Understanding Society

EXPLAINER

Should terminally ill people get early pensions?

End of life charity Marie Curie launched a campaign in 2023 calling on the government to start paying state pensions early for people who are diagnosed with a terminal illness. This followed a report, Poverty at the end of life in the UK, which used Understanding Society data

The findings

The report, by Juliet Stone and Donald Hirsch at the Centre for Research in Social Policy at Loughborough University, says more than 90,000 people a year experience poverty during the last year of their lives.

It also showed that:

- 6% of people dying fell into poverty in the last year or two years of their life
- 13% of working age parents who die have recently fallen into poverty

Pathways into poverty

Using Understanding Society, and the Social Metrics Commission's definition of poverty, the report also identified four trajectories of poverty in the five years before a person's death:

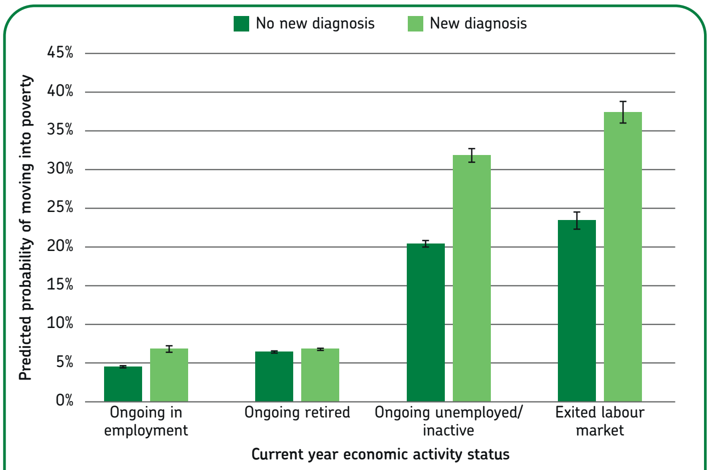
- never in poverty
- mostly in poverty
- moving into poverty at the end of life
- moving in and out of poverty at the end of life.

Within these, they found differences by age, ethnicity, housing tenure, health, and employment status.

If people died at pension age, three quarters did not experience poverty in the last five years of life, but if they were of working age, the majority experienced poverty at some point in the last five years of their lives. "A substantial minority", the research says, "move below the poverty line in the last two years of life, or experience movement in and out of poverty."

People in minority ethnic groups were "particularly likely to move into poverty at the end of life, or to be consistently in poverty", and people who rented their home were more at risk than those who owned or had a mortgage.

In the last five years of life, "reporting a newly diagnosed health condition shows a significant association with moving into poverty during the same 12 month period". Also, people who were consistently unemployed or 'inactive' were likely to move into poverty, but the group at the highest risk was those who had been in work, but had to stop working. These last two risk factors interacted: people who were unemployed or economically inactive, or left the labour market, saw their risk of moving into poverty increase substantially if they were also diagnosed with a new health condition.



Predicted probability of moving into poverty at the end of life by economic activity and health status

Using the data

The authors worked out the relationship between poverty and mortality, and examined pathways into poverty at the end of life, using Understanding Society data covering 2009-19. They divided the sample into four age groups – 20-44, 45-64, 65-79 and 80+ – and calculated the proportion of people in each group who were in poverty. Because Understanding Society follows people over time, they were also able to see if those who died had been in poverty in the last 12 months of their life.

At each wave, Understanding Society asks about people included in the previous wave, and if any participant has died since the last interview. As the report says, "While this is unlikely to capture every death during follow-up, this is the best and largest available source of data that provides longitudinal information on mortality and other sociodemographic characteristics for the same people over time".

The poverty trajectories identified in the report were based on respondents who had participated in at least five years of the Understanding Society survey and were later recorded as having died.

The report also uses:

- data from the Family Resources Survey to estimate poverty in different groups of the population
- mortality rates from the Office for National Statistics, National Records of Scotland, and the Northern Ireland Statistics and Research Agency
- local area data on poverty from the Indices of Multiple Deprivation.

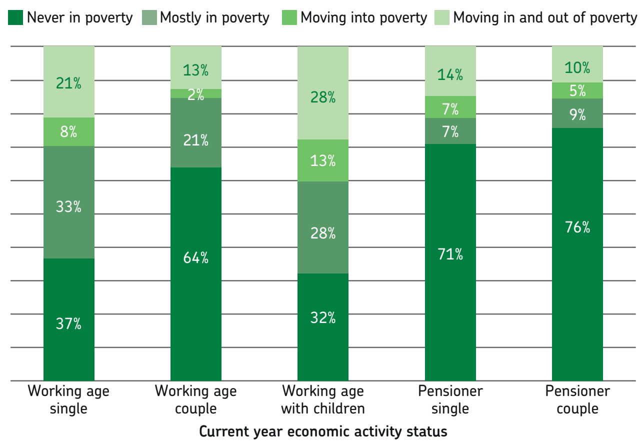
> the sheer extent of poverty in minority ethnic groups at the end of life is a major cause for concern

Poverty at the end of life in the UK was written by Juliet Stone and Donald Hirsch, Centre for Research in Social Policy, Loughborough University

Printed on carbon balanced paper.

Conclusions

The factors driving financial difficulties are more complicated for people of working age than they are for pensioners, because they can include giving up work, and therefore salary. Household composition is important, too: families with children are particularly vulnerable to moving into poverty in the last 12 months of life.



Risk of poverty trajectory by family type

The report says, "This suggests that additional financial support is needed to address, for example, loss of income and the added pressures of childcare and mortgage costs." On the question of ethnicity, it adds: "While inequalities in poverty risk between white and minority ethnic groups are no greater for those who are dying than for those not dying, the sheer extent of poverty in minority ethnic groups at the end of life is a major cause for concern, and suggests that targeted support is needed."

Next steps

Marie Curie, which provides nursing and hospice care, and other services related to dying, death and bereavement, wants terminally ill people of working age to:

- be entitled to claim the State Pension
- get targeted help with energy bills
- get help with childcare costs.

It adds that the change would cost £114m a year, which is 0.1% of the annual state pension bill.

Read Poverty at the end of life in the UK (PDF)

Read more about Marie Curie's campaign