

# Report reveals 'patchy and inconsistent' end-of-life care in England and Wales

September 3 2024

---



Credit: Pixabay/CC0 Public Domain

One in three dying people in England and Wales was severely or overwhelmingly affected by pain in the last week of life, with bereaved people reporting how difficult it was to get joined-up support from

health and care professionals at home.

These are among the conclusions of "Time to Care: findings from a nationally representative survey of experiences at the end of life in England and Wales," a new report produced by King's College London's Cicely Saunders Institute, Hull York Medical School at University of Hull, and the University of Cambridge.

"Time to Care" aims to describe the outcomes, experiences, and use of care services by people affected by dying, death, and bereavement in England and Wales. It is the [final report](#) from the Marie Curie Better End of life program.

The report found 1 in 5 dying people had no contact with their GP in the last three months of life.

Half of people surveyed (49%) said their dying loved one visited A&E at least once in their final three months of life, and 1 in 8 people who died in hospital had been there less than 24 hours.

Half of respondents (49%) in the study were also unhappy with at least one aspect of the care the person who died received, and of those, 1 in 8 people made a formal complaint. Fewer than half of respondents said they had a key contact person to coordinate their care. This meant responsibility for care fell on informal caregivers (family and friends), who often felt unprepared and unsupported.

Professor Stephen Barclay, from the Department of Public Health & Primary Care at the University of Cambridge, a researcher on the project and a practicing GP, said, "GPs, Community Nurses and the wider Primary Care Team have a central and often under-recognized role in the care of people approaching and at the end of their lives. But they are under enormous pressure with increasing workloads,

diminishing workforces and inadequate investment over recent years.

"Increasing numbers of people have been dying in the community during and following the COVID-19 pandemic, at home or in care homes. This important survey, undertaken at a time when the NHS was beginning to recover from the worst of the pandemic, reveals how clinical teams in all settings are struggling to meet the needs of this vulnerable patient group.

"The out-of-hours period, which comprises two-thirds of the week, is particularly difficult for patients and their families. Across the U.K., GPs and Community Nurses want to provide excellent palliative and end of life care, but the necessary 'time to care' is currently often squeezed.

"The new U.K. government's focus on care close to home is welcome. This report highlights the need for a radical repurposing of NHS funding to resource primary care for that ambition to be achieved."

The research report is based on a survey sent by the Office for National Statistics in 2023 to a nationally representative sample of people who had registered the death of a family member in the prior six to 10 months. Only non-sudden causes of death were included. Responses were received from 1,179 people, making this the largest nationally representative post-bereavement survey in England and Wales for a decade.

Professor Katherine Sleeman, from King's College London and lead researcher on the project, said, "This study reveals patchy and inconsistent provision of care for people approaching the end of life.

"While there were examples of excellent care—including in the community, in [care homes](#), and in hospitals—the overall picture is of services that are overstretched, and of health and care staff lacking the time they need to consistently provide high-quality care. '

"This means that dying people miss out on treatment and care for their symptoms, and families are left feeling unprepared and unsupported, which has lasting emotional repercussions into bereavement.

The researchers say the findings are concerning, considering the aging population and the expected increase in palliative care needs across the U.K. By 2048, there will be an additional 147,000 people in the U.K. who need palliative care before they die, an increase of 25%.

"Without a corresponding increase in the capacity of primary and community care teams to support these people as they approach the end of life, the quality of care is likely to further suffer," said Professor Sleeman. "It has never been more important to ensure high-quality [palliative care](#) for all who need it."

Annette Weatherley, Marie Curie chief nursing officer, added, "The findings are shocking. Too many people are dying in avoidable pain, struggling with breathlessness and other debilitating symptoms because of the difficulties they face accessing the end-of-life care they need from overstretched GPs and other health and care workers.

"Without [urgent action](#), gaps in access to palliative and end of life care will only grow.

"It is a critical time to improve palliative and end of life care. People at the end of life should be able to have the very best possible care. There is only one chance to get it right at the end of life. Yet, as the evidence shows, too many people are being failed by a system faced with extreme financial and workforce pressures. It's time for governments to step up and fix care of the dying."

**More information:** Report: [www.mariecurie.org.uk/globalas ... e-to-care-report.pdf](http://www.mariecurie.org.uk/globalas...e-to-care-report.pdf)

Provided by University of Cambridge

Citation: Report reveals 'patchy and inconsistent' end-of-life care in England and Wales (2024, September 3) retrieved 7 September 2024 from <https://medicalxpress.com/news/2024-09-reveals-patchy-inconsistent-life-england.html>

This document is subject to copyright. Apart from any fair dealing for the purpose of private study or research, no part may be reproduced without the written permission. The content is provided for information purposes only.