

# 'Silent epidemic of grief' leaves bereaved and bereavement care practitioners struggling

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Major changes in bereavement care have occurred during the COVID-19 pandemic, amid a flood of demand for help from bereaved people, according to new research from the University of Cambridge. The first

major study of pandemic-related changes in bereavement care has found that the switch to remote working has helped some services to reach out, but many practitioners feel they do not have capacity to meet people's needs.

It is estimated that for every death, nine people are affected by bereavement. The scale of the impact of the COVID-19 pandemic on those bereaved is now becoming apparent, whether the death was from COVID or from other causes.

Those whose loved ones have died with COVID-19 have had to cope with sudden and unexpected death, deaths in intensive care units, and with seeing loved ones suffer severe symptoms including breathlessness and agitation at the end of life. Social distancing measures have meant restricted visiting at the end of life, leaving some to die alone. Viewing the deceased person's body and funeral proceedings have been severely curtailed, with major impact on those bereaved from all causes, not only from COVID-19. All these factors mean that the risks of complicated and prolonged grief responses have become higher during the pandemic.

In research published today in *BMJ Open*, researchers at Cambridge's Department of Public Health and Primary Care report the results of an online survey sent to health and social care staff in August 2020, inviting them to describe their experiences and views about changes in bereavement care. 805 people responded, including those working in community, care home, hospital and hospice settings across the UK and Ireland.

Services faced initial challenges adapting to changing national government guidelines. Some bereavement services were suspended due to staff being furloughed or redeployed, particularly specialist bereavement services. Volunteer support in hospitals and hospices was reduced and some services saw increased waiting lists.

"We had 600% increase in deaths for a 3-week period. Dealing with the backlog of bereavement support was challenging," said one palliative medicine doctor.

Bereavement care fell to a wider range of staff members, including some with limited experience. Some people reported that services were under-resourced before the pandemic and that the pandemic would worsen the situation and add new difficulties due to the complex grief reactions.

The biggest change has been the switch to remote methods of providing support—such as telephone and video—which was reported by 90% of respondents. Adapting care to online or telephone formats was particularly challenging, with limited access to the equipment needed and limited staff training in their use.

The move to remote support has been a double-edged sword. On one hand, it increased some opportunities for bereavement support. Services supporting children and young people at times reported these groups to be more receptive to online support and hospices and hospital teams reported widening access to their bereavement support. However, practitioners described the remote work as "draining" and difficult to manage, alongside their own emotional strains during the pandemic.

Some practitioners feared being overwhelmed by demand: "We are really only seeing those who have been bereaved in Jan/Feb so far, so there may be many more to come," said one Community Listening Service Coordinator.

The changes to services were reported to have disrupted the ability to offer emotional support: "It has felt as though we are dealing with them at arm's length whereas we would be there to hold their hands, give them a hug as needed," said a palliative medicine doctor.

Many respondents expressed grave concerns over the long-term impacts on bereaved people, highlighting the inability or restrictions on being with the dying patient as having a profound impact in bereavement.

"Many people who died were denied opportunity to die in their preferred place of care / preferred place of death and died in suboptimal environments to receive their care in last days," said a GP.

While those bereaved from COVID-19 and non-COVID conditions were similarly affected by the restrictions, specific challenges related to COVID-19 were reported. Some respondents described relatives' anger at having COVID-19 on the death certificate. One Bereavement Specialist Liaison Nurse said that the disease "seemed to have a 'stigma' for some". This sense of stigma was thought to exacerbate peoples' feelings of having failed to protect their family member from COVID-19.

Concerns were raised over a large and 'invisible cohort of people' who may not access support or for whom support will be restricted, leading to greater unmet need. "There may be a silent epidemic of grief that we have not yet picked up on," said a Palliative Medicine Doctor.

Dr. Caroline Pearce, the lead researcher, said: "Bereavement care has undergone major changes in both acute and community settings affecting bereaved people, clinicians, support workers and the wider health and social care system. The increased need for [bereavement](#) care has challenged practitioners as they have taken on new responsibilities and skills and shifted to remote and electronic working. The increased potential for prolonged and complicated grief responses among those bereaved during this period is particularly concerning."

Andy Langford, Clinical Director, CRUSE Bereavement Care, added: "Speaking about grief remains an area of public discomfort, and it is

important practitioners encourage bereaved people to view grief as a 'valid' reason to seek help from health and community services, as well as from those they trust in their communities. It was heartening that many respondents reported the development of new and expanded services, but it is imperative that these are made sustainable in the longer-term. The need isn't going away."

**More information:** Pearce, C et al. 'A silent epidemic of grief': a survey of bereavement care provision in the UK and Ireland during the COVID-19 pandemic. *BMJ Open*; 1 March 2021; [DOI: 10.1136/bmjopen-2020-046872](https://doi.org/10.1136/bmjopen-2020-046872)

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