

Dying in poverty



Care and support
through terminal illness

8,200 people experience poverty at the end of life every year in Scotland

New research into poverty at the end of life in Scotland (and the UK) undertaken by Marie Curie and Loughborough University Centre for Research in Social Policy. Full UK report here: mariecurie.org.uk/dyinginpoverty.

Key findings

- 1. 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 people struggling to make ends meet, and force those who were already on the threshold below the poverty line.
- 2. One in four working age people (aged 20–64) and one in eight pensioners (aged 65+) in Scotland experience in poverty in the last year of their life.**
- 3. Areas of high deprivation in Scotland¹ are linked with the areas most affected by poverty at the end of life.**
- 4. Working age people with dependent children are more likely to experience poverty at the end of life.**
- 5. Women are more likely to experience poverty than men due to long-standing, structural inequality** in the labour market, lower individual retirement income, and disproportionate unpaid care responsibilities. These inequalities are significantly magnified at the end of life.

Marie Curie is calling for:

- 1. Scottish Government to commit to increasing the Child Payment beyond the standard rate for terminally ill claimants of working age with dependent children**
- 2. a whole-system approach to tackling poverty at the end of life and deprivation in parallel, instead of addressing them as single issues**
- 3. Scottish Government to commit to extending eligibility for the upcoming Scottish Carer's Assistance for up to six months after the person's caring role ends**
- 4. the State Pension to be paid to terminally ill people of working age.**

Definition of poverty

The definition of poverty used in this research is from the Social Metrics Commission (SMC). The SMC definition of poverty uses household income after housing costs as its primary basis, but with two key adjustments²:

1. All material resources are incorporated, not just incomes, including available liquid assets.

2. The measure takes account of inescapable costs, including childcare and the extra costs of disability, by deducting them from income.

A more detailed report on UK implications from poverty at the end of life is here: mariecurie.org.uk/dyinginpoverty.

Study and methodology

New research by Marie Curie and Loughborough University Centre for Research in Social Policy examined the number of people who die in poverty in Scotland (and the UK) each year, and how the risk of being in poverty at the end of life varies for different groups.

Researchers combined administrative data on mortality rates at different ages with survey data that allows estimates of the poverty rates

in the general population at different ages and the relationship between poverty and mortality among individuals and households.

How people transition into poverty at the end of life was also investigated through conducting sequence analysis and event history analysis on data from the Understanding Society household survey.

² <https://socialmetricscommission.org.uk/>

The picture in Scotland

In 2019, 8,275 adults in Scotland died in poverty.

We already know that healthy life expectancy for people in the most deprived areas of Scotland is more than 24 years lower than in the least deprived areas for both men and women, and in the most deprived areas men and women spent more than a third of their life in poor health³.

This research emphasises the clear links between deprivation and poverty, and the importance of considering and addressing them in parallel, not as singular issues.

The differentiation in age and locality of people dying in Scotland is the consequence of long-standing structural inequality which is magnified at the end of life for people with a terminal illness, their families and carers. This has resulted in:

One in four working age people who die, and one in eight pensioners, in Scotland being in poverty at the end of their lives.

Table 1: Number/proportion of people experiencing poverty in their last year of life in Scotland, 2019

Age	Number in poverty in the last year of life	Proportion in poverty in the last year of life
20–64	2,801	26.5%
65+	5,474	12.2%
Total	8,275	14.9%

³ National Records of Scotland; Healthy Life Expectancy 2018–20

Key findings and implications

Fuel poverty at the end of life

On average, almost a quarter of Scottish households live in fuel poverty, with some of the most rural areas across the country being the most affected⁴:

- 40% of households in the Western Isles
- 33% in Highland
- 32% in Moray and Argyll & Bute.

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 deteriorates⁵.

Average energy bills have also been shown to almost double after a diagnosis of motor neurone disease⁶; a condition that will affect many patients while they are of working age. This has worsened in recent months as energy prices have skyrocketed in Scotland (and the UK):

Marie Curie is calling for the Scottish Government to commit to extending eligibility of the upcoming Winter Heating Assistance to terminally ill people, even if they are under 65 years old.

As energy prices in Scotland continue to rise, entitling all terminally ill people to access this support will reduce the risk of working age people in Scotland falling into poverty as a result of their condition.

Housing poverty at the end of life

Many terminally ill people prefer to receive palliative care and die at home where that is possible. **In 2020–21, over 90% of the last six months of life of those who died was spent in community settings⁷.**

But as a terminal illness progresses, adaptations to the home are often needed to meet terminally ill people's needs and help them to remain independent for as long as possible. Not only do terminally ill people face significant barriers getting the equipment and home adaptations they need, but these are also extremely expensive.

Marie Curie is calling for Scottish Local Authorities to commit to fast-tracking terminally ill people eligible for financial and non-financial support through the Scheme of Assistance, and through the use of a BASRiS form.

Locality

Given the long-standing prevalence of deprivation in Scotland, **neither deprivation or poverty should be considered or responded to as single issues**. The vicious cycle of poverty, deprivation and social exclusion affects thousands each year, and has deepened as a result of the pandemic with twice as many deaths from Covid-19 in the most socioeconomically deprived areas than in the least⁸.

When the research is analysed alongside the Scottish Index of Multiple deprivation, which measures deprivation across the country, **there are clear links between areas of high deprivation in Scotland and poverty at the end of life particularly in Glasgow, Dundee and Inverclyde⁹.**

4 Energy Action Scotland; [Scottish Fuel Poverty Map](#) (full list of Local Authorities available)

5 Marie Curie (2020). The vicious cycle of fuel poverty and terminal illness

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

7 Public Health Scotland; last six months of life spent in the community

8 National Records of Scotland; Deaths from Coronavirus

9 Scottish Index of Multiple Deprivation

Table 2: shows estimated proportion of people experiencing poverty in the final 12 months of life in 2019 by age group and local authority, and proportion claiming working age benefits 2016
(Source: [Nomis](#); [Official Labour Market Statistics](#); [Out of Work Benefits](#))

Local Authority	Age 20–64			Age 65+	
	No. in poverty in the last year of life (2019)	Proportion in poverty in the last year of life (2019) (rounded up or down to the nearest 0.5%)	Proportion claiming key working age benefits (2016) (rounded up or down to nearest 0.5%)	No. in poverty in the last year of life (2019)	Proportion in poverty in the last year of life (2019) (rounded up or down to nearest 0.5%)
Glasgow	551	35%	18%	811	17.5%
Dundee	107	31%	17%	198	15%
West Dunbartonshire	59	29%	18.5%	115	14%
Aberdeen	114	28%	9%	232	13.5%
Edinburgh	210	27.5%	9%	455	13%
Inverclyde	58	27%	18.5%	110	13%
North Lanarkshire	212	26.5%	16%	357	12.5%
North Ayrshire	87	26%	18%	172	12.5%
Renfrewshire	96	26%	14.5%	203	12.5%
Clackmannanshire	32	26%	15.5%	58	12%
East Ayrshire	73	25%	16.5%	145	12%
West Lothian	78	25%	13%	148	12%
Fife	174	24.5%	13.5%	390	11.5%
Falkirk	82	24.5%	13%	165	11.5%
Scottish Borders	45	24.5%	11%	127	11.5%
South Lanarkshire	152	24.5%	14%	326	11.5%
Dumfries & Galloway	67	24%	13%	181	11%
East Lothian	34	24%	9%	96	11%
Angus	46	24%	12%	133	11%
Midlothian	40	24%	12%	83	11%
Stirling	41	23.5%	9.5%	86	11%
Argyll & Bute	40	23.5%	11.5%	99	11%
Shetland	9	23.5%	7.5%	17	11%
Highland	102	23%	10.5%	234	11%
South Ayrshire	50	23%	14.5%	138	11%
Perth & Kinross	55	23%	10%	155	11%
Moray	30	23%	10%	96	10.5%
Western Isles	10	22%	10.5%	32	10%
Orkney	7	22%	9%	20	10%
Aberdeenshire	88	21%	8%	202	9.5%
East Renfrewshire	23	21%	9%	74	9%
East Dunbartonshire	28	20%	9%	88	9%

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

Table 2 shows:

- **Approximately one third of working age people and one fifth of pensioners experience poverty at the end of life in Glasgow, Dundee and West Dunbartonshire.**
- **Almost one fifth in these three Local Authorities were claiming key working age benefits.**

This clearly evidences deep rooted, systemic inequality in how terminally ill people, their families and carers are affected by unprecedented levels of financial hardship from decades of structural inequality, and how this is magnified through poverty at the end of life. It highlights:

The urgent need for whole-system reform in Scotland to tackle deprivation and poverty at the end of life in parallel, not as separate issues.

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. While the data set from Marie Curie and Loughborough University's research is only available on a UK wide level, the implications for Scotland are clear.

In Scotland we already know that¹⁰:

- Single adults (of all ages) and particularly single parent families (at 38%) experience higher levels of poverty than all people.
- Families with children, in particular almost 1 in 3 people in large families (families with three or more children, 32%), live in poverty.
- The poverty rate for people in minority ethnic families is more than double that of people in white families.
- 54% of people who are in families where no one is working are in poverty.

- Poverty rates for people in families that have part-time work are triple (at 30%) those of people in families where at least one person is in full-time work (at 10%).

Among people nearing the end of life in the UK, Marie Curie and Loughborough University's research has found that:

- 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 the group most likely to be 'mostly in poverty' during the last five years of life, and 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 being:
 - around 1.5 times more likely to move into poverty than single people of working or pension age
 - six times more likely to move into poverty than people in working age couples without children.

No matter their circumstances, parents must find a way to meet the costs of looking after their children. This is no different for families affected by terminal illness, yet it presents a much greater challenge:

Many working age parents affected by terminal illness who are unable to work will miss out on support with the costs of childcare despite being impacted by the additional costs of terminal illness, making childcare less affordable.

The Scottish Government doubled the Child Payment for low income families in 2022, aspects of which can be used to support childcare costs if that is the parents' choosing, and this is a good step in the right direction.

¹⁰ Joseph Rowntree Foundation; [Poverty in Scotland 2021](#)

However, there needs to be more done to support terminally ill people with dependent children who are already living in relative or persistent poverty, or at risk of moving into poverty because of a combination of childcare costs, other household bills such as energy and food, and end of life care costs:

The Scottish Government must commit to increasing the Child Payment beyond the standard rate for terminally ill claimants of working age with dependent children.

- Glasgow, Dundee and West Dunbartonshire were amongst several areas in Scotland which reflected the lowest proportion of lone parent families in employment¹³.

This evidence plainly highlights long-standing, structural inequality in the labour market, lower individual retirement income, and unpaid care responsibilities which have a significantly disproportionate impact on women. These inequalities don't lessen at the end of life, they magnify.

Women and unpaid care

Marie Curie and Loughborough University's research has found that (on a UK scale) 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. But these are not new findings.

In Scotland we already know that^{11,12}:

- Less than 12% of women receive the full basic state pension based on their own contributions.
- A woman's average retirement income is 53% of a man's because they take time out to care.
- The average woman working full-time is paid 15% less than a man. The pay gap is 35% less per hour for part-time workers.
- In Scotland in 2019, there were an estimated 144,000 lone parent families with dependent children in Scotland, 25% of all families with dependent children.
- The vast majority (92%) of lone parents in Scotland are women.
- Lone parent families are more likely to live in deprived areas.

Marie Curie and Loughborough University's research has highlighted that (on a UK level):

- If working age women lose their job or give up work, nearly two thirds have savings that would last a month or less, while a third have savings that would last less than a week¹⁴.
- 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 condition¹⁵.
- Exiting the labour market is the single biggest risk factor for falling below the poverty line in the last years of life.

Existing research has also shown that^{16,17,18}:

- Around 70% of unpaid carers in Scotland are female.
- Women take on caring responsibilities twelve years earlier than men.
- The average person in Scotland has a 50:50 chance of caring by age 49, long before they reach retirement age.
- 69% of people claiming Carers Allowance (to May 2021) were women.

11 Engender: [Taking forward the Government Economic Strategy; a discussion paper on tackling poverty, inequality and deprivation in Scotland](#)

12 Public Health Scotland: [Child Poverty in Scotland; priority groups; lone parent families](#)

13 Based on those claiming tax credits (full list at Public Health Scotland: [Child Poverty in Scotland; priority groups; lone parent families](#))

14 Ibid

15 Marie Curie 2019 Op. Cit.

16 [Carers Scotland; Facts and Figures](#)

17 Scottish Government; [Carers Census Scotland 2019-20 and 2020-21](#)

18 Disability, Carer Benefits to May 2021; Social Security Scotland

The role of being a carer has a huge impact on the life of the person they are caring for. Costs for unpaid care are usually categorised into three main areas¹⁹, and have risen sharply during the pandemic:

1. **Work related** (e.g. changes in employment such as going part-time or giving up work entirely)
2. **Carer time costs** (related to time investment required by carers)
3. **'Out of pocket costs'** (direct outgoings including transport, food, medicines).

In Scotland, carers have access to an Adult Carer Support Plan (ACSP) or Young Carers Statement (YCS) from their local authority to ensure that a carer's information, wishes, plans and goals for caring are captured. But this can also lead to further statutory support such as respite care or direct payments to support the person in their caring role.

The financial burden of caring is currently recognised through the Carer's Allowance, and Carer's Allowance Supplement in Scotland, which some carers are eligible for.

But once a caring role comes to an end it can have a significant impact on the carer's wellbeing, financial position, relationships and virtually every aspect of their life. Much of the support provided to them while they were a carer is withdrawn following the death of the person they were caring for. It is imperative that urgent action is taken to address this, and as such:

Scottish Government must commit to extending eligibility for the upcoming Scottish Carers Assistance Payment for up to six months after the person's caring role ends.

19 Gardiner, C et al *Equity and the financial costs of informal care giving in palliative care: a critical debate* BMC Palliative Care 2020

What does this research mean?

Marie Curie and Loughborough University's research has truly laid bare the extent of end of life poverty in Scotland. Being terminally ill and reaching the end of life can substantially increase a person's risk of experiencing poverty,

and **decades of structural inequality has been a driving factor in one in four working age people, and one in eight pensioners in Scotland, dying in poverty at the end of life.**

What needs to happen?

While the Scottish Government's implementation of a clinical judgement definition of terminal illness under the Special Rules for Terminal Illness for disability benefits in Scotland is welcome, meaning terminally ill people no longer have to prove they have less than six months to live to be fast-tracked for disability benefits, the 'double burden' of income loss and increased costs brought on by a terminal illness can leave people struggling to make ends meet, and force those who were already on the threshold below the poverty line.

There is an urgent need for systematic reform to ensure that terminally ill people, their families and carers are not faced with unprecedented financial hardship in the final years, months, weeks, days and hours of their lives. This will require a whole-system approach, collaboration and transformative leadership on national and local levels.

Marie Curie is calling for:

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- 2. a whole-system approach to tackling poverty at the end of life and deprivation in parallel, instead of addressing them as single issues**
- 3. the Scottish Government to commit to extending eligibility of the upcoming Winter Heating Assistance to terminally ill people, even if they are under 65 years old**
- 4. Scottish Local Authorities to commit to fast-tracking terminally ill people eligible for financial and non-financial support through the Scheme of Assistance, and through the use of a BASRiS form**
- 5. Scottish Government to commit to extending eligibility for the upcoming Scottish Carer's Assistance for up to six months after the person's caring role ends**
- 6. the State Pension to be paid to terminally ill people of any working age.**

About Marie Curie in Scotland

Marie Curie provides care and support for people living with a terminal illness and their families and carers. We provide support through our two hospices in Glasgow and Edinburgh, as well as our community nursing services across 31 local authority areas, and our volunteer led services.

We also provide nationwide support through our information and support service including our national helpline. Marie Curie is also the biggest charitable funder of palliative care research in the UK. In 2020/21, we provided

care for over 9,000 people living with a terminal illness, as well as their families and carers across Scotland; our highest ever since the charity was established in 1948.

Our vision is for a better life for people living with a terminal illness, their families and carers. Our mission is to help people living with a terminal illness, their families and carers, make the most of the time they have together by delivering expert care, emotional support, research and guidance.



For further information contact:

Ellie Wagstaff

Policy and Public Affairs Manager for Scotland, Marie Curie

ellie.wagstaff@mariecurie.org.uk

@MarieCurieSCO