

Exploring the financial and employment impacts of end of life unpaid caregiving in the UK: Policy briefing

January 2025

About Marie Curie

Marie Curie is the UK's leading end of life charity. We are here for anyone with an illness they're likely to die from, and those close to them. We bring 75 years of experience and leading research to the care we give at home, in our hospices and over the phone. And we push for a better end of life for all by campaigning and sharing research to change the system.

Executive Summary

- New research has found that there are an estimated 150,000 – 180,000 unpaid household carers (those living in the same home as the person they are caring for). Overall, it is estimated there could be up to 762,000 end of life carers in the UK each year.
- 16% of unpaid household carers will become end of life carers at some point.
- 15% of unpaid household end of life carers were found to be living in poverty. This number increases in the year following a bereavement by 47% (to 22%)¹.
- Many unpaid end of life carers of working age are struggling to balance their caring and employment responsibilities.
- There is an urgent need for policy changes aimed at improving financial and employment outcomes for end of life carers, including extending Carer's Allowance entitlement from two months to six months after a bereavement and introducing paid Carer's Leave for employees with unpaid caring responsibilities.

¹ This is using the Poverty Index as defined by the Social Metric Commission – one of two measures of poverty used in this research. Using the other (whether above or below a threshold of 60% of the median household equivalised income), shows 10% of unpaid household carers are living in poverty, rising to 32% in the year following a bereavement.

Introduction

Unpaid carers (who are often family members but can also be friends or other people providing care and support without payment) play a critical role in providing support and care to individuals at the end of life, often juggling multiple responsibilities and facing significant emotional and practical challenges. Evidence consistently shows that the presence of a carer leads to better outcomes for patients at the end of life and alleviates pressure on the healthcare system².

There is a significant financial burden associated with unpaid caregiving at the end of life, which has been intensified by the ongoing cost of living crisis - nearly two-thirds of carers feel that rising costs have had negative impacts on their physical and mental health³.

Unpaid caring can also affect carers' employment, exacerbating financial pressures by forcing them to take unpaid leave, change jobs, use annual or sick leave, or even leave employment entirely to meet the demands of caring⁴.

This briefing presents key findings from important new research into the financial and employment impacts of providing unpaid care to someone approaching the end of life and explores their policy implications. It also includes lived experience testimony from Audrey, who cared for her husband at the end of his life.

'Exploring the financial and employment impacts of end of life unpaid caregiving in the UK' fills gaps in research evidence in this area.

This new research also provides the first UK population level estimates of the number of end of life carers annually.

The researchers from the University of Sheffield, the University of Leeds and Loughborough University analysed data from the UK Household Longitudinal Survey, as well as population data from the Office of National Statistics and data from the Health Survey for England. The research was supported by patient and public involvement collaborators and was funded by Marie Curie.

The full report is available [here](#).

² Hospice UK (2018) [Carers Report : 10 recommendations for achieving organisational change](#).

³ Carers UK (2023). [State of Caring 2023: The impact of caring on finances](#)

⁴ Gardiner C, Taylor B, Goodwin H, Robinson J, Gott M. Employment and family caregiving in palliative care: An international qualitative study. *Palliative Medicine*. 2022 Jun;36(6):986-993.

There are hundreds of thousands of unpaid carers across the UK providing care to people at the end of life

This research has produced the first population level estimates of the number of unpaid household end of life carers in the UK. It suggests that a minimum of 150,000 people, and potentially up to 762,000 people each year are caring for someone at the end of life⁵. The upper estimate would equate to around 1% of the UK population.

The research also explored the characteristics of the end of life caring community, to further understanding of this understudied group of people. There was a notable overrepresentation of females among end of life carers compared to carers overall, which is concerning given the existing evidence of various gender inequalities in end of life care⁶. End of life carers were also found to be older on average than carers overall (who are in turn older on average than the general population). In other ways, including in ethnic makeup and geographical representation across the UK, end of life carers more closely resemble the general population.

CASE STUDY

Audrey, 64, from County Durham, shares her experience of caring for her husband of 37 years, Eddie, when he was diagnosed with pancreatic cancer.

"Before all of this, Eddie had a really good wage. I worked for the NHS full time, then went down to part time so I could look after him. He got PIP [Personal Independence Payment] and ESA [Employment and Support Allowance]. We had to both apply for Universal Credit, but because I was working, they took my wages off what he was getting, so he was only getting £39 a month."

"I didn't have enough money to pay all the bills, and the credit cards and things, so that's when I had to declare myself bankrupt. I tried to not burden Eddie about money, but sometimes you have to because you have to talk about things. One morning I said to him, 'Eddie, I need to talk to you. We're having problems with money, and I'm going to have to declare myself bankrupt.' He got really upset and cried. Both of us cried together. You know, you're worried about the person that you love dying, and then you're having to worry about money on top of that. Nearly three years on, I am still dealing with the consequences of going bankrupt. I have only now been able to get credit from some places to try and rebuild a good credit history."

⁵ The wide variation in estimates is attributable to the different sources used by the researchers. Data from the UK Household Longitudinal Survey indicates that there are at least 150,000 -180,00 end of life carers in the UK annually living in the same home as the person they are caring for. Data from the Health Survey for England indicates that the number of end of life carers overall (including those living in a different home from the person they are caring for) could be as high as 686,000 - 762,000.)

⁶ Gott M, Morgan T, Williams L. Gender and palliative care: a call to arms. *Palliat Care Soc Pract.* 2020 Oct 15;14:

Too many end of life carers are struggling financially

It was already well established that those who provide unpaid care are at a greater risk of living in poverty than those who do not. These new findings demonstrate that end of life carers are at an even greater risk of poverty than other unpaid carers.

The financial burden of end of life caring can be substantial. The research found that a large number of carers (15%) were living in poverty. This finding echoes separate research findings by Marie Curie around the extent of poverty at the end of life – 111,000 people are dying in poverty each year in the UK, more than 300 people every day⁷. Terminal illness can cause a significant reduction in a household's income, and bring increased energy, transport and childcare costs, which can affect both the terminally ill person and the household carer.

For many end of life carers, financial pressures worsen after the transition into bereavement

Worryingly, our findings also reveal that being an end of life carer leads to a substantial increase in poverty in the year after providing care. The likelihood of a carer being in poverty increased by 47% after the death of the person being cared for, with household income falling during this period. This research builds on previous findings, including those of the UK Commission on Bereavement which found that 43% of bereaved adults experience financial difficulties because of their bereavement, often resulting from a drop in household income⁸.

In addition to adjusting to a very different family income, bereavement also brings significant additional costs, including paying for the funeral and settling debts, all while needing to maintain mortgage or rent payments. More than one in ten (11%) bereaved people are forced to move home as a direct result of their bereavement, with private renters, young people and those living in London most affected⁹. We welcome the Government legislating through its Renters Rights Bill to amend Ground 7 (Death of a Tenant) as a ground for eviction, which will provide greater housing security for bereaved tenants in the private rented sector.

Marie Curie also welcomes the introduction of bereavement leave in the Employment Rights Bill, however it is important that bereavement leave is paid to help mitigate the financial impacts of bereavement and to ensure that workers are not penalised financially for taking the time to grieve the death of a loved one, or forced to return to work before they are ready, increasing the risk of disturbed grief and associated mental health impacts.

⁷ Marie Curie (2024). [Dying in Poverty 2024: Exploring poverty and fuel poverty at the end of life in the UK.](#)

⁸ UK Commission on Bereavement (2022). [Bereavement is everybody's business.](#)

⁹ Marie Curie (2024). [Housing insecurity through bereavement.](#)

Too many end of life carers are struggling to balance their employment and caring duties

Many end of life carers are of working age and therefore potentially need to balance responsibilities around caring and working. End of life caring can impact significantly on the carer's professional life. Marie Curie's Better End of Life research found many end of life carers struggling financially as a consequence of having to take unpaid leave, change jobs, take annual/sick leave, or leave employment entirely in order to cope with the demands of caring.¹⁰

We welcome the new entitlement to a week of unpaid Carer's Leave introduced through the passage of the Carer's Leave Act, but as it is unpaid many carers will not be able to benefit from it (particularly those on low incomes). There is strong evidence indicating that offering working carers access to paid Carer's Leave, as is available in some other countries, could deliver significant benefits for carers, employers and the economy^{11 12}. The UK Government should use its Employment Rights Bill to set a path towards introducing paid Carers Leave.

We need a greater focus on the needs of end of life carers and to improve the coordination of care

Identification of carers is a significant barrier to carers accessing the support they need and are eligible for in their caring role. Recognising their statutory duties under the Care Act, local authorities must ensure every carer is offered a Carer's Needs Assessment at least annually, with prompt follow up after initial invitation and whenever their caring responsibilities change. This should include an assessment of financial needs.

We also require changes in policy and practice to improve palliative and end of life care. Too many people are struggling to access the joined-up care and support they and their unpaid carers need at the end of life, while a lack of co-ordination can create challenges for carers in knowing who to contact for help or understanding what is available. Better community care that is easier to navigate, including ensuring good provision of out of hours support, could help to reduce the burden on unpaid end of life carers.

¹⁰ Marie Curie (2024). [Better End of Life: Time to care.](#)

¹¹ Carers UK (2024). [Taking the next step for working carers. Introducing a new right to paid Carer's Leave.](#)

¹² Gardiner C (2024). [Financial support at the end of life: an international comparison: Churchill Fellowship Final Report](#)

Policy recommendations

These new research findings show a clear need for policy changes to improve support for end of life carers.

- 1) The Department for Work and Pensions should:
 - extend Carer's Allowance entitlement from two months to six months after a bereavement;
 - guarantee a State Pension-level of income for working-age people living with a terminal illness, to provide better financial support for them and their household at the end of life;
 - raise awareness and improve communication about Bereavement Support Payment and extend eligibility to those whose partner was unable to make sufficient National Insurance contributions due to sickness or disability; and
 - raise awareness and improve communication about Funeral Expenses Payment and extend this benefit to currently excluded groups, including students.
- 2) The Ministry for Housing, Communities and Local Government should enhance protections for bereaved tenants by extending the exemption from the Under Occupancy Charge (bedroom tax) from three months to one year after a bereavement.
- 3) The UK Government should legislate through its Employment Rights Bill to introduce a new statutory right to:
 - paid Carer's Leave for employees with unpaid caring responsibilities; and
 - paid Bereavement Leave of at least two weeks.
- 4) Local authorities should ensure that every carer of someone with a terminal illness is offered a Carers Needs Assessment at least annually (including an assessment of financial need), and when their caring role ends to support the transition into bereavement.

For more information:

Matt Whittle, Senior Policy Manager (matthew.whittle@mariecurie.org.uk)