



Care and support
through terminal illness

Dying in poverty

Examining poverty at the end of life in the UK
Implications for Northern Ireland

Introduction

The number of people living with terminal illnesses in Northern Ireland has grown substantially over recent decades, and will only continue to increase in the years ahead. While policy conversations in this area tend to focus on health and social care service provision, an often-forgotten component that can significantly shape someone's end of life experience is their financial wellbeing.

Simply put, a dying person can have the best doctors and nurses in the world, but if they're struggling to put food on the table or heat their home, they will not enjoy the best quality of life possible.

This paper is based primarily on research that was commissioned by Marie Curie in 2021 and carried out by the Centre for Research in Social Policy at Loughborough University. That research examines the number of people who die in poverty across the UK as a whole, and individually in Northern Ireland, England, Scotland and Wales. It also assessed the risk of being in poverty at the end of life for different age groups.

We've known for a long time that many households impacted by terminal illnesses may struggle financially, but for the first time, this paper exposes the true scale of poverty at the end of life in Northern Ireland.

It shows that thousands of local people are reaching the end of their lives facing poverty – unable to make the most of the time they have left because of unaffordable bills and the constant worry about making ends meet.

It highlights the unequal impact of poverty at the end of life on different age groups and in different areas of Northern Ireland, and it makes a series of recommendations to help address the problem.

With the cost of living spiralling across the UK, policymakers and service providers need to renew their focus on the financial hardship facing terminally ill people and their loved ones. We hope this paper will make a small contribution to that crucial debate and act as a catalyst for much-needed change across Northern Ireland.

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 2,000 people died in poverty in Northern Ireland in 2019.
- One in four terminally ill people of working age spent their end of life in poverty in Northern Ireland.
- Working age people at the end of life were twice as likely to be in poverty as pensioners.
- People living in Belfast, Derry & Strabane, and Newry, Mourne & Down had the highest rates of people dying in poverty.

Recommendations to the Northern Ireland Executive

- **Terminally ill people of working age must be given access to the State Pension.**
- **Introduce a Warm Home Discount scheme and reform the eligibility criteria for Winter Fuel Payments.**
- **Make additional support with the costs of childcare available to all terminally ill parents.**
- **Improve financial support for carers by increasing the value of the Carer Element of Universal Credit.**
- **Introduce a Carers Allowance Supplement in Northern Ireland.**
- **Introduce a new 'self-care element' to Universal Credit to replace the Severe Disability Premium.**
- **Remove restrictions on Support for Mortgage Interest loans to terminally ill people.**

Recommendation to pension and life insurance providers

- **Ensure all working age terminally ill people can access the financial support they need from their policies.**

The picture in Northern Ireland

One in every seven people who died in Northern Ireland in 2019 was below the poverty line – 2,033 adults in Northern Ireland died in poverty.

Across Northern Ireland, the Belfast City Council area had the highest proportion of both working age people and pensioners who experienced

poverty in their last year of life, followed by Derry City and Strabane and Newry, Mourne and Down. In Belfast, nearly one in three working age people experienced poverty in the last 12 months of their life. Table 2 shows the proportion of working age people and pensioners dying in poverty in each of Northern Ireland's local government areas.

Table 1: Estimated number/proportion of people experiencing poverty in their last year of life in Northern Ireland in 2019

Age group	Number in poverty in last year of life	Proportion in poverty in last year of life
20–64	699	25.6%
65+	1,334	10.3%
Total	2,033	13.0%

Table 2: Proportion of working age people and pensioners dying in poverty, 2019 (NI local government areas)

Local Authority	% working age people died in poverty	% pensioners died in poverty
Belfast	29.6%	12.2%
Derry & Strabane	28.0%	11.6%
Newry, Mourne & Down	24.5%	10.1%
Fermagh & Omagh	24.4%	10.0%
Armagh, Banbridge & Craigavon	24.3%	10.0%
Causeway Coast & Glens	24.1%	9.9%
Mid Ulster	23.9%	9.8%
Antrim & Newtownabbey	23.5%	9.6%
Mid and East Antrim	23.5%	9.6%
Lisburn & Castlereagh	23.3%	9.5%
Ards & North Down	23.0%	9.4%

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

Summary of key research findings

Working age poverty at the end of life

Our findings show that the prevalence of poverty among people at the end of life is high across Northern Ireland as a whole, but it isn't felt equally by all age groups or in all areas.

More than one in four working age people in their last year of life in Northern Ireland were below the poverty line in 2019 – people of working age in Northern Ireland are more than twice as likely to experience poverty in the last year of life than pensioners.

This is likely explained by a range of factors. Being diagnosed with a terminal illness has a significant impact on a person's ability to continue work, and many loved ones will also reduce their working hours in order to provide informal care. More than four in five working age people affected by terminal illness in the UK report income loss as a result, with many giving up work entirely as their condition progresses or due to symptom burden. This means household income may take a drastic hit at the same time as people are faced with significant extra costs as a result of their illness – including expensive equipment and home adaptations, the costs of travelling to medical appointments and higher energy bills.

Those of pension age tend to be better protected from all of the trends above when they reach the end of life because of policies like the 'triple lock' on State Pensions and the greater likelihood of having savings and investments¹ to fall back on. Recent analysis from the Joseph Rowntree Foundation shows that one of the primary drivers

of the reduction in pensioner poverty in Northern Ireland since 2009 has been increased up-take of the State Pension among those in the bottom quintile of the income distribution².

By contrast, over the last decade the generosity of the social security system for those of working age has declined. Many terminally ill people of working age will come to rely on welfare support as a significant or primary source of income, but policies like the benefits freeze and below-inflation uprating have devalued the social security safety net and left it increasingly ineffective as a safeguard against poverty.

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 – restrictive rules governing these payouts mean that many families affected by terminal illness cannot access their savings until very near the end of life if at all.

Marie Curie is calling for terminally ill people of working age to be given access to the State Pension. The stark difference in the risk of poverty at the end of life between working age people and pensioners underlines the ineffectiveness of the working age benefits system as safeguard against poverty compared to the State Pension.

For many people the end of their life comes too early to enjoy this protection – even though they have paid into the system all of their lives. It cannot be right that a terminal illness leaves a working age person significantly more at risk of poverty in their final months and years, simply because they are not yet 'old enough.'

1 Resolution Foundation (2019). *An intergenerational audit for the UK: 2019*.

2 Joseph Rowntree Foundation (2022). *Poverty in Northern Ireland 2022*.

3 Demos (2017). *MND costs: Exploring the financial impact of motor neurone disease*.

Fuel poverty at the end of life

Terminally ill people are already at a heightened risk of experiencing fuel poverty, as their symptoms will often make them feel colder and they will spend increasing amounts of time at home with the heating on as their condition deteriorates.

To use just one example, average energy bills have been shown to almost double after a diagnosis of motor neurone disease³ – a condition that will affect many patients while they are of working age. This situation has gotten much worse as energy prices have skyrocketed across the UK during recent months, with many more families affected by terminal illness at risk of fuel poverty.

The support provided by the Warm Home Discount scheme has been described as a ‘lifeline’ for people in Great Britain – but no such scheme exists in Northern Ireland. Meanwhile, while people in Northern Ireland may receive support from Winter Fuel Payments, the restrictive eligibility criteria exclude those under the age of 65.

Marie Curie is calling for the introduction of a Warm Home Discount scheme and reform of the eligibility criteria for Winter Fuel Payments.

As energy bills in Northern Ireland continue to spiral, the Northern Ireland Executive must establish a local Warm Home Discount scheme that can be accessed automatically by anyone diagnosed with a terminal illness.

As outlined above, working age people are particularly vulnerable to poverty at the end of life – further extending support with the rising cost of energy by entitling terminally ill people aged under 65 to access Winter Fuel Payments will reduce the risk of working age people in Northern Ireland falling into poverty as a result of their condition.

Families with dependent children

Our UK-wide research shows that 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. While Northern Ireland-level data is not available, we can reasonably assume that this trend exists locally.

There has been a systemic lack of investment in Northern Ireland’s childcare sector for a number of years, with many parents finding the cost of quality childcare unaffordable⁴. Over 40% of local parents report having to regularly use the likes of overdrafts, credit cards and payday loans to cover childcare costs, and this rises to 55% among lone parents⁵.

Under ordinary circumstances, then, parents in Northern Ireland are struggling with the costs of childcare, this will be exacerbated by the additional financial pressures caused by a terminal illness.

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 give up work entirely.

Marie Curie is calling for the Northern Ireland Executive to make additional support with the costs of childcare available to all terminally ill parents. Support with childcare can be a lifeline for parents faced with balancing looking after their children and living with the impact of terminal illness. 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 without worrying about falling into poverty.

4 Employers for Childcare (2022). *Assembly election manifesto 2022*.

5 Employers for Childcare (2021). *Northern Ireland childcare survey 2021*.

The social security system

Our social security safety net should provide a safeguard against poverty – but too often it is failing to do so.

Many terminally ill people of working age will come to rely on welfare support as a significant or primary source of income, but policies like the benefits freeze and below-inflation uprating have devalued the social security safety net and left it increasingly ineffective as a safeguard against poverty.

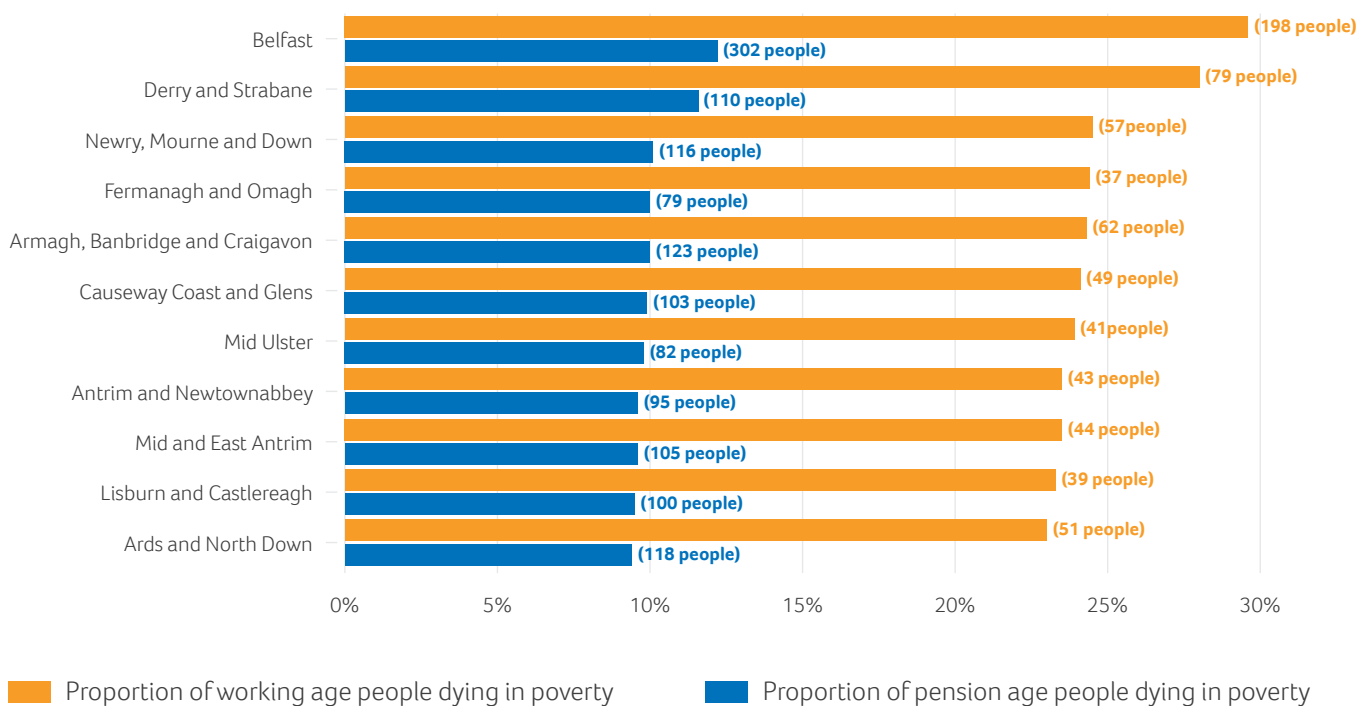
Looking at the varying rates of poverty among dying people across Northern Ireland’s council areas against claimant data for key working age benefits in 2019^{6,7} (Fig 1), we see that there is a general trend that, the higher proportion of people claiming key working age benefits in a council area, the higher the likelihood of poverty among working age people at the end of life.

While many factors will affect a person’s risk of poverty, the strong correlation between people claiming working age benefits and poverty rates suggests that these benefits, in their current form, are insufficient to protect dying people from poverty.

Marie Curie welcomes recent reform of the Special Rules for Terminal Illness in social security law, but these changes alone will not be sufficient to stop people at the end of life falling below the poverty line. Scrapping the six-month rule will allow dying people to access welfare support more quickly, but it doesn’t make the working age benefits system any more generous. It is clear, therefore, that further social security policy interventions are needed.

People who live alone are already more likely to experience poverty than the general population. This risk is likely to be significantly increased

Fig 1: Proportion of working age people dying in poverty/proportion claiming key working age benefits, local government area 2019



6 The Department for Communities’ list of key working age benefits is: Disability Living Allowance, Employment and Support Allowance, Incapacity Benefit, Income Support, Job Seekers’ Allowance, Personal Independence Payment, Carers Allowance and Severe Disablement Allowance.

7 Calculated using data from Department for Communities (2020). *Benefit statistics summary publication: Client group analysis – November 2019*.

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 abolition of the Severe Disability Premium – which provided additional financial support for people who live alone to help pay for care costs – under Universal Credit will leave new terminally ill claimants who live alone worse off and at a higher risk of falling into poverty at the end of their lives, as a result of struggling to afford private care support.

Restrictions should also be removed to allow terminally ill people of any age to access Support for Mortgage Interest loans 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.

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 population. 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 poverty.

The twice-yearly Carers Allowance Supplement payments for carers in Scotland have been shown to make a positive difference, particularly in helping carers who are struggling financially to pay for essential household expenses which may otherwise have been unaffordable⁸. We support the introduction of a Carers Allowance Supplement in Northern Ireland, which should be paid at the same value as the scheme in Scotland.

Marie Curie is calling for the Northern Ireland Executive to:

- **Introduce a new ‘self-care element’ to Universal Credit to replace the Severe Disability Premium.**
- **Remove restrictions on Support for Mortgage Interest loans to terminally ill people.**
- **Improve financial support for carers by increasing the value of the Carer Element of Universal Credit.**
- **Introduce a Carers Allowance Supplement in Northern Ireland.**

Support from private pensions and life insurance

Beyond the welfare system, the financial support provided by payouts from private pensions or life insurance policies can be invaluable for working age people who are diagnosed with terminal illnesses. However, the restrictive rules imposed by many providers mean that dying people cannot access the money they’re entitled to until they are very near the end of life – often having to prove that they have a life expectancy of less than six or 12 months in order to be eligible.

The unpredictable nature of many terminal conditions may make this burden of proof unachievable. This may leave a dying person unable to access the financial support they need until it is too late, if at all – plunging them and their loved ones into a position of poverty.

Marie Curie is calling for pension and life insurance providers to ensure all working age terminally ill people can access the financial support they need from their policies, regardless of life expectancy and prognosis.

8 Scottish Government (2020). *The evaluation of Carer’s Allowance Supplement*.



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