

DATA INSIGHTS_

Deprivation and informal care at the end of life

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Informal care is a pillar of our healthcare systems: around 1 in 8 people are identified as carers in the United Kingdom. At the end of life, unpaid carers provide substantial help with activities of daily living, including communication with healthcare professionals and handling medication. However, the availability of informal carers and factors influencing access to them are not well researched. Our research highlights that people who live in poorer neighbourhoods or have a lower socio-economic position themselves are more likely to live alone at the end of life and thus do not have access to informal care within their own household.

WHAT WE DID

We linked the Scottish Census 2011 to death records and community health records to look at everyone who died within a year of the Census. Living alone was used as an indicator that shows who does not have access to informal care in the household, and housing tenure and the Scottish Index of Multiple Deprivation represented measures of deprivation on the individual and the neighbourhood level respectively. Since people living in different housing and different neighbourhoods may also differ in other characteristics, we also accounted for variations in age, gender, and cause of death.

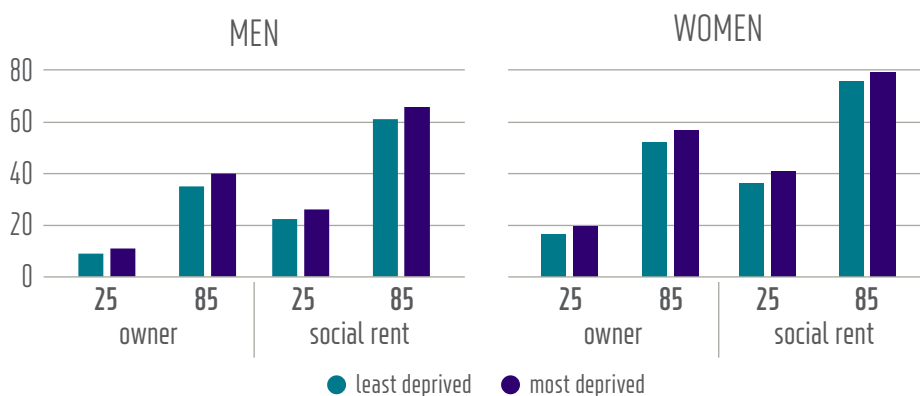
WHY IT MATTERS

Survey research suggests many people would prefer to die at home. Moreover, with increasing death rates and population ageing leading to a higher need for care at the end of life, formal care resources are strained and support from informal carers is needed. In the [Palliative and End of Life Care Strategic Framework for Action](#), the Scottish Government declared equal access to end of life care a goal. Our research shows that informal care, especially intense informal care at the end of life that requires the informal carer to live in the same household, is not equally available to all population groups.

WHAT WE FOUND

- 1 More than a third (34.1%) of people in their last year of life lived alone in 2011/12. People were more likely to live with others the closer they were to dying.
- 2 Housing tenure is strongly connected to the risk of living alone: after controlling for differences in age, gender, cause of death, neighbourhood deprivation, and proximity to death, odds of living alone in the last year of life were 2.9 higher for people in social housing and 2.3 times higher for people living in private rent than they were for home owners.
- 3 Neighbourhood deprivation also influences the availability of informal care: people in the most deprived area quintiles of Scotland were 1.2 times as likely to live alone as those in the least deprived areas.
- 4 The below graph provides an overview of the probability of living alone by the discussed factors:

Rate of living alone by neighbourhood deprivation and housing tenure (%)



WHAT NEXT?

Knowledge on informal care availability is still scarce. Our study provides first insights into informal care access at the end of life, but it is still restricted to within-household care. A previous study by Broese van Groenou et al (2006) indicated that people in lower socio-economic positions may draw more on support in the neighbourhood as opposed to from within the household. More data on who receives informal care and who provides it are needed. These data would not only help to uncover gaps in informal care provision that need to be addressed by intensifying formal care but would also help in better understanding how informal and formal care work together.

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