

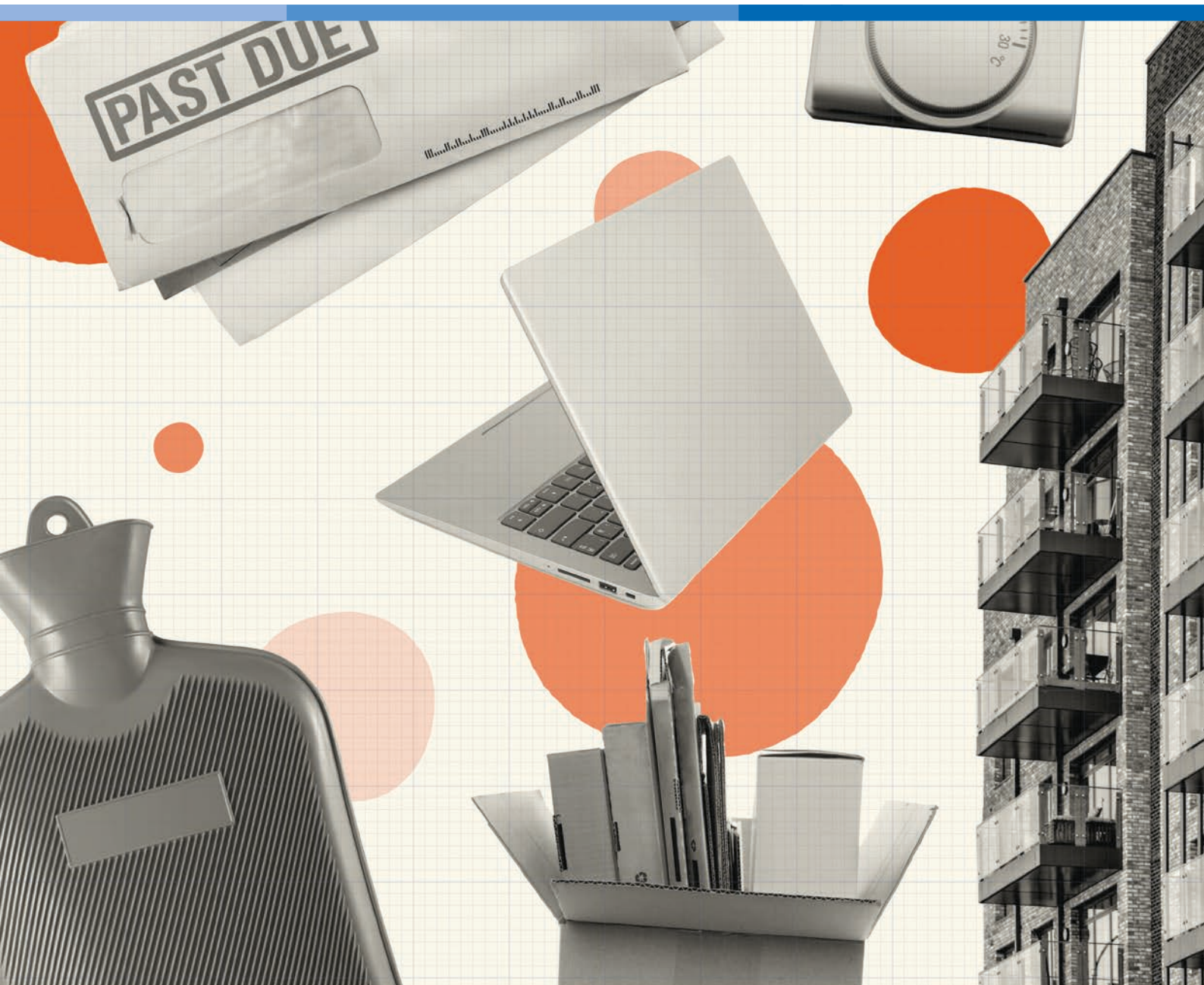


Gofal a chefnogaeth
drwy salwch terfynol

Care and support
through terminal illness

Dying in poverty

Examining poverty at the end of life in the UK
Implications for Wales



Introduction

Wales has the highest poverty rate of all the UK nations. Before the pandemic, 700,000 people were living in poverty¹. But the risk of poverty is not spread equally across the population, and the link between poverty and ill health is well-documented. 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 year because of lost income and additional costs families face. As energy prices soar, many terminally ill people are struggling to pay their heating bills – risking worsening symptoms, new infections, and even hastening death.

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.

This paper reveals the scale of end of life poverty in Wales. It shows that having a terminal illness can substantially increase a person's risk of experiencing poverty. In Wales, dying people are more likely to experience poverty at the end of their lives than in any other nation of the UK, and

working age people are at an ever greater risk of dying below the poverty line.

Thousands of vulnerable people are reaching the end of their lives unable to make the most of the time they have left because of spiralling bills and constant worries about making ends meet. Healthcare services can only do so much to support people to die well. Policymakers and service providers must also focus their attention on the financial hardship facing terminally ill people and their families.

We hope this paper and its recommendations will act as a catalyst to explore solutions for helping dying people in Wales avoid spending their final days in poverty.

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

- People in Wales are more likely to experience poverty at the end of life than in any other UK nation.
- More than 6,600 people die in poverty in Wales each year.
- One in three terminally ill people of working age spend their end of life in poverty in Wales.
- Working age people at the end of life are twice as likely to be in poverty than pensioners.
- People living in Cardiff, Newport, Blaneau Gwent and Swansea have the highest risk of dying in poverty.

¹ JRF (2020) *Poverty in Wales 2020*. All additional references can be found in to Marie Curie (2022) *Dying in Poverty* (mariecurie.org.uk/dyinginpoverty)

Recommendations to the Welsh Government

- Ensure that terminally ill people can access support from the Warm Homes Nest Health Pilot Scheme by explicitly including terminal illness within the eligibility criteria.
- Ensure that health and social care professionals are routinely and effectively signposting terminally ill people and their carers to welfare benefits advice.
- Review the support for childcare costs available to terminally ill parents.

Recommendations to Welsh Local Authorities

- Review eligibility criteria for the Council Tax Reduction Scheme to ensure terminally ill people can 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, income and assets of applicants for Disabled Facilities Grants, and fast-track the processing and payments of grants to people living with terminal illness.
- Use their influence within Regional Partnership Boards to encourage health board compliance with NICE guideline NG6: *Excess winter deaths and illness and the health risks associated with cold homes*. Among many initiatives, NICE NG6 requires boards to develop a strategy to address the health consequences of cold homes.

Recommendation to Welsh employers

- 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.

Many of the levers to address poverty at the end of life rest with the UK Government. Our recommendations to the UK Government which would affect people in Wales are set out in our full Marie Curie policy report *Dying in Poverty* (mariecurie.org.uk/dyinginpoverty). These include:

- Terminally ill people of working age must be given access to the State Pension.
- The UK Government must do more to understand and address employment, income and wealth inequalities experienced by women and people from minority ethnic groups.
- Make additional support with the costs of childcare through Universal Credit available to all terminally ill parents.
- Introduce a new 'self-care element' to Universal Credit to replace the Severe Disability Premium.
- Ensure that those with a terminal illness are eligible for Winter Fuel Payments even if they are under 65 years old.
- 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 and extending eligibility for Carer's Allowance for up to six months after the person's caring role ends.

The picture in Wales

One in every five people who died in Wales in 2019 was below the poverty line – 6,660 adults died in poverty.

Almost one in three (30%) working age people who died in 2019 spent the last year of their life in poverty (see Table 1).

Working age people in the last year of life see their risk of being in poverty increase by a third (32%) compared to working age people who are not in the last year of life. Those of working age were also almost twice as likely to die in poverty than those of pension age.

Cardiff had the highest rates of poverty at the end of life, where 36% of working age people and 23% of pensioners die in poverty.

Table 2 shows the proportion of working age people and pensioners dying in poverty in each local authority area in Wales.

Table 1: Number and proportion of people in Wales dying in poverty, 2019 by age and mortality status

	In last year of life		Not in last year of life	
	Number	%	Number	%
Working age (20–64 years)	1,512	30.4%	421,203	23%
Pensioners (65+ years)	5,148	18.4%	91,161	15.1%
Total population aged 20+	6,660	20%	512,364	21%

Table 2: Proportion of working age people and pensioners dying in poverty, 2019 by local authority area

Local authority	% working age people in poverty in last year of life	% pensioners in poverty in last year of life
Cardiff	36.20%	22.7%
Newport	33.40%	20.6%
Blaenau Gwent	32.60%	20.1%
Swansea	32.40%	19.9%
Merthyr Tydfil	31.30%	19.1%
Wrexham	31.00%	18.9%
Torfaen	30.30%	18.4%
Gwynedd	30.30%	18.4%
Neath Port Talbot	30.20%	18.3%
Rhondda Cynon Taf	30.00%	18.2%
Denbighshire	29.7%	18.0%
Caerphilly	29.7%	18.0%
Isle of Anglesey	29.2%	17.6%
Pembrokeshire	29.1%	17.6%
Ceredigion	29.1%	17.5%
Conwy	28.9%	17.4%
Vale of Glamorgan	28.5%	17.1%
Bridgend	28.5%	17.1%
Carmarthenshire	28.4%	17.1%
Powys	28.0%	16.8%
Flintshire	27.3%	16.3%
Monmouthshire	26.4%	15.7%

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

Who is dying in poverty and why?

Many people will have experienced poverty throughout their lives and continue to experience it as they reach the end of life. Others, however, are driven into poverty as a result of becoming ill. In this study, those who died between the ages of 20–64 years had a 32% higher risk of being in poverty compared to others in the same age group who were not in the last year of life. But among people of all age groups and in every part of Wales, being at the end of life is associated with a substantial increase in the risk of poverty compared to the local population.

A diagnosis of terminal illness is not only devastating for the health and wellbeing of a person and their loved ones – it can also have a devastating financial impact. 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. More information about the financial impact of terminal illness is available in Marie Curie's report, *The cost of dying*.

Working age people

Working age people (20–64 years) who died in Wales in 2019 were almost twice as likely as those of pension age (65 years and over) to experience poverty at the end of life. During the last five years of life, both being diagnosed 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 interact, with many people being forced to give up work because of their condition. More than four in five working age people affected by terminal illness report income loss as a result, with many giving up work entirely as their condition progresses or due to symptom burden.

By contrast, our UK-wide research shows three quarters of people dying after pension age in the UK have not experienced poverty at all in the five years before their death. This is in part a reflection of welcome efforts by successive governments to tackle pensioner poverty, such as the State

Pension triple lock. 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.

While social security powers are reserved to Westminster and many of the levers to address poverty rest with the UK Government, Wales-specific social security measures can still play an important role in easing cost of living pressures, as demonstrated throughout the pandemic.

We urge the Welsh Government to explore the recommendations in Marie Curie's full policy report – including moving forward with commitments to scrap the 'six-month rule' in the Special Rules for Terminal Illness and giving terminally ill people of working age entitlement to claim the State Pension – in a Welsh context and influence the UK Government to deliver on the changes necessary to benefit the Welsh population.

In addition, Marie Curie is calling on the Welsh Government to ensure that terminally ill people can access support from the Warm Homes Nest Health Pilot Scheme by explicitly including terminal illness within the eligibility criteria.

Marie Curie is also calling on the Welsh Government to ensure that health and social care professionals are routinely and effectively signposting terminally ill people and their carers to welfare benefits advice.

We also know that lost income and withdrawal from the labour market is a key reason why terminally ill people of working age experience poverty at the end of life.

Marie Curie is therefore calling on employers in Wales to 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.

Working age people with dependent children

Among people nearing the end of life, those in families with dependent children are the most vulnerable to experiencing poverty in the last five years of their life. The analysis shows that they are also the most likely to be 'moving in and out of poverty' during this period.

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 on the Welsh Government to acknowledge that working age people with dependent children are the most vulnerable to experiencing poverty at the end of life, and review the support for childcare costs available to terminally ill parents.

Locality

The risk of poverty at the end of life between different local authority areas in Wales broadly reflects the pattern of poverty risk among the general population. Large urban areas such as Cardiff and Newport have a markedly higher rate (see Table 2 on page 5).

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.

Marie Curie is calling on Welsh Local Authorities to:

- **Prioritise people with a terminal illness for Discretionary Housing Payments to help them meet their housing costs.**
- **Consider the outgoings, income and assets of applicants for Disabled Facilities Grants, and fast-track the processing and payments of grants to people living with terminal illness.**
- **Use their influence within Regional Partnership Boards to encourage health board compliance with NICE guideline NG6: *Excess winter deaths and illness and the health risks associated with cold homes*. Among many initiatives, NICE NG6 requires boards to develop a strategy to address the health consequences of cold homes.**

Women and people from minority ethnic groups

The research shows that women have a higher risk of poverty at the end of life than men, reflecting higher levels of poverty than men in the general population and persistent employment and income inequalities.

Similarly, there is a substantially higher risk of experiencing poverty among people from minority ethnic groups than white ethnic groups, both in the general population and at the end of life.

While terminal illness and reaching the end of life are not the causes of these inequalities, they are magnified by the additional financial impact of a terminal illness, which effectively 'locks in' the inequalities women and people from minority ethnic groups have experienced throughout their lives.

They are therefore likely to be less able to afford the additional costs and income loss brought on by terminal illness, and at particular risk of being below the poverty line as they reach the end of their lives.



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