



Care and support
through terminal illness

Dying in poverty

Exploring poverty at the end of life in the UK



Contents

Foreword	4
Key facts	5
Executive summary	6
Summary of recommendations	8
Introduction	10
CHAPTER 1 Working age and pensioner poverty	13
CHAPTER 2 Groups at particular risk of poverty	19
CHAPTER 3 Disparities between the UK nations	27
CHAPTER 4 Disparities between local authority areas	31
Conclusions	36
References	37

Foreword

Nobody should die in poverty.

People approaching the end of their lives should be able to spend the last months and years of life focusing on what really matters – making memories with their families and loved ones, living as well as they can for as long as they are able.

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

Poverty affects too many people in our society throughout their lives – more than one in six of us lives below the poverty line. As the new research in this report shows, too many people in our society die in poverty as well – more than 90,000 every year.

What is even more shocking is that being diagnosed with a terminal illness and reaching the end of life increases a person's risk of falling below the poverty line. Even those who were previously getting by can be forced into poverty, when they are already at the most vulnerable time in their lives, by the financial impact of a terminal illness.

For those of working age this risk is particularly pronounced – more than one in every four people who dies in working age is below the poverty line in their last year of life. Those who have been more likely to experience poverty throughout their lives – including women, people from minority ethnic communities and parents with young children – are also at greater risk of falling into poverty at the end of their lives.

This is nothing short of a national indignity.

Marie Curie fears that this will only grow in the coming years. Recent rises in prices have led to a cost of living crisis in the UK as more people struggle to afford to make ends meet. This report shows that the UK is also facing a 'cost of dying crisis,' with many more people affected by terminal illness at risk of falling into poverty as a result of lost income, higher prices and a working age benefits system that is increasingly failing to safeguard people from poverty at the end of life.

Too often our social security net is failing to protect people living with terminal illness from falling below the poverty line. The recommendations in this report would begin to address this failure, by ensuring that everybody is able to access more of the financial support they need with the cost of housing, energy, childcare, and disability at the end of life.

In particular, it argues that the State Pension – the most effective safeguard against poverty in our social security system – should not be denied to working age people with a terminal illness simply because their lives will be cut short before they reach pension age.

I urge the UK, devolved and local governments, politicians, and policymakers to take up the recommendations in this report and make ensuring that nobody in our society dies in poverty an urgent national priority.



Matthew Reed
Chief Executive, Marie Curie
May 2022

Key facts

90,000

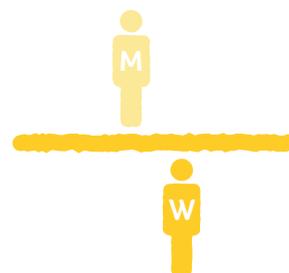
90,000 people die in poverty every year in the UK.



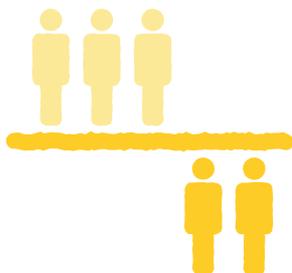
1 in 4 terminally ill people of working age spend the last year of their lives in poverty.



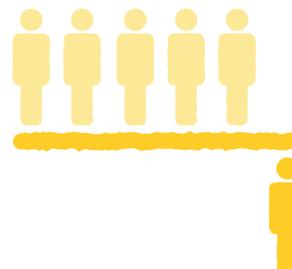
Working age people at the end of life are twice as likely to be in poverty than those of pension age.



Women are more likely to fall below the poverty line at the end of life than men.



2 in 5 working age people from minority ethnic groups die below the poverty line.



1 in 6 pensioners are below the poverty line at the end of life.



Working age people with children are more likely than any other group to fall below the poverty line at the end of life.



People living in London, the North West and the North East of England have the highest risk of dying in poverty.

Executive summary

Poverty affects more than 90,000 people in the UK every year at the end of their lives – one in six of those who die in the UK, every year, die below the poverty line.

Many people will have experienced poverty throughout their lives and continue to experience it as they reach the end of life. Many others, however, are driven into poverty as a result of reaching the end of their lives – a diagnosis of terminal illness is not only devastating for the health and wellbeing of a person and their loved ones, but can have a devastating financial impact as well. The combination of income loss and additional costs brought on by terminal illness can lead to significant financial strain and drive even families who were previously getting by into poverty.

This report reveals not only the scale of poverty at the end of life in the UK, but for the first time exposes exactly how terminal illness and poverty interact. Among people of all age groups and demographics, and in every part of the UK, being at the end of life is associated with a substantial increase in the risk of poverty compared to the general population.

For those who die at working age, the risks are even higher. Without the fixed income provided by the State Pension and other lifetime savings to rely on, the risk of being in poverty rises more than a third for those at the end of life compared to other working age adults, with more than one in four working age people dying in poverty. Working age people are more than twice as likely to experience poverty in their last year of life than those of pension age. Leaving the labour market, and subsequently having to rely on the working age benefits system as the main or only source of income, is the single largest risk factor predicting a fall below the poverty line at the end of life.

Working age families with children are particularly vulnerable to moving into poverty after a diagnosis of terminal illness as a result of childcare costs and the impact of one or both parents potentially having to leave work. The impact of a slide into poverty on these families will not only affect the

person at the end of their life, but leave their children experiencing poverty at the beginning of theirs.

This report also reveals that, for many of the groups in our society that are most likely to experience poverty throughout their lives, the risk is magnified by reaching the end of life. Structural inequalities – such as the fact that women are three times more likely to be in part-time employment than men and more likely to be in low-paid work, or that people from minority ethnic communities of all ages, on average, have a lower overall household wealth and are less likely to own their own homes – contribute to these groups facing a substantially higher risk of poverty at the end of life. Terminal illness is not the cause of these inequalities, but exacerbates their impact, contributing to a significantly higher risk of falling into poverty, or deeper into poverty, at the end of life.

This pattern is repeated across every nation and region of the UK. While the relative risk of poverty at the end of life closely reflects differences in the risk of poverty between the UK's nations and local authority areas among the general population, those at the end of life see a substantial increase in the likelihood they will experience poverty compared to the rest of the local population.

Our social security net should provide a safeguard against poverty, but too often it is failing to do so. The real-terms devaluation of working age benefits relative to wages and the State Pension over the last decade has left the working age benefits system increasingly ineffective as a safeguard against poverty for people at the end of life, with too much financial support for those at risk of poverty being either unavailable to too many people at the end of life, or insufficient to support them to make ends meet after the additional costs brought on by terminal illness.

Marie Curie welcomes recent changes to the benefits system that will make it easier for terminally ill people to access support quickly – scrapping of the 'six-month rule' governing fast-track access to benefits under the Special

Rules for Terminal Illness is a significant step forwards that will enable many more dying people to obtain benefits quickly. However, these changes alone will not go far enough to prevent people at the end of life from falling below the poverty line.

The recommendations in this report aim to address these issues and ensure that nobody living with a terminal illness has to deal with financial insecurity and poverty at what is already the most vulnerable time in their life.

Extending financial support for people at the end of life – with the cost of disability through Universal Credit, with housing through Council Tax Support and Discretionary Housing Payments, with energy bills through the Warm Home Discount, with childcare costs, and uprating support for carers – would begin to address the additional costs that see many people with terminal illness at a higher risk of poverty.

However, there is one recommendation which has a greater power to prevent poverty at the end of

life than any other. The State Pension is the single most effective safeguard against poverty in our social security system. By extending the State Pension to working age people living with terminal illness, we can prevent thousands of people and their dependents from falling into poverty. It simply isn't right that so many people miss out on this safeguard – in many cases after having contributed to our state pension system all their lives through National Insurance Contributions – and find themselves in poverty, simply because they have the misfortune to reach the end of life before they are 'old enough.'

Marie Curie believes that nobody should die in poverty. Everyone should be able to focus on what really matters to them in the time they have left, and not have to worry about their finances or struggle to make ends meet. Addressing poverty among people at the end of life must be an urgent priority for the UK, devolved and local governments.



Summary of recommendations

Recommendations for the UK Government	CHAPTER 1 <ul style="list-style-type: none"> • Terminally ill people of working age must be entitled to claim the State Pension. • The UK Government must implement changes to the Special Rules for Terminal Illness affecting PIP, DLA and Attendance Allowance quickly and keep the impact of these changes under review.
Recommendations for the UK and Devolved Governments	CHAPTER 2 <ul style="list-style-type: none"> • The UK and devolved governments must do more to understand and address employment and income inequality between men and women, and the impact this has on poverty at the end of life. • The UK and devolved governments must do more to understand and address employment, income and wealth inequalities experienced by people from minority ethnic groups and the impact this has on poverty at the end of life. • The UK and devolved governments must make additional support with the costs of childcare – through Universal Credit, the 2 year old offer, and 30 hours entitlement for 3–4 year olds – available to all terminally ill parents. CHAPTER 3 <ul style="list-style-type: none"> • The UK Department for Work & Pensions and the Northern Ireland Department for Communities must introduce a new ‘self-care element’ to Universal Credit to replace the Severe Disability Premium. • The UK Department for Work & Pensions and Northern Ireland Department for Communities must ensure that those with a terminal illness are eligible for Winter Fuel Payments even if they are under 65 years old. The Scottish Government must also ensure this is the case for Winter Heating Assistance from November 2022. • The UK Department for Work & Pensions and Northern Ireland Department for Communities should remove restrictions on Support for Mortgage Interest loans to terminally ill people. • The UK Department for Work & Pensions, Scottish Government Social Security Directorate and Northern Ireland Department for Communities must improve financial support for carers by increasing the value of the Carer Element of Universal Credit, and extending the eligibility of Carer’s Allowance and the upcoming Scottish Carer’s Assistance for up to six months after the person’s caring role ends.

Recommendations for Local Authorities	CHAPTER 3 <ul style="list-style-type: none"> • Local authorities must review their eligibility criteria for Council Tax Support and make terminally ill people, as well as family carers of terminally ill people, eligible to claim regardless of their age or savings. • Local authorities should prioritise people with a terminal illness for Discretionary Housing Payments to help them meet their housing costs. • Local authorities must consider the outgoings of applicants for Disabled Facilities Grants in England & Wales as well as income and assets and fast-track the processing and payment of grants to people living with terminal illness. In Scotland, Local Authorities must commit to fast-tracking terminally ill people eligible for financial and non-financial support through the Scheme of Assistance. • Local authorities in England must use their leadership role on Health & Wellbeing Boards and Integrated Care Systems to ensure these bodies audit their compliance with NICE's NG6 recommendations.
Recommendations for pension providers and insurers	CHAPTER 1 <ul style="list-style-type: none"> • Pension providers and insurers must make it easier for working age people to access their private pension savings or life insurance policies if they are diagnosed with a terminal illness.
Recommendations for employers	CHAPTER 1 <ul style="list-style-type: none"> • Employers must support employees who have been diagnosed with a terminal illness to continue working if they wish to, and ensure that they do not dismiss any employee with a terminal illness because of their condition.

Introduction

More than 14 million people in the UK¹ – 22% of the population – experience poverty each year.

The link between poverty and ill-health is well-documented. People who are experiencing poverty face health inequalities throughout their lives – they are more likely to have long-term health conditions, face barriers to accessing healthcare services and have a lower life expectancy than those on higher incomes². Ill-health is also a driver of poverty – half of all people who live in poverty live in a household where at least one person is living with a disability or long-term health condition³. Simply put, experiencing poverty is bad for your health, and ill-health is bad for your financial wellbeing.

This relationship between health and wealth continues to the end of life – the financial impact of terminal illness on a household can be as much as £12,000-16,000 per year⁴ as a result of the lost income and additional costs families often face. In 2021 the All-Party Parliamentary Group for Terminal Illness found significant risk of housing and fuel poverty among people living with long-term health conditions and those at the end of life, with 40% of all fuel-poor households including at least one person with a long-term illness or disability and those from low-income households less likely to be able to die at home⁵.

While more than one in five people experience poverty each year, the risk of poverty is far from equal across the population. Poverty rates are higher among people from minority ethnic groups, families with children and people who live in certain parts of the country like London, the North East, and the West Midlands⁶. People of working age are more likely to experience poverty than those who are over the pension age⁷.

Despite the well-established link between poverty and ill-health, and even though the risk of dying at any age has been established to be higher in more deprived areas than better-off areas⁸, the existing data does not tell us how many people die experiencing poverty each year in the UK or which groups are most at risk.

Background to this report

In 2021 Marie Curie commissioned the Centre for Research in Social Policy at Loughborough University to examine the number of people who die in poverty in the UK each year, how the risk of being in poverty at the end of life varies for different groups of the population, and the ‘pathways’ into poverty at the end of life that put different people and groups at particular risk of experiencing poverty.

The Centre for Research in Social Policy combined administrative data for the UK on mortality rates at different ages, with survey data that allows estimates of a) the poverty rates in the general population at different ages, and b) the relationship between poverty and mortality among individuals and households. The researchers also investigated how people move into poverty at the end of life through conducting sequence analysis and event history analysis on data from the Understanding Society household survey.

The full research report from the Centre for Research in Social Policy, *Poverty at the end of life in the UK*, can be read [here](#).

This report considers the key findings of the Centre for Research in Social Policy’s study in light of the broader public policy context in the UK, provides commentary on its implications for policy and gives recommendations to national and local policymakers. **Unless otherwise cited, all statistics in this report come from the Centre for Research in Social Policy’s study.**

Defining poverty

There are several ways of defining poverty and no single definition is universally accepted.

The Joseph Rowntree Foundation defines poverty as being:

“When a person’s resources (mainly their material resources) are not sufficient to meet their minimum needs (including social participation).”⁹

The Department for Work & Pensions, which publishes official poverty estimates for the United Kingdom in its annual *Households below average income* (HBAI) publication¹⁰, uses the following definitions of ‘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.

For the purposes of the above definitions, income can be measured either before or after housing costs have been deducted (BHC or AHC). As lower-income households spend a larger share of their household income on housing costs, poverty levels are generally higher when incomes are measured after housing costs.

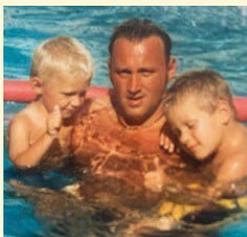
Since 2018, the **Social Metrics Commission**¹¹ has been publishing estimates of poverty in the UK based upon a new definition of poverty which considers the extent to which someone’s resources, after housing costs, meet their needs¹². This measure considers so-called ‘inescapable costs’ such as childcare and disability, which some households face and that make them more likely to experience poverty. In practice, the definition accounts for the cost of disability by deducting the value of disability benefits (such as Personal Independence Payments or Disability Living Allowance) from a household’s available resources as a proxy for these costs.

It considers all available financial resources a household has, such as savings or investments, in addition to income. It also includes groups previously omitted from poverty statistics, like those living on the streets and those just above the low-income threshold but in overcrowded housing.

In 2020 the Department for Work & Pensions evaluated the Social Metrics Commission’s work and concluded that it could form the basis of a new measure of poverty for official statistics¹³.

Most of the findings of the Centre for Research in Social Policy’s study, and consequently in this report, therefore use the Social Metrics Commission’s definition of poverty. While there remain some limitations to this definition – it is likely that simply deducting the value of disability benefits from available resources understates the impact of disability on a household’s finances – we believe it to be the most comprehensive definition 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.

Victor's story



Victor has terminal cancer and lost his job during the Covid-19 pandemic

“I haven't got enough money, really, to live.

I often borrow from loan sharks, for which you can borrow £20, pay back £40 – that sort of thing.

I've had days where I've got no food in my cupboard.

Finances are really difficult. It is really hard for me. I am broke and I don't have an overdraft. I don't have savings anywhere. So, when it's gone it's gone.

As soon as I got made redundant, my landlord, who also knew of my circumstances, evicted me. He served a Section 21, a no-fault eviction on me. I wasn't in arrears. During that time, I only got Housing Allowance. My rent was £1,150, the Local Housing Allowance is £700 or £697, so I was always going to be behind on my rent. During that period my rent caught up.

My landlord knew I was terminally ill, he knew Covid had hit. Then he found out I was being made redundant, and knew I couldn't pay my rent, probably. The rest is history. But, because of my circumstances and because of the eviction bans, it took him nearly until September last year to get me out. But by the time I did go out, obviously I was quite a lot behind in arrears.

I ended up homeless, living in an old car.

Eventually I got my PIP and my Motability. I get the maximum allowance. And it's an indefinite payment, because of my illness. So, it can never be challenged. But I had to go to court for this. The DWP took it all the way and it only got awarded it last November.

My PIP was a massively backdated payment. For about £5,000 or something when came in. But to be honest, I didn't even notice, it was gone within a week. Paid off debts. And I bought a caravan [to live in] whilst I was homeless.

The the hole gets deeper and deeper and deeper. So, you're borrowing off one loan shark to pay back another. You're literally robbing Peter to pay Paul. I've had to do that only this week.

When I stop and think about it, there's so much I want to do in my life. I haven't had a holiday for years, and there are things I want to see. I want to be around for my children. I hurt. I'm in pain and I know I'm ill.

I'm desperate to work properly.”

“I haven't got enough money, really, to live ... I've had days where I've got no food in my cupboard.”

CHAPTER 1

Working age and pensioner poverty

In the latest year for which figures are available (2019), **more than 90,000 people died in poverty in the UK** – meaning just over **15%** of the nearly 605,000 people who died in the UK that year^{14,15,16} had experienced poverty in the last year before their death.

Of the 90,000 people who died experiencing poverty, around **68,000** were of pension age (over 65) while around **25,000** were of working age (20–64 years).

Table 1 below shows the estimated number and proportion of both people of working age and pensioners in poverty in 2019, showing both those who died and those who did not in that year, according to the Social Metrics Commission's definition of poverty.

The relative risk of working age vs. pensioner poverty

Even though the great majority of people who die are of pension age, it is those of working age (aged 20–64) who are at greater relative risk of experiencing poverty at the end of their lives. A little over 90,000 people of working age died in 2019 in the UK – meaning more than one in four (28%) experienced poverty in the year before their death. Meanwhile, while 68,000 people of pension age experienced poverty in their last year of life, this represents 13% of the nearly 510,000 deaths among this group.

For a working age person, the risk of being in poverty rises from 21% among all working age adults to 28% if they are in their last year of life, an increase of one third – compared to an increase in risk of just under one fifth (from 11% to 13%) among pensioners. Those of working age are therefore more than twice as likely to experience poverty in their last year of life than those of pension age, and see their risk of falling below the poverty line at the end of life increase nearly twice as much.

The impact of poverty among working age terminally ill people frequently predates their last year of life. The majority of people who die at working age have experienced poverty at some point in the five years before their death, with a substantial minority falling below the poverty line in the last two years of life or experiencing movement in and out of poverty in the years before their death.

This partly reflects the fact that working age people are more likely to experience poverty than older people in the general population¹⁷ – even among people who are not in the last year of life, the risk of being in poverty for people of working age is double that of those of pension age (20% vs. 11%).

However, those of working age are particularly vulnerable to falling below the poverty line in the aftermath of a diagnosis of terminal illness. During the last five years of life, both being diagnosed

Table 1. Number and proportion of people in poverty in the UK in 2019 (mortality status and age group)

	In last year of life		Not in last year of life	
	Number	%	Number	%
Working age (20–64 years)	24,910	27.6%	8,192,360	20.6%
Pensioners (65+ years)	67,950	13.4%	1,227,048	10.9%
Total population aged 20+	92,860	15.5%	9,419,408	18.5%

with a new health condition and leaving the labour market are associated with significant increases in the risk of poverty over the next year – these risks will interact, with many people being forced to give up work as a result of their condition. More than four in five working age people affected by terminal illness report income loss as a result¹⁸, with many giving up work entirely as their condition progresses or due to symptom burden.

By contrast, three quarters of people dying after pension age have not experienced poverty at all in the five years before their death. This is in part reflective of welcome efforts to tackle pensioner poverty by successive governments in the 21st century, such as the State Pension triple lock.

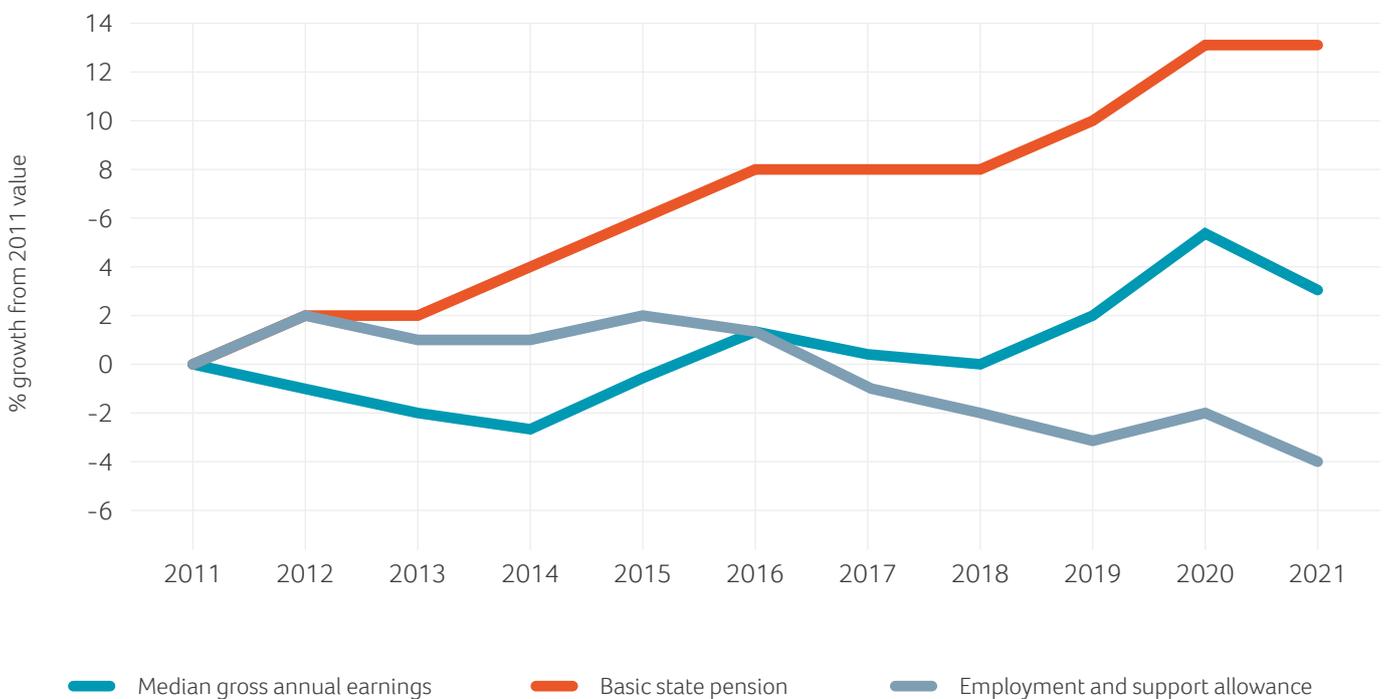
The relatively higher risk of falling into poverty among working age people who die having left the labour market is likely a reflection of the fact that over the last decade the social security system has become less generous for working age people relative to wages (see Fig 1 below).

Compared to the standard measure of poverty (below 60% of median income after housing costs), the Social Metrics Commission definition of poverty employed by the Centre for Research in Social Policy shows a markedly greater difference in the risk of poverty between working age people and those of pension age.

The Social Metrics Commission’s definition of poverty – which better captures the value of social security benefits, non-income assets such as savings and investments, as well as ‘inescapable costs’ like housing, childcare, and disability – is likely to more accurately reflect the greater risk of poverty at the end of life among working age people compared to those of pension age.

Working age people are more likely to have childcare costs than those of pension age, less likely to have significant savings and investments¹⁹ and, if they are in the last year of life, more likely to rely on disability benefits – as many as two-thirds of people living with terminal illness rely on benefits as their sole or main source of income²⁰.

Fig 1. Relative value of wages, working age benefits and pensions 2011–2021



(Sources: Office for National Statistics²¹, Rightsnet²², Rateinflation²³)

(NB: Real-terms value of wages, pensions and working age benefits calculated relative to inflation 2011–2021 using Consumer Price Index; Median Gross Annual Earnings are used as a proxy for wage growth 2011–2021; the Basic State Pension is used as a proxy for the value of pensions 2011–2021 as the New State Pension was not introduced until 2016; Employment & Support Allowance – rate for a single person aged over 25 with support component – is used as a proxy for the value of working age benefits 2011–2021 as other benefits like Universal Credit and Personal Independence Payments were not introduced until 2013)

Working age benefits and pensions

Nobody should face the end of their life worrying about how to make ends meet, but given that so many people living with terminal illness rely on the social security system as their main source of income, the fall in the relative value of working age benefits since 2011 is a significant concern. Not only are working age people who become terminally ill and come to rely on benefits worse off compared to their previous financial position, they are worse off than they would have been ten years ago.

Marie Curie welcomes recent changes to the benefits system that will make it easier for terminally ill people to access support quickly. In particular, the scrapping of the ‘six-month rule’ governing access to support under the Special Rules for Terminal Illness is a significant step forwards that will enable many more dying people to obtain benefits quickly.

However, these changes alone will not go far enough to prevent people at the end of life from falling below the poverty line. While the Special Rules for Terminal Illness help people get access to benefits such as Universal Credit and Personal Independence Payments more quickly, they do not make the working age benefits system more generous.

The devaluing of the social security safety net has left the working age benefits system increasingly ineffective as a safeguard against poverty and left thousands of terminally ill people every year facing poverty in the last year of their lives, at a time when they are most in need of support.

The inflation-proofing of the State Pension over the same period via the triple lock and its rise in value relative to wages and working age benefits means that pensioners are better protected from the financial impact of terminal illness than working age people. This level of protection should be available to – and expected by – everybody at the end of their lives, not only those who have already retired.

Work-based benefits and private savings

Leaving the labour market leads to a significant increase in a working age person’s risk of falling below the poverty line in their last years of life. In many cases, being unable to continue working means working age people miss out on benefits accrued through their employment.

Upon being diagnosed with a terminal illness, a person’s employer will often go through a formal process of establishing whether they are still able to do their job, and any reasonable adjustments they need. This then sets a bar, making it easier for the employer to dismiss that person if their condition subsequently deteriorates²⁴. If a terminally ill employee is dismissed in this way, they will not only lose their immediate income but will lose the right to any death in service benefit their employer may offer.

Terminally ill people of working age may also struggle more than those who have already retired to access financial support in the form of private pension savings or life insurance. The average size of a pension pot in the UK is in excess of £60,000²⁵ and the average life insurance policy is worth nearly £80,000²⁶.

Being able to access these savings – either in the form of a life insurance payout or the payment of a ‘terminal illness lump sum’ from a private pension – will support working age families at risk of falling below the poverty line in the aftermath of a terminal diagnosis. However, restrictive rules governing these payouts mean that many families affected by terminal illness cannot access this financial lifeline until very near the end of life – often until the insurer or pension provider is satisfied that somebody has fewer than six or twelve months to live²⁷ – if at all.

As outlined above, the financial impact of terminal illness affects the majority of working age people before their last year of life. Restricting a person’s ability to access their savings or insurance policies until the last year of life means those funds often come too late to help, putting them and their families at risk of falling below the poverty line in the months and years leading up to their death.

Recommendations

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

The State Pension was introduced to protect people from poverty and destitution after the end of their working lives. For many people however, the end of their lives come too early to enjoy this protection – even though they have paid into the system all of their lives.

It cannot be right that giving up work to make the most of what time they have left – or being forced to give up work due to the impact of their condition – leaves a person significantly more at risk of poverty in their final months and years, simply because they are not yet ‘old enough.’

The State Pension should be there for all of us at the end of our lives – whenever that time comes. Everybody with a terminal illness must be entitled to claim the State Pension to ensure they can spend what time they have living as well as they are able, not struggling to make ends meet.

2. Pension providers and insurers must make it easier for working age people to access their private pension savings or life insurance policies if they are diagnosed with a terminal illness. Being able to access these savings can be the difference between a person being able to cope with the income loss and additional costs brought on by their illness and falling into poverty at the end of their lives – but too many people are unable to benefit from the savings they have made until it is too late.

The All-Party Parliamentary Group for Terminal Illness found in 2019 that restricting financial support for terminally ill people to those who may die within a given timescale is arbitrary and unsupported by clinical evidence²⁸ – this applies as much to people accessing their own savings or insurance policies as it does to the benefit system. Enabling all working age people with a diagnosed terminal illness, regardless of their prognosis, to access the savings they have made throughout their working lives will support thousands of people and families every year at the end of life and spare many the risk of falling below the poverty line in their final years.

3. The UK Government must implement changes to the Special Rules for Terminal Illness affecting PIP, DLA and Attendance Allowance quickly and keep the impact of these changes under review. Marie Curie welcomes the scrapping of the ‘six-month rule’ in benefits law by the UK and devolved governments. The UK Department for Work & Pensions has recently implemented this change for Universal Credit and Employment & Support Allowance – it must now act quickly to give effect to these changes for other relevant benefits.

These changes alone will not go far enough to prevent people at the end of life from falling below the poverty line. The UK Government must monitor the impact of its changes to the Special Rules to Terminal Illness and keep further changes under review.

continued on page 17

Recommendations *continued*

4. Employers must support employees who have been diagnosed with a terminal illness to continue working if they wish to, and ensure that they do not dismiss any employee with a terminal illness because of their condition. The decision of whether or not to continue working after being diagnosed with a terminal illness must be that person's alone. While many terminally ill people choose not to, many others wish to continue working as long as they are able to, and may need support to do so.

Dismissing a terminally ill employee because of their condition not only deprives them of their immediate income, but also any death in service benefit they may be entitled to. Given the high risk of working age people with terminal illness falling below the poverty line after leaving work, employers should do everything they can to support employees to remain in work as long as they wish to after being diagnosed and never use their condition as a way to push them out of work.



Helen's story



Helen, from Derbyshire, is in her 70s and has multiple myeloma and lupus

“The price rises make it very difficult. Whichever way you look at it, you’ve really got to save for everything.

I have to put extra jumpers on. I’ll put a soft jacket or a soft coat. I’ve got a down-filled, full length dressing gown and sheepskin boots. With me having my myeloma, you really do feel the cold.

It’s important I stay warm because I lose the circulation in my hands and feet. If I get cold, I stay cold all day and have to go to bed. So, I often go to bed early, sometimes at 6pm. It definitely affects my condition if I get cold because I feel bad for anything up to a week afterwards.

I can be ill for a couple of days. I feel ill, sluggish. I can’t get warm. It takes me two or three days to get over it. You feel nauseous and you feel tired. Have you ever felt so tired that you want to stay still even though you know you are cold and you need to move? You’re too tired to make yourself a wheat bag or a hot drink. You think, why should I bother?

I turned the central heating off in January because it was getting too expensive. All through the winter months from October

to January, I only had it on two hours a day. It came on first thing in the morning and then at 5pm in the evening.

I hadn’t felt like that until I got into this situation with multiple myeloma. It’s really difficult. That’s the difference that I have to make in choosing whether to have heat or not. If the central heating is on it’s not bad. I can get up in the morning, have my shower, get dressed in the warm. Without it I wonder why I bother. I feel that cold I really can’t be bothered to move. Sometimes I feel that bad I’m ill.

When it’s bad and really cold I’ll force myself to get up to feed the dog and the cat, and then I’ll make myself a drink and go back to bed. I don’t bother eating.

I would like to see all people with cancer such as mine be eligible for a sum specifically for heating in the winter months. I get the Winter Fuel Payment. I get money into my account for that. I would like to see a sum given in the same way for all people with terminal illness having to deal with the winter and price rises.”

“I turned the central heating off in January because it was getting too expensive.”

CHAPTER 2

Groups at particular risk of poverty

In addition to the substantially higher risk of poverty at the end of life among people of working age, the Centre for Research in Social Policy's study found other groups of the population were at a higher risk of poverty – in particular women, people from minority ethnic groups and families with dependent children.

In each case, the higher risk of poverty at the end of life among these groups is reflective of a higher risk in the general population (i.e. among those who are not near the end of life)²⁹.

Women

Women are more likely than men to experience poverty whether or not they are at the end of life, as Table 2 below shows. Among those in the last year of life in 2019, 26.7% of men and 28% of women of working age were below the poverty line. The increase in risk of poverty for those in the last year of life compared to those not at the end of life is similar for both men and women of working age, with both seeing their risk of poverty rise by around a third compared to those not in the last year of life. This indicates that the elevated risk of poverty among working age women at the end of life is reflective of the higher general likelihood of women to experience poverty than men.

Among those of pension age, however, the risk of poverty at the end of life increases more substantially for women than for men. Pension age men in their last year of life see their risk of falling below poverty line rise by 15% compared to male pensioners not in the last year of life, whereas pension age women in the last year of life saw their risk of poverty rise nearly a quarter (23%) compared to pension age women not in the last year of life.

It is well-known that women are more likely to experience poverty than men³⁰. Among the working age population, women are three times more likely to be in part-time employment than men³¹, with women also disproportionately represented in low pay jobs – more than a quarter of women in work earn less than the real Living Wage, compared to just 16% of men³².

As a result, if they were to lose their job or give up work, nearly two-thirds of working age women have savings that would last a month or less while a third have savings that would last less than a week³³. This is likely to be a particular driver of the increase in poverty risk among working age women in their last year of life – more than four in five people with some terminal illnesses report income loss as a result of their condition³⁴, and the

Table 2. Number and proportion of people in poverty in the UK, 2019 (mortality status, age group and sex)

	In last year of life		Not in last year of life	
	Number	%	Number	%
Men				
Working age	14,559	26.7%	3,965,886	20.1%
Pensioners	27,952	11.5%	519,710	10.0%
Women				
Working age	9,996	28.0%	4,241,836	21.2%
Pensioners	36,861	13.9%	686,962	11.3%

Centre for Research in Social Policy's study found that exiting the labour market is the single biggest risk factor for falling below the poverty line in the last years of life.

Women are also more likely to have dependent children and childcare costs than men³⁵, while nine out of ten lone parents are women³⁶. As outlined later in this report, working age people with dependent children are more likely to experience poverty in their last years of life, with this therefore affecting women more than men.

Among pensioners, women have lower individual retirement incomes than men, reflecting lower average employment over their working lives and lower lifetime earnings than men, and a higher likelihood of having taken time out of the labour market or working part-time to raise children³⁷. Retired women are therefore likely to be living closer to the poverty line than men, on average, and having a higher risk of being pushed into poverty by the additional costs associated with terminal illness.

Women aged over 70 in the UK are more than twice as likely as men to live alone³⁸, reflecting women's higher average life expectancy³⁹. Living alone is associated with a higher risk of poverty among both the working age and pension age population, with 29% of single pensioners experiencing poverty in their last years of life compared to just 21% of pensioners living in a couple according to the Centre for Research in Social Policy's study.

The higher risk of poverty at the end of life for women of both working age and pension age is, therefore, representative of inequalities built up throughout their lives that mean they are less well-placed, on average, than men to bear the

additional costs brought on by terminal illness and faced by people at the end of their lives. These inequalities do not go away at the end of life – instead, they persist and are magnified, with especially retired women's risk of poverty at the end of life increasing at a higher rate than that of men.

Recommendation

5. The UK and devolved governments must do more to understand and address employment and income inequality between men and women, and the impact this has on poverty at the end of life.

Women are substantially more likely than men to be unemployed, underemployed or in low-paid work than men, leading to lower average lifetime earnings that leave them closer to the poverty line during their working lives and disadvantage them in retirement. Women are also more likely to have childcare costs during their working lives, and to live alone after they retire – both factors that increase a person's risk of poverty.

While terminal illness and reaching the end of life are not the causes of these inequalities, they effectively 'lock in' the inequalities women have experienced throughout their lives, meaning women are more likely than men to be in poverty in their last year of life than men. We must do more to reduce these inequalities throughout women's lives – by the time somebody has been diagnosed with a terminal illness it is often too late.

People from minority ethnic groups

There is a substantially higher risk of experiencing poverty among people from minority ethnic groups than people from white ethnic groups⁴⁰, both in the general population⁴¹ and at the end of life. As Table 3 below shows, among those in the last year of life in 2019, 42.5% of working age people and 26.9% of pensioners from minority ethnic groups were below the poverty line, compared to 25.4% of working age people and 13.2% of pensioners from white ethnic groups.

Despite the overall higher risk of poverty at the end of life experienced by people from minority ethnic groups, the additional risk of falling below the poverty line associated with being in the last year of life is actually lower for them than for people in white ethnic groups. People from white ethnic groups see their risk of being in poverty rise by a more than a third (working age) and more than a fifth (pensioners) in the last year of life, compared to an increase of around one-sixth (working age) and 5% (pensioners) among people from minority ethnic groups. This underlines that the overall higher risk of being in poverty at the end of life for people in minority ethnic groups is reflective of a higher risk in the general population.

While the Centre for Research in Social Policy's study was unable to compare differences in poverty at the end of life between minority ethnic groups, other estimates of poverty have shown significant

variation between the incidence of poverty between people in these groups in the general population – with 32% of people in families where the head of household is Asian/British Asian experiencing poverty compared to 46% of people in families where the head of household is Black/African/Caribbean/Black British⁴². In another study, 50% of all Bangladeshis, 46% of all Pakistanis and 42% of all Black/African/Caribbean/Black British people were in the most deprived fifth of the population after meeting housing costs, compared with 20% of all white British people⁴³.

Given that the Centre for Research in Social Policy found that the risk of experiencing poverty in the last year of life rose similarly for those in minority ethnic groups and those in white ethnic groups, compared to the general population, it may also be the case that the relative risk of experiencing poverty at the end of life also rises at a similar rate for different minority ethnic groups as well.

This would suggest that the biggest factor determining a person from a given ethnic group's risk of falling below the poverty line at the end of their life is their risk of experiencing poverty throughout their life, as opposed to any specific additional risk brought on by terminal illness. However, the fact that in absolute terms, more than one in four pensioners and more than two in five people of working age from minority ethnic groups are below the poverty line in their last year of life is a cause for significant concern.

Table 3. Number and proportion of people in poverty in the UK in 2019 (mortality status, age group and ethnicity)

	In last year of life		Not in last year of life	
	Number	%	Number	%
White ethnic groups				
Working age	19,755	25.4%	6,078,907	18.5%
Pensioners	63,949	13.2%	1,261,183	10.8%
Minority ethnic groups				
Working age	5,353	42.5%	1,924,072	36.2%
Pensioners	6,250	26.9%	144,296	25.7%

For people of working age, people from minority ethnic groups are less likely to be in employment than people from white ethnic groups in all parts of the UK, with women from minority ethnic groups particularly less likely to be in employment than women from white ethnic groups⁴⁴. Households from minority ethnic groups also have a lower household income, on average, than those from white ethnic groups, with Bangladeshi and Pakistani households having a particularly lower average income than those from other minority ethnic groups⁴⁵.

Similarly, people from minority ethnic groups of all ages, on average, have a lower overall household wealth (including property, savings, and pensions) than people from white ethnic groups, with particularly low average household wealth among Black African and Bangladeshi households⁴⁶.

The UK Government's Race Disparity Audit in 2020 found that in every age and socio-economic group, households from white ethnic groups were more likely to own their own homes than all minority ethnic households combined, with minority ethnic households also much more likely to rent privately and to spend a higher proportion of their incomes on rent⁴⁷. This is particularly relevant as the Centre for Research in Social Policy's study found that housing tenure is a strong predictor of being in poverty at the end of life, with renters (both private and social) at a significantly higher risk than those who own their own home.

People from minority ethnic groups – of both working age and pension age – are therefore more likely to be experiencing poverty before they reach the end of life, with lower average incomes and overall household wealth than people from white ethnic groups, and more likely to be renting and spending a larger share of their income in housing costs. They are therefore likely to be less able to afford the additional costs and income loss brought on by terminal illness than people from white ethnic groups, and at particular risk of being below the poverty line as they reach the end of their lives.

As with the situation experienced by women, as described above, these inequalities are not principally driven by terminal illness or reaching the end of life, but the additional financial pressures associated with a terminal diagnosis are likely to expand and amplify the inequalities experienced by people from minority ethnic groups throughout their lives.

Recommendation

6. The UK and devolved governments must do more to understand and address employment, income and wealth inequalities experienced by people from minority ethnic groups and the impact this has on poverty at the end of life.

People from minority ethnic groups are less likely to be in employment and more likely to be in lower paid work throughout their working lives, and more likely to have lower household wealth and to be renting throughout their whole lives. Each of these is a significant risk factor in a person's likelihood of experiencing poverty at the end of their lives.

Terminal illness or reaching the end of life are not the beginning of the inequalities faced by people from minority ethnic groups, but the additional burdens brought on at the end of life throw these lifelong inequalities into even sharper relief, with 27% of pensioners and 42% of working age people from minority ethnic groups living the last year of their lives below the poverty line. We must do more to reduce these inequalities before people reach the end of their lives, when it is often too late to address them.

Families with dependent children

Families with dependent children are more likely than people who don't have children (or who don't have children living with them) to experience poverty. Among the general population, 48% of people in lone-parent families are in poverty compared to 27% of single people without children, and 26% of people in couple families with children are in poverty compared to just 11% of people in couple families without children⁴⁸.

Among people nearing the end of life, as Table 4 below shows, people in families with children are the most vulnerable of all family types to experiencing poverty in the last five years of life. They are not only the group most likely to be 'mostly in poverty' during the last five years of life, but also the most likely to be 'moving in and out of poverty' during this period.

Two out of three working age terminally ill people with children will experience poverty in their last five years of life. They are also significantly more likely than people in any other family type to move into poverty in their last five years of life, having not experienced it before, being around 1.5 times more likely to move into poverty than single people of working or pension age, and six times more likely to move into poverty than people in working age couples without children.

Compared to working age couples without children, two-parent households are more likely to be 'one-earner' households (i.e. with only one adult working)⁴⁹. Even among 'two-earner' households, where both parents are in

employment, the impact of terminal illness on household income will be significant if the other earner is forced to reduce their paid employment to provide care. Nearly two-thirds of carers provide in excess of fifty hours of care per week, with one in five working carers having reduced their hours as a result of their caring responsibilities⁵⁰.

Families with dependent children are therefore likely to be less able to absorb the income loss associated with a diagnosis of terminal illness than other household types, with the potential for a significant reduction in household finances if one or both earners are either diagnosed with terminal illness themselves, or have to reduce or give up paid work to care for a non-working partner who has been diagnosed with a terminal illness.

The financial pressures brought on by terminal illness will only be more intense for the UK's 3 million lone-parent families⁵¹, should the working age parent be diagnosed with a terminal condition. Lone parents already have the highest risk of poverty among working age adults, with 43% in poverty⁵² – they are less likely to have significant savings than two-parent households and more likely to be spending a higher proportion of their income on 'inescapable costs' like housing, energy and childcare costs. The effects of income loss after diagnosis and the additional costs brought on by terminal illness, including higher energy bills, will hit these families particularly hard and are likely to push many more below the poverty line or into deeper poverty at the end of life.

Table 4. Risk of being in each poverty trajectory group in the UK (family type, adjusted for sex)

Family type	Poverty trajectory in last five years of life			
	Never in poverty	Mostly in poverty	Moving into poverty	Moving in and out of poverty
Working age single	36.7%	33.4%	8.4%	21.4%
Working age couple	64.0%	21.3%	2.1%	12.5%
Working age with children	32.0%	27.7%	12.6%	27.7%
Pensioner single	71.3%	7.2%	7.0%	14.5%
Pensioner couple	75.6%	8.7%	5.3%	10.4%

Unlike working age people without children and pensioners, working age people with children are likely to be paying a significant proportion of their income in childcare costs. The UK already has one of the most expensive childcare systems in the world, with the average cost of childcare reaching around half of women's median earnings for some families⁵³ and costs having risen 4–5% in the last year⁵⁴. These costs are 'inescapable' and will further reduce a family with dependent children's ability to absorb the additional costs of terminal illness compared to families without children.

As outlined above, women are more likely to have dependent children than men – women are the head of household in the majority of lone-parent families⁵⁵, while mothers with children are less likely to be in employment than fathers, and more likely to have reduced their working hours due to childcare commitments if they are in employment than men⁵⁶. The greater risks of poverty at the end of life among women and among families with children will therefore intersect, with women who have dependent children at a particularly high risk of falling below the poverty line after a diagnosis of terminal illness or at the end of life.

While the UK and devolved governments do provide some support for low-income families with childcare costs, in many cases this is only available to in-work parents. Parents who are eligible for Universal Credit can claim back up to 85% of the cost of childcare, for example – but only if they are in work or have a job offer. While some hours of free childcare are available to all parents of children aged 3–4 even if their parent is not working, and some parents of children aged 2 on a low income, this is not available for parents of school-aged children.

The Scottish Child Payment has recently doubled to £20 per week, available to low-income families looking after children under the age of six to support the costs of family living, including childcare. The payment is available to families with more than one child under 6, and applications can be claimed regardless of whether parents are working, but must be claiming certain benefits including Universal Credit.

Given the fact that childcare is an 'inescapable' cost and that more than four in five working age families affected by terminal illness report income loss as a result⁵⁷, with many people having to give up work entirely as a result of their condition, 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.

The symptoms of many terminal illnesses – including fatigue, nausea, breathlessness, increasing frailty, and advancing and often severe disability – mean that many terminally ill parents of school-age children will need support with childcare. The impact of caring for a terminally ill loved one will also be significant on partners in two-parent households, with the majority of carers reporting effects on their mental and physical health and wellbeing⁵⁸.

Support with childcare could therefore be a lifeline for these families and 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

7. The UK and devolved governments must make additional support with the costs of childcare – through Universal Credit, the 2 year old offer, and 30 hours entitlement for 3–4 year olds – available to all terminally ill parents. No matter their circumstances, parents have to find a way to meet the costs of looking after their children. This is no different for families affected by terminal illness, even as they face the likelihood of rising costs brought on by illness and one or both parents having to reduce their working hours or giving up work entirely.

Support with childcare can be a lifeline for parents living with the impact of terminal illness. Restricting financial support with the cost of childcare means that many terminally ill parents and carers of terminally ill partners are faced with significant expense at a time when they are already likely to be under financial strain, putting them – and their children – at risk of poverty. Making financial support with childcare available to all terminally ill parents will help them and their families make the most of the time they have left together.



Melanie's story



Melanie, 48, has terminal cancer. She lives in the Scottish Highlands with her husband and 7 year old son

“My biggest fear is next winter because I don't think we will be able to heat the house. Petrol is absolutely astronomical, and you need a car to get around. It was never a problem before. But it's how it is.

With cancer, there are these rose-tinted glasses. That everything will be fine. But it's not like that. When you're actually in the thick of it, you see people struggling to eat and struggling to survive because they can't afford their mortgage, or they can't afford to do anything. And the government is not helping. I know there's Universal Credit. But I don't really think that helps with the cost of living that we're going through.

I mean, with electricity bills, we're in rented accommodation so we're pre-paid. It's not like we have a couple of days to try and sort the payments. On a prepay meter, when it goes, it goes. As soon as my bones get cold, they hurt. It's very painful. We have to keep the house warm. But with the energy prices going up we can't do that. There's no way we're going to be able to afford it.

We're already paying £30 on gas a week through the winter. That's going to go up to £60 a week. We can't afford that. It's not going to happen.

I can easily get infections. Even a common cold, with someone with severe cancer it can kill them. I've got to think: what's

my health going to be like, being in a cold house?

And now we're having to cut back on food, cut back on electricity and gas.

I've got a really aggressive form of cancer and we just can't control it. So, there is the likelihood that we're not going to be able to do this winter what we did last winter. I've already started stockpiling winter blankets and hot water bottles. That's probably the only thing that's going to keep us going.

The major issue we have financially is my partner, Thomas. He has to look after me. He has to take me to the hospital. There you go with petrol costs, because I don't drive and I can't walk so he has to drive me wherever I need to go. As a cancer patient, you're in and out of hospital all the time for scans or injections or bloods or whatever.

He also has to look after our 7 year old son. He has to take him to school, drop him off, pick him up. He is having to reduce his work to look after me and my son – which means he has a reduction in his salary.

Thomas has good days and bad days. Obviously, he has to do everything now. He fears about me going which is completely understandable and he worries about the future between him and Joseph, whether he can be a good dad and financially support our son.

He doesn't have anybody to talk to. And I've seen this with people who've gone through cancer. They're the ones who are leaving their jobs and sacrificing the financial aspect to look after the patient. But there's no support for them.”

CHAPTER 3

Disparities between the UK nations

The pattern described above – of working age people being at greater relative risk of poverty at the end of life than pensioners, despite the majority of deaths (and deaths in poverty) occurring among those aged over 65 – is repeated in every nation of the UK.

However, the risk of poverty at the end of life is not the same across the UK, as highlighted in Table 5 below. There is a particularly high risk in Wales (all age groups), and the risk is also higher in England than in Scotland and Northern Ireland.

This pattern is reflective of differences in poverty rates between the UK nations in the general population⁵⁹, where poverty rates are generally higher than the UK average for people living in Wales and slightly lower for people living in Scotland and Northern Ireland.

Benefits policy in the UK nations

Social security policy is only partly in the control of some of the UK's devolved nations. Benefits policy is almost fully devolved to the Northern Ireland Executive⁶⁰, although in practice the Executive operates on a 'principle of parity' with Westminster where people in Northern Ireland pay the same rate of Income Tax and National Insurance contributions as those in Great Britain and

therefore have entitlement to the same benefits at the same rates. Meanwhile, working age benefits policy is partly devolved to the Scottish Government⁶¹, although the UK Government reserves responsibility for some benefits such as Universal Credit and Pension Credit. The UK Government reserves responsibility for the State Pension in England, Scotland and Wales and over working age benefits policy in England and Wales⁶².

Nevertheless, the stark difference in the risk of poverty faced by people at the end of life in different parts of the UK is a cause for concern and must be acted upon by policymakers in the UK's devolved nations to the fullest extent each is able to do so.

Marie Curie welcomes the decision of governments in all four UK nations to scrap the so-called 'six-month rule' which limited access to benefits under the Special Rules for Terminal Illness to only those with six months or fewer to live, forcing others to endure long delays for the financial support they rely upon.

However, as outlined earlier in this report it is clear that simply widening access to fast-track support from the working age benefits system is not enough to reduce the risk of terminally ill people falling into poverty at the end of life.

Table 5. Number and proportion of people in poverty at the end of life by age group, 2019 (UK nations)

	Working age (20–64 years) in last year of life		Pensioners (65+ years) in last year of life	
	Number	%	Number	%
England	19,848	27.5%	55,724	13.3%
Northern Ireland	699	25.7%	1,334	10.4%
Scotland	2,801	26.5%	5,746	12.2%
Wales	1,512	30.4%	5,148	18.4%

A number of recent reforms have made the underlying working age benefits system less generous, and further increased the gap between the amount of benefits received and the financial support people need to stay above the poverty line.

People who live alone are already more likely to experience poverty than the general population⁶³. This risk is likely to be significantly increased among those living with long term disability or who are at the end of life due to the significant additional cost of paying for care. The average hourly rate for a carer, for example, is around £20 and a live-in carer can cost around £650 a week⁶⁴.

The Severe Disability Premium (SDP), available to people living alone who do not have a carer in receipt of Carer's Allowance to look after them, provides critical support for people living alone and struggling with these additional care costs, but this has been abolished for new Universal Credit claimants. The loss of this premium could leave new claimants as much as £44–84 worse off each week⁶⁵. This is likely to lead to many people with terminal illnesses facing higher costs, and a higher risk of falling into poverty at the end of their lives, as a result of struggling to afford private care support.

People living with terminal illness and their families are also particularly vulnerable to fuel poverty, as the APPG for Terminal Illness found in 2021. The average energy bill of a terminally ill person doubles after their diagnosis, in large part due to the need for their homes to be kept warm to deal with physical symptoms, while the other associated costs of living with terminal illness reduce the ability of households to cope with these rising costs⁶⁶.

Marie Curie is particularly concerned in the context of recent and continuing rises in energy prices that many more families affected by terminal illness will be driven into poverty as the result of

higher fuel bills. While the UK's governments do provide support with energy costs, this support is often not designed with the needs of terminally ill people in mind, with many – especially those aged under 65 – unable to claim Winter Fuel Payments despite being particularly at risk of fuel poverty⁶⁷. People on low incomes living with a terminal illness are not also automatically eligible to claim support via the Warm Home Discount scheme unless they are over pension age, as automatic entitlement is available only to those receiving the guarantee element of Pension Credit⁶⁸.

Similarly, terminally ill people who are homeowners are unable to immediately access support with their housing costs via Support for Mortgage Interest loans unless they are over pension age and receiving Pension Credit⁶⁹. Working age homeowners who are receiving Universal Credit or Employment & Support Allowance may be eligible, but only after they have been receiving those benefits for nine months. This inflexibility leaves working age people affected by the financial impact of terminal illness unable to benefit from support with housing costs – an inescapable cost – for many months, potentially pushing them below the poverty line until support becomes available.

The impact on household finances brought on by terminal illness is not limited to the person who is terminally ill – nearly two-thirds of carers spend in excess of 50 hours every week caregiving and carers are less likely to work full-time than the general population⁷⁰.

Where a family member reduces or stops working to care for a loved one living with a terminal illness, the impact on household income is compounded, creating a 'double burden' on household finances which increases their risk of poverty⁷¹. It is therefore unsurprising that 31% of carers looking after terminally ill loved ones say they are struggling to make ends meet⁷².

Recommendations

8. The UK Department for Work & Pensions and the Northern Ireland Department for Communities must introduce a new 'self-care element' to Universal Credit to replace the Severe Disability Premium.

People who live alone are already at particular risk of poverty and this risk is compounded for people who need support from a carer and have to pay for this. The Severe Disability Premium provided critical support with these costs and its removal will leave many terminally ill people at higher risk of poverty as a result.

This 'self-care element' should be made available to all Universal Credit claimants who meet the eligibility criteria to have somebody receive Carer's Allowance or a carer element to look after them, but do not have somebody to do so.

9. The UK Department for Work & Pensions and Northern Ireland Department for Communities must ensure that those with a terminal illness are eligible for Winter Fuel Payments even if they are under 65 years old, and people on low income with a terminal illness are automatically eligible for the Warm Home Discount. The Scottish Government must also ensure this is the case for Winter Heating Assistance from November 2022.

Terminal illness can affect a person at any time of their life and at any time of year – limiting financial support to those of a certain age or in certain circumstances means that terminally ill people are denied the support they desperately need.

Given the particular vulnerability of terminally ill people and those at the end of life to fuel poverty, support with energy costs for them under Winter Fuel Payment/Winter Heating Assistance must be fast-tracked and available to be claimed at any time of year.

10. The UK Department for Work & Pensions and Northern Ireland Department for Communities should remove restrictions on Support for Mortgage Interest loans to terminally ill people if they meet the criteria to receive one, even if they are not in receipt of Pension Credit.

Limiting fast track support with mortgage costs only to pensioners leaves working age terminally ill people at risk of falling below the poverty line by denying them support with an inescapable cost at a time when their income is likely to have fallen and their other costs are rising.

11. The UK Department for Work & Pensions, Scottish Government Social Security Directorate and Northern Ireland Department for Communities must improve financial support for carers by increasing the value of the Carer Element of Universal Credit, and extending eligibility of Carer's Allowance and the upcoming Scottish Carer's Assistance for up to six months after the person's caring role ends.

Households where one person is living with a terminal illness or nearing the end of life, and another is caring for them full-time, are at significant risk of falling below the poverty line, with this risk persisting for carers even after their loved one has died.

Carers of people approaching the end of life must be able to focus on looking after their loved ones and making the most of the time they have left together, not worrying about their finances.

Teresa's story



Teresa, 64, lives in Brighton and has chronic obstructive pulmonary disease (COPD).

"I am being evicted in eight weeks. I applied to go into council housing. I went onto the housing register based on my disability. I was going to be re-housed as I'm deemed homeless.

It's the stress on the body. And you feel very alone. I'm scared that I will be evicted and end up in the gutter. I'm seriously scared that if I let all this take over and I worry about it I'm only going to get more ill. I am already terminally ill.

I can't even cook my food with my arm. I didn't eat last night. I get one hour of care a day. Now they're trying to say I need to take medication for my mental health issues, that they've created.

We hardly use the gas. I told the council I cannot afford it, and they left us all last

winter with no heating. It's cold. I never thought that I'd end up in this position. I don't know where to go, I don't know what to do. I don't know what I've done wrong or what I can do to make it right. And it will be another year with no heating.

A new place to live would be like winning the lottery. I would have my independence; I could get in my mobility electric scooter. Get out. Get to the beach. Talk to people. Be nice to other people. I don't have that opportunity to do that.

My friends say, 'you've got to get prepared for the worst.' I want someone to be on my side.

I'm not asking to be treated any better or more special than anyone else. I am seriously struggling.

"I'm scared that I will be evicted and end up in the gutter."

CHAPTER 4

Disparities between local authority areas

As with disparities between the UK nations, the risk of poverty at the end of life between different local authority areas follows the same pattern as the headline trends in the Centre for Research in Social Policy's study, and reflects the pattern of poverty risk among the general population. The three local authority areas with the highest risk of poverty among people at the end of life are in London, reflecting wider trends in the regional experience of poverty⁷³. Other large urban areas in the North of England, Midlands and Wales, including Manchester, Birmingham and Cardiff,

also show a markedly higher risk of local residents experiencing poverty at the end of their lives.

Tables 6 and 7 below show the 20 local authority areas with the highest proportion of working age residents and pensioners who died experiencing poverty in 2019.

Figures 2 and 3 on page 32 show the relative risk of poverty at the end of life among working age people and pensioners in every local authority area of the UK.

Table 6. Number and proportion of working age people dying in poverty, 2019 (top 20 UK local authorities)

Local Authority	Region	Number died in poverty	% died in poverty
Tower Hamlets	London	102	44.0%
Newham	London	163	43.5%
Hackney	London	128	42.0%
Manchester	North West	314	41.5%
Birmingham	West Midlands	645	41.5%
Leicester	East Midlands	168	39.8%
Slough	South East	70	39.3%
Southwark	London	142	39.2%
Newcastle upon Tyne	North East	156	38.7%
Brent	London	124	38.4%
Westminster	London	87	38.2%
Wolverhampton	West Midlands	153	38.0%
Lambeth	London	139	37.7%
Islington	London	100	37.6%
Nottingham	East Midlands	167	37.2%
Sandwell	West Midlands	187	37.1%
Middlesbrough	North East	98	37.0%
Lewisham	London	135	36.2%
Cardiff	Wales	169	36.2%
Camden	London	96	36.1%

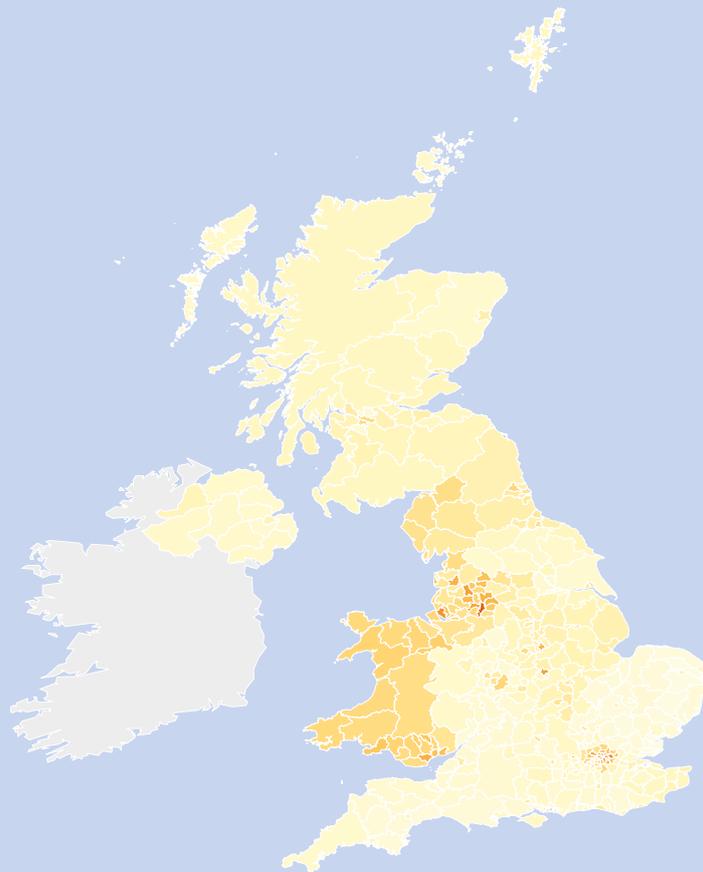
Table 7. Number and proportion of pensioners dying in poverty, 2019 (top 20 UK local authorities)

Local Authority	Region	Number died in poverty	% died in poverty
Manchester	North West	822	32.0%
Tower Hamlets	London	201	27.3%
Newham	London	251	26.9%
Hackney	London	198	26.0%
Liverpool	North West	922	25.9%
Leicester	East Midlands	482	24.3%
Blackburn with Darwen	North West	260	24.2%
Southwark	London	228	24.1%
Brent	London	317	23.6%
Salford	North West	400	23.6%
Westminster	London	191	23.5%
Lambeth	London	235	23.1%
Islington	London	182	23.0%
Cardiff	Wales	512	22.7%
Nottingham	East Midlands	428	22.5%
Preston	North West	231	22.4%
Rochdale	North West	362	22.3%
Lewisham	London	257	22.2%
Camden	London	190	22.1%
Oldham	North West	388	21.8%

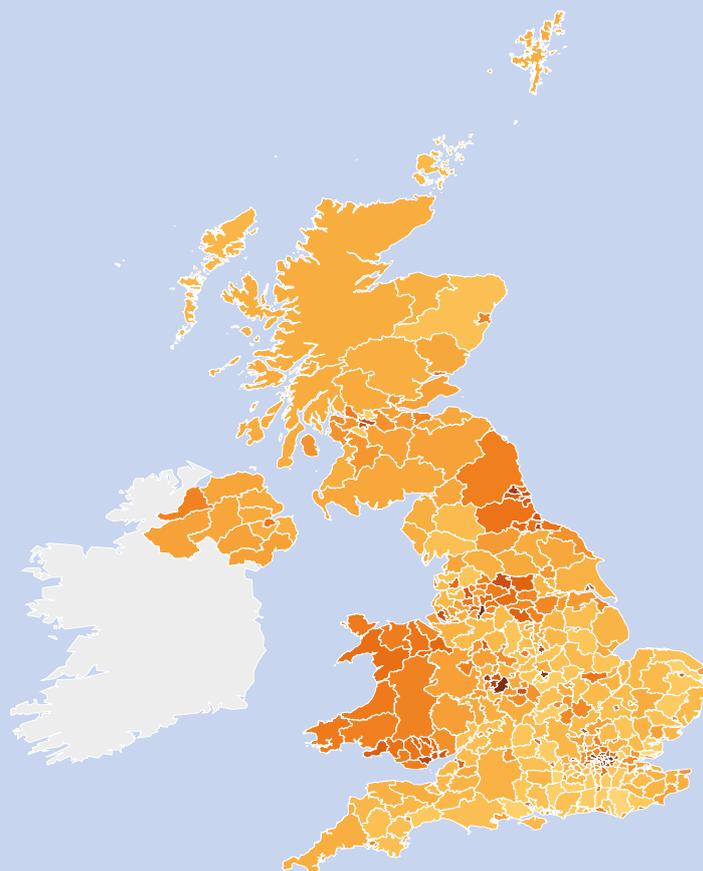
People in poverty in their last year of life

6.9%  44%

People of pension age



People of working age



Source: *Poverty at the end of life in the UK* (2022), Loughborough University

Local government support for people facing poverty

While much social security policy is outside the control of local government, there are important steps that local authorities can take to support local residents who are experiencing poverty or who are at risk of falling below the poverty line.

Given the scale of hardship among people living with terminal illness and approaching the end of life in some local authority areas, it is imperative that local policymakers in these areas – and all local government areas in the UK – urgently examine the assistance they are providing to people at risk of financial hardship in their area and take steps to ensure they are adequately supporting those nearing the end of life.

Council Tax Support (also known as Council Tax Reduction) can be a lifeline for households on a low income or claiming certain benefits, providing support from the local authority towards some – or in some cases all – of the cost of Council Tax. While Council Tax Support is a welcome means to support people who are hardest hit by a tax that is widely regarded as regressive and which disproportionately falls upon those least able to pay⁷⁴, both eligibility for the payment and the amount of support a person can get vary considerably across the country⁷⁵.

Although some terminally ill people may be able to claim (if, for example, they are receiving Pension Credit or have a low income) if they are under State Pension age, in many areas they may not get their full Council Tax costs covered. This means that, despite the particular risk of poverty faced by working age people at the end of life and the particularly high additional costs faced by terminally ill people⁷⁶, many will miss out on support with their Council Tax bills that is available to those who have already retired.

Similarly, Discretionary Housing Payments can be a vital source of support for households struggling to meet their housing costs due to either the Removal of the Spare Room Subsidy (RSRS, the ‘bedroom tax’) or if the Local Housing Allowance (LHA) is insufficient to meet their rent. The RSRS has seen one in five households on Universal Credit with a housing entitlement receive an

average monthly reduction of £70⁷⁷, while LHA rates have fallen considerably behind average rents in recent years⁷⁸.

As with Council Tax Support, however, eligibility criteria for Discretionary Housing Payments vary across the country and there is no requirement for local authorities to consider whether a person is terminally ill before deciding whether or not to make a payment. Given that the Centre for Research in Social Policy found housing tenure to be a strong predictor of households falling into poverty at the end of life – with those in private and social rented accommodation more at risk – there is a strong case to ensure that terminally ill people are made eligible for this support in all cases.

People living with terminal illness may need adaptations to their home to continue living at home with disability caused by their condition. The cost of these adaptations can be significant – the mean cost of major adaptations (such as installing a stairlift or wet room) is more than £16,000⁷⁹. Schemes like the Disabled Facilities Grant (DFG) in England and Wales provide financial support towards the cost of these adaptations but are beset by slow delivery timescales – in 2016/17 two in five English local authorities failed to pay all DFGs within a year of them being approved⁸⁰.

In addition, the DFG means test considers income and assets but does not consider outgoings. This means that the test fails to account for the real costs of living with terminal illness – the additional household costs brought on by terminal illness can be as much as £12,000–£16,000 each year⁸¹ – while the means test thresholds themselves have not kept pace with inflation and housing costs⁸². In practice, this means many terminally ill people are denied the financial support to make their home accessible despite not having the means to pay for it themselves.

Local authorities can also support residents at risk of fuel poverty and the health impacts of living in cold housing. The National Institute for Clinical Excellence (NICE) has issued guidelines which make a number of recommendations to Health & Wellbeing Boards (HWBs) in England and equivalent bodies in devolved nations, with recommendations including ensuring strategies are in place to address the impact of cold homes

and commissioning local single-point-of-contact health and housing referral services to support vulnerable people in cold homes⁸³.

However, implementation of the NICE NG6 guideline is patchy, with 40% of HWBs in England not having a cold homes strategy in place and only just over half having a single-point-of-contact

referral service in place⁸⁴. Local authorities can and must use their leadership role on HWBs (and Integrated Care Systems in England, which will have overlapping functions with HWBs from July 2022⁸⁵) to push for more progress on the implementation of NG6.

Recommendations

12. Local authorities must review their eligibility criteria for Council Tax Support and make terminally ill people eligible to claim up to 100% of council tax regardless of their age.

The variation in both eligibility for and support provided by Council Tax Support makes it difficult for many terminally ill people to know if they can claim assistance.

Those reaching the end of life are at a significantly higher risk of falling below the poverty line than the general population – this risk is especially pronounced for people of working age. In light of this, and the significant additional costs that households living with terminal illness face, it is inappropriate that many terminally ill people will be unable to claim Council Tax Support based on their age.

13. Local authorities should prioritise people with a terminal illness for Discretionary Housing Payments to help them meet their housing costs

if they are affected by the Removal of the Spare Room Subsidy, or if the Local Housing Allowance is insufficient to meet their housing costs.

Given that people living in social or private rented accommodation are at particular risk of falling into poverty at the end of their lives, and that lower-income renters spend

a higher proportion of their income on housing costs even after benefits are paid⁸⁶, councils should ensure those nearing the end of life are duly prioritised for support with their housing costs.

14. Local authorities must consider the outgoings of applicants for Disabled Facilities Grants as well as income and assets, and fast-track the processing and payment of grants to people living with terminal illness. In Scotland, Local authorities must fast-track terminally ill people eligible for financial and non-financial support through the Scheme of Assistance.

The high level of additional costs faced by people living with terminal illness or approaching the end of life are such that a means test which only considers income and assets risks unfairly denying them much-needed financial support with home adaptations.

Fast-tracking the processing and payment of grants will support people to stay in their homes towards the end of their lives without having to wait months before knowing whether or not they will receive financial support with the cost of adaptations, or before receiving that support after a payment is approved.

continued on page 17

Recommendations *continued*

15. Local authorities in England must use their leadership role on Health & Wellbeing Boards and Integrated Care Systems to ensure these bodies audit their compliance with NICE's NG6 recommendations on the health risks associated with cold homes, identify any gaps in compliance that exist and develop an action plan to urgently address these gaps.

Terminally ill people and those nearing the end of life are particularly vulnerable to fuel poverty – as energy prices rise, many more terminally ill people are at risk of falling below the poverty line as a result of spiralling energy costs and facing the health impacts of living in cold homes. Improving compliance with NICE's NG6 guidelines will ensure local authorities are doing all they can to support terminally ill people who are at risk of fuel poverty.



Conclusions

For the first time, this report lays bare the scale of poverty at the end of life in the UK.

More than 90,000 people every year – one in every six people who dies in the UK – reach the end of their life below the poverty line. As with the experience of poverty throughout life, people of all ages, from all walks of life and in every part of the UK are potentially at risk of dying in poverty.

Perhaps the most shocking revelation in this report is that the very fact of being terminally ill and reaching the end of life can substantially increase a person's risk of experiencing poverty. The 'double burden' of income loss and increased costs brought on by a terminal illness can leave even those who were previously comfortably-off struggling to make ends meet, and push those who were already on lower incomes or struggling to get by below the poverty line.

The Centre for Research in Social Policy's study has highlighted the unacceptably high risk of poverty at the end of life faced by too many groups within our society: working age people; families with dependent children; and shamefully, those from groups in our society that are already disadvantaged and at a higher risk of poverty throughout their lives – people from minority ethnic groups, women, and those from the UK's large urban centres.

For many of these groups, terminal illness is not the cause of the inequalities they face, but instead it magnifies existing and lifelong inequalities at the end of life. For others, the financial pressures brought on by terminal illness are the trigger that pushes them into poverty in the last months and years of their lives.

Too often, our social security system is failing to act as the safety net it was intended to be for those living with terminal illness and at the end of life. The real terms value of working age benefits has fallen significantly over the last decade, while too many benefits and other forms of financial support are unavailable to too many people living with terminal illness, leaving them ineffective as a safeguard against poverty for people at the end of life.

The end result is that too many families affected by terminal illness are falling through the safety net at the most vulnerable time in their lives – and falling below the poverty line.

The recommendations in this report would begin to address poverty at the end of life in the UK and help lift thousands of people and families each year out of poverty at the end of their lives – by making more benefits and financial support available to people and families at the end of life, by uprating the support we provide to carers and terminally ill people who live alone, and by ensuring the State Pension, the most effective safeguard against poverty in our social security system, is available to everybody at the end of their lives.

The UK, devolved, and local governments must now take urgent action to address the unacceptable risk of poverty at the end of life revealed by this report.

Nobody should die in poverty, forced to make impossible choices about whether to eat or heat their homes, worrying about how to pay their bills and make ends meet. Instead, they must be able to focus on what each of us would want at the end of our own lives – making memories with our loved ones and living as well as we can for as long as we are able.

References

1. Social Metrics Commission. [Measuring poverty 2020: A report of the Social Metrics Commission](#). July 2020.
2. King's Fund. [What are health inequalities?](#) February 2020.
3. *Ibid.*
4. Marie Curie. [The cost of dying](#). December 2019.
5. All-Party Parliamentary Group for Terminal Illness. [No place like home? Report of the APPG for Terminal Illness inquiry into housing and fuel poverty at the end of life](#). July 2021.
6. Social Metrics Commission 2020 *Op. Cit.*
7. *Ibid.*
8. Office for National Statistics. [Changing trends in mortality by national indices of deprivation](#). March 2020.
9. Goulden C and D'Arcy C. [A definition of poverty](#). Joseph Rowntree Foundation. September 2014.
10. Department for Work & Pensions. [Households below average income: an analysis of the income distribution FYE 1995 to FYE 2020](#). March 2021.
11. The Social Metrics Commission (SMC) is an independent and non-partisan commission formed to develop a new approach to poverty measurement. It includes, among others, commissioners from the Legatum Foundation, the Institute for Fiscal Studies, the London School of Economics and the Joseph Rowntree Foundation.
12. Social Metrics Commission 2020 *Op. Cit.*
13. Department for Work & Pensions. [Development of a new measure of poverty: statistical notice](#). February 2021.
14. Office for National Statistics. [Deaths registered in England and Wales: 2019 edition of this dataset](#). Obtained February 2022.
15. National Records of Scotland. [Deaths Time Series Data: Deaths, by sex and 5 year age groups, Scotland, 1901 to 2020](#). Obtained February 2022.
16. Northern Ireland Statistics & Research Agency. [Death Statistics: Deaths by age 1955–2020](#). Obtained February 2022.
17. Social Metrics Commission 2020 *Op. Cit.*
18. Marie Curie 2019 *Op. Cit.*
19. Resolution Foundation. [An Intergenerational Audit for the UK: 2019](#). June 2019.
20. Marie Curie 2019 *Op. Cit.*
21. Office for National Statistics. [Annual Survey of Hours and Earnings time series of selected estimates](#). October 2021.
22. Rightsnet. [Benefit and tax credit rates](#). Accessed March 2022.
23. Rateinflation. [United Kingdom Consumer Price Index: 1988 to 2022](#). Accessed March 2022.
24. Trades Union Congress. [Dying to Work](#). Accessed March 2022.
25. Financial Conduct Authority. [Retirement income market data 2020/21](#). December 2021.
26. Association of British Insurers. [Record amount paid out to help families cope with bereavement, ill health, and injury](#). May 2021.
27. All-Party Parliamentary Group for Terminal Illness. [Six months to live?: Report of the All-Party Parliamentary Group for Terminal Illness inquiry into the legal definition of terminal illness](#). July 2019.
28. *Ibid.*
29. Social Metrics Commission 2020 *Op. Cit.*
30. Age UK. [Making ends meet: Why pensioner poverty is still an issue](#). September 2021.
31. Women's Budget Group. [Women, Employment and Earnings](#). March 2020.
32. Fawcett Society. [No safety net for UK's worst paid women](#). March 2018.
33. *Ibid.*
34. Marie Curie 2019 *Op. Cit.*
35. Office for National Statistics. [Families and the labour market, UK: 2019](#). October 2019.
36. Office for National Statistics. [Families and households](#). March 2022.
37. Age UK 2021 *Op. Cit.*
38. Office for National Statistics. [People living alone aged 65 years old and over, by specific age group and sex, UK, 1996 to 2019](#). March 2020.
39. Office for National Statistics. [National life tables – life expectancy in the UK: 2018 to 2020](#). September 2021.

40. Due to limited sample sizes, the Centre for Research in Social Policy's study was only to make a reliable comparison between white ethnic groups (including British, Northern Irish, Irish, gypsy/Irish traveller and 'any other white background') and other ethnic groups, referred to here as 'minority ethnic groups.' Marie Curie recognises that there are likely to be important differences in experience within these groups as well as between them. However, the study's findings nevertheless provide important insight into the relative risk of poverty at the end of life among minority ethnic groups in the UK.
41. Social Metrics Commission 2020 *Op. Cit.*
42. *Ibid.*
43. Institute of Health Equity. [Health Equity in England: The Marmot Review 10 years on.](#) February 2020.
44. Office for National Statistics. [Ethnicity facts and figures: Unemployment.](#) January 2021.
45. House of Commons Library. [Which ethnic groups are most affected by income inequality?](#) August 2020.
46. Office for National Statistics. [Household wealth in Great Britain by ethnicity.](#) November 2020.
47. Cabinet Office. [Race Disparity Audit: Summary Findings from the Ethnicity Facts and Figures website.](#) March 2018.
48. Social Metrics Commission 2020 *Op. Cit.*
49. ONS 2019 *Op. Cit.*
50. Carers UK. [State of Caring 2021.](#) November 2021.
51. ONS 2022 *Op. Cit.*
52. Joseph Rowntree Foundation. [UK Poverty 2022: The essential guide to understanding poverty in the UK.](#) January 2022.
53. OECD. [Is childcare affordable?](#) June 2020.
54. Coram Family and Childcare. [Childcare survey 2021.](#) March 2021.
55. ONS 2022 *Op. Cit.*
56. ONS 2019 *Op. Cit.*
57. Marie Curie 2019 *Op. Cit.*
58. Carers UK 2021 *Op. Cit.*
59. Social Metrics Commission 2020 *Op. Cit.*
60. Cabinet Office and Northern Ireland Office. [Devolution settlement: Northern Ireland.](#) September 2019.
61. Scottish Government. [Responsibility for benefits: overview.](#) February 2017.
62. House of Commons Library. [Social security powers in the UK.](#) November 2020.
63. Social Metrics Commission 2020 *Op. Cit.*
64. NHS Choices. [Paying for your own care \(self funding\).](#) Accessed March 2022.
65. APPG for Terminal Illness 2021 *Op. Cit.*
66. *Ibid.*
67. *Ibid.*
68. *Ibid.*
69. Gov.uk. [Support for Mortgage Interest.](#) Accessed March 2022.
70. Carers UK 2021 *Op. Cit.*
71. Essue BM, Beaton A, Hull C, Belfrage J, Thompson S, Meachen M, Gillespie JA. [Living with economic hardship at the end of life.](#) BMJ Supportive & Palliative Care. June 2015.
72. Carers UK 2021 *Op. Cit.*
73. Social Metrics Commission 2020 *Op. Cit.*
74. Adam S, Hodge L, Phillips D and Xu X. [Revaluation and reform: bringing council tax in England into the 21st century.](#) Institute for Fiscal Studies. March 2020.
75. Age UK. [Council Tax Support.](#) Accessed March 2022.
76. Marie Curie 2019 *Op. Cit.*
77. APPG for Terminal Illness 2021 *Op. Cit.*
78. *Ibid.*
79. Mackintosh S, Smith P, Garrett H, Davidson M, Morgan G and Russell R. [Disabled Facilities Grant \(DFG\) and Other Adaptations – External Review.](#) Ministry of Housing, Communities & Local Government. December 2018.
80. APPG for Terminal Illness 2021 *Op. Cit.*
81. Marie Curie 2019 *Op. Cit.*
82. APPG for Terminal Illness 2021 *Op. Cit.*
83. National Institute for Clinical Excellence. [NICE Guideline NG6: Excess winter deaths and illness and the health risks associated with cold homes.](#) March 2015.
84. Marie Curie. [The vicious cycle of fuel poverty and terminal illness.](#) November 2020.
85. The King's Fund. [The health and social care White Paper explained.](#) March 2021.
86. Joyce R, Mitchell M, Norris Keiller A. [The cost of housing or low-income renters.](#) Institute for Fiscal Studies. October 2017.



For more information:

Mark Jackson

Policy Manager for England, Marie Curie

T: 0207 091 6640

E: Mark.Jackson@mariecurie.org.uk

Thank you to everyone who supports us
and makes our work possible. To find out
how we can help or to make a donation,
visit our website mariecurie.org.uk