

# Caregivers and staff delivering end-of-life care need long-term support, research finds

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Palliative care staff and caregivers may now need longer-term support mechanisms under a new post-lockdown public health approach, a new study reveals.

Researchers found that end-of-life care changed significantly during the COVID-19 pandemic—reducing formal care [support](#) services and increasing the burden upon first-time caregivers as [family members](#) chose to die at home rather than alone in a hospice.

[Publishing their findings](#) today in *Frontiers in Public Health*, the researchers highlight people's reluctance to go into hospices during lockdown, due to fears that loved ones could not visit. However, supporting people to die at home became more demanding as face-to-face support reduced.

Despite staff efforts to provide dignified, [quality care](#), the pandemic forced hospices to focus on essential 'physical care' rather than the important, holistic aspects of palliative care—creating psychological suffering for both staff and caregivers.

University of Birmingham researchers recommend [policy makers](#) consider improving how caregivers are identified and assessed. They also advocate improving resources for wider end-of-life care education to support caregivers, as well as health and social care staff.

The research team identified four key themes from interviews with staff and caregivers in England and Scotland that defined their lockdown experience:

- Changing Preferences—people chose to die at home rather than isolated in a hospice;
- Missed Opportunities—not having others around robbed families and patients of chances to make memories;
- The Lone Caregiver—family caregivers had limited practical and [emotional support](#) which for many was challenging, lonely and, exhausting;
- Procedure vs. Person-centered Care—restrictions forced care to

focus on the physical not the holistic aspects of palliative care important to people such as massage therapies and support groups, some of which have not been reinstated.

Principal Investigator Cara Bailey, Professor of End-of-Life Care at the University of Birmingham, commented, "The COVID-19 pandemic undoubtedly had a major impact on [end-of-life care](#) for all involved—particularly the lack of choice at the very end of life which has had a detrimental impact on peoples experience and their ability to grieve. The lack of social connectivity and ability to mark life and death has longer term implications for society as whole."

"Our findings indicate that a public health approach to care, where health, social care and community systems work together is essential. Lockdown brought huge pressures to bear on staff, caregivers, patients, and communities. We need to learn from both the breakthroughs and challenges of that time to restore palliative care as an integrated system of care."

"COVID-19's impact was evident in hospice care; missed opportunities, the overwhelming role of the lone caregiver and the changing nature of palliative care as process took priority. Practice as hospice staff knew it before has not resumed taking a toll on the workforce and directly changing the delivery of palliative care."

The study notes that managing people's expectations of health and social care will be challenging. Clear public health messaging and actions are needed, alongside sustainable educational resources and support for health and social care professionals, caregivers, and citizens.

Richard Meade, Director of Caregivers UK, commented, "Sadly, unpaid caregivers have always struggled to get the support they need to care for people at home, including at the end of life. The pandemic amplified the

intensity of the care and support they had to provide without support or help, leading many facing a breakdown in their own health."

"Without unpaid caregivers, caring for someone at home becomes difficult, if not impossible. We must learn the lessons of the pandemic to ensure now and in the future that we recognize, value and support caregivers and ensure they get the support they need. Only by doing this will we enable them to continue to care, but also to enjoy a life outside of caring which is their right."

Ellie Wagstaff, Senior Policy Manager at Marie Curie Scotland, commented, "The pandemic exacerbated the fragilities in the already fractured health and social care system. Families stepped up and took on the role as caregivers to ensure their loved ones died at home with their comforts in familiar surroundings, and most importantly, so they didn't die alone."

"But what is concerning is that many caregivers did not receive all the physical, emotional, and financial support they desperately needed. This research has shown how important support for caregivers is when looking after someone who is terminally ill, and the impact on their physical, mental, and financial health without it."

"Existing Marie Curie research shows that come 2040, that up to 10,000 more people will be dying with palliative care needs, and two thirds of those deaths will be at home in the coming decade, so there will inevitably be a similar increase in the number of caregivers."

"Scottish and UK Governments have a responsibility to develop more robust support for caregivers both now and in the years to come. This includes a national public awareness campaign to support caregiver identification and increased financial and bereavement support."

**More information:** Cara Bailey et al, "Palliative care is so much more than that": a qualitative study exploring experiences of hospice staff and bereaved carers during the COVID-19 pandemic, *Frontiers in Public Health* (2023). DOI: [10.3389/fpubh.2023.1139313](https://doi.org/10.3389/fpubh.2023.1139313).  
[www.frontiersin.org/articles/10.3389/fpubh.2023.1139313/full](https://www.frontiersin.org/articles/10.3389/fpubh.2023.1139313/full)

Provided by University of Birmingham

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