

Study report 1: Grief experience and support needs of people bereaved during the Covid-19 pandemic

Findings from the first 532 people who responded to the survey

What is this study about?

People bereaved during the Covid-19 crisis face significant challenges that affect their experience of grief. We asked people bereaved in the UK since 16 March 2020 to take part in a national survey to understand and give voice to their experiences during this challenging time. This report gives a short summary of our initial findings based on the first 532 surveys people completed between August and November 2020. For more information and study updates, please visit:

www.covidbereavement.com

Who completed the survey?

Below is a summary of who took part and what they experienced:

Who people had lost:

Most people had lost a parent:

- a parent (60%)
- a spouse/partner (20%)
- a grandparent (9%)
- a sibling (3%)
- a child (3%)
- other (18%)

14%

had lost more than one person.

Participants' ages ranged from 18 to 88 years (average age 48 years)



55%

of those who were bereaved reported that their loved one had died at a hospital, 22% at home, 15% in a care home and 5% in a hospice.



Most survey respondents were female:

91%

5 months

average time between bereavement and completing the survey

Cause of death

46% of the deaths occurred with a confirmed or suspected COVID-19 infection.

30% died of cancer and 33% of other causes (e.g. other long-term conditions, heart attacks, old age, accidents).

3%

of respondents were from an ethnic minority background.

Key findings - Care experiences at the end of life

People described how they experienced the care their loved one received at the end of their life and what support they were given after their loved one's death. Communication problems with healthcare providers were commonly reported, although some people shared positive care experiences.



Communication problems with healthcare providers

Difficulties finding out about their loved one's condition

- Difficulties getting information about their loved ones
- Misinformation regarding their loved one's condition and hospital policies
- Perceived insensitivity

“

“When the hospital wouldn't let me in with my dad from the ambulance, that is the last time I saw him. It was a Friday and we couldn't get to speak to anyone until the Tuesday. It was hard to get through...There was very little info. and no support and no contact.”

(Bereaved daughter)

”



Lack of involvement and support

Lack of involvement in care decisions and lack of support after their loved one's death

23%

of respondents said they were 'never' involved in care decisions

36%

did not feel at all supported by healthcare professionals after the death

51%

were not provided with any information about bereavement support



21% felt 'always' involved in decisions about the care of their loved one



26% felt very or fairly well supported by healthcare providers immediately after the death



36% did receive such information at the time of death or during a follow-up call



Positive care experiences

Compassion, kindness and flexibility

- A sense that staff were doing their best
- Staff showing compassion and kindness
- Flexible visiting arrangements
- Relatives feeling that they were kept well-informed about their loved one's condition and care

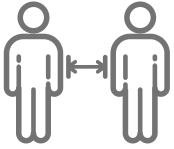
“

“The hospice was amazing; such a breath of fresh air compared to other parts of the system. The people were lovely and the rules around visiting were much more relaxed. I got to spend some special time with [my wife] in her last four days.”

(Bereaved husband)

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Key findings - Problems before/during/after their loved one's death



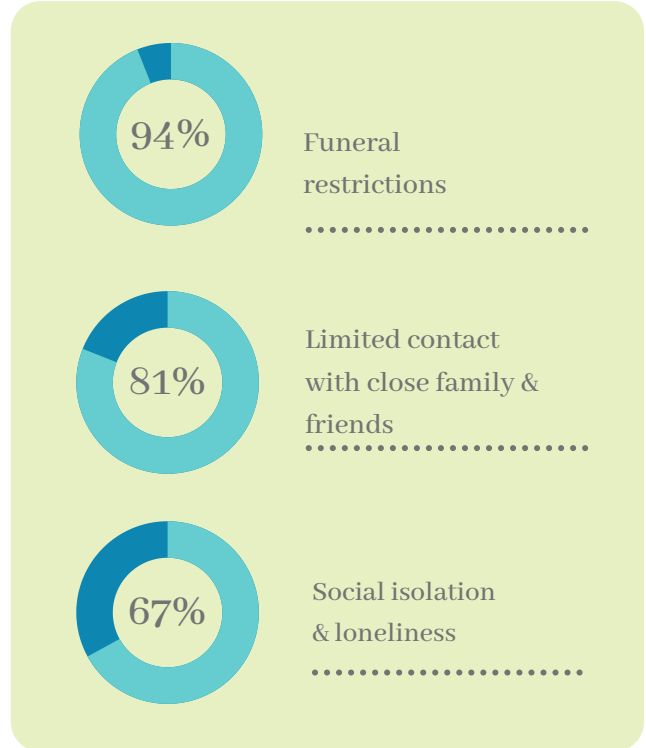
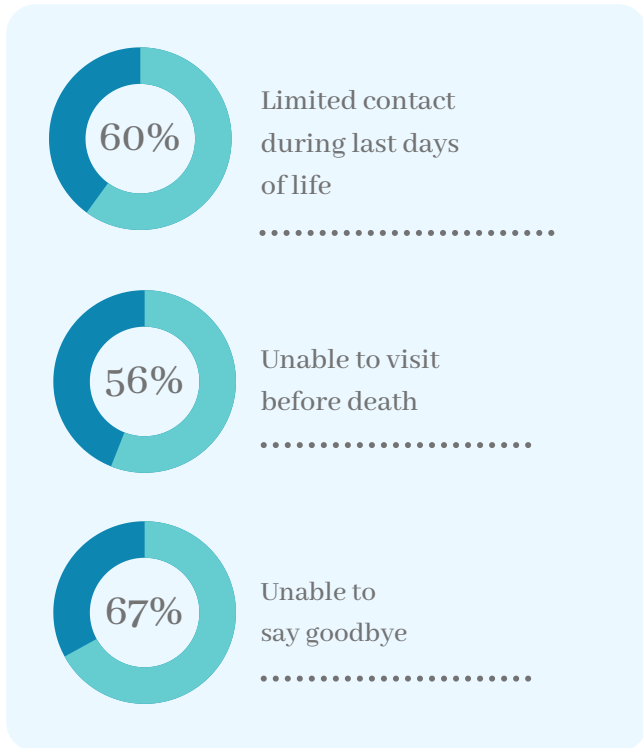
Pandemic-specific problems

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Separation, social isolation & restricted funeral arrangements

Between 56% and 94% of people were faced with the following experiences:

Before and during their loved one's death

After their loved one's death



More than half of the people who completed the survey reported 5 or 6 of the experiences shown above.

These experiences were highly distressing and affected the grieving process. Some people described difficulties 'finding closure' and beginning to grieve as a result.

“
"I felt alone and isolated when she died, unable to grieve properly with my family. [I] met up with my family after her death, but felt it was against the 'rules', [the] funeral was small and [I] still feel we haven't properly said goodbye. So many of her friends often ask when we will we be able to do a memorial service. [It] feels as though her life has gone and [she has] not been fully recognised for the person she was."
.....
(Bereaved sister)

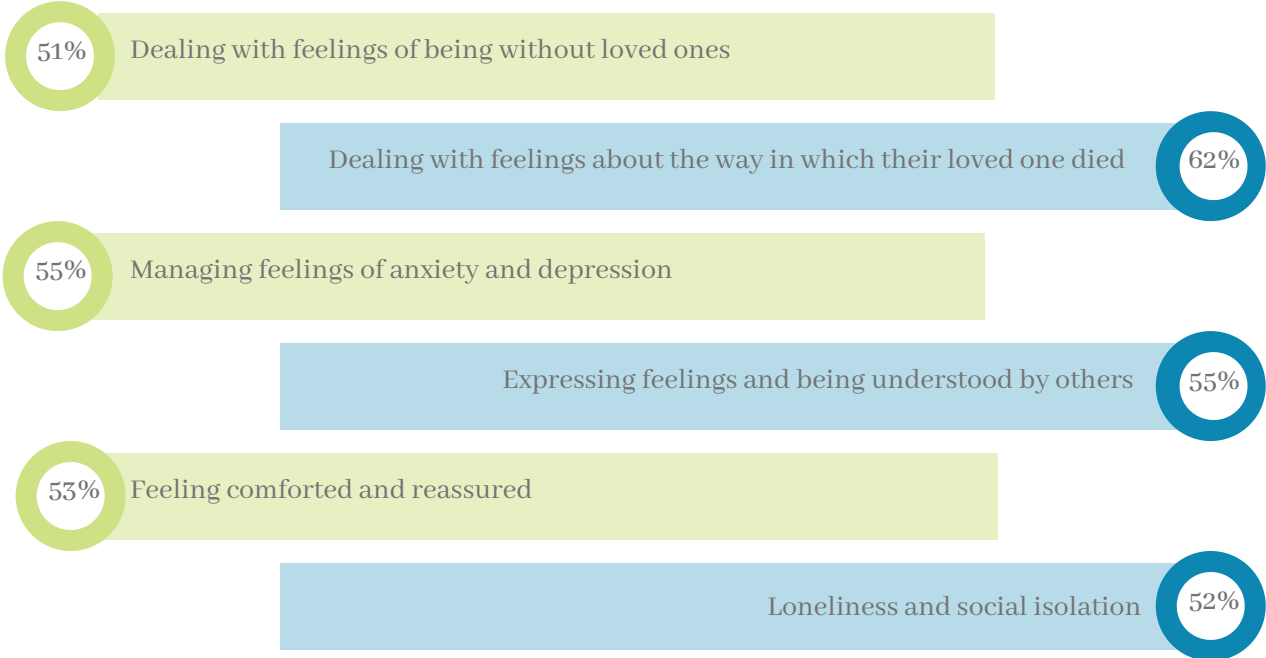
Key findings - Support needs



Support needs

Needs for emotional and psycho-social support

Over half of people had experienced high or fairly high needs for support with:



People also described concerns directly relating to the ongoing pandemic:

Anxiety about catching the virus

Distress caused by others questioning the seriousness of the virus

Distress caused by others not observing social distancing rules

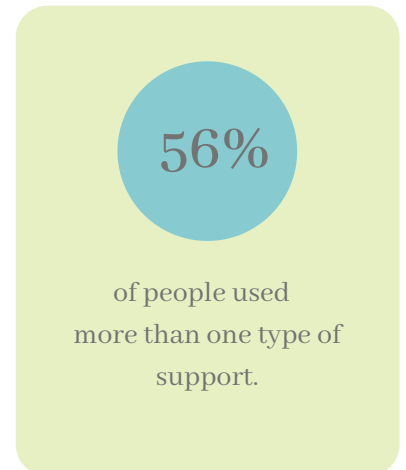
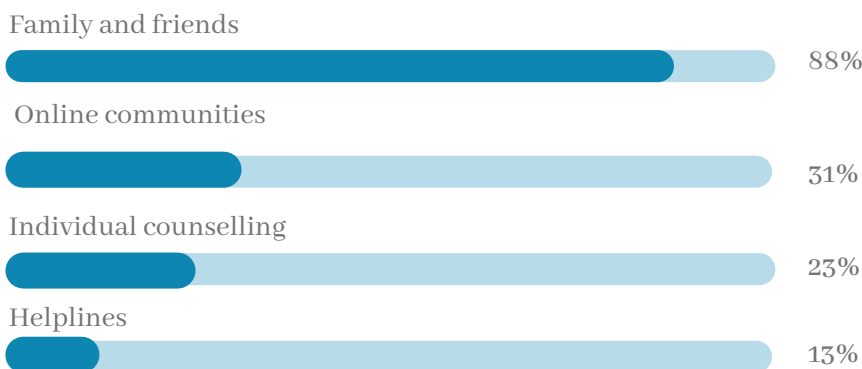
Anger over the Government's perceived mishandling of the pandemic



Support use and access to support

Sources of support people used

People described using the following sources of support:



Key findings - Difficulties getting support



Barriers and difficulties accessing support

What difficulties did people face when seeking support?

Family and friends

Most respondents received support from family and friends, however:

41%

had had difficulties with getting support from family and friends

26%

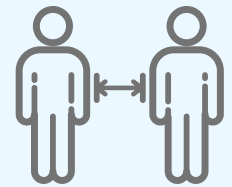
said that family and friends had not been able to support them the way they wanted

20%

felt uncomfortable asking for help and support from friends or family

In their comments, people described:

- Struggling with without face-to-face contact and opportunities for physical comfort
- Finding it difficult to share their feelings and often feeling that others didn't understand
- Feeling that people had less time, empathy and support to give due to the ongoing pandemic



Bereavement services

59% of people had not tried to access support from bereavement services.

26%

of people felt uncomfortable asking for support from bereavement services

13%

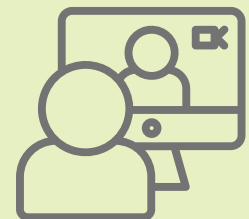
said they did not know how to get support from bereavement services

46%

of those who tried to get support from bereavement services experienced difficulties

People wrote about the following difficulties they faced when considering bereavement support:

- Limited availability and long waiting lists for bereavement support in some areas
- Feeling put off by remote support options (e.g. counselling over the phone/video call)
- Lack of information about where to get help
- A need for COVID-19 death-specific bereavement support
- Feeling less entitled to support if loved one died of a non-COVID illness



Conclusion and recommendations

These initial results show how difficult it has been for many people bereaved during the pandemic. Lots of people who completed the survey had difficulties getting the support they needed, especially emotional support.

Our initial recommendations are:



Improved communication with healthcare teams at the end of life

- Known point and method of contact with the care team
- Regular updates for family members
- Supporting family involvement in decision-making about their loved one's care



Keeping families and patients connected

- Family visiting should be enabled as far as is safely possible
- Remote communication methods should be readily available where visiting is restricted



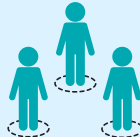
Support and information from healthcare providers after a death

- Opportunities to discuss questions relating to patient care and the death
- Information about locally and nationally available bereavement support



Raising awareness of bereavement support options

- More public information needed about the support that is available
- GPs should have relevant information about local bereavement support services and be able to refer bereaved patients to the support they need



Increased provision of bereavement services

- Expansion of services in areas with long waiting lists
- Offer different ways to access safe face-to-face and group support as well as online and telephone support



Help with loneliness and isolation

- More flexible support bubble arrangements for the recently bereaved whilst social restrictions continue
- Safe provision of informal community based supports and activities

For more information and study updates, please visit: www.covidbereavement.com or contact Dr Emily Harrop by email (harrope@cardiff.ac.uk) or on 02920 687184.