Marie Curie

Dying in Poverty 2024

Exploring poverty and fuel poverty at the end of life in the UK

Contents

Foreword

Nobody should die in poverty.

The last months, weeks and days of someone's life should be a time to focus on what really matters: making memories with family and friends and living as well as you possibly can.

But too often financial pressures add unnecessary worry, uncertainty and strain to what is already a difficult time. Loss of income and rising costs create instability at a time of life when security is vital.

In our previous report, we found that 93,000 people a year died in poverty. Today, that number has risen to 111,000. That's more than 300 people every day.

Of course, this highlights the persistence of poverty across the UK – which in turn reflects the erosion of the social security system that should be there to support us all when we need it. But in every analysis conducted as part of this report, rates of poverty among people at the end of life were greater than the rest of the population.

Poverty affects some groups much more than others. Women are more likely to die in poverty than men, and people from minoritised ethnic groups are more likely to die in poverty than white people. Some parts of the UK have many more people dying in poverty than others. We also know that people of working age are more likely to die in poverty than people of retirement age.

That's why we are calling on the UK Government to guarantee a pension-level income to people living with a terminal illness who are of working age. This is important today, but our analysis also shows that without change, even more people will die in poverty as planned increases to the State Pension Age go ahead.

We also know that energy costs can increase dramatically for someone living with a terminal illness. This forces households to either cut back on other essentials in order to pay their bills, or see adverse impacts on their quality of life and health due to a cost they simply can't meet.

For the first time, our analysis has looked at how many people die not just in poverty, but in fuel poverty. These people are forced to spend a large amount of their income on energy and are left with less than the minimum needed to live a dignified life.

At least 128,000 people died in fuel poverty in 2022. Each one of those is one person who died struggling to heat their homes or run vital medical equipment. We are calling for a social tariff that will cut the costs of energy bills faced by people at the end of life, as well as better and more consistent rebate schemes to cover the cost of using medical devices at home.

Poverty is deeply ingrained in the United Kingdom, and it will not end overnight. The recommendations we make in this report are the vital first steps towards ensuring everyone can live with dignity to the very end of their lives, not die in poverty.

We at Marie Curie look forward to working with local authorities, devolved governments and the UK Government to make this happen.

Matthew Reed
Chief Executive, Marie Curie
November 2024

Key facts

More than **300 people die in poverty every day** – 111,000 per year.

A social tariff could prevent up to **54,000** people dying in fuel poverty.

Women are more likely to die in poverty than men.

110,000

people over 65 **die in fuel poverty** every year.

47%

of **Black people** who die while still of working age **face poverty at the end of life**.

If planned rises to the State Pension Age go ahead, over **15,000 people** a year **will die before accessing the State Pension**.

Fuel poverty in the last year of life is most common in **London**, the **North East of England** and **Northern Ireland**.

Executive summary

IN 2023, 111,000 people died in poverty. That's more than one in six people spending their last months, weeks and days on an income below the poverty line.

This report updates the analysis conducted for Marie Curie's 2022 report *Dying in Poverty*, looking at who dies in poverty and the pathways that lead them there. For the first time, however, it also includes analysis of who dies in fuel poverty.

Some people who die in poverty are in poverty before the last year of their life. Across the UK, one in five people are in poverty at any one time, in part because of the inadequacies of the social security system. But the combination of loss of income and higher costs that often accompany a terminal illness raises the risk of poverty for people at the end of their life, even for families who were previously comfortable. Across every breakdown, whether age, ethnicity, sex or location, people in the last year of their life are at higher risk of poverty than the people not in the last year of life.

One especially stark dividing line is age. A key reason for this is that the State Pension and other pensioner benefits are normally paid at a significantly higher rate than the equivalent financial support for people of working age. Research conducted by Marie Curie suggests that without change, planned increases to the State Pension Age will mean thousands more people will die before receiving the State Pension, and more will die in poverty every year.

Guaranteeing working-age people with less than a year to live a pension-level entitlement to financial support would make a big difference to families facing this situation, without imposing a large cost to the government. In fact, it would cost just 0.1% of current spending on the State Pension.[1]

The analysis also highlights alarming differences between other demographic groups. People from minoritised ethnic groups are more likely than white people to die in poverty, and among these groups 47% of working-age Black people die in poverty.

Women are at greater risk of dying in poverty than men – a gap that has increased for working-age women since our previous report.

The analysis also calls attention to stark differences between local authorities and regions, with people in some local authorities being almost three times as likely to die in poverty as in others.

Fuel poverty is particularly acute at the end of life, and terminal illness can lead to much higher energy usage – sometimes running into thousands of extra pounds every year. This combination of low-income, high-energy prices and high energy needs leads to up to 128,000 people dying in fuel poverty, with 110,000 being aged 65 and over.

Introducing a social tariff that halves energy bills could lift 54,000 people out of fuel poverty at the end of life and reduce the fuel poverty faced by 74,000 more. It is the single step that would do the most to alleviate fuel poverty among people at the end of life.

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 the one used in Scotland, which considers both spend on energy and income after energy costs have been met.

The report also includes estimates of additional deaths before State Pension Age, if planned increases go ahead. This analysis was carried out by Marie Curie's quantitative research team, and uses data from national statistics agencies.

Introduction

EVERY year in the UK, more than 14 million people – over one in five of us – experience poverty.[2]

Poverty is often seen as just a matter of financial resources, but it also has a clear link to health. This link runs in both directions. 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 ultimately have lower overall life and healthy life expectancy.

Ill health can also drive poverty. People living with a disability or a long-term health condition (including terminal illnesses) are less likely to be in paid work,[3] or if they are, they're likely to be paid less.[4]

Unfortunately, this relationship between poverty and health persists even at the end of life. Terminal illness can cause a significant reduction to a household's income. For example, if the person living with a terminal illness or another household member need to reduce or stop working due to health or caring responsibilities. At the same time, it can also have significant impacts on expenditure, with costs like energy, transport and childcare often increasing dramatically. We also know that poverty at the end of life doesn't only affect the dying person – it affects unpaid carers as well. Marie Curie has commissioned research into the financial and employment impacts of caring for someone at the end of their life, and the interim findings show that poverty rates among carers increase after the cared-for person's death.[5]

The impact of poverty is 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 people with a disability, and social and private renters.[6]

Background to this report

In 2021, Marie Curie commissioned the Centre for Research in Social Policy at Loughborough University to examine the number and proportion of people who die in poverty in the UK, how this varies for different groups, and the "pathways" into poverty at the end of life. This led to Marie Curie's landmark report, *Dying in Poverty*, in 2022, which set out the findings and made a series of policy recommendations.[7]

This report is based on further analysis from the Centre for Research in Social Policy, which builds on the evidence from *Dying in Poverty* in two ways. Firstly, it provides an update to the analysis of poverty using figures from 2023, after nearly two years of high inflation.

Secondly, it provides, for the first time, estimates of fuel poverty experienced by people at the end of life. Previous research has found that energy costs can rise significantly at the end of life due to factors such as the need to power medical equipment or store medicines safely, increased time spent at home and corresponding higher fuel usage, and increased need to maintain a particular body temperature caused by some terminal conditions.

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 (BHC or AHC). 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 some 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 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[8] that it was developing the "Below Average Resources" statistics as "Official Statistics in Development" to provide a new additional measure of poverty based on the approach proposed by the Social Metrics Commission.

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's the most comprehensive definition currently available, and the most evidence-based way to account for the additional costs of disability and ill-health on a person's financial situation, and therefore their risk of experiencing poverty.

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 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 Understanding Society, which uses the categories in the census.

Sex

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

Gillian and Una's story

GILLIAN is 50 and lives in Scotland. She works as a nursing assistant and has three children and six grandchildren.

"My mum Una was diagnosed with lung cancer in September 2020. She passed away in January 2021 at 65 years old. My mum was a care worker working 14-hour shifts. By the time she got her diagnosis, she was already well progressed and becoming less able to work. She had been sent home from work a number of times due to not being fit enough to work. Without the diagnosis, they didn't know what was wrong with her.

"She went from having a full-time wage to having half her pay. She still had her rent, council tax and bills to pay. I had moved in with her because I was working 12-hour shifts, so it was easier for me to move in with her to care for her while I was still working. She didn't like to admit to me that she didn't have money for food, but I went to do a shop for her one day and she had to tell me she didn't have the money to pay for it.

"Mum felt the cold quicker than other people because of her cancer. I noticed very quickly when I moved in that the house was a lot colder than it should have been. I would find her sitting in her pyjamas, a house coat and a blanket, worrying about putting her heating on because of the cost. I would tell her it was important for her health to keep the heating on to stay warm, but I soon realised it was off due to the cost.

"Her finances did eventually end up getting sorted out, but by the time the money came in, it was only a few weeks before she died. She wasn't fit or healthy enough to benefit from it. Her consultant had given us

Gillian (right) and her mum, Una (left)

a form, which was supposed to fast track her benefits. It took me a long time to get the form filled in because it was so complex, and I was trying to care for her and work all at the same time. It put such a strain on my mum that she really didn't need at the time.

"The last thing that anyone needs when they know they're dying is to be worrying about financial issues. People shouldn't have to cope with that on top of everything that they're already going through. If mum could have had access to her state pension before she died it would have helped. She'd worked her whole life, paid her taxes, and she was never able to benefit from that. I think people with terminal illness should be able to have early access to the state pension at a time when they need it most."

1. Who dies in poverty?

IN 2023, the latest year for which data is available, an estimated 111,000 people died in poverty in the UK. This represents 18% of all people who died in that year. Compared to 2019, this is an increase of almost 20,000 people every year, and an increase in the dying in poverty rate of 2.5 percentage points since 2019.

This headline figure is striking and shocking, but it masks some important differences between the risk of experiencing poverty at the end of life between different groups.

Differences by age

The analysis shows that working-age people are at a much greater risk of dying in poverty: 28% of these people who died in 2023 died in poverty, compared to 16% of pension-age people. The risk of being in poverty at the end of life has increased since 2019 for both groups, but has increased by more for people of pension age. It's not clear what has driven this increase, although potential factors could include greater numbers of people renting into retirement.

While the total number of pensioners who die in poverty is greater than the number of working-age adults who die in poverty, the greater proportion of working-age people dying in poverty demonstrates the need for particular action in this area.

Additionally, being in the last year of life if you are of working age has a bigger impact on your risk of being in poverty than if you are of pension age. For people of working age, the risk of being in poverty rises by 6.1 percentage points if you are in the last year of life, while for pension-age people the rise is smaller (3 percentage points).

These differences are likely to be driven by several factors. One is simply the greater poverty rate across the working-age population (21.8%) compared to those

Table 1: Poverty rates in the last year of life by age

	Poverty rate in the last year of life	Poverty rate among people not in the last year of life	Percentage increase in risk in last year of life
Working age	27.9%	21.8%	+28%
Pension age	16.1%	13.1%	+23%

aged 65+ (13.2%). This is reflected in the fact that the vast majority of people aged of working age who die have experienced poverty at some point in the five years before their death.

Another factor is loss of income. People living with terminal conditions often report loss of income, through reduced hours or needing to leave work altogether. This effect might not only be felt by the person living with a terminal illness, but also by others in their household if they have to take on caring responsibilities and reduce or give up their own work. This is more likely to affect working-age people than pension-age people, and the combination of exiting the labour market and being diagnosed with a new health condition greatly increases the risk of moving into poverty – higher even than people who were already out of the labour market. There was an even stronger association between people who exit the labour market and are diagnosed with a new health condition, which further suggests that needing to leave work because of a terminal condition may be an important driver of poverty at the end of life.

Differences in the availability of support through the social security system for people of working and pension age are also likely to play a part. We look further at this in Chapter 2.

Finally, the cost of childcare is more likely to affect people of working age than of pension age, due the greater likelihood of working-age people being primary carers for children. We discuss issues around childcare later in this chapter.

Differences by ethnicity

People from minoritised ethnic groups are more likely to be in poverty throughout their lives. This reflects disadvantages in wider society, including education,[9] healthcare,[10] and employment.[11] For some particular groups, these figures are extremely high – poverty rates among Bangladeshi households, for example, are estimated to be as high as 53%.[12] 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.[13]

Given this starting point, it's therefore 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's a clearly disproportionate impact: 25% of working-age white people aged between 20-64 who died did so in poverty, compared to a shocking 47% of Black people, 43% of Asian people and 37% of people who are mixed race or have another ethnicity.

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

Table 2: Poverty rates in the last year of life by ethnicity among working-age people

		Poverty rate in the last year of life	Poverty rate among people not in the last year of life	Percentage change in risk in last year of life
Working-age	White	25.2%	19.8%	+27%
	Black	47%	39.1%	+20%
	Asian	42.8%	35.4%	+21%
	Mixed/other	37.2%	30.5%%	+22%
Pension-age	White	15.5%	11.8%	+31%
	Black	31.5%	26.4%	+19%
	Asian	27.1%	22.7%	+19%
	Mixed/other	27.2%	22.3%	+22%

Partly because of the higher underlying prevalence of poverty among minoritised ethnic groups, their overall poverty rates changed less in the last year of life – there are simply fewer non-poor households to become poor due to a terminal condition. It is, however, very possible that households that are already in poverty prior to the last year of their life become poorer.

Recommendation

The UK and devolved governments should collect and publish data and indicators on the employment, income and wealth inequalities experienced by people from minoritised ethnic groups, as well as the impact this has on poverty at the end of life. They should then take steps to address those gaps.

Differences by sex

Women are more likely than men to die in poverty. In 2023, 29.5% of working-age women who died did so in poverty, compared to 25.4% of men. This represents a change compared to 2019. Since then, women of this age have become more likely to die in poverty, whereas men have become slightly less likely to. The increase in the relative risk of being in poverty at the end of life is also greater for women than it is for men.

There are likely many reasons underlying this difference. Women's lifetime earnings are less than two-thirds of men's,[14] which reflects a combination of women being less likely to be in employment, and that they are likely to work fewer hours and earn less per hour if they are. Women are also less likely to have savings than men[15] – which combined with lower income, means they are more likely to rely on social security. They are also more likely to have responsibility for childcare, which can limit earnings and progression, and adds an "inescapable cost". Another potential explanation, particularly for pension-age women, is their increased life expectancy compared to men, which in part drives their greater likelihood to live alone.[16]

Table 3: Poverty rates in the last year of life by sex

		Poverty rate in the last year of life	Poverty rate among people not in the last year of life	Percentage increase in risk in last year of life
Working-age	Men	25.4%	21%	+21%
	Women	29.5%	22.5%	+31%
Pension-age	Men	14.5%	12.6%	+15%
	Women	17.5%	14.4%	+22%

It's less clear what has driven the more recent change since our last report, but one possibility is the greater reliance on the social security system among women.[17] Although benefits were uprated in line with inflation between 2019-2023, this comes with a lag, and earnings growth was high over the same period.

A similar disparity exists among pension-age people, although the poverty rates are lower. This is likely to be a combination of private savings and the remaining 'State Pension gap' between men and women.[18]

Recommendation

The UK and devolved governments should collect and publish data and indicators on the employment, income and wealth inequalities between men and women, as well as the impact this has on poverty at the end of life. They should then take steps to address those gaps.

Families with dependent children

Working-age families with children are particularly vulnerable to moving into poverty after a diagnosis of terminal illness because of childcare costs and the impact of one or both parents potentially having to leave work. The impact of sliding into poverty on these families not only affects the person at the end of their life, but leaves their children experiencing poverty at the beginning of theirs.

Childcare is an inescapable cost for most working parents, who have to find a way to meet the costs of paid help to look after their children, even if they are living with a terminal illness. Childcare costs in the UK are high compared to other countries, with some couples spending up to a quarter of their wages on childcare on average.[19] More information about childcare policies is set out in Chapter 2.

Given these costs, it's not surprising that families with children are at particular risk of poverty as they approach the end of life. Fewer than half of households with children are not in poverty at any point in the last five years of their lives. This makes them the second-greatest family type at risk of experiencing poverty at this time, after working-age single households.

Families with children are also the most likely family type to enter poverty for the two years before a member living with a terminal illness dies, having not been in poverty previously. This could be due

Table 4: Risk of being in each poverty trajectory group by key characteristics, adjusted for sex

Family Type	Poverty trajectory in the last five years of life			
	Never in poverty	Mostly in poverty	Moving into poverty	Moving in and out of poverty
Working-age single	37.3%	33.6%	9.5%	19.6%
Working-age couple	64.4%	17.4%	4.5%	13.7%
Working-age households with children	41.3%	23.9%	12.9%	22%
Pensioner single	72.2%	7.2%	6.9%	13.7%
Pensioner couple	78.1%	7.8%	5.2%	8.9%

to a combination of the reduced income following a terminal diagnosis, higher costs associated with children and the unavailability of the full 30-hour entitlement for younger children that working families receive.

Women are also more likely to have dependent children than men, making up the majority of lone-parent families in 2023. There are 2.7 million lone-parent families headed by women (85% of all such families), compared to 477,000 (15%) headed by men.[20] We also know that lone-mother families tend to have lower savings and be more in debt than dual couple households with children. They have also seen the fastest rise in poverty, with 40% of working-age single parents now in poverty.[21]

Differences by geography

Populations across the UK are not the same and nor are poverty rates. So, it's not surprising that rates of poverty at the end of life are also not equal.

Among working-age people, poverty rates in the North East in the last year of life were 34% – a full 50% higher than the areas with the lowest rates of end of life poverty. For pension-age people, Yorkshire and the Humber had the highest poverty rates at the end of life at 22.8%, nearly three quarters higher than the lowest region.

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 20 local authorities with the highest percentages of working-age and pension-age people dying in poverty. In the previous report, local authorities in London dominated the list of areas in which the higher proportion of people died in poverty, but in this report, the North East and North West now fare worse, representing half of the top twenty areas. Among pensioners, Yorkshire and the Humber and the North West of England have the highest rates, again reflecting wider regional differences.

We look more closely at the financial support available from national governments and local authorities in Chapter 2, and at local government responsibilities around fuel poverty in Chapter 3.

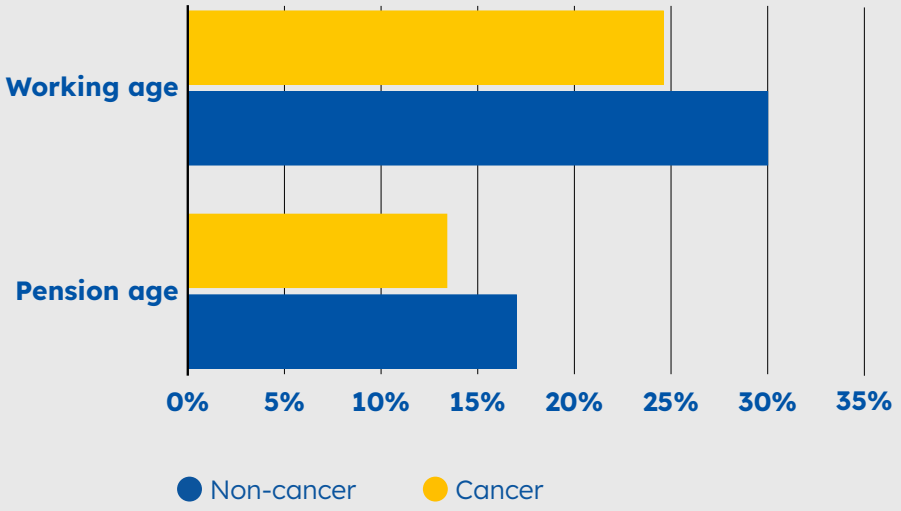
Table 5: Top 20 local authorities with the highest percentage of working-age people dying in 2023 who were in poverty

Local Authority	Region	% in poverty among those who died
Middlesbrough	North East	44.5%
Manchester	North West	42.3%
Birmingham	West Midlands	39.9%
Blackburn with Darwen	North West	39.1%
Newcastle upon Tyne	North East	39.1%
Leicester	East Midlands	38.4%
Hartlepool	North East	37.6%
Tower Hamlets	London	37.5%
Liverpool	North West	37.3%
Sandwell	West Midlands	37.2%
Blackpool	North West	36.8%
South Tyneside	North East	36.6%
Wolverhampton	West Midlands	36.5%
Salford	North West	35.6%
Kingston upon Hull, City of	Yorkshire and The Humber	35.4%
Bradford	Yorkshire and The Humber	35.3%
Luton	East of England	35.2%
Nottingham	East Midlands	35.1%
Blaenau Gwent	Wales	35.1%
Sunderland	North East	34.9%

Table 6: Top 20 local authorities with the highest percentage of pensioners dying in 2023 who were in poverty

Local Authority	Region	% in poverty among those who died
Manchester	North West	29.7%
Tower Hamlets	London	29.6%
Kingston upon Hull, City of	Yorkshire and The Humber	29.0%
Bradford	Yorkshire and The Humber	28.9%
Leicester	East Midlands	27.4%
Blackburn with Darwen	North West	26.9%
Newham	London	26.8%
Liverpool	North West	25.2%
Birmingham	West Midlands	25.2%
Blackpool	North West	24.8%
City of London	London	24.7%
Luton	East of England	24.6%
Nottingham	East Midlands	24.4%
Middlesbrough	North East	24.2%
Slough	South East	24.2%
Hackney	London	24.2%
Sheffield	Yorkshire and The Humber	24.0%
Brent	London	24.0%
Salford	North West	23.8%
Barking and Dagenham	London	23.6%

Figure 1: Rates of poverty in the last year of life by diagnosis



Differences in diagnosis

As in our previous report, people in the last year of their life with a cancer diagnosis had lower rates of poverty than people living with other conditions (including respiratory or heart conditions, or other conditions like motor neurone disease). For working-age people, this gap has reduced since 2019, but widened for pension-age people.

This disparity 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, if these differences were reflected in access to financial support or advice services. No matter what someone's diagnosis may be, financial security at the end of life is essential if they are to live as well as possible for as long as possible. So, this disparity between conditions is highly concerning.

Recommendation

Governments should ensure better access to information, support and advice on financial support for people living with non-malignant terminal conditions.

Poverty-proofing palliative and end of life care

Much of the action needed to end poverty at the end of life requires national and local policy change, but this doesn't mean that providers of palliative and end of life care, such as hospices, are powerless to mitigate the impact of poverty.

What is palliative and end of life care?

Palliative care offers physical, emotional, psychological and practical support to people with any illness they're likely to die from, including symptom management. It can be offered at any point after a terminal diagnosis.

End of life care is part of palliative care. It is treatment, care and support for people who are thought to be in the last year of life, though some people may receive end of life care for longer, or only in their last weeks or days.

How hospice and end of life care staff can help address poverty

In 2024, Marie Curie commissioned Children North East to undertake a project looking at how to "poverty-proof" hospice provision and ensure it is appropriate and accessible to people regardless of their financial situation.

To do this, Children North East conducted a series of interviews with patients, staff and people in the local community of Marie Curie's hospice in Bradford. They used the insights from this to identify a series of potential barriers and what action can be taken.

Together, Marie Curie and Children North East have produced a workforce guide designed to provide practical steps for people and organisations providing palliative care in order to reduce the impact of poverty.

The full report is available on Marie Curie's website.[22] The common barriers identified in the report are:

1. communication
2. navigating and negotiating appointments
3. housing challenges
4. health-related costs
5. patient empowerment
6. travel
7. staff awareness and guidance.

Different settings will face different combinations of challenges, but the key recommendations to consider are:

1. **Talk about poverty.** Open up conversations universally and routinely as part of patient care.
2. **Be accessible in communities.** Become more visible in communities to make hospice services accessible and attractive to everyone.
3. **Hospice Care at Home.** Ensure that the impact of poverty on people's homes is considered, not just on their interactions with a hospice.
4. **Be open and upfront about the additional costs of healthcare.** Many people are unaware of extra costs that can crop up, so doing more to proactively educate on this subject can help with budgeting and ease financial burden.
5. **Know how to help through money advice and signposting.** Consider what form of a "one-stop shop" for money advice and support could be right for your organisation.
6. **Ask and listen.** One of the most important things that a service can do is actively and directly ask patients what works for them and what they need.

2. Financial support at the end of life

SOMEONE'S financial situation at the end of their life directly affects their likelihood of being in poverty. These resources could be earnings, benefits payments or income from other sources like income protection schemes.

The Department for Work and Pensions sets benefits policy for England and Wales, and sets policy for the State Pension and means-tested benefits for Great Britain. Responsibility for Scottish disability benefits is being gradually devolved to the Scottish Government.

Benefits policy is almost fully devolved to the Northern Ireland Executive, although in practice the Executive operates on a "principle of parity" with Westminster, whereby people in Northern Ireland pay the same rate of Income Tax and National Insurance contributions as those in Great Britain, and therefore are entitled to the same benefits at the same rates.[23]

While specific processes and expedited access routes to benefits for people living with terminal illness are welcome, the current lack of information sharing across departments creates a risk that support does not reach everyone it needs to. GP surgeries, for example, keep Supportive

Recommendation

The UK government, alongside devolved and local governments, should establish a joint action plan to end poverty and fuel poverty at the end of life across the UK. This should be taken forward alongside the policy changes set out in this report, and include measures to improve the identification, recording and sharing of information about people living with terminal conditions, both in the last 12 months of life and with longer prognoses.

and Palliative Care Registers, but these are not used by other departments to identify people who might be eligible for PIP under the Special Rules, or for extra support during the Universal Credit migration process. This places the onus on the dying person or their family to repeatedly inform different organisations of their condition, which in turn raises the risk of people falling through the cracks.

Means-tested, working-age benefits

As set out in Chapter 1, people who die when they are of working age are at greater risk of dying in poverty than pension-aged people. This makes the operation of the working-age benefit system particularly important, as it's the final safety net protecting people from destitution.

For working-age people on a low income, the main benefit is Universal Credit, which is designed and administered by the Department for Work and Pensions (DWP). This has replaced six "legacy benefits" for new claims and is means-tested based on household income and savings. People with recent National Insurance Contributions can also claim contributory or "new-style" Employment and Support Allowance or Jobseekers' Allowance.

People claiming Universal Credit with less than a year to live automatically receive an extra amount called the Limited Capability for Work-Related Activity (LCWRA) element, under the Special Rules for End of Life (SREL). People living with a terminal illness who are expected to live longer than this will need to undergo a Work Capability Assessment, and might need to look for work or undertake work-related activity, or risk having their benefits reduced through a sanction.

However, for many seriously ill people, including people at the end of life, Universal Credit can provide far less support than Employment and Support Allowance (ESA). This is because additional "premiums" in ESA do not exist in Universal Credit. In particular, the Severe Disability Premium, paid to people with a serious illness or disability if no-one claims Carer's Allowance for caring for them, does not exist within Universal Credit. In Employment and Support Allowance, this is worth £81.50 a week for a single person or £163 a week for a couple if both qualify.[24] This affects new Universal Credit claimants, and many current ESA claimants who move under managed migration will be worse off over time as their Transitional Protection erodes.[25]

Recommendation

The Department for Work and Pensions and the Department for Communities 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.

Universal Credit has strict rules around how capital affects a Universal Credit award, or entitlement altogether. Any eligible capital over £6,000 affects an award, and if someone has more than £16,000 of capital, they are not entitled to Universal Credit at all. These values (originally introduced for predecessor benefits) have not changed since the 1992 Social Security Administration Act.

The Universal Credit Regulations 2013 set out some circumstances in which capital can be disregarded for a period. These circumstances do not, however, 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, and 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 terminally ill person to pass on to their family after their death, or to help with funeral costs.

There is 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.* Extending this disregard to critical illness or life insurance payouts would provide much-needed comfort to terminally ill people and their families. This would provide a significant benefit, 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 and the Department for Communities should amend Universal Credit capital regulations to disregard payments received under a critical illness or life insurance policy for a period of at least 12 months.

There are still several hundred thousand people receiving legacy benefits who are due to move to Universal Credit over the course of 2024 and 2025. The Department for Work and Pensions is moving recipients of these benefits to Universal Credit by the end of 2025,[26] in a process called "managed migration". Claimants are sent a migration notice, which gives a three-month deadline to make a claim to Universal Credit. The National Audit Office found that over a fifth of households receiving legacy benefits who received a migration notice had not claimed Universal Credit but nonetheless had their benefits stopped.[27]

We are concerned about the pace of these plans, including for vulnerable groups such as people living with a terminal condition. People living with a terminal illness are a "deferred group", meaning that where the Department is aware of this, the claimant should not be transferred until "[a] process is designed to include them, if that is appropriate in their circumstances",[28] but we're concerned that the speeding up of issuing migration notices across 2024 and 2025 will risk people living with a terminal illness being left without the money they need to live on in the last period of their life. This is a particular concern for claimants with a terminal illness receiving Child Tax Credits, as the government's current position is that Tax Credits will stop in April 2025. If someone has not been able to make a claim for Universal Credit by this point because they are dealing with the challenges of parenthood and a terminal illness, as it stands their Tax Credits will nonetheless be stopped.

Additionally, the Department may not know which claimants have a terminal illness – risking leaving people who are unable to engage with the process having their benefits stopped altogether, or having to go through a series of bureaucratic hoops to maintain their entitlement at a point when they should be focusing on what really matters.

Recommendation

DWP should work with HMRC to put contingency plans in place to ensure people are able to continue to receive Tax Credits beyond April 2025 where they have genuinely been unable to make a claim to Universal Credit, for example due to terminal illness.

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

Recommendation

DWP should postpone the migration to Universal Credit for anyone it knows is living with a terminal illness – for example, because they have successfully applied for ESA or PIP under the Special Rules for End of Life.

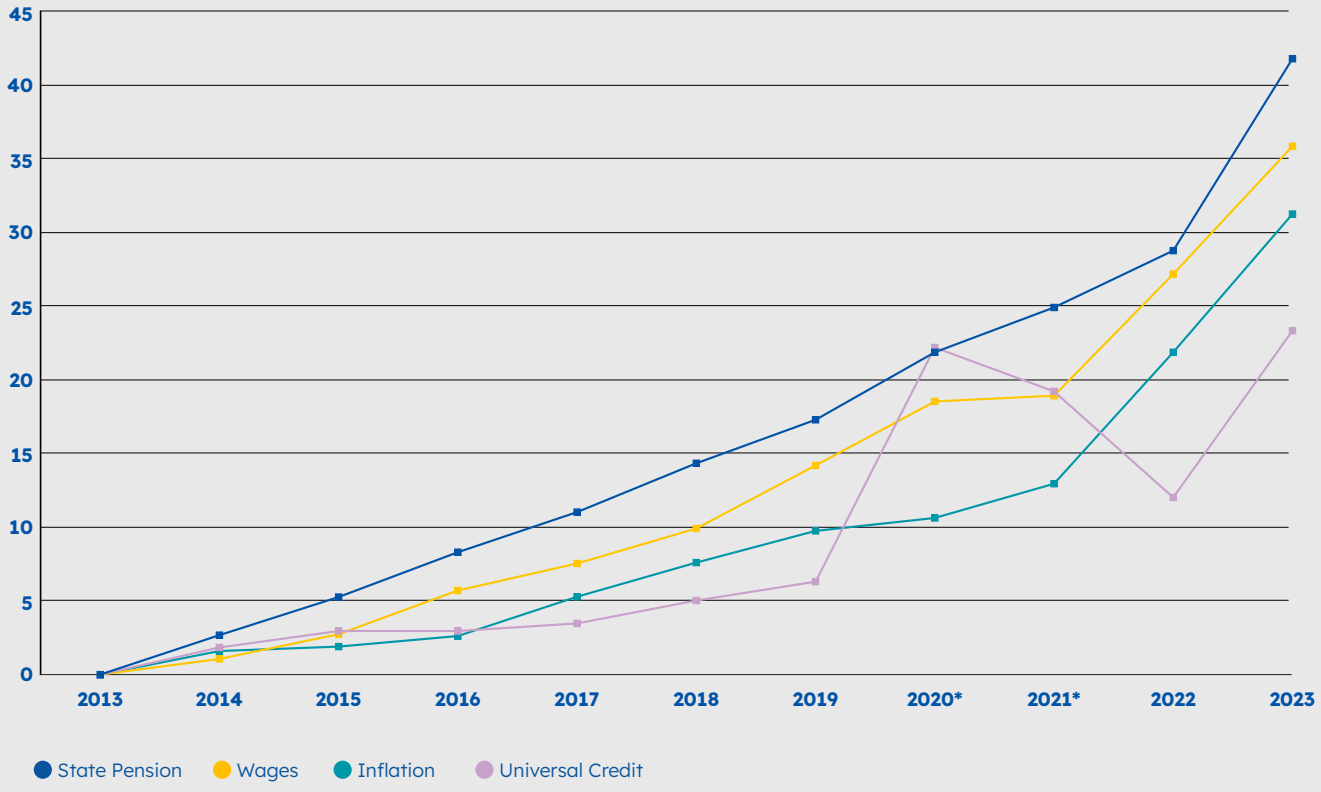
Because the Department will be unaware of some people who are living with a terminal illness, it should also guarantee that no-one will have their legacy benefits stopped if the Department has not been able to contact them.

The new State Pension and Pension Credit

The new State Pension is considerably more generous than basic working-age benefits, and has increased in real-terms in recent years thanks to the 'triple lock' (see Figure 2). Someone can receive an amount of the State Pension after making or being credited with 10 years of National Insurance Contributions (NICs), and the full amount after 35 years. Pensioners on a low income can also receive Pension Credit, to top up their weekly income.

In contrast, as set out above, working-age benefits have been subject to a range of real-term cuts and freezes that have reduced their value considerably. These differences are likely to drive much of the difference between the risk of dying in

Figure 2: Relative value of selected benefits, inflation and wages, 2013-2023 (2013=0)



Universal Credit includes both the Standard Allowance for a single household over 25, and the LCWRA element.

* Between April 2020 and October 2021, the £20-a-week 'uplift' for Universal Credit increased the Standard Allowance. This chart uses the average monthly amount for someone receiving Universal Credit across the whole of those years.

poverty between working-age people and people aged 65+ (nearly all of whom will be over pension age).

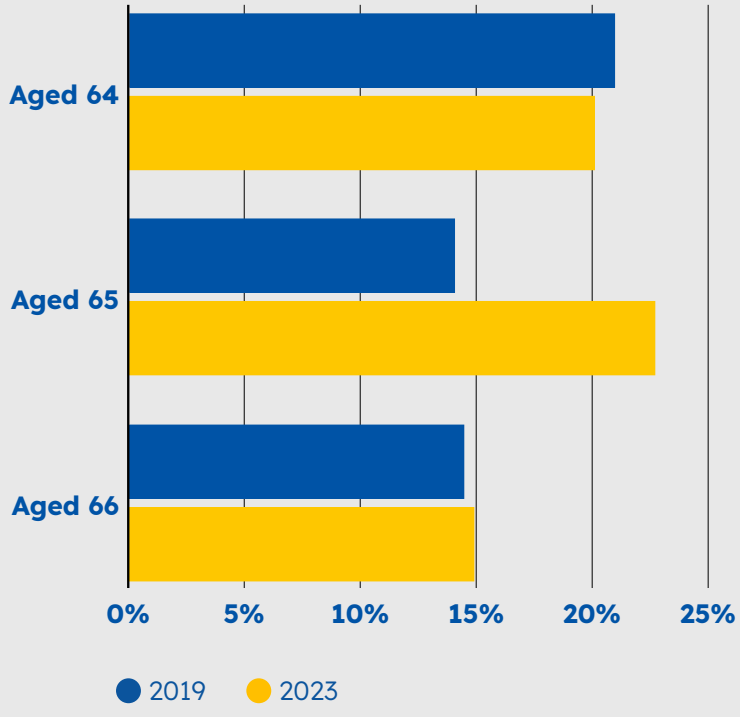
The Centre for Social Policy Research also estimated the poverty rate for people aged 65, an age at which in 2019 someone would be eligible for the State Pension, but in 2023 would not – as well as at age 64 and 66. Compared to 2019, the 2023 poverty rates for 64 and 66-year-olds remained stable – but the poverty rate for 65-year-olds increased by more than 50%. This is very likely to be due to the impact of this age group no longer being eligible for the State Pension.

Without policy change, more working-age people will die in poverty every year because they aren't old enough to qualify for the State Pension. Recent research by Marie Curie has estimated the additional number of people who would die without receiving the State Pension if the State Pension Age was increased.[29] The planned rise in State Pension Age to 67 in 2026/27 will lead to an extra 7,700 individuals dying before receiving any State Pension every year. With an increase to age 68, as currently proposed to happen between 2041 and 2043, an extra 15,800 people per year compared to today would be denied the State Pension before they died.

People who die under the State Pension Age currently cannot access the State Pension, simply because they die too young. And as the analysis in this report shows, people aged between 20-64 are more likely than the over-65s to be in poverty when they die. This points to a simple solution to cut working-age poverty at the end of life: give early access to the State Pension to someone who's dying.

This change would give far greater security to people at the end of life, without putting significant pressure on public finances: previous analysis by the Centre for Research in Social Policy suggests that this could add as little as 0.1% to the government's spending on the State

Figure 3: Estimated poverty rates by single-year age



Pension, while almost halving rates of poverty among working-age people in the last year of their life[30] – and of course, lessening the poverty among those not lifted out of poverty altogether.

In order to access the full State Pension, someone needs to have made 35 qualifying years on their National Insurance record. Around a quarter of people under State Pension Age in the last year of life have done this, so would be entitled to the full State Pension, but the majority would not.[31] Migrant populations on low incomes in particular would be disadvantaged, because at any given age they are likely to have fewer qualifying years on their National Insurance record, a pattern that persists into retirement and helps to drive higher rates of pensioner poverty among minoritised ethnic groups.[32] While the State Pension entitlement gap between men is now much smaller than it was, women are another group who are more likely to have gaps in their National Insurance record, so this measure alone would risk exacerbating sex inequality.[33]

For people over the State Pension Age who don't qualify for the full State Pension and don't have other sources of income, Pension Credit Guarantee Credit provides an important top-up. We therefore propose introducing a similar mechanism within Universal Credit, by also including a Pension Credit Element.

Extra-cost disability benefits

For people living with a long-term health condition or a disability, further financial support is available through "extra-cost" benefits. These are not means-tested. For working-age people this is Personal Independence Payment (PIP), and for people over pension age this is Attendance Allowance (AA). The Scottish Government is gradually taking responsibility for Personal Independence Payment (which is now called the Adult Disability Payment), and from late 2024 will begin to do the same for Attendance Allowance (which will be called the Pension Age Disability Payment).

Following the 'Scrap Six Months' campaign led by Marie Curie and the Motor Neurone Disease Association, people living with a terminal condition and less than a year to live can now access these benefits under the Special Rules for End of Life (SREL), which fast-tracks an application and automatically entitles someone to the Enhanced Rate of the Daily Living component. In Scotland, there is no requirement for a particular expected remaining time of life to receive the Adult Disability Payment, and successful applicants who apply under the Special Rules are automatically entitled to the Enhanced Rate of the Mobility component as well.

Analysis of government data conducted by Marie Curie has found that 95% of people claiming PIP in England and Wales

Recommendation

Working-age people living with a terminal condition with less than a year to live should be guaranteed to receive at least a State Pension-level income.

We propose achieving this using two routes. Firstly, people in this situation should receive the State Pension based on their NIC record. Secondly, if a working-age person living with a terminal illness has not made enough NICs to receive the full State Pension and receives Universal Credit, they should receive a Pension Credit Element within Universal Credit to top this up to a level equivalent to the State Pension. This could replace the Limited Capability for Work and Work-Related Activity (LCWRA) element, and be offset against new-style ESA if received.

under the SREL also receive the Enhanced Rate of Mobility.[34] Making this automatic would reduce the administrative burden on clinicians and the DWP, provide greater certainty to people at the end of life, and cost the government under £4 million a year.

These benefits, and the speed and ease of access to them, are of vital importance to people at the end of their lives. However, the previous Government published a Green Paper which proposed a range of fundamental changes to how PIP operates, including potentially ending the current system of direct cash payments and the new Government has yet to propose a new approach.

Recommendation

The Department for Work and Pensions and the Department for Communities in Northern Ireland should extend automatic entitlement to PIP under the SREL to include the Enhanced Rate of Mobility, in line with practice in Scotland.

Recommendation

The Department for Work and Pensions should maintain the system of direct cash payments for PIP recipients.

Local government

Local authorities also have the power to take action on improving the financial situation of people dying in poverty, particularly in relation to council tax and rent arrears. Council tax and rent arrears are both "priority debts" due to the potential consequences of non-payment, and council tax is often pursued aggressively by councils using enforcement agents (bailiffs). So, action to support people living with a terminal illness in affording these important bills – whether by reducing what they have to pay or increasing the support available – can have a real impact on both their financial situation and wider wellbeing.

Council Tax Support provides a reduction in someone's council tax bill depending on their income. Since 2013, the Great Britain-wide system of Council Tax Benefit has ended, and local authorities in England have had the discretion to set their own rates of Council Tax Support for working-age people. Scotland introduced its own national scheme, while Welsh local authorities had limited discretion, having to operate within guidance issued by the Welsh Ministers on an annual basis. The Welsh Government has recently passed legislation that is expected to lead to a more uniform system across Wales from 2026.[35]

Since then, in part due to the wider financial pressure local authorities are under, most councils at least in England have reduced the support available, increasing the amount that low-income residents are required to contribute towards council tax. In 2024/25, around two-thirds of local authorities in England have a minimum payment that is owed by someone with no income, with some requiring a minimum payment of half of the original bill.[36]

When this support was localised, the English and Welsh governments chose not to give councils discretion over council tax support for people of pension age. Some councils have "protected groups" who are exempted from paying council tax altogether, such as care leavers under 25, or people in receipt of disability or caring-related benefits. Many, however, do not, and currently no local authority in England includes people living with a terminal illness specifically as a protected group.

The equivalent system in Northern Ireland is called Rate Relief, or Rate Rebate for Universal Credit claimants.[37] This provides a full rebate to anyone on a sufficiently low income.

Recommendation

Local authorities in England should review their Council Tax Support schemes and ensure that households on a low income that include someone living with a terminal illness are adequately supported, for example by making them a protected group. The Scottish government should do the same for its national scheme.

The Welsh government should ensure that working-age people living with a terminal illness are eligible for Council Tax Reduction under the national scheme that will apply from 2026.

Local authorities also distribute Discretionary Housing Payments. These are pots of money provided by national governments to local authorities that can be used to support renters with housing costs, such as paying off arrears, making up a shortfall between Local Housing Allowance and someone's actual rent or undoing the effect of the Spare Room Subsidy. Local authorities are allowed to increase these up to a limit of 150% of the original allocation, although in the last year for which data is available, the average council in England and Wales topped their allocation up by just 12%,[38] reflecting wider funding challenges.

Recommendation

Local authorities and other decision-makers should prioritise households which include someone living with a terminal illness if an application for a Discretionary Housing Payment is made.

In national guidance, households including someone living with a terminal illness should be designated as a priority for an award of Discretionary Housing Payments.

Other discretionary support

Local authorities and devolved governments have access to other ways to support people living with terminal illness, such as the Household Support Fund in England (which was recently extended until the end of 2025/26), the Scottish Welfare Payment, the Discretionary Assistance Fund in Wales, and Discretionary Support Grants in Northern Ireland. They also have the ability to write off council tax arrears (known as "Section 13A" applications in England and Wales). While these sources of emergency financial assistance are not substitutes for a wider benefits system that provides guaranteed security, they have an important role to play in responding to unexpected circumstances.

Recommendation

Local authorities and other decision-makers should include households which include someone living with a terminal illness as a priority group for other discretionary support schemes, such as the Household Support Fund or equivalents, and ensure they can access them without unnecessary delay or bureaucracy.

Government support for childcare

Parents living with a terminal illness are not automatically eligible for childcare entitlements including universal childcare and tax-free childcare in the UK. Eligibility for the different funded early education and childcare schemes across the UK, normally depends on two things: the age of your child; and your working status or income.

Parents living with a terminal illness will over time become unable to work due to their declining health, and their partner or other loved one will often also be forced

to reduce or give up their paid work to become a carer. These people would not be entitled to childcare payments which would enable their children to attend childcare facilities. For these households, access to childcare is vital as they become unable to provide at-home childcare due to their terminal diagnosis or their responsibilities as a carer.

Many working-age parents affected by terminal illness will miss out on support with the costs of childcare despite being impacted by the additional costs of terminal illness, which will make childcare less affordable for them.

Support with childcare could therefore be a lifeline for these families and could give both parents and children much-needed respite. Without childcare support, terminal illness risks pushing those parents, and their children, further below the poverty line.

Recommendation

The UK and devolved governments should provide parents living with a terminal illness access to all childcare entitlements that in-work parents are entitled to, including Universal Childcare and Tax-free Childcare.

Employment

This chapter has focused on support provided by government, but for many working-age people at the end of life, income from work, insurance, or occupational or statutory sick pay can also provide valuable financial support.

Research conducted by Marie Curie alongside the What Works Centre for Wellbeing has highlighted significant variability across employers' practices, policies and procedures – an "employer lottery."[39] At best, employers can provide flexible and compassionate support to employees with a terminal condition and allow people who wish to continue working to do so for as long as they are able. But at worst, inflexible employment practices can significantly add to the stress of living with a terminal condition, such as automatically triggering HR processes if someone takes "too many" sick days due to a terminal condition.

Where an employer does not offer an occupational sick pay scheme, or if someone has been unable to work for longer than such a scheme will support them for, employees are entitled to Statutory Sick Pay (SSP). The operation of this scheme has been widely criticised for several reasons, including the level of payment, the lack of support from the first day of sickness, and the lack of flexibility that means that it does not cover phased absences or returns to work,[40, 41] which may be particularly needed for people living with terminal illnesses whose condition might fluctuate. The recently-introduced Employment Rights Bill proposes to tackle some of these issues, but more is needed to ensure Statutory Sick Pay fully supports people living with a terminal illness.

Recommendation

Employers should ensure that their processes, policies and sick pay schemes are appropriate for someone living with a terminal diagnosis.

Recommendation

Relevant Ministers of the UK Government and NI Assembly should review the administration and design of Statutory Sick Pay to make sure it meets the needs of people living with terminal illness.

Simona and David's story

SIMONA moved to the UK from Italy in 2004, and she has two children who are 16 and 18. Simona's husband, David, died in June 2024 from a stage four glioblastoma, six months after he was diagnosed.

"We are still adjusting to life after David's death, it feels so weird. David was diagnosed on 27 December 2023 with stage four brain cancer, a glioblastoma. We knew straight away that this diagnosis was terminal, and he was given six months to live. The day he was diagnosed, he became paralysed down the right side of his body, and then after that he became fully paralysed and bedbound.

"All the medical equipment he needed was electric. It really raised the cost of our energy bills, and I still have an outstanding bill of £5,000 from the energy company. David was granted NHS Continuing Healthcare for his care needs, but none of this covered our energy bills. It was all down to our pocket, which was a real struggle.

"David had to stop working straight away after his diagnosis, because he couldn't walk or move. We both had to start claiming state benefits due to me also stopping work to be David's full-time carer. The amount of money we had through state benefits was barely enough to get us to the end of the month. There was no allowance for any extras.

"His condition meant that he was constantly cold, so we had to keep the heating on all the time. We discussed this with our energy companies, and the only things they provided was an electric blanket and a discount of £200 – it wasn't enough.

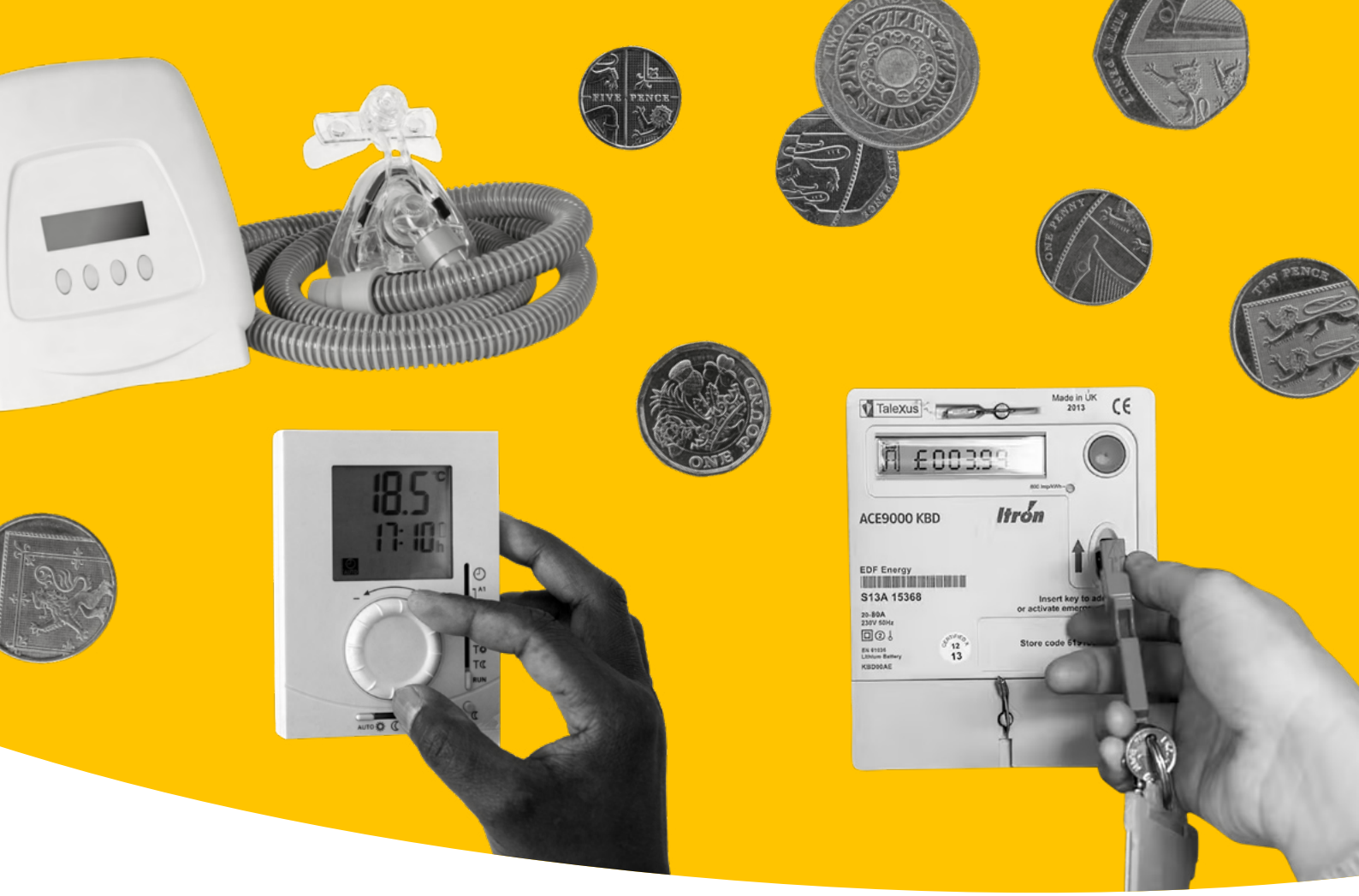
"As soon as we had the NHS Continuing Healthcare funding, there were no allowances to help us with electricity or gas bills. It was all about carers and hospital equipment, but nobody was taking into account the cost of running these items. People living with terminal illnesses need the heating on constantly, the lights need to be on for the carers, David couldn't swallow anymore, and all of his equipment was powered by electricity.

"When David was on oxygen towards the end of his life, I spoke to the provider as the oxygen machine needed to be on all the time. They told me they would refund the cost of running the equipment, and later I had a cheque through the post from them for £13.

"The most expensive piece of equipment we had was David's hospital mattress that had a pump to change his position and help to avoid bed sores. This needed to be on all the time so used a lot of energy. The mattress was supplied by the hospital, but the cost of running it came directly out of our pockets.

“Families who have a loved one with a terminal illness need a cap on energy bills. Their loved ones depend on this equipment, and they need reassurance that they can keep the generators on that are powering all this equipment without worrying about the cost. Families shouldn’t have to worry about whether they can afford to power a stairlift or not.

“David has been paying his taxes his whole life. It makes me really sad and frustrated to think that all this money will get wasted. He could have been more financially supported if he’d been able to access the state pension early. It would have made a big difference to us.”



3. Fuel poverty

ENERGY costs are one of the biggest costs that can increase when someone is at the end of their life. This can be due to needing to run medical devices, needing to maintain a particular body temperature or simply spending more time at home. For some people this can be extremely expensive. The Motor Neurone Disease Association, for example, has found that some people living with the condition spend more than £10,000 a year to power devices.[42]

Marie Curie's previous research has highlighted the inconsistency and unavailability of rebate schemes for medical devices,[43] which can place additional financial strain on people living with a terminal illness. More than two in five people seeking emergency support to top up a prepayment meter have a critical need for energy,[44] which can include needs caused by terminal illness.

Being unable to afford energy also causes financial stress and the discomfort of living in a cold or dark home. It can also directly affect health, including causing or worsening respiratory problems, worsening mental health, and increasing risk of heart attack.[45] These factors could both cause higher rates of admission to hospital, as well as re-admissions if someone is discharged into a cold home and their recovery slows or stalls as a result.

As a result, as a part of this year's *Dying in Poverty* research, Marie Curie commissioned the Centre for Research in Social Policy to undertake new analysis looking specifically at who dies in fuel 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 (MIS).
- **Wales and Northern Ireland:** Fuel costs to maintain a satisfactory heating regime are more than 10% of their full household income to maintain a satisfactory heating regime.

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

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

In the analysis, the only way to identify who has fuel costs necessary to maintain a satisfactory heating regime of over 10% of their income was to look at who spends that amount. 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.

Who dies in fuel poverty?

Across the population, at least 128,000 people died in fuel poverty in 2022 – more than one in five of all people who died that year.

As with deaths in poverty, this picture was not identical among different groups. But unlike deaths in poverty, there was relatively little difference between the fuel poverty rate for working-age people aged 20–64 compared to pension-age people, which could be due to higher fuel usage among older people compensating for higher income.[46]

There are, however, clear differences between regions, as shown in Figure 4 on page 32. The highest rates of deaths in fuel poverty for people aged under 65 were seen in London, where 25.7% of people who die do so in fuel poverty, compared to 17.9% in the wider South East. London's housing stock is on average more energy efficient than other parts of England and Wales, partly due to it having a greater proportion of flats,[47] so it is likely that this high rate of fuel poverty is instead driven by housing costs (linked to tenure) and low income.

Among pension-age people, the rate of fuel poverty in the last year of life was also high in London (25.6%), but was even higher in Northern Ireland, where 27.2% die in fuel poverty. This compares to 16.3% in the South East of England.

As with the analysis of deaths in poverty in Chapter 1, there are also distinctions between demographic groups, as set out in Table 7 on page 33.

Due to sample sizes, this analysis is not able to provide as detailed a breakdown between different types of conditions or ethnic groups, but these findings underscore the need to understand and address these disparities. The increased risk of fuel poverty among minoritised ethnic households compared to white households at the end of life is not as

stark as the increased risk of poverty set out in Chapter 1, but still represents a considerable increase. Given the over-representation of minoritised ethnic groups among social and private rented tenants,[48] the rates of fuel poverty at the end of life among these groups is particularly concerning. As with poverty at the end of life, there is also an increased rate of fuel poverty among people at the end of life with a non-cancer diagnosis compared to people living with a cancer diagnosis.

Figure 4: Fuel poverty in last year of life by age and region

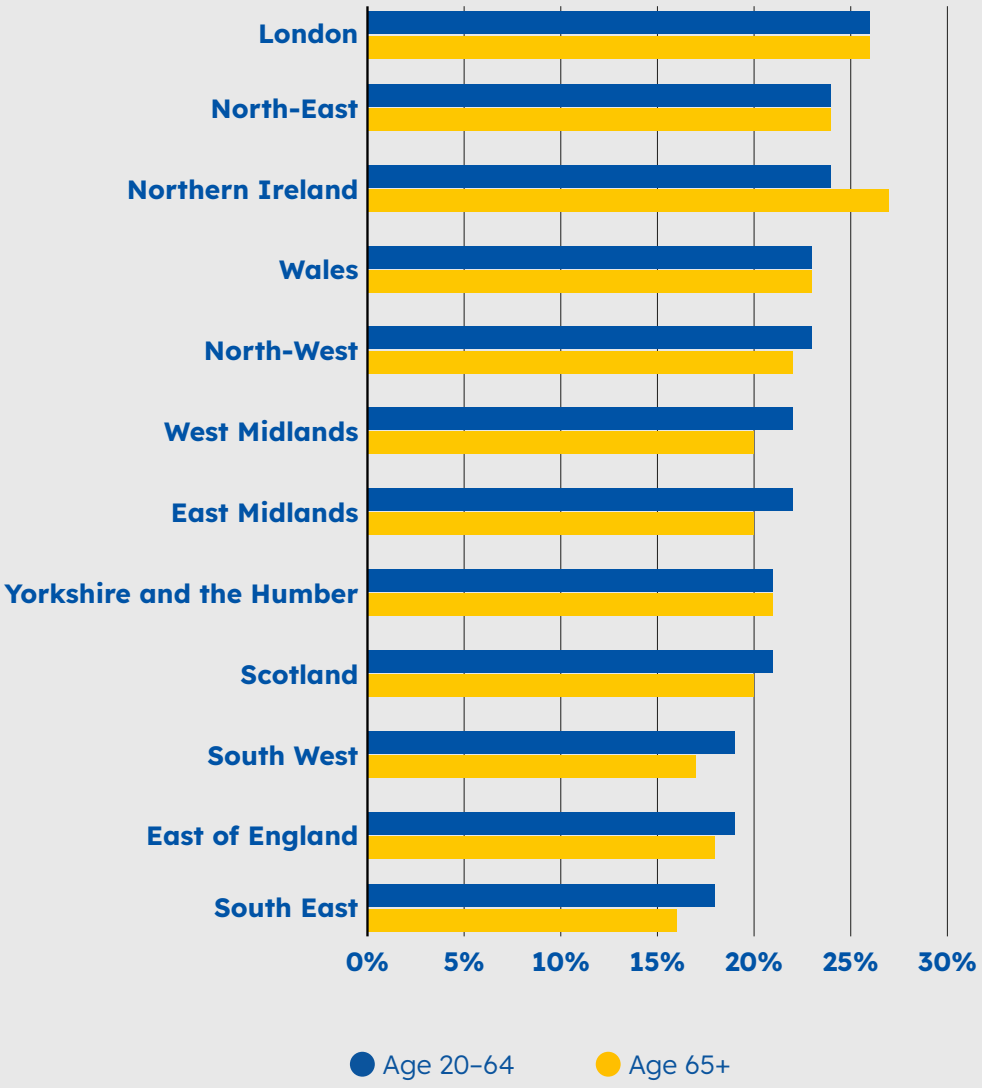


Table 7: Fuel poverty rates at end of life by age and selected demographics

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

Change in fuel spend at the end of life

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

The period covered by this analysis was a time of rising prices, so energy spending increased for households regardless of whether they are in the last year of their life. Overall, people at the end of life saw their energy spend increase more than households not at the end of life across each nation of the UK. This figure is particularly high for people at the end of life in Northern Ireland, which is concerning. One possibility is that households relying on oil for heating stockpiled it due to concerns about prices rising further, although it is less clear why they would have done so to a greater extent than households not at the end of life.

While the difference in increases in nations aside from Northern Ireland are relatively small, this doesn't mean that energy needs don't increase at the end of life. For example, some people might choose or need to go into hospital at the end of their life, or they may travel for regular treatments like dialysis, rather than incur higher energy bills at home. It's also possible that the impact of higher energy spend among households that can afford this is counterbalanced by much lower increases from households facing financial pressure, so the average masks variation.

There are also indications that some of the limited increase in spending at the end of life is associated with (in)ability to

pay, or potentially unwillingness to build up debt for dependents, rather than a lack of need to use more energy. In particular, unemployed households at the end of life saw a very small increase in energy spending compared to other household types or unemployed households not in the last year of life. This is also true for households who reported being behind on some or all household bills – all factors that might indicate a deliberate or forced under-consumption of energy.

There was also an increase in spending across fuel types, again with a significant increase for people at the end of life who use oil for heating. This is particularly concerning given the prevalence of this fuel type among rural and island communities, which exacerbates the "rural premium" of the cost of living and dying that they experience more generally.[49] Perhaps counter-intuitively, people in the last year of life with an electricity prepayment meter saw their electricity spending rise less than households not at the end of life. One possible explanation is that households with electricity prepayment meters were choosing to top up their electricity meter less, in order to prioritise their spending on gas (typically used for cooking and heating).

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

Figure 5: Median change in spending on energy by nation between 2021-22

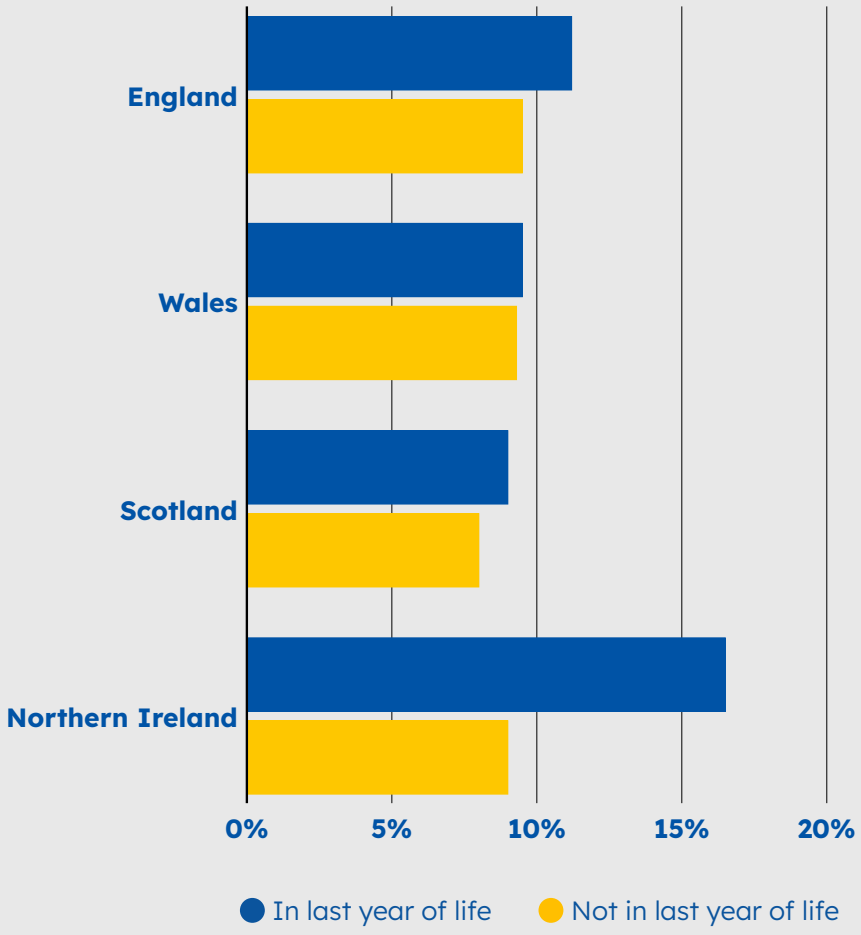
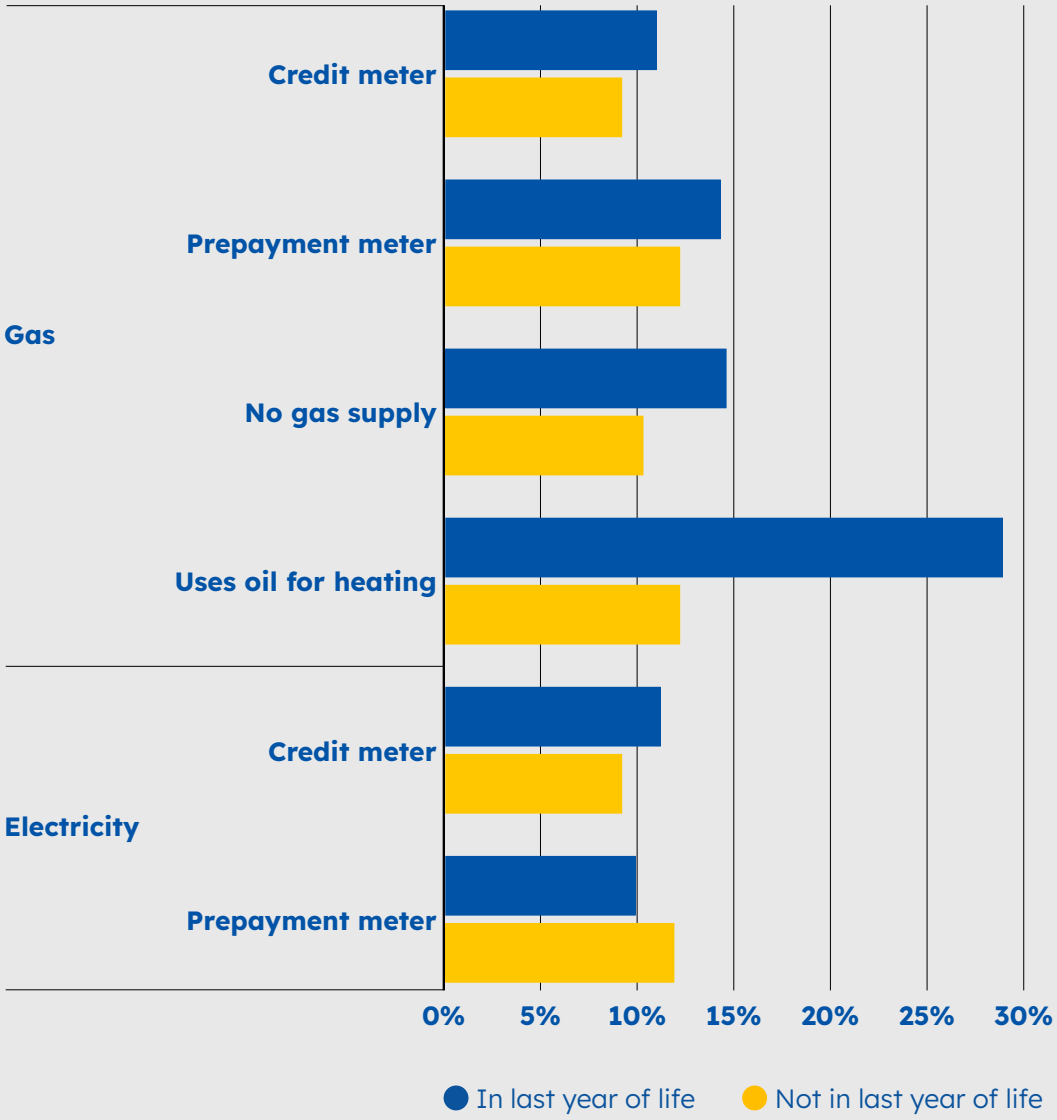


Figure 6: Change in spending by fuel type between 2021-22



In Great Britain, following concerns raised by Marie Curie and other charities working with vulnerable groups, Ofgem has banned the forced installation of prepayment meters for households considered especially vulnerable, explicitly including those that include someone with a terminal illness. Suppliers are also expected to review whether a prepayment meter remains appropriate on at least an annual basis, or when they otherwise become aware it might no longer be appropriate. For example, it might have been appropriate to install the prepayment meter, but someone in the household might now have a terminal condition, meaning that this is no longer an appropriate payment method due to the risk of self-disconnection.[50]

In Northern Ireland, the Utility Regulator is planning a review of its codes of practice on prepayment meters and payment of bills in 2025/26.

Recommendation

Ofgem should actively monitor supplier compliance with licence conditions around self-disconnection, forcible installations, and ongoing reviews of appropriateness of prepayment meters.

Recommendation

The Northern Ireland Utility Regulator should ensure its reviews of codes of practice on prepayment meters and payment of bills provide adequate protections for households which include someone living with a terminal illness.

What can alleviate fuel poverty?

In one way, fuel poverty is little different from poverty. Measures that directly increase someone's available income, like the financial support discussed in Chapter 2, can improve their ability to afford fuel.

However, there are also particular measures that can and should be taken to provide support for fuel costs, specifically. This is better targeted to people who have high fuel costs, which may be caused by the reality of living with a terminal condition.

Measures to improve energy efficiency can also reduce energy bills. But such work can take time and be disruptive. Both factors mean that they are not likely to be suitable for people approaching the end of their lives, and so more immediate forms of support are needed alongside improving energy efficiency, which will deliver benefits to people at the end of their lives in future years.

A social tariff

In some other consumer markets, like water and telecoms, social tariffs are available to support people on low incomes and/or with high usage needs. This reflects that these are essential products and services in modern society. But despite typical energy bills being far higher than water or telecoms, and energy being essential for health and quality of life, there is no such tariff in the UK energy tariff.

A social tariff that reduces energy bills for people who cannot afford the energy that they need to use is long overdue. Marie Curie does not have a view on the detailed design of such a scheme, provided it delivers meaningful reductions to energy bills and is available to people living with a terminal illness. One such proposal has come from Age UK.[51] Under this proposal, certain households would receive a 50% discount on their energy bill (similar to existing social tariff schemes in water). The Centre for Research in Social Policy looked at the impact of this on people who die in fuel poverty and found that it could lift up to 54,000 people out of fuel poverty at the end of life, which could reduce rates of fuel poverty among pension-age people nearly by half.

This figure is likely to be an overestimate of the actual impact, as it does not account for potential behaviour change. Some households who received a 50% discount

Table 8: Potential impact of introducing a social tariff on fuel poverty at the end of life

	In fuel poverty	Still in fuel poverty with a social tariff	Potential reduction in fuel poverty from a social tariff
Working-age	18,000	13,500	4,500 (25%)
Pension-age	110,000	60,690	49,310 (45%)

would use more energy afterwards, and so could remain in fuel poverty. For example, if they were currently under-consuming energy but the discount enabled them to get closer to using the amount they needed to use, resulting in more comfortable living conditions. However, as discussed elsewhere in this report, the headline estimate of fuel poverty is likely to be an underestimate of fuel poverty, if need rather than just spending was taken into account. Even with that behaviour change, a social tariff would reduce fuel poverty. And those households who remain in fuel poverty would of course still benefit by being in less deep fuel poverty.

It's also notable that even with a significant social tariff discount and no behaviour change, at least 74,000 people would not be lifted out of fuel poverty at the end of their life because their current energy usage is more than 20% of their income. This demonstrates both the urgent need for significant action to address fuel poverty, and that a social tariff would need to be combined with other measures to end fuel poverty at the end of life.

Such a tariff should apply across fuel types, although we recognise that the implementation would need particular consideration in Northern Ireland given the prevalence of heating oil as a source of fuel.

Recommendation

The Department for Energy Security and Net Zero should introduce a social tariff for energy. That tariff should provide at least a 50% reduction on bills, and be available to people living with a terminal illness to help them meet the extra costs of terminal illness at a time when their income is likely to have fallen.

Other support for energy costs

Across the nations of the UK, there are a range of different measures to provide money to different groups who are considered to need extra support. These are summarised in Table 9.

None of these schemes provide guaranteed support to someone with a terminal illness, although in some cases someone with a terminal illness will be eligible. A social tariff would deliver simpler, more consistent

Table 9: Summary of direct support for energy costs

Scheme	Summary of criteria	Support	Nations covered
Warm Home Discount[52]	Receive Pension Credit Guarantee Credit, or receive certain means-tested benefits and have high energy need	£150 a year taken off energy bill	GB (criteria differ in Scotland) – no comparable scheme in Northern Ireland
Winter Fuel Payment[53, 54]	Age and receipt of certain benefits	£100–300 a year	UK (devolved in NI and Scotland)
Cold Weather Payment[55]	Receipt of certain means-tested benefits, and temperatures over a 7-day period	£25 per cold period	England, Wales, Northern Ireland
Winter Heating Payment (from winter 2025/26)[56]	Receipt of certain means-tested benefits, in most cases with a disability element	£58.75 a year	Scotland

and more comprehensive support than these piecemeal schemes, but this will take primary legislation and then time to design and implement.

Recommendation

At least until a social tariff is introduced, UK and national governments should ensure that people living 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.

In July 2024, the Chancellor of the Exchequer announced plans to restrict eligibility of the Winter Fuel Payment to pensioners in England and Wales also receiving a means-tested benefit (in practice, mostly Pension Credit).[57] In principle, this will better target the payment to low-income households. However, these criteria don't take someone's energy needs into account, even if they are only just above the threshold for receiving Pension Credit. The Scottish and Northern Ireland governments have since confirmed they will take similar approaches due to the consequential impact of the Westminster Government's decision.[58, 59]

Recommendation

The UK and national governments should protect the Winter Fuel Payment or devolved equivalents for pensioners living with a terminal illness, even if they do not receive Pension Credit or another means-tested benefit.

The Winter Fuel Payment or equivalents should also be made available to people of working age living with a terminal illness.

Rebates for medical equipment

One of the reasons for an increase in energy usage could be related to the use of at-home medical equipment to treat medical conditions, such as oxygen concentrators for chronic lung conditions or haemodialysis for kidney failure or end-stage renal disease. Other examples may be a ventilator, suction device, feeding pump, electric wheelchair or powered hospital bed. Many patients will require the use of these medical devices for periods throughout the day or even constantly, which will lead to a rapid increase in their energy bills.

The cost of running essential at-home medical equipment is yet another expense for those already under serious financial pressure. After the cost of running medical equipment, and their other increased heating and power needs, dying people's energy bills can be 75% higher than the average household's, depending on their condition.

> **"Without this equipment my husband would not have been able to spend his last days at home with his family, but we had to cut back on other things as the gas and electric prices increased so much."**
>
> **Gail**

In addition to the financial impact, high energy costs can have an indirect impact on the health and wellbeing of someone with a terminal illness. Being unable to keep the home environment at the right temperature due to the cost of energy, struggling to afford the cost of running medical devices, or having to choose heating over eating and not having sufficient nutrition risks making people's conditions worse and reducing their quality of life. This increases the risk that they will

be unable to be cared for at home and must be admitted to hospital. The high cost of running medical devices similarly risks more people living with a terminal illness choosing to receive their treatment in hospital given the cost of receiving treatment at home.

In Marie Curie's report, *One Charge too Many*, we found a concerning lack of data held by NHS Trusts on the number of their patients using common medical devices.[60] In March 2023, Marie Curie submitted Freedom of Information requests to NHS Trusts, requesting data on the number of patients in each Trust area who were using common medical devices in their homes. However, most Trusts were unable to provide this data – there was insufficient data in Scotland, and only 23% of NHS Trusts in England were able to provide even partial data, typically on a limited number of devices (commonly oxygen concentrators), with most Trusts reporting that this information was either not held or could not be provided without incurring significant cost.

This lack of data is concerning. It means that most NHS Trusts are unable to report on the number of patients using at-home medical devices in their area. Therefore, estimating the size of this population is a significant challenge.

Additionally, the report found that despite many people living with a terminal illness needing to use such devices as part of their care and treatment, they are often not rebated for the energy cost of powering them. Rebate schemes for the cost of powering medical devices only exist for oxygen concentrators and dialysis machines, and in practice these schemes either refund patients three months in arrears (oxygen concentration) or are inconsistently administered across the country. Patients who use other medical devices receive no rebate at all. These patients are in effect paying out of pocket for the cost of their own treatment.

Recommendation

NHS Trusts should record and report information on the number of patients in their area who are using medical devices at home. The UK and devolved nation governments should use this to introduce an up-front rebate scheme for the use of the all at-home medical devices.

Action from Integrated Care Boards and Health and Wellbeing Boards

Since its publication in 2015, the National Institute for Health and Care Excellence's (NICE) NG6 guideline[61] has been recognised as a landmark resource for understanding and deploying appropriate action to support those at risk of worsening health because of cold homes and fuel poverty.

The NICE NG6 guideline covers reducing the health risks – including preventable deaths – associated with living in a cold home. It applies in England, is a guide in Wales, and has been endorsed by the Department of Health in Northern Ireland.

We know the consequences of struggling to meet increased costs can be severe: it can lead to new infections, make existing symptoms flare up or become worse, and affect mental wellbeing. Last year, National Energy Action and Marie Curie examined how the recommendations in NG6 are being delivered, with specific consideration of what this means for people at the end of life in England and Wales.[62]

Taking the Temperature of NG6, a review of how the NICE Guideline NG6 is delivering warm and safe homes and what more can be done for vulnerable people, takes steps to close an evidence gap. It details collaborative research undertaken by National Energy Action and Marie Curie to examine what is happening in relation to five out of the 12 NG6 recommendations.

The five selected NG6 recommendations – which focus on the importance of a strategy, single point of contact, safe discharge and public awareness – were those identified as more or most pertinent to those at the end of life or with a terminal illness.

The report highlights some case studies, such as the London boroughs of Richmond and Wandsworth Councils producing and implementing a winter plan that is based on the Cold Weather Plan for England. Also, NHS Herefordshire Integrated Care Board provides a range of support services, including the provision of energy-related advice and information that can be accessed by vulnerable people being discharged from hospital.

But our analysis shows that there is still much work to be done to deliver universal action on the recommendations set out in NG6. The research also highlights that progress to date has been patchy and inconsistent, and the report's recommendations highlight the need for further analysis of NG6 and the programmes or schemes that are delivered under it.

Recommendation

Health and Wellbeing Boards and their equivalents should ensure their Joint Strategic Needs Assessments and Health and Wellbeing Board Strategies (or equivalents) outline solutions and strategic activity to minimise winter deaths. NG6 implementation should complement existing strategies and plans, specifically in the context of terminal illness, for example, in end of life or palliative care plans.

Recommendation

Where NG6 doesn't apply, relevant bodies should ensure they have plans in place to minimise winter deaths and health impacts of cold homes or fuel poverty, particularly in relation to terminal illness, and that this is incorporated into care plans.

The full recommendations to ensure the implementation of the NICE NG6 guidance to best support people living with a terminal illness living in cold homes or in fuel poverty can be found in the full report.

Miranda's story

I HAVE Spinal Muscular Atrophy (SMA) type II. I am 58, which is extremely old (although not unprecedented) for someone with this medical condition. I have lost many friends to SMA, which is incredibly painful, and I don't expect to live as long as my parents.

"I have a little movement in my right hand but not much other movement in my body. I can't feed, bathe or dress myself. I can't even wipe my own bum! I need BiPAP ventilation to support my weak breathing overnight, and the machine has to be kept charged along with my backup ventilator. I have a ceiling track hoist, a cough assist machine (which I use daily to clear my chest of secretions), and I use a suction machine to vacuum things out of my throat. Along with my powered wheelchair, all of these devices and their batteries have to be kept charged at all times.

"I have bad osteoporosis and extreme spinal deformity and joint contractures, so looking after me is very complicated. Being taken for a wee takes at least 45 minutes. My jaw muscles are weak, so chewing is an issue and a sandwich takes me a couple of hours to eat – a proper dinner takes me a good three hours. Getting me up, dressed and into my chair is at least a three-hour job on a good day. I can no longer travel sitting in my wheelchair in an adapted vehicle as I am so weak that I topple over going round corners or over speed bumps and potholes, so I am now housebound. Thankfully, my speech is unaffected so far.

"My mother is 90 and in a nursing home. Because I can't go to see her, I recently spent £320 on a pair of tablet computers so that we can see each other via the internet.

"My mum and two aunts used to take care of me during the day so that my husband could go out to work, but he still had to do all the 'heavy work,' like getting me up, bathing me, taking me to the toilet and putting me to bed. Eventually, that all got too much, so my husband gave up work to be my full-time carer.

"The drop in our income was huge. We probably coped better than a lot of people would have done because we both grew up in poverty, so it didn't come as a shock and we knew lots of cheap recipes from our mothers.

"Buying any capital items, such as a new armchair or fridge, has been a bit of a struggle financially but a massive struggle psychologically. It's so stressful spending most of our savings on a single item. We worry that we will need another expensive item or house repair before we've saved up again and we worry that we might have bought something which won't last for at least ten years.

"Experiences like going to the theatre or having a meal out only happen at birthdays as a treat, and saving for a break in Cornwall became difficult but incredibly important to us.

"We hardly ever buy clothes. Aside from knickers, the last thing I bought was a couple of years ago, which was a poncho that I wear every day as a dressing gown costing £17. My husband bought some clippers years ago so he could cut his own hair and I get him to crop mine too, rather than paying a hairdresser.

"Our heating bills are sky high because I feel the cold badly and my body is too weak to shiver and generate heat. I also

have to buy a new pressure sore prevention cushion for my commode every year at £250.

“An expense which able-bodied people tend not to think of is visiting friends and family in other parts of the country. We live hundreds of miles away from our family, who don’t live in wheelchair-accessible housing so, before I became housebound, whenever we visited any of them or any of our friends, we had to stay in hotels, which would cost a fortune. It was very difficult once we were on means-tested benefits.

“We’ve both suffered from depression for years. We have had a pervading sense of hopelessness and despair for a very long time and have suicidal thoughts on a semi-regular basis. However, my husband turns 66 this year and qualifies for his State Pension. His income will go up by £4,500 when he changes to State Pension from Carer’s Allowance and Income Support. I can’t tell you how much we’re looking forward to it!”

Marie Curie's Energy Support Service

Marie Curie's Energy Support Service (ESS) started in October 2022, funded by the Gas Distribution Networks – the four companies that manage gas distribution across Great Britain.

We deliver this service through:

- specialist Energy Support Officers working on our Support Line
- our Hospice Care at Home service, with healthcare staff trained to spot signs of fuel poverty in people's homes, have conversations about the Priority Services Register, and signpost to our information and support services
- our Companions service, with volunteers trained to talk to people they support about fuel poverty and signpost to our information and support services.

To support this, our website has a Help with energy bills if you're affected by terminal illness webpage and a booklet, *Help with energy bills and the cost of living*, which can be downloaded or ordered, free of charge. We also have a benefits calculator on our website.

Between December 2022 and June 2024, we supported almost 4,000 people with energy-related enquiries to our Support Line, and people used the benefits calculator to identify a total of £1.5 million in additional income they're entitled to each week.

If you or someone you know needs support with any practical, clinical or emotional part of terminal illness, including energy or money issues, call us for free on 0800 090 2309 or contact support@mariecurie.org.uk to speak with our trained team.

Conclusion and recommendations

This report has set out the stark reality of dying in the United Kingdom today. Since our last report in 2022, the number of people dying in poverty has increased – and we now know the shockingly high number of people dying in fuel poverty, struggling to heat their homes and run vital medical equipment in their final months, weeks and days.

It doesn't need to be this way. There are steps that local, national, and the UK government should take now to reduce the financial strain that the end of life can bring, ensuring everyone is able to live as well as possible for as long as possible.

The key steps that would make the biggest difference to people living with a terminal illness are to guarantee a pension-level income for working-age people living with a terminal illness, and to introduce a social tariff for energy bills. These would provide meaningful, direct support, and help to substantially reduce the additional uncertainty, stress and health impacts of poverty at the end of life.

The end of life will always bring challenges. But neither poverty nor fuel poverty need to be among them. With 300 people a day dying in poverty, and almost 350 a day dying in fuel poverty, there is no time to lose.

Recommendations in this report

Improving understanding and data-sharing

This report has highlighted the gaps in understanding of the causes of inequality between different groups, and in ensuring people living with a terminal illness can access all the support currently available to them.

Recommendation: The UK and devolved governments should collect and publish data and indicators on the employment, income and wealth inequalities experienced by people from minoritised ethnic groups, as well as the impact this has on poverty at the end of life. They should then take steps to address those gaps.

Recommendation: The UK and devolved governments should collect and publish data and indicators on the employment, income and wealth inequalities between men and women, as well as the impact this has on poverty at the end of life. They should then take steps to address those gaps.

Recommendation: Governments should ensure better access to information, support and advice on financial support for people living with non-malignant terminal conditions.

Recommendation: The UK government, alongside devolved and local governments, should establish a joint action plan to end poverty and fuel poverty at the end of life across the UK. This should be taken forward alongside the policy changes set out in this report, and include measures to improve the identification, recording and sharing of information about people living with terminal conditions, both in the last 12 months of life and with longer prognoses.

National benefits systems

There are also serious shortcomings in the local and national working-age benefits system for people living with a terminal condition that helps to explain part of the higher risk of dying in poverty for working-age people.

Recommendation: The Department for Work and Pensions and the Department for Communities 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 and the Department for Communities should amend Universal Credit capital regulations to disregard payments received under a critical illness or life insurance policy for a period of at least 12 months.

Recommendation: DWP should work with HMRC to put contingency plans in place to ensure people are able to continue to receive Tax Credits beyond April 2025 where they have genuinely been unable to make a claim to Universal Credit, for example due to terminal illness.

Recommendation: DWP should postpone the migration to Universal Credit for anyone it knows is living with a terminal illness – for example, because they have successfully applied for ESA or PIP under the Special Rules for End of Life.

Because there will be people the Department is unaware is living with a terminal illness, it should also guarantee that no-one will have their legacy benefits stopped if the Department has not been able to contact them.

Recommendation: Working-age people living with a terminal condition with less than a year to live should be guaranteed to receive at least a State Pension-level income.

We propose achieving this using two routes. Firstly, people in this situation should receive the State Pension based on their NIC record. Secondly, if a working-age person living with a terminal illness has not made enough NICs to receive the full State Pension and receives Universal Credit, they should receive a Pension Credit Element within Universal Credit to top this up to a level equivalent to the State Pension. This could replace the Limited Capability for Work and Work-Related Activity (LCWRA) element, and be offset against new-style ESA if received.

Recommendation: The Department for Work and Pensions and the Department for Communities in Northern Ireland should extend automatic entitlement to PIP under the SREL to include the Enhanced Rate of Mobility, in line with practice in Scotland.

Recommendation: The Department for Work and Pensions should maintain the system of direct cash payments for PIP recipients.

Local and devolved support with finances

Local authorities and national governments should ensure that the financial support they can offer, including schemes intended to help with emergency situations, are available to people living with a terminal illness.

Recommendation: Local authorities in England should review their Council Tax Support schemes and ensure that households on a low income that include someone living with a terminal illness are adequately supported, for example by making them a protected group. The Scottish government should do the same for its national scheme.

The Welsh government should ensure that working-age people living with a terminal illness are eligible for Council Tax Reduction under the national scheme that will apply from 2026.

Recommendation: Local authorities and other decision-makers should prioritise

households containing someone living with a terminal illness if an application for a Discretionary Housing Payment is made.

In national guidance, households including someone living with a terminal illness should be designated as a priority for an award of Discretionary Housing Payments.

Recommendation: Local authorities and other decision-makers should include households containing someone living with a terminal illness as a priority group for other discretionary support schemes, such as the Household Support Fund or equivalents, and ensure they can access them without unnecessary delay or bureaucracy.

Recommendation: The UK and devolved governments should provide parents living with a terminal illness access to all childcare entitlements that in-work parents are entitled to, including Universal Childcare and Tax-free Childcare.

Energy costs, self-disconnection, and cold homes

For the first time, this report has demonstrated the scale of fuel poverty among people at the end of life. This needs urgent action to ensure that people at the end of life do not spend their final months, weeks, and days in cold homes, or leave their relatives with unmanageable debt.

Recommendation: Ofgem should actively monitor supplier compliance with licence conditions around self-disconnection, forcible installations, and ongoing reviews of appropriateness of prepayment meters.

Recommendation: The Northern Ireland Utility Regulator should ensure its reviews of codes of practice on prepayment meters and payment of bills provide adequate protections for households containing someone living with a terminal illness.

Recommendation: The Department for Energy Security and Net Zero should introduce a social tariff for energy. That tariff should provide at least a 50% reduction on bills, and be available to people living with a terminal illness to help them meet the extra costs of terminal illness at a time when their income is likely to have fallen.

Recommendation: At least until a social tariff is introduced, UK and national governments should ensure that people living 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 UK and national governments should protect the Winter Fuel Payment or devolved equivalents for pensioners living with a terminal illness, even if they do not receive Pension Credit or another means-tested benefit.

The Winter Fuel Payment or equivalents should also be made available to people of working age living with a terminal illness.

Recommendation: NHS Trusts should record and report information on the number of patients in their area who are using medical devices at home. The UK and devolved nation governments should use this to introduce an up-front rebate scheme for the use of the all at-home medical devices.

Recommendation: Health and Wellbeing Boards and their equivalents should ensure their Joint Strategic Needs Assessments and Health and Wellbeing Board Strategies (or equivalents) outline solutions and strategic activity to minimise winter deaths. NG6 implementation should complement existing strategies and plans, specifically in the context of terminal illness, for example, in end of life or palliative care plans.

Recommendation: Where NG6 doesn't apply, relevant bodies should ensure they have plans in place to minimise winter deaths and health impacts of cold homes or fuel poverty, particularly in relation to terminal illness, and that this is incorporated into care plans.

Other recommendations

Many people living with a terminal illness want, and are able to, continue working to some degree after their diagnosis. It's essential that they are properly supported to do so.

Recommendation: Employers should ensure that their processes, policies, and sick pay schemes are appropriate for someone with a terminal diagnosis.

Recommendation: Relevant Ministers of the UK Government and NI Assembly should review the administration and design of Statutory Sick Pay to make sure it meets the needs of people living with a terminal illness.

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