

Dying in poverty

Examining poverty at the end of life in the UK Implications for Local Authorities





Introduction

he link between poverty and ill health is well-documented. People living below the poverty line are more likely to experience health inequalities throughout their lives, while experiencing ill health is a driver of poverty. Simply put, being in poverty is bad for your health and ill health is bad for your financial wellbeing.

This relationship 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 year, with terminally ill people also at particular risk of fuel poverty and less likely to be able to die at home.

Despite these well-established links, pre-existing data did not tell us how many people die experiencing poverty each year in the UK or which groups are most at risk.

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 according to the Social Metrics Commission's definition of poverty, 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 findings of this research lay bare the scale of end of life poverty in the UK for the first time. It shows that having a terminal illness can substantially increase a person's risk of experiencing poverty, and working age people with a terminal illness are particularly vulnerable to falling below the poverty line.

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

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: mariecurie.org.uk/ povertyatendoflifeintheuk

The full Marie Curie policy report, *Dying in Poverty*, can be read here: mariecurie.org.uk/dyinginpoverty

Key facts

- More than 90,000 people die in poverty in the UK each year.
- More than one in four terminally ill people of working age spend the end of life in poverty.
- Working age people at the end of life are twice as likely to be in poverty than pensioners.
- The three local authorities with the highest risk of poverty among people at the end of life are in London
- Other large urban areas including Manchester, Birmingham and Cardiff, also show a markedly higher risk of local residents experiencing poverty at the end of their lives.

Recommendations to Local Authorities

- 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.
- Prioritise people with a terminal illness for Discretionary Housing Payments to help them meet their housing costs.
- 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.

Poverty at the end of life

ne in every six people who died in the UK in 2019 was below the poverty line – more than 90,000 adults died in poverty.

The risk of poverty at the end of life across the UK follows the same pattern of poverty risk across the general population, with London, North East and

Table 1. Number and proportion of working age people dying in poverty, 2019 (top 20 UK local authorities)

higher risk of local residents experiencing poverty at the end of life. Tables 1 and 2 show the 20 Local Authorities across the UK with the highest proportion of working age people and pensioners dying in poverty.

West of England and Midlands showing a markedly

Table 2. Number and proportion of pensioners dying in poverty, 2019 (top 20 UK local authorities)

Local Authority	Region	Number died in poverty	% died in poverty	Loca	l Authority	Region	Number died in poverty	% died in poverty
Tower Hamlets	London	102	44.0%	Mano	chester	North West	822	32.0%
Newham	London	163	43.5%	Towe	r Hamlets	London	201	27.3%
Hackney	London	128	42.0%	Newl	nam	London	251	26.9%
Manchester	North West	314	41.5%	Hack	ney	London	198	26.0%
Birmingham	West Midlands	645	41.5%	Liver	pool	North West	922	25.9%
Leicester	East Midlands	168	39.8%	Leicester		East Midlands	482	24.3%
Slough	South East	70	39.3%	Blackburn with Darwen		North West	260	24.2%
Southwark	London	142	39.2%	South	nwark	London	228	24.1%
Newcastle upon Tyne	North East	156	38.7%	Brent	-	London	317	23.6%
Brent	London	124	38.4%	Salfo	rd	North West	400	23.6%
Westminster	London	87	38.2%	West	minster	London	191	23.5%
Wolverhampton	West Midlands	153	38.0%	Lambeth		London	235	23.1%
Lambeth	London	139	37.7%	Isling	ton	London	182	23.0%
Islington	London	100	37.6%	Cardi	ff	Wales	512	22.7%
Nottingham	East Midlands	167	37.2%	Nottingham		East Midlands	428	22.5%
Sandwell	West Midlands	187	37.1%	Prest	on	North West	231	22.4%
Middlesbrough	North East	98	37.0%	Roch	dale	North West	362	22.3%
Lewisham	London	135	36.2%	Lewis	sham	London	257	22.2%
Cardiff	Wales	169	36.2%	Camo	den	London	190	22.1%
Camden	London	96	36.1%	Oldh	am	North West	388	21.8%

You can view findings for all UK local authorities at mariecurie.org.uk/poverty

Working age and 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. More than one in four working age people who die are below the poverty line in their last year of life – meaning working age people who die are twice as likely to be in poverty as pensioners.

Leaving the labour market, and subsequently having to rely on the working age benefits system, is the single largest risk factor predicting a fall below the poverty line at the end of life. Without the fixed income provided by the State Pension and other lifetime savings to rely on, dying people of working age see their risk of falling below the poverty line rise by a third compared to other working age people.

By contrast, welcome efforts to tackle pensioner poverty by successive governments in the 21st century such as the State Pension triple lock mean that three-quarters of pensioners have never experienced poverty in the five years before their death and a pensioner's risk of poverty at the end of life is half that of a working age person.

Inequalities in the risk of poverty at the end of life

Women and people from ethnic minorities and families with dependent children are at 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.

Women are three times more likely to be in part-time employment than men in the working age population, and are disproportionally represented in low pay jobs. Women are also more likely to have dependent children and childcare costs than men, and are less likely to have substantial savings to fall back on if they leave the labour market.

Similarly, people from minority ethnic groups are at a substantially higher risk of experiencing

poverty than white ethnic groups, both in the general population and at the end of life. People from minority ethnic groups are likely to have 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.

Families with dependent children

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. Parents with dependent children are the most at risk of falling below the poverty line in the last five years of life.

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 families and costs having risen 4–5% in the last year.

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. 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 result, 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.

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.

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. Despite the particular risk of poverty faced by

terminally ill people of working age, many local authorities provide only limited support to those under State Pension age.

Marie Curie is calling for local authorities to 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. In light of the significant additional costs faced by terminally ill people and the particular vulnerability of working age people who die to falling below the poverty line, it is inappropriate that many terminally ill people will be unable to claim Council Tax Support based on their age.

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. 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.

Marie Curie is calling for local authorities to 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 rented accommodation are at particular risk of falling into poverty at the end of their lives, councils should ensure those nearing the end of life are duly prioritised for support with their housing costs.

People living with terminal illness may need adaptations to their home to continue living at home with disability caused by their condition. Schemes like the Disabled Facilities Grant (DFG) provide financial support towards the cost of these adaptations; however, the means test to determine eligibility for a DFG considers income and assets but does not consider outgoings. This fails to account for the real costs of living with terminal

illness, while the means test thresholds themselves have not kept pace with inflation and housing costs. 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.

Marie Curie is calling for local authorities to 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. The high level of additional costs faced by people living with terminal illness are such that the means test must consider their outgoings to ensure people are not unfairly denied support. 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.

Local authorities in England can also support local 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. However, our research has shown 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 place.

Marie Curie is calling for local authorities in England to use their leadership role on Health & Wellbeing Boards and Integrated Care Systems to ensure these bodies audit their compliance with NICE's NG6 recommendations.

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.



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