poverty at the end of life are not equal either.

A third of working age people who die in the North East of England die in poverty – the highest rate of any nation or region. That is 50% higher than the East of England, which had the lowest rate of working age deaths in poverty. Pension age people, meanwhile, are more likely to die in poverty in Yorkshire and the Humber than anywhere else.

The picture for fuel poverty is different, with working age people more likely to die in fuel poverty in London than any other region. The highest rate of deaths in fuel poverty among pensioners is found in Northern Ireland.

Across every region and nation of the UK, people at the end of life are more likely to be in poverty than those not at the end of life.

There is also a large amount of variation among the proportion of people dying in poverty across local authorities. Tables 5 and 6 show the ten local authorities with the highest percentages of working age and pension age people dying in poverty, and fuel poverty.

Table 4: Rates of deaths in poverty and fuel poverty by age and sex

Poverty at the end of life	Working age	Men	28%
		Women	29%
	Pension age	Men	15%
		Women	15%
Fuel poverty at the end of life	Working age	Men	23%
		Women	20%
	Pension age	Men	18%
		Women	23%

Table 5: Local authorities with the highest rates of working age deaths in poverty and fuel poverty

Working age deaths in poverty		Working age deaths in fuel poverty	
Local authority	**Rate**	**Local authority**	**Rate**
Birmingham	42.4%	Hackney	31.2%
Manchester	40.9%	Tower Hamlets	30.9%
Sandwell	39.6%	Islington	30.7%
Blackburn with Darwen	39.3%	Southwark	29.1%
Middlesbrough	39.2%	Lambeth	28.5%
Tower Hamlets	39.1%	Camden	28.4%
Wolverhampton	38.9%	Westminster	28.3%
Bradford	38.0%	Manchester	28.2%
Leicester	37.7%	Hammersmith and Fulham	28.1%
Kingston upon Hull	37.4%	Newham	28.0%

Table 6: Local authorities with the highest rates of pension age deaths in poverty and fuel poverty

Pension age deaths in poverty		Pension age deaths in fuel poverty	
Local authority	**Rate**	**Local authority**	**Rate**
Tower Hamlets	32.2%	Hackney	32.3%
Newham	29.3%	Tower Hamlets	31.9%
Brent	26.7%	Islington	31.7%
Barking and Dagenham	26.3%	Derry City and Strabane	31.2%
Manchester	26.3%	Belfast	30.8%
Hackney	26.2%	Southwark	30.0%
Southwark	25.4%	Lambeth	29.3%
Blackburn with Darwen	24.9%	Camden	29.1%
Ealing	24.8%	Westminster	29.1%
Bradford	24.7%	Hammersmith and Fulham	28.8%

Differences by diagnosis

Different life-limiting conditions can have different impacts on someone's financial situation. Whatever the diagnosis, financial security at the end of life is essential.

It is concerning that there remains a notable difference between the likelihood of dying in poverty and fuel poverty based on diagnosis in the year before death. People with a diagnosis of cancer are less likely to be in poverty at the end of life than people with other conditions (which could include respiratory or heart conditions, or neurodegenerative conditions like motor neurone disease).

These disparities could be linked to known differences between the experiences of palliative care and access to services for patients with cancer and non-cancer diagnoses. For example, people with non-cancer diagnoses are less likely to have contact with palliative care services,[xii] which may in turn reduce their awareness of or access to financial support or advice services.

Differences in fuel poverty by fuel type

Households who depend upon electricity for their heating are much more likely to experience fuel poverty than those who have gas heating or heating from other sources, such as oil or solid fuel. This is consistent with our previous report, which found that households without a gas supply have an increased risk of being fuel poor.

Figure 4: Rates of deaths in poverty and fuel poverty by diagnosis in last year before death

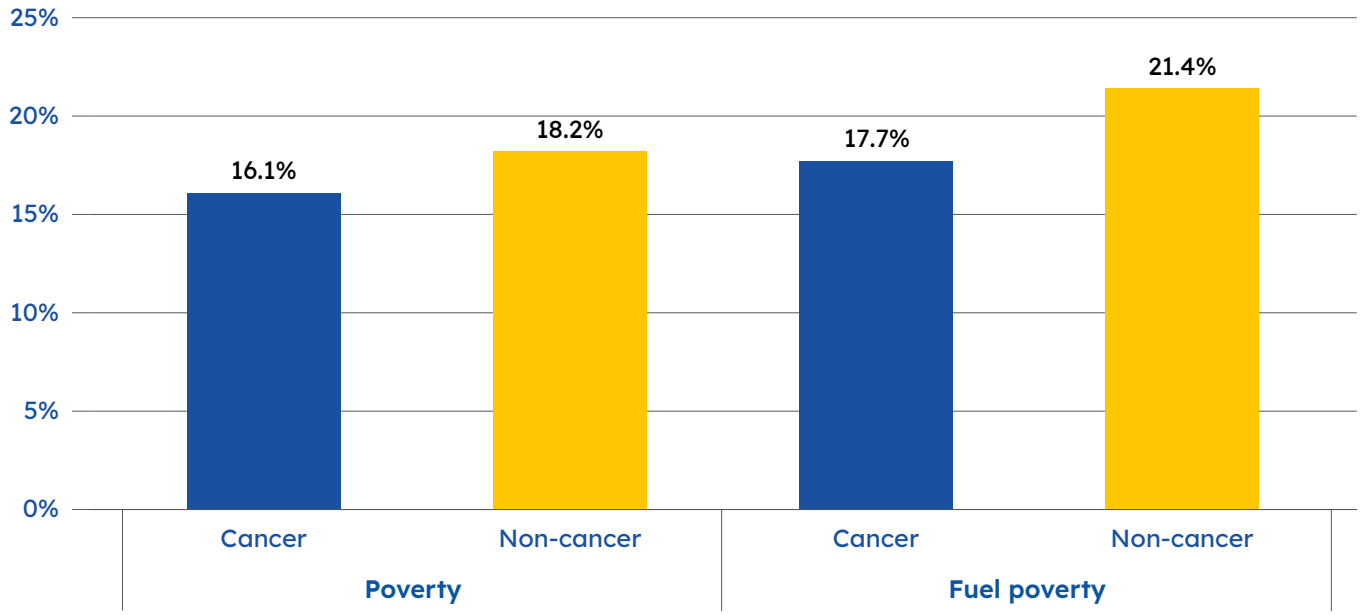


Table 7: Deaths in poverty by fuel source

Source of heating	Poverty rate
Electricity	26%
Gas	20.4%
Other (eg oil or solid fuel)	21%

The Minimum Income Standard and material deprivation

An alternative way of looking at financial difficulty at the end of life is to look at whether households reach the Minimum Income Standard (MIS).[xiii] This aims to produce a comprehensive basket of goods and services that members of the public agree is needed for a socially acceptable standard of living, and which can be converted to a weekly cost. It includes the items that households need to be able to afford to meet material needs such as food, clothing and shelter, as well as to have the opportunities and choices required to participate in society. Having an income below the MIS threshold for a particular household type is therefore an indicator of a household being unable to meet their minimum needs.

Using this measure suggests that at least 162,000 people die each year with an income below the MIS – strongly suggesting that they are in financial difficulty.

Table 8: Number of people in the last year of life with income below the Minimum Income Standard by age

	Number	%
Working age (20-64)	35,000	43.9%
Pension age (65+)	127,000	25.1%

We can also look at whether people at the end of life experience material deprivation. The questions asked in Understanding Society that determine whether someone is classed as in material deprivation differ for working age and pension age households. Overall, 26% of working age people are in material deprivation in the last year of life, in comparison to 13% of pensioners – this equates to 86,000 people overall.

Looking in more detail at these findings helps us better understand the reality of life for people in the last year of life who face material deprivation.

Table 9: Selected material deprivation items for working age people at the end of life

Do you (and your family/partner) have…	Proportion of people experiencing material deprivation who say they do not have this due to being unable to afford it
Enough money to replace or repair major electrical goods such as a refrigerator or a washing machine, when broken?	92%
Enough money to replace any worn out furniture?	90%
A small amount of money to spend each week on yourself (not on your family)?	69%
Enough money to keep your house in a decent state of repair?	47%
Household contents insurance?	39%
Enough money to keep up with bills and regular debt repayments?	24%

The questions asked of pensioners are different. Unlike working age people, the survey does not distinguish between deprived of something due to cost, or due to other factors (such as health or disability).

Table 10: Selected material deprivation items for pension age people at the end of life

Question	Proportion of people in material deprivation answering "No"
Do you go out socially at least once a month?	77%
Do you have access to a car or taxi whenever one is needed?	44%
Would you be able to pay an unexpected expense of £200?	42%
Would the cooker be able to be replaced if it broke down?	35%
Do you see friends or family at least once a month?	29%
Do you have your hair done or cut regularly?	25%
Is your home kept in a good state of repair?	20%
Do you eat at least one filling meal a day	15%
Do you have a telephone to use, whenever one is needed?	13%
Do you have a warm waterproof coat?	8%

These figures are deeply concerning, and bring home the reality of dying in material deprivation. The idea that someone could die with a broken washing machine, worn-out furniture, or in a property in a poor state of repair should be completely unacceptable. Even if these events don't occur, it demonstrates the precarity of people's lives and the stress and fear of something going wrong. Financial insecurity at the end of life doesn't just cause unacceptable living conditions. It robs someone of peace of mind that if something did go wrong, they would be able to manage.

John and Christine's story

Me and Christine were together over 40 years. We met on a night out in 1983. I was with my friends at a presentation do, I met Christine and that was it – we were together all those years.

It's very difficult without her. She was 70 when she passed away. She had MS for over 30 years. She had breast cancer in 1996 which she survived. Then she was diagnosed with ovarian cancer in 2021. She had all the treatment, the hysterectomy and the chemo. Everything was looking good. Then in July 2024 she was told it had come back, and it was terminal. She passed away on the 4th of December that year.

I took early retirement in 2015 to look after Christine. At the time, Christine was getting PIP. She found the application awful. We got through it because we had to. We got help with our rent and council tax and things like that. We were never given all the information we wanted. I never claimed carer's allowance until we found out Christine had cancer, and then it was because Macmillan got involved and said, "You should have been getting this." We lost about six years of that. We were living off our savings really.

For PIP, you had to fill in this form, and it was asking "how many times do you soil yourself in a day?" It was really degrading. Christine at that point wasn't in that situation, but even just to answer the questions, it made her feel as if she was begging. On the day of her assessment, when you have to go and meet someone and they ask you to do all this, that and the other which she couldn't do, we had to go to the local recreation centre. All of these people are walking past with gym equipment and bags over their shoulders, having a good time, while we're sat there looking like we were waiting to be executed or something.

We had savings because we had to move house to get Christine on one level. We were trying to get a bungalow, and we couldn't get her one, so we applied for a flat and we got it. We had our own house, so we sold the house which meant we had money from the house to live on.

I was worrying about money. It was worse without Christine. I had to then apply for Universal Credit, which I've never done before. When you lose someone that you've loved for all those years, the financial side of it is not the most important obviously, but it becomes extremely difficult. I even had to start paying bedroom tax. It's just horrible. I couldn't apply for bereavement allowance because we weren't married. How ridiculous is that? Everyone knew that we were together all those years, and yet that's just the way it is.

It was hard paying the bills. On Universal Credit you don't get enough to live on. The savings were coming down, and I wanted to get a little memorial for Christine at the crematorium. I thought it would be nice for me to have a place to go to and be with her but that all had to come out of my savings.

When you lose the person you're caring for, you lose everything. You don't just lose the person you love, you lose your way of life. When you become a carer, that's where your focus is. Christine is the love of my life and it was an honour to look after her. When she's gone, you think, "what do I do now?" It's as if you lose your purpose in life. When you've got all the financial pressures on top of that, it seems to make it even worse.

2. Gaps in financial support for people at the end of life

Deaths in poverty and fuel poverty are not inevitable. In this section, we set out the key gaps that contribute to the stark figures from Chapter 1 that need to be addressed.

An inadequate national benefits system

The benefits system is society's last backstop against poverty and, ultimately, destitution. Yet as the figures in this report show, it is failing to protect people at the end of life.

The importance of the benefits system is demonstrated by new analysis breaking down income sources for people in the last year of life. For working age people, the benefits system provides around half of their household income in the last year of life. This proportion increases over the last five years of their life, which is highly likely to relate to reduced income from work due to health and caring responsibilities.

For pension age people in the last year of life, the reliance on benefits (including the State Pension) is even greater, at 67% of household income. This changes far less in the five years preceding their death.

Figure 5: Sources of income for working age people in the last years of life

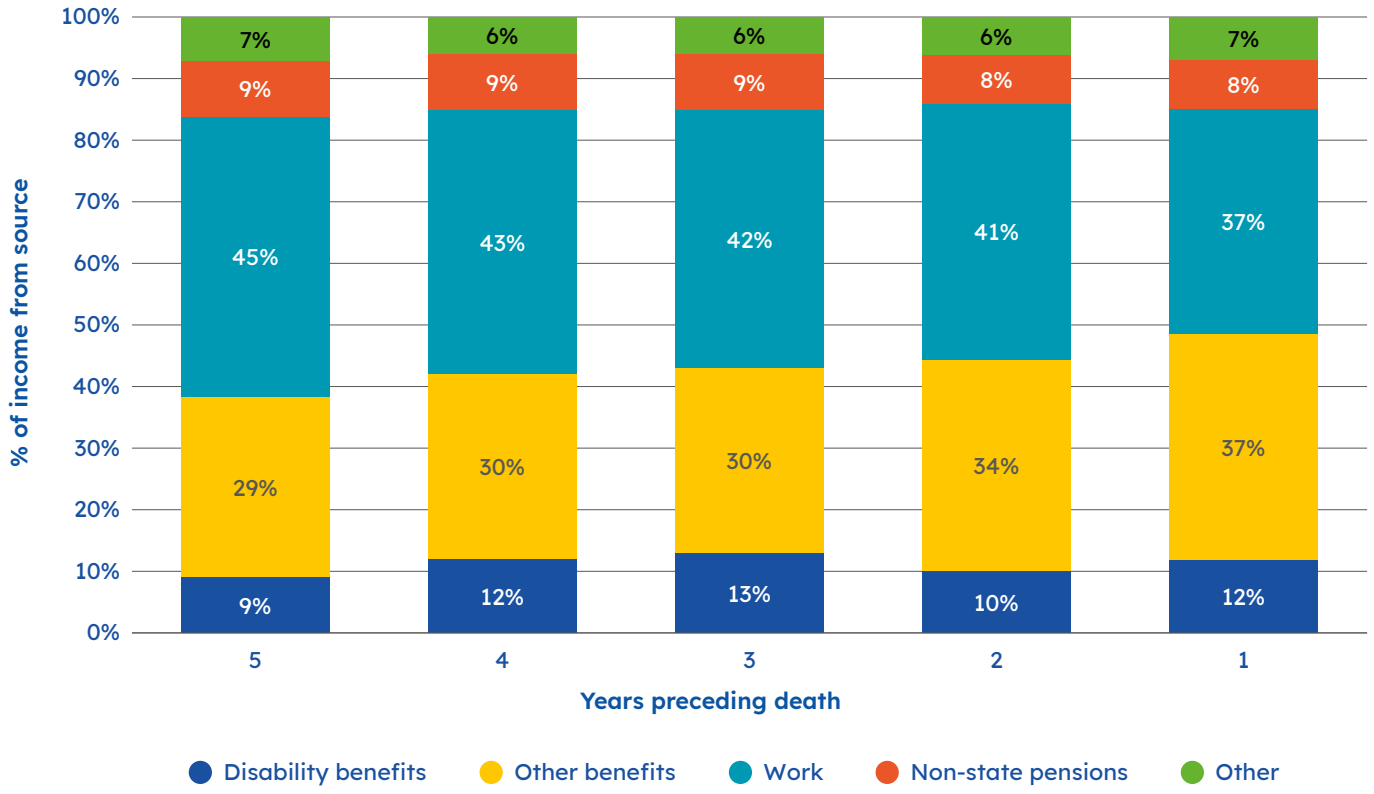
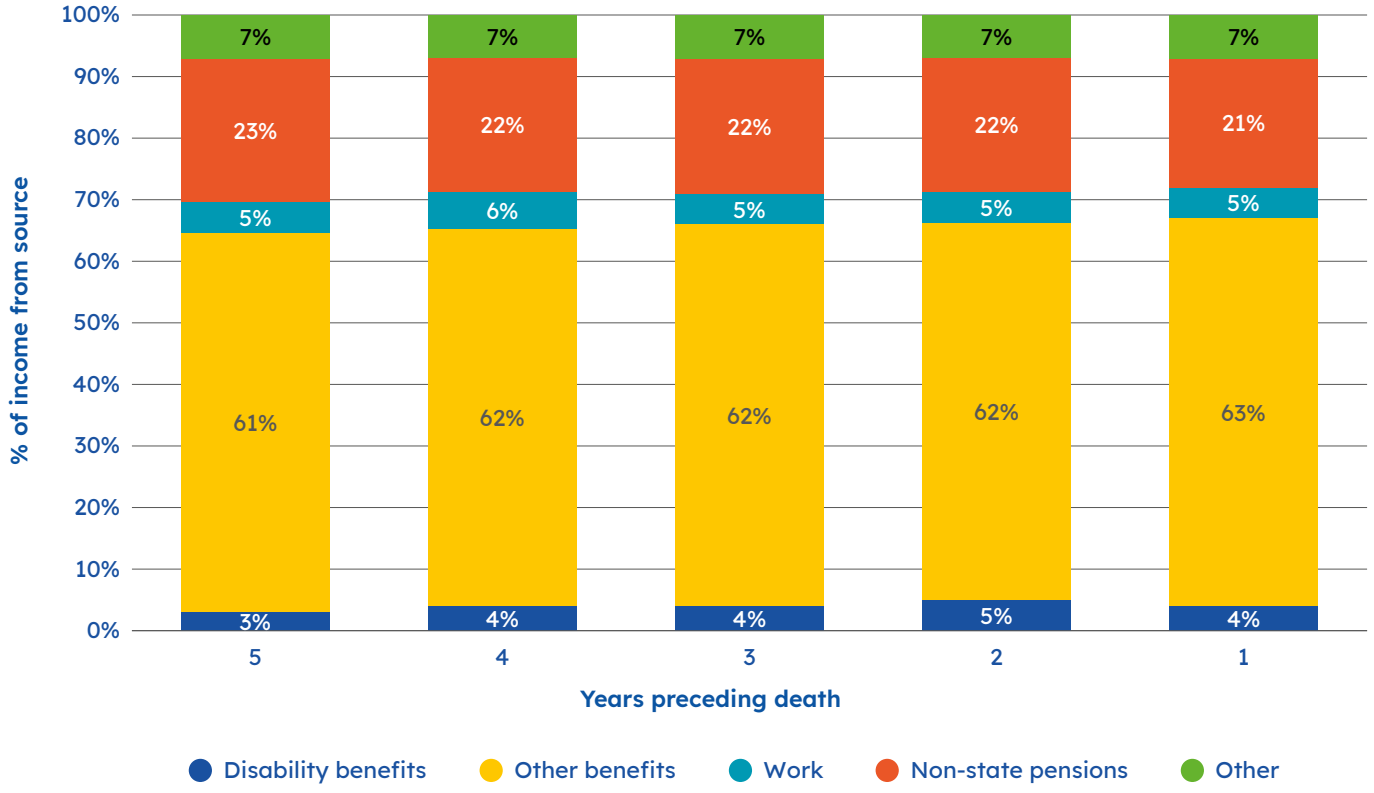


Figure 6: Sources of income for pension age people in the last years of life

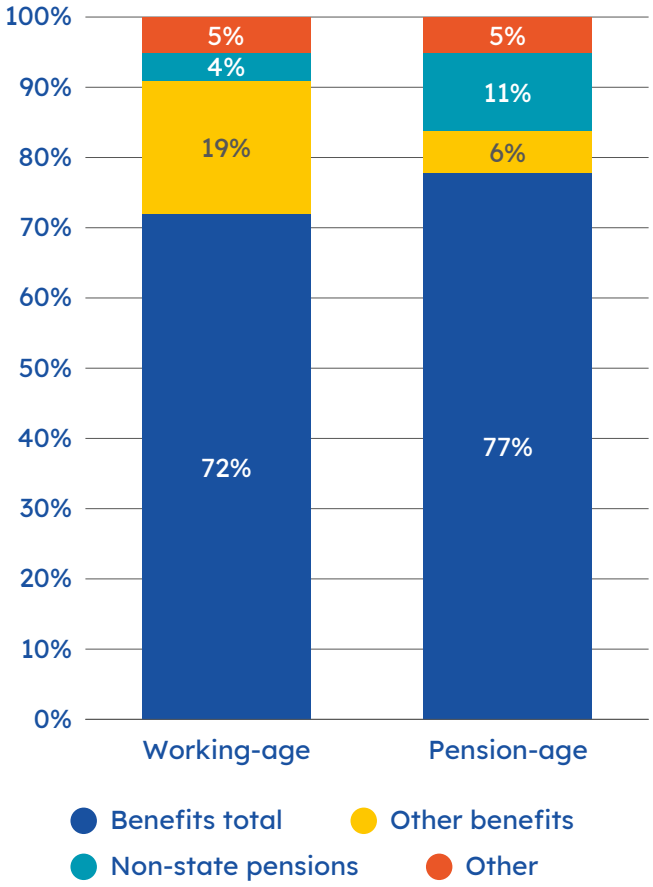


This clearly demonstrates the importance of working age benefits for people in the last year of life. But their significance becomes even starker if we look at the income sources of people in poverty in the last year of life.

For working age people in poverty at the end of life, almost three-quarters of their income comes from the benefits system (just over twice the proportion of people not at the end of life). For pension age people, the last year of life is associated with a slight increase in reliance on benefits. These figures show the huge significance of improving the benefits system for people in the last year of life. It also reveals how the system is currently failing people who rely on it, especially those of working age.

There are some welcome protections in the benefits system for people living with a terminal illness. These provide guaranteed and fast-track access to disability benefits.[4]

Figure 7: Income sources in the last year of life among people in poverty



1. These include 'extra costs' benefits such as PIP and Attendance Allowance, and the Limited Capability for Work and Work-Related Activity (LCWRA) element of Universal Credit.

Table 11: Special Rules within the benefits system

Benefit	Region	Criteria	Impact
PIP & Disability Living Allowance	England, Wales, NI	Special Rules for Terminal Illness: Clinician would not be surprised if claimant died in the next 12 month due to their condition	Guaranteed, fast-track access to the Enhanced Daily Living Component (PIP) or Care Component (DLA) Most claimants also receive the Enhanced Mobility Component
Attendance Allowance			Guaranteed fast-track access to the Enhanced Daily Living Component
New-Style ESA	UK		Guaranteed, fast-track access to the Support Group
Universal Credit			Guaranteed fast-track access to the LCWRA element, at the higher rate from April 2026
		Severe Conditions Criteria: Claimant already qualifies for LCWRA, on the basis of a 'constant' health condition (not necessarily a terminal condition)	Guaranteed access to the Limited Capability for Work and Work-Related Activity (LCWRA) element, at the higher rate from April 2026
Adult Disability Payment	Scotland	Special Rules for Terminal Illness (Scotland): Patient is in the advanced stages of a condition that they are likely to die from	Guaranteed, fast-track access to the Enhanced Daily Living Component (PIP) or Care Component (DLA), as well as the Mobility Component
Child Disability Payment			
Pension Age Disability Payment			Guaranteed fast-track access to the Enhanced Daily Living Component.

As set out later in this report, some local authorities in England are also taking steps to provides additional support with Council Tax to people with an SR1 form.

These protections are important, but don't reach all people with a terminal illness. In particular, people who have a terminal illness but are in the relatively early stages of the condition cannot access these protections. They have to use the uncertain, stressful, and time-consuming 'normal' assessment processes for disability benefits. Although their condition is only going to worsen, they have to wait for this point before being guaranteed additional support. While the definition of terminal illness used in devolved disability benefits in Scotland is still relatively new, we have also heard anecdotal

evidence that this is successfully expanding access to this route for people with terminal illnesses who struggle to meet the strict prognosis-based definition used in the rest of the UK.

What's more, if someone with terminal. illness relies on Universal Credit, they may have to meet Jobcentre requirements or face a cut to their benefits. The pen portrait below, based on Marie Curie's clinical expertise, demonstrates how inappropriate this is.

Pen portrait – Huntington's Disease

Huntington's Disease is a progressive, neurodegenerative disorder. There is currently no cure, and no treatments that can stop the symptoms getting worse.

Jasper has Huntington's Disease, which causes him difficulty concentrating and memory problems. He has noticed some changes in his mood, including mood swings, and he also has some slight jerking movements which he is unable to control. However, he does not qualify for either the Special Rules for End of Life, nor the Severe Conditions Criteria.

This means he's not able to receive the additional health-related Universal Credit and has to get by on the basic rate. Jasper's symptoms are going to worsen over time, not improve. Yet because he is in the Limited Capability for Work group in Universal Credit, he has to undertake 'work-related activity' – work that his condition is only going to gradually move him further away from. If he doesn't do these activities, he could have his benefits cut by a sanction.

This pen portrait is not a case study, but a realistic scenario based on Marie Curie's clinical expertise.

Recommendation

The Department for Work and Pensions should expand eligibility for the Severe Conditions Criteria in Universal Credit to include someone with a life-limiting, progressive condition who currently meets the criteria for Limited Capability for Work.

Recommendation

The Department for Work and Pensions should review whether introducing the definition of terminal illness used by Social Security Scotland would provide greater certainty and security for people living with terminal illness in the rest of the UK.

The protections offered by the Special Rules and the Severe Conditions Criteria, while important for those who can access them, are not enough. This is particularly true for people of working age, who face significantly higher rates of deaths in poverty than people over pension age. A major contributor to this is the working age benefits system, which provides hundreds of pounds a month less to someone aged 64 compared to someone aged 66.

Figure 8: Comparison of weekly benefits for working age vs. pension age households including someone with a terminal illness

Based on childless households in receipt of Universal Credit/Pension Credit and maximum rates of PIP/ Attendance Allowance. For couples, one partner is assumed to be providing care.

This is a deeply unjust situation. People unfortunate enough to be diagnosed with a terminal illness before they reach pension age have the same additional costs and financial concerns as pensioners. They are, generally, closer than average to pension age, and are likely to have paid National Insurance Contributions for many years – yet will die before they benefit from them. They are also a group who should not, for obvious reasons, be considered likely to return to work.

The policy rationale behind the State Pension and Pension Credit is to provide a guaranteed minimum level of income for people not expected to work again as a result of their age. Working age people living with a terminal illness are similarly not expected to work again (due to their health), yet receive far less support.

Without urgent reform, this situation will only worsen. The Triple Lock will continue to increase the value of the State Pension beyond that of working age benefits, even with the welcome provisions in the Universal Credit Act to increase the Standard Allowance above inflation in coming years. As a result, the gap between working age and pension age incomes will widen.

What's more, existing plans to raise the State Pension Age will increase the number of people dying before they can access the pensioner benefits system. Analysis by Marie Curie suggests that 15,800 more people could die before reaching pension age.[xiv] With the current rates of working age deaths in poverty, this would mean an additional 4,500 working age people dying in poverty. The Pensions Commission, due to report to government in 2027, may well lead to further increases in future.

There are two steps that need to be taken. Firstly, the forthcoming Pensions Commission should explicitly consider how the State Pension itself could be opened up to people of working age with a terminal

condition. Previous reviews of the State Pension have considered the viability of varying the State Pension by actuarially-estimated life expectancy. They have not specifically considered how the State Pension could be provided to people of working age with a terminal condition.

Secondly, the government should increase the amount of Universal Credit paid to claimants with a terminal illness, so it is equal to the Pension Credit Guarantee amount. The Universal Credit Act will create different values of the Health Element for different groups, so this could be implemented by changing these values for claims under the Special Rules for Terminal Illness, and for people meeting the Severe Conditions Criteria with a life-limiting condition. Alternatively, a 'Pension Credit Element' could be introduced in Universal Credit. Even if access to the State Pension is expanded, this step is essential to provide financial security to people on the lowest incomes, particularly those who do not have 35 years of National Insurance Contributions (for example due to age, or having lived abroad for part of their working life).

Previous research has estimated that measures like these would cost just 0.1% of current spend on the State Pension – while making a significant impact on levels of deaths in poverty among working age people.[xv xvi]

Recommendation

People of working age living with a terminal illness should be guaranteed a State Pension level of income. As part of this, the Pensions Commission should explore how access to the State Pension could be provided to people of working age who are living with a terminal illness.

In Chapter 1 of this report, we highlighted the higher rates of poverty at the end of life for single people. The move from Employment Support Allowance (ESA) to Universal Credit risks exacerbating this. Within ESA, the Severe Disability Premium could be paid to people with a serious illness or disability if no one claims Carer's Allowance for caring for them. This is worth £82.90 a week for a single person. However, this does not exist within Universal Credit. Reintroducing this would be a practical way to provide greater financial protection to households on low incomes facing care needs who have no one providing that care for them.

Recommendation

The Department for Work and Pensions should introduce a new 'self-care element' in Universal Credit, for households with care needs for whom no-one is claiming Carers' Allowance or the Universal Credit Carers' Element.

The pension age benefits system does not eliminate poverty, but it provides a greater protection against it than the working age benefits system. Yet almost one in six pensioners dying in poverty remains unacceptably high. Despite the differences in proportion, a far greater number of pensioners die than working age people.

Recommendation

The Department for Work and Pensions should continue to promote the uptake of Pension Credit among eligible households.

No Recourse to Public Funds

This section has mostly focused on the inadequacy of current support. However, it is important to note that there are also people with a terminal condition who are not able to access the benefits system as they have No Recourse of Public Funds (NRPF), either because of conditions attached to their visa, or because they do not have a valid visa.

Research funded by Marie Curie and conducted by the University of Stirling, cited by the All-Party Parliamentary Group for Hospice and End of Life Care, has found that people with this immigration status often experience extreme financial hardship and destitution, and are often primarily supported by non-statutory services.[xvii] Someone with NRPF who has a terminal illness needs the same support as anyone else. While there is scope to grant access in this situation as an 'exceptional circumstance', this research suggests that in practice this is not happening, leaving people in exceptionally precarious situations. It's important to address this issue. The number of people with NRPF is set to increase if proposals in the government's White Paper on Immigration are brought forward.[xviii]

Recommendation

Government should review its guidance on granting access to public funds to ensure it clearly covers people diagnosed with a terminal illness. It should also work with healthcare and administrative professionals to ensure rights to medical and palliative care for people with No Recourse to Public Funds are understood and upheld.

Gaps in recognition of the unique needs and circumstances of people living with a terminal illness

The protections set out above relate to the amount of money someone might receive in their 'standard' benefit award. However, there are other aspects of the benefits system and other governmental support that do not properly recognise the unique needs of people living with terminal illness.

Support for housing costs

Within Universal Credit for working age households, and Housing Benefit for pension age households, the Local Housing Allowance (LHA) sets the maximum financial support that someone can receive for a privately rented property through Universal Credit. This is based on the 30th percentile of rents in a given area for a given property size, although it is often frozen at a previous year's level. The result is that around half of households in receipt of Universal Credit have rents higher than the applicable LHA. In some cases, this can be topped up from earnings – but in others, it must be topped up from benefits intended for other purposes (such as disability benefits), or else the person will have no choice but to accrue rent arrears.

A terminal diagnosis can have a sudden and significant impact on a household's finances. It is entirely possible for a household to have a private rented tenancy that is above their LHA, but affordable. This situation then dramatically changes after a diagnosis, as income drops and other costs increase.

The intention of the LHA is to encourage households in receipt of benefits to move to more affordable property or to increase their earnings. Whatever the merits of this argument for most households, it is entirely inappropriate for people with a terminal condition. People in this situation are clearly not likely to be able to increase their

earnings. The last thing someone living with and/or caring for someone with a terminal illness needs is to go through the difficult, disruptive and stressful situation of looking for a new property and moving home.

Meanwhile, people diagnosed with a terminal illness who have a mortgage, cannot receive support through Universal Credit or Housing Benefit, but might be able to apply for Support for Mortgage Interest. However, this is only available after a household has received Universal Credit for three consecutive months (whereas for Pension Credit, it is available immediately).

Recommendation

The Department for Work and Pensions should explore ways to provide additional support for housing costs for people with a terminal illness living in privately rented properties above the Local Housing Allowance. This could be, for example, by raising the cap from the 30th to the 50th percentile.

Recommendation

Working age people living with a terminal illness should be able to apply for Support for Mortgage Interest at the same time they start to receive Universal Credit.

Childcare

Being diagnosed with a terminal illness is difficult at any point, but perhaps even more so for a parent facing the prospect of never seeing their child grow up. The symptoms of many terminal illnesses – including pain, fatigue, nausea, breathlessness, increasing frailty, and advancing and often severe disability – mean that many parents with a terminal illness will need support with childcare. As shown in Chapter 1, working age households with children are among the most likely to experience poverty at the end of life.

However, the current systems of free childcare across the UK, and the support for childcare costs within Universal Credit, are strongly weighted towards people who need support because they are working. Yet parents who are impacted by a terminal illness are not supported in this way.

Support with childcare could be vital lifeline for these families, and give both parents and children much-needed respite. If these families are ineligible for free childcare, or support with the cost of childcare, they will either be unable to benefit from this or have to find another way to meet the cost.

Recommendation

The Department for Work and Pensions should ensure working age parents with a terminal illness receive support for childcare costs even if they don't meet the work-related requirements.

Recommendation

The Department for Education and devolved administrations should extend entitlements to free childcare for working age parents with a terminal illness, even if they don't meet the work-related requirements.

Capital limits

Within means-tested benefits such as Universal Credit and Housing Benefit, there are strict limits on the capital someone can have. In most circumstances the first £6,000 is disregarded. A taper is applied between £6-£16.000 which reduces the award by £4.35 for every full or part £250. If someone has over £16,000 of capital, they cannot claim these benefits and are expected to draw on their savings instead.

The treatment of capital in Pension Credit, however, is much more lenient. The first £10,000 is disregarded, then every additional full or part £500 in savings is treated as £1 of income a week.[4] The table below shows the impact of this.

Table 11: Comparison of impact of capital on means-tested benefits for single claimants[5]

Amount of capital	Universal Credit Standard Allowance & Health Element		Pension Credit Guarantee Element & Additional Amount for Disability		Extra amount received by Pension Credit claimant
	Impact	Amount remaining	Impact	Amount remaining	
£5,000	No impact	£823	No impact	£1,343	£520
£10,000	-£70	£753	No impact	£1,343	£590
£15,000	-£157	£666	-£43	£1,300	£1,143
£20,000	Ineligible for any Universal Credit	-	-£87	£1,256	£1,256
£50,000	Ineligible for any Universal Credit	-	-£347	£996	£996

This significant difference exacerbates the disparity in initial amounts someone is eligible for. Someone aged 64 with a terminal illness and £50,000 of savings would receive no Universal Credit at all. Yet if that same person was two years older, they would still be entitled to hundreds of pounds a month in Pension Credit.

Recommendation

The Department for Work and Pensions should align the capital rules within Universal Credit for households containing someone with a terminal illness to those applying to Pension Credit.

2. If someone receives Pension Credit and Housing Benefit, only the Pension Credit treatment of capital is applied.
3. For ease of comparison, claimant is assumed to have no other income. Universal Credit claimant is over 25. Pension Credit amount converted from weekly to monthly.

Aside from the general treatment of capital, there is also no exemption for payments received from a life or critical illness insurance policy. This means that someone with a policy that pays out after a terminal diagnosis may have to use this money for basic living costs rather than to help meet extra costs. These could be funeral costs, paying for meaningful experiences at the end of life, or simply supporting their family after they've died.

The Universal Credit Regulations 2013 set out circumstances when capital can be disregarded for a period. These circumstances do not include a payment in relation to a terminal illness under a critical illness or life insurance policy. That means that if someone makes a claim under a life insurance policy and receives more than £6,000 (or the payout takes their capital to over that amount), their Universal Credit would be reduced. If the payout meant they had over £16,000 in capital, they would be entitled to no Universal Credit at all. That not only means someone's terminal illness denies them means-tested support from the government, but also that money would not be available for the dying person to pass on to their family after their death, or to help with funeral costs.

There is also precedent for disregarding payments made as a result of a health-related payment. Section 75 of the regulations disregards sums awarded or agreed in relation to personal injury for 12 months.[4] Extending this disregard to critical illness or life insurance payouts would provide much-needed comfort to people living with terminal illness and their families. This would provide a significant benefit to affected households, although we would expect it only to apply to a small number of people: they would need to have such an insurance policy and otherwise qualify for Universal Credit.

Recommendation

The Department for Work and Pensions should disregard life insurance or critical illness cover payouts received due a terminal diagnosis from calculations of a household's capital for Universal Credit, for a period of at least 12 months.

Conditionality in Universal Credit

Under the current Universal Credit system, someone who receives the Limited Capability for Work and Work-Related Activity element has no conditionality attached. This matters, because the other side of conditionality is the risk of a benefit sanction. This is a reduction in your benefits due to not meeting the requirements set by a JobCentre.

Currently, the conditionality group you are placed in depends on the outcome of a Work Capability Assessment. The Pathways to Work Green Paper proposes abolishing this assessment, but it is not clear what will replace it. The same Green Paper sets out an intention to move towards a system where most claimants, including those who receive additional money due to their health, have a 'baseline expectation of engagement' with the JobCentre.[xix]

This expectation is not appropriate for people qualifying for a disability-related benefit under the Special Rules for Terminal Illness, and any new system must guarantee that people in this category will not have any form of conditionality applied.

Another group that requires particular attention are people in the relatively early stages of a condition that is life-limiting and degenerative (see pen portrait below). An assessment of someone's health at a given point in time might conclude that they are currently able to take steps towards work. But it should also consider the likely trajectory of that condition. That trajectory

4. And potentially longer, depending on how the sum is then used.

affects the realistic likelihood of them actually returning to work – and therefore whether there is any point to requiring them to undertake work-related activity.

Pen portrait – Corticobasal degeneration

Corticobasal degeneration (CBD) is a rare condition caused by brain cells becoming damaged or dying. It causes gradually worsening problems with lots of daily activities, and the average life expectancy after symptoms start to appear is six to eight years.

Sathnam is in the early stages of CBD. He has some difficulties swallowing and speech, as well as fine motor tasks such as writing, and sometimes struggles with his balance and falls. He doesn't yet need any assistance with activities of daily living, but things often take him longer to do than they used to. These symptoms are not enough to score him enough points on the Work Capability Assessment to be placed in the Limited Capability for Work and Work-Related Activity (LCWRA) group – meaning he does not meet the Severe Conditions Criteria. He's also not expected to die in the next 12 months, so does not qualify under the Special Rules for End of Life.

Sathnam's condition is sadly only going to worsen. Yet until it does, he has to live on basic Universal Credit, and has to undertake activity that is supposed to move him closer to returning to work – something he is not realistically ever going to do. This is not only entirely unnecessary, but it puts him at risk of having his benefits reduced by a sanction.

This pen portrait is not a case study, but a realistic scenario based on Marie Curie's clinical expertise

This is a problem under the current system, and was unfortunately not addressed by the recent Universal Credit Act. With the Pathways to Work Green Paper setting out government's intention to scrap the Work Capability Assessment from 2028/29 there is an opportunity to design a system that properly takes the needs and circumstances of terminally ill people into account.

Recommendation

Assessments of whether someone should be subject to conditionality, including whatever system replaces the Work Capability Assessment, should consider the likely trajectory of their condition as well as their current function. People with degenerative terminal conditions should not be expected to prepare for work that they are not realistically going to return to.

The five week wait for Universal Credit

When someone first makes a claim to Universal Credit, the first payment is not paid until five weeks later (and then usually every month on that same day). This delay is widely recognised as causing hardship, and needs reform.[xx xxi xxii xxiii]

The Special Rules provide expedited access to the Health Element of Universal Credit. However, someone making a new and valid claim under the Special Rules must still wait five weeks for their first payment. This can cause financial hardship at the very moment someone is dealing with a recent terminal diagnosis. It could also cause potential debt, with someone taking out an advanced payment to help meet costs in that time.

Recommendation

People living with a terminal illness and making a new application for Universal Credit should not have to wait five weeks for the first payment. Government should provide a non-repayable grant, not a loan, for households in this situation.

Other benefits lacking a fast-track route

The Special Rules apply to 'extra costs' disability benefits, as well as Universal Credit. However, they do not apply to other benefits, such as Carer's Allowance, the Carer Element of Universal Credit, or the Additional Amount for Disability within Pension Credit. These benefits can take several weeks to process. This can cause financial hardship while waiting for the claim to be processed, and in some cases can be time that the dying person does not have.

Recommendation

Fast-track access should be provided for all benefits likely to be claimed by households including someone living with terminal illness, including carer benefits.

Localised support

The majority of financial support in the UK comes from national bodies like the Department for Work and Pensions or equivalents in the devolved nations. However, there are still important roles to play for more localised support schemes.

One key area in which local councils can take action is with council tax for working age households. In Scotland, Wales, and Northern Ireland these schemes are set centrally by devolved administrations. In England, they have been the responsibility of individual councils for over a decade. As a result of financial pressures on councils, many of these schemes have become less generous over time, with some minimum payments (the amount paid by a household someone with no earned income) as high as 50% of the full bill.

Council Tax is one of the larger household bills and enforcement can often escalate very quickly to bailiff action if arrears build up. Households in which someone has a terminal illness already face significant financial pressures and should be prioritised for support with council tax bills.

We were therefore delighted when earlier this year Manchester City Council became the first council in the country to implement specific, additional support for households in which someone has a terminal illness.

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.

We recognise the financial pressures that local councils are under, but the number of people who would benefit from this change, and so the additional cost to a council, are small in any given area. Manchester City Council shows that there are not insurmountable barriers to making these changes. There is no reason other councils cannot follow suit.

Action by individual councils is welcomed and important. Ultimately, there is no reason for someone's financial security at the end of life to be subject to where they live. We want to see national governments amend relevant legislation to guarantee

support for households including someone with a terminal illness.

Recommendation

The UK government, as well as devolved administrations, should ensure that people living with terminal illness are guaranteed support for council tax. Until that point, individual councils in England should consider how they can provide similar support in their area.

The Spending Review in summer 2025[xxiv] included the announcement of the Crisis and Resilience Fund, which will replace Discretionary Housing Payments (DHPs) and the Household Support Fund (HSF) from April 2026. This is intended to "provide preventative support to households as well as assist them when in crisis". Clearly, a terminal diagnosis can be a trigger for such a crisis. It is vital that the Fund's design and operation is suitable for people living with terminal conditions.

Recommendation

The forthcoming Crisis and Resilience Fund should specify that people with a terminal condition in financial difficulty are a priority group for support and there should be a fast-track route for applications from people in this situation.

A lack of support for energy costs

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. We support 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. They can take time to install, and/or for the financial benefits to be felt. That's time that people with a terminal illness do not have. Such measures can also be disruptive, which is not what someone resting at home needs.

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. The Motor Neurone Disease Association has found that in some cases, electricity costs can rise to £10,000 a year in the late stages of the condition.[xxv]

That means there is an unavoidable need for direct bill support to ensure people living with terminal illness can do so in comfort. Current support across the UK is fragmented and limited, even with the welcome widening of the Warm Homes Discount from winter 2025-26.

Table 12: Summary of direct support for energy costs

Scheme	Summary of criteria	Support	Nations covered
Warm Home Discount[xxvi]	Receive Pension Credit Guarantee Credit, or receive certain means-tested benefits	£150 a year taken off energy bill	GB (criteria differ in Scotland) – no comparable scheme in Northern Ireland
Winter Fuel Payment[xxvii]	Age and household income	£100-300 a year	UK (devolved in NI & Scotland)
Cold Weather Payment[xxviii]	Receipt of certain means-tested benefits, and temperatures over a seven day period	£25 per cold period	England, Wales, Northern Ireland
Winter Heating Payment (from winter 2025-26)[xxix]	Receipt of certain means-tested benefits, in most cases with a disability element	£59.75 a year	Scotland

None of these schemes are specifically targeted at people living with terminal illness, and the most valuable form of support, the Winter Fuel Payment, is restricted to people over pension age.

A social tariff

Taken together, the Warm Home Discount and the Winter Fuel Payment amount to only around a quarter of the energy price cap for an average household.[xxx] While this does help, it is clearly insufficient to make significant inroads into fuel poverty. A far more comprehensive approach is needed.

In our previous report, we estimated the number of people who could be lifted out of fuel poverty at the end of life if their energy bills were halved. This found that such a tariff could lift up to 42% of people out of fuel poverty at the end of life, and reduce the fuel poverty faced by the remaining 58%. These are upper limits for the proportion of households whose fuel poverty would be ended or reduced with such a scheme – as in practice, some households would respond to a reduction in energy costs by using more energy (that currently they might be avoiding using due to the cost). This would still, mean they were in a better position than today, even if they remain in fuel poverty. They would be living in greater comfort, be more able to run medical devices that improve their quality of life or simply have less worry about their energy bills.

Even with a large direct reduction in energy costs faced by households at the end of life, there would still be large numbers of households in fuel poverty. These are households in more difficult financial circumstances to start with.

Other ways of providing direct bill support could have advantages over a simple proportional bill reduction, as set out in a recent report by Public First.[xxxi] Whatever approach is chosen, it is crucial that it provides far more substantial support for eligible households than current schemes and is available to people living with terminal illness.

Recommendation

The Department for Energy Security and Net Zero should introduce a social tariff for energy, or equivalent direct bill support. It 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.

Recommendation

At least until a social tariff is introduced, UK and national governments should ensure that people with a terminal illness are able to access existing schemes to help with the cost of energy. This should include exploring ways to provide people in Northern Ireland with an equivalent to the Warm Home Discount.

Recommendation

The Winter Fuel Payment and equivalents should be available to anyone with a terminal illness, regardless of age.

Medical devices

Another significant gap in the 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 research has 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.[xxxii]

Struggling to pay these costs can have a significant impact. In some cases, people living with terminal illness could 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 care preferences simply due to cost. People might avoid using the devices to the extent they should, risking their safety, comfort, or dignity.

Recommendation

The Department of Health should ensure that there is a single, simple and comprehensive, scheme providing upfront support with the running costs of medical devices provided by the NHS.

Louise's story

Harry was 18 years old in the middle of his apprenticeship, doing really well. His manager took him out for a meal one night with a few of the other apprentices. He came back really drunk, and then he just had the hangover from hell. The next day, he was a little better, then on the Monday he woke up with a severe headache and then started having a seizure so we called an ambulance.

He went to theatre that night and they saved his life. He was minutes from death. He was on intensive care and had an MRI, and that's when they found he had these two glioblastomas. He had radiotherapy, he had chemotherapy. They stopped his chemotherapy on the second round because there was a third tumour growing. He was referred to the hospice and we have hospice at home, and that's where we are still, three-and-a-half years on. Caring for Harry is 24/7. He has seizures a lot now. Harry can never be left alone, so me or my husband have to be with him at all times. It's a lot for all of us, my daughter included. She is the only one working, bless her.

I stopped working when Harry was diagnosed. My NHS pension is not brilliant after 36 years, I've got to say, but it's an income. My husband was working from home at the time because it was covid. He worked in the public sector and they wanted him back in the office. As well as seizures, Harry experiences personality changes and has very poor short-term memory, so my husband asked if he could stay working from home. They were not in agreeance with that, so he ended up taking severance pay. That's what we're living off.

We don't get benefits because I'm retired. My husband was on ESA for six months but then it all stops, so we get the Carer's Allowance, that's it. Harry gets PIP, so that paid for his wheelchair and stuff, and he pays us 'keep', as he calls it. You feel awful taking it off of him, but that helps us look after him. The severance money is literally paying the mortgage, and then my money has dipped right down as well.

He gets full PIP. The teenage cancer unit were brilliant, they did all that for us. They also got his disability badge. They are phenomenal. But yeah, cost of living and stuff, it's just tough. Obviously Harry has to be taken to appointments. This is where, if we were employed, it wouldn't have worked. He can't go on his own, he has to have us with him. The Carer's Allowance is appalling. It's really awful. They say you can go to work and earn up to £196 a week – they need to come here and see that I can't work. Neither can my husband. We do this full time, without a break. Harry's employers have sickness insurance and so they have paid him. It's not a lot, and they will take that off of his ESA. That insurance stops this month because that only goes for three years.

Harry worries about us financially. I don't care about money at the moment, because my time is with Harry and that's the most important thing. If I have to beg, borrow or steal, or remortgage the house or whatever, I'll do that. We just live day to day. My husband has golf and I do cold water swimming for my mental health – that's all we do. That doesn't cost a lot.

At the moment we struggle. We're very careful with what we spend, but we are lucky enough that we are surviving. I don't know how other people do it, I really don't. Single parents and stuff – I sit there and think, "Gosh, if I was on my own, I don't know how I would do it."

Conclusion and recommendations

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.

While there is no single solution, there are key areas that matter, and practical steps governments across the UK 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 UK in which people with a terminal illness can live their final months, weeks, and days in financial security, focused on making memories, not on making ends meet.

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

Recommendations in this report

Improving understanding

Recommendation: National governments must take action to understand and address the wider inequalities that persist into the last year of life among people from minoritised ethnic communities, as well as specific barriers to accessing available support after a terminal diagnosis.

Improving national benefits systems

Recommendation: The Department for Work and Pensions should expand eligibility

for the Severe Conditions Criteria in Universal Credit to include someone with a life-limiting, progressive condition who currently meets the criteria for Limited Capability for Work.

Recommendation: The Department for Work and Pensions should review whether introducing the definition of terminal illness used by Social Security Scotland would provide greater certainty and security for people living with terminal illness in the rest of the UK.

Recommendation: People of working age living with a terminal illness should be guaranteed a State Pension-level of income. As part of this, the Pensions Commission should explore how access to the State Pension could be provided to people of working age who are living with a terminal illness.

Recommendation: The Department for Work and Pensions should introduce a new 'self-care element' in Universal Credit, for households with care needs for whom no-one is claiming Carers' Allowance or the Universal Credit Carers' Element.

Recommendation: The Department for Work and Pensions should continue to promote the uptake of Pension Credit among eligible households.

Recommendation: The government should review its guidance on granting access to public funds to ensure it clearly covers people diagnosed with a terminal illness. It should also work with healthcare and administrative professionals to ensure rights to medical and palliative care for people with No Recourse to Public Funds are understood and upheld.

Recommendation: The Department for Work and Pensions should explore ways to provide additional support for housing costs for people with a terminal illness living in privately rented properties above the Local Housing Allowance. This could be, for example, by raising the cap from the 30th to the 50th percentile.

Recommendation: Working age people living with a terminal illness should be able to apply for Support for Mortgage Interest at the same time they start to receive Universal Credit.

Recommendation: The Department for Work and Pensions should ensure working age parents with a terminal illness receive support for childcare costs even if they don't meet the work-related requirements.

Recommendation: The Department for Education and devolved administrations should extend entitlements to free childcare for working age parents with a terminal illness, even if they don't meet the work-related requirements.

Recommendation: The Department for Work and Pensions should align the capital rules within Universal Credit for households containing someone with a terminal illness to those applying to Pension Credit.

Recommendation: The Department for Work and Pensions should disregard life insurance or critical illness cover payouts received due a terminal diagnosis from calculations of a household's capital for Universal Credit, for a period of at least 12 months.

Recommendation: Assessments of whether someone should be subject to conditionality, including whatever system replaces the Work Capability Assessment, should consider the likely trajectory of their condition as well as their current function. People with degenerative terminal conditions should not be expected to prepare for work that they are not realistically going to return to.

Recommendation: People living with a terminal illness and making a new application for Universal Credit should not have to wait five weeks for the first payment. Government should provide a non-repayable grant, not a loan, for households in this situation.

Recommendation: Fast-track access should be provided for all benefits likely to be claimed by households including someone living with terminal illness, including carer benefits.

Improving local support

Recommendation: The UK government, as well as devolved administrations, should ensure that people living with terminal illness are guaranteed support for council tax. Until that point, individual councils in England should consider how they can provide similar support in their area.

Recommendation: The forthcoming Crisis and Resilience Fund should specify that people with a terminal condition in financial difficulty are a priority group for support, and there should be a fast-track route for applications from people in this situation.

Support for energy costs

Recommendation: The Department for Energy Security and Net Zero 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.

Recommendation: At least until a social tariff is introduced, UK and national governments should ensure that people with a terminal illness are able to access existing schemes to help with the cost of energy. This should include exploring ways to provide people in Northern Ireland with an equivalent to the Warm Home Discount.

Recommendation: The Winter Fuel Payment and equivalents should be available to anyone with a terminal illness, regardless of age.

Recommendation: The Department of Health should ensure that there is a single, simple and comprehensive, scheme providing upfront support with the running costs of medical devices provided by the NHS.

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