


# Bereavement during COVID-19: The experiences of those bereaved and the voluntary sector services supporting them

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# COVID-19 in the UK

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- 20% increase in deaths in a year
- 143,000 deaths in the UK since March 2020 (124k in England, c.9400 Scotland)
- In addition to 500,000-600,000 deaths every year in the UK
- If each death leaves c.9 people bereaved (Verdery et al. PNAS 2020), over **8.4 million bereaved** in pandemic times
- Significant challenges to those grieving and the people supporting them

# Aims and methods

1. Document the grief experiences, support needs and use of bereavement support by people bereaved during the COVID-19 pandemic
    - Longitudinal online survey of people bereaved from 16 March 2020-Jan 2021 in UK
    - Qualitative interviews with survey participants
  2. Understand the adaptations, challenges and innovation involved in delivering equitable bereavement support
    - Cross-sectional online survey of bereavement services (1 March-14 May 2021); qualitative interviews with c.10 case study organisations
- Inform end-of-life care processes and bereavement support during and beyond pandemic

# Papers

- Interim report: [Supporting people bereaved during COVID-19: Study Report 1](#), 27 November 2020
- [Support needs and barriers to accessing support: Baseline results of a mixed-methods national survey of people bereaved during the COVID-19 pandemic](#) (Harrop et al. Pall Med, 22 Oct 2021)
- [Place, cause and expectedness of death and relationship to the deceased are associated with poorer experiences of end-of-life care and challenges in early bereavement: Risk factors from an online survey of people bereaved during the COVID-19 pandemic](#) (Selman et al. 2021, Preprint <https://doi.org/10.1101/2021.09.09.21263341>)

See [Covidbereavement.com](https://www.covidbereavement.com)

# Survey of bereaved people: Sample characteristics (n=711)

## Participants:

- 88.6% female, 10.4% male, 1% other
- Mean age 49.5 years (SD 12.9, range = 18 to 90)
- 4.7% from ethnic minority backgrounds
- **Person who died:** 55.6% parent, 21.4% partner/spouse 7.6% grandparents
- **Time since death:** Median = 5 months (Range: 1 day to 9 months)
- 77.6% did not expect their loved one to die (e.g. from a terminal illness)

## People who died:

- Mean age 72.2 years (SD 16.1, range = 4 months gestation – 102 years)
- **Place of death:** 58% hospital, 22% home, 13% care home, 5% hospice (1.8% other/don't know)
- **Cause of death:**
  - 39% confirmed COVID-19, 5% suspected COVID-19
  - 56.2% non-COVID, including cancer (22%)

# Experiences of end-of-life care (EoLC)

- 22% of respondents said they were 'never' involved in decisions about the care of their loved one; 22% said they were 'always' involved
- 18% said they were not at all informed about the approaching death; 32% said they were fully informed
- 35% felt not at all supported by healthcare professionals immediately after the death; 28% very or fairly well supported
- 45% were not contacted by the hospital/care provider after the death; 35% were contacted
- 48% were not provided with any information about bereavement support

Note: Between 12 and 20% answered not relevant to these questions e.g because no HCPs involved, not next of kin

# Pandemic-specific difficulties before and after the death

When your loved one died, did you experience any of the following?	%
Unable to visit them prior to their death	54.3%
Limited contact with them in last days of their life	57.8%
Unable to say goodbye as I would have liked	63.9%
Restricted funeral arrangements	93.4%
Social isolation and loneliness	66.7%
Limited contact with other close relatives or friends	80.7%

- 51% of participants had 5 or 6 of these experiences

# Risk factors for sub-optimal EoLC & pandemic-related challenges

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## 1. Place of death (hospital/care home/hospice/home):

- Deaths in hospital/care home increased likelihood of: being unable to visit prior to death, unable to say goodbye as wanted, limited contact in last days of life (all  $P < 0.001$ )
- Deaths in hospice/at home increased the likelihood of: being involved in care decisions ( $P < 0.001$ ), well supported by healthcare professionals (HCPs) after the death ( $P = 0.003$ )
- Hospice deaths increased the likelihood of being given bereavement support information, which was least likely for care home deaths ( $P < 0.001$ )

Preprint available [here](#)



## 2. Cause of death: Bereavement due to COVID-19:

- decreased the likelihood of: involvement in care decisions ( $P < 0.001$ ), feeling well supported by HCPs after the death ( $P < 0.001$ )
- increased the likelihood of: being unable to say goodbye (OR=0.348; 95% CI: 0.2 to 0.605), social isolation and loneliness (OR=0.439; 95% CI: 0.261 to 0.739), limited contact with relatives/friends (OR=0.465; 95% CI: 0.254 to 0.852).

3. **Expected deaths** were associated with higher likelihood of feeling involved, informed, and well supported by HCPs (all  $P < 0.001$ ).

4. **Relationship:** Deceased being a partner or child increased the likelihood of knowing the contact details for the responsible care professional ( $P = 0.001$ ), being able to visit ( $P < 0.001$ ) and given bereavement support information ( $P < 0.001$ ).

- Being a bereaved partner strongly increased odds of social isolation and loneliness, e.g. OR = 0.092 (95% CI: 0.028 to 0.297) partner versus distant family member.

# Qualitative themes: Communication at EoL

## Negative

Difficulty getting information

Misinformation: about patient and visiting policies

Perceived insensitivity

Lack of involvement in decisions

Inadequate support following the death

## Positive

Doing their best

Compassion and kindness

Able to visit/spend time with loved one

Well-informed about patient condition/care

Hospice and specialist palliative care

*(Wife) was admitted there as an emergency and I had to chase for updates all the time. No fewer than ten people promised updates and to get back to me but I received not one call-back.*

*(Bereaved husband ID391)*

*The two nurses & one of the consultants I had communication with were so empathetic & took their time to explain things & support me in anyway they could during those 5 days. I was aware of how stressed & tired they were but they had a lot of time for me & I'll never forget that. (Bereaved daughter ID016)*

# Impacts on grieving

- Enduring guilt, anger, sadness at being unable to say goodbye or be with their dying loved one
- Being unable to host conventional funerals or wakes; difficult to find closure or begin to grieve
- Trauma of travelling to crematorium alone, sitting apart and returning to empty houses
- Disruption of emotional support most needed from close family and friends –acute isolation

*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, PID\_134)*

# COVID-19 deaths – Additional stressors

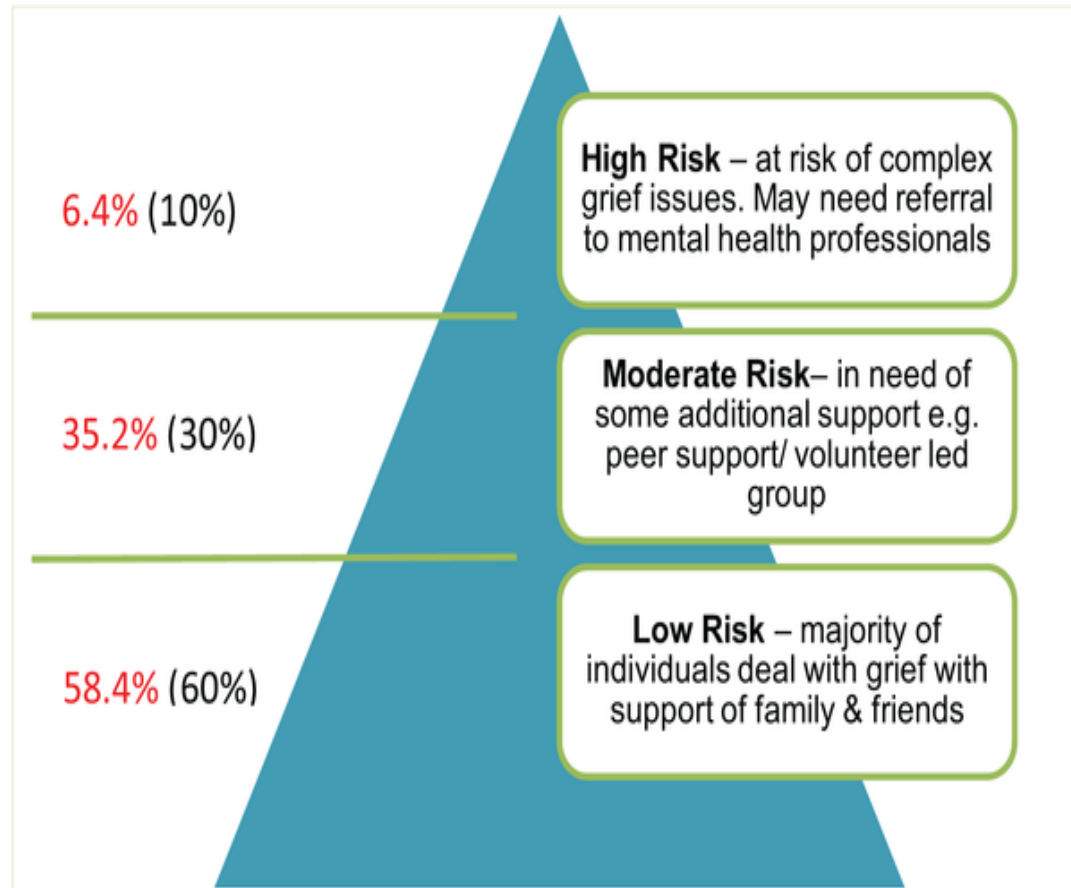
- Ongoing threat of the virus – fears of dying of COVID-19 or passing it on to vulnerable family members
- Anger and anxiety over how the pandemic is being handled
- Distress caused by other people questioning the seriousness of the pandemic and not observing social distancing rules

*“I fear that the same will happen to me as I’m diabetic and have two autistic sons and I don’t want them to go through losing their mum in the same way. I’m terrified of them going to school and getting infected. How can I grieve when I’m terrified and trying to protect them?”*

Bereaved daughter, ID\_012

Please tell us how much help or support you have needed over last 3 months:	High or fairly high level of support needed
Dealing with my feelings about the way my loved one died	60%
Expressing my feelings and feeling understood by others	53%
Feelings of anxiety and depression	53%
Feeling comforted and reassured	52%
Loneliness and social isolation	52%
Dealing with my feelings about being without my loved one	50%
Regaining sense of purpose and meaning in life	47%
Finding balance between grieving and other areas of life	45%
Managing and maintaining my relationships with friends and family	36%
Participating in work, leisure or other regular activities (e.g. shopping, housework)	34%
Getting relevant information and advice e.g. legal, financial, available support	24%
Practical tasks e.g. managing the funeral, registering the death, other paperwork etc.	24%
Looking after myself/family e.g. getting food, medication, childcare	15%

# Public health model



- Predicted (in brackets) and Actual Proportions for the three risk groups (Aoun et al 2015, Australian Survey)

In this study:

- **Over half (51%)** demonstrated high or severe levels of overall vulnerability in grief, assessed via the Adult Attitude to Grief Scale (Severe = 28%, high = 23%, low = 48%)

- **Only 26%** of our respondents with high/severe vulnerability were accessing formal Tier 2/3 support

**Only 29%** of all respondents felt they **didn't need** bereavement service support "because my friends and family provide me with enough support"

# Accessing formal support

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- 51% were not provided with any information about bereavement support
- Most had not tried to access support from a bereavement service (59%) or GP (60%)
- Of those who had sought this support, 56% had experienced difficulties accessing bereavement services (52% for GP)
- Reasons for not accessing formal support:
  - “I have felt uncomfortable asking for support from bereavement services” (27%)
  - “I do not think it would help me” (18%)
  - “The support I wanted from bereavement services was not available to me” (15%)
  - “I do not know how to get support from bereavement services” (14%)

# Accessing support from family & friends

- 87% said they had used support from family and friends to cope
- But 39% reported difficulties getting this support
- “Friends/family have not been able to support me in the way I wanted” (25%)
- “I have felt uncomfortable asking for help or support from friends or family” (19%)

- Main problems related to the pandemic context: difficulty connecting and communicating with friends and family, lack of understanding and empathy

*Whilst friends try to be helpful and kind - they don't understand the anger which is also part of this grief... not enough infection control procedures were put in place within our hospitals. (Bereaved daughter, ID 632)*



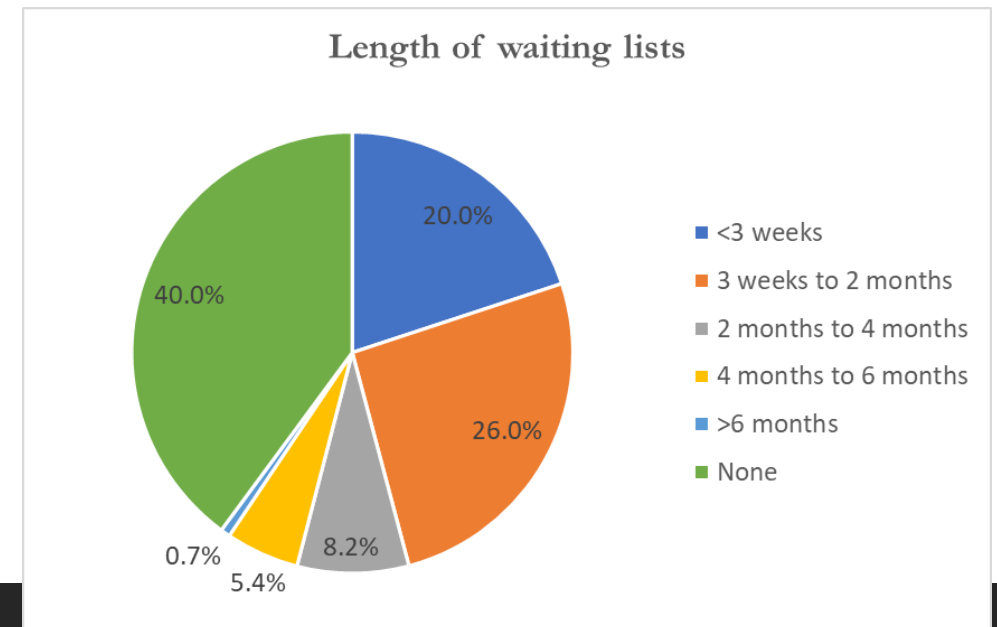
# Conclusions & recommendations

- Exceptionally difficult sets of experiences associated with bereavement during the pandemic
  - High level of disruption to end of life, death and mourning practices as well as social support networks
  - High levels of need for emotional and therapeutic support
  - Significant difficulties in getting these met – either through formal services or through friends and family
- Increased resourcing, provision and tailoring of services; cultural- and crisis-competent
  - Raise awareness of bereavement support options; provide accessible information and resources after a death – GPs/primary care to signpost
  - Help with loneliness and social isolation e.g. compassionate communities, educational and social initiatives

# Survey of bereavement services

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- Participants from 147 voluntary and community sector bereavement services:
  - 53% served specific counties or smaller regions; 16% were UK-wide
  - 36% were hospice or palliative care services, 15% national bereavement charities or NGOs; 12% local bereavement charities
  - 68% provide support following all causes of death
  - 33% after specific causes of death
- Variation in how referrals have changed:
  - 46% demand higher than usual
  - 35% demand lower than usual



# Impact

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- 78.2% had changed services due to Covid, with 51.7% introducing new services
- Significant reduction in provision of all **face-to-face** support including:
  - peer group meetings (50% to 4.1%, OR 0.04)
  - facilitated group meetings (78% to 11%, OR 0.04)
  - 1:1 support (87% to 27%, OR 0.06)
  - specialist intervention (44% to 16%, OR 0.25)
- **Online** and, to a lesser extent, telephone provision saw major increases
  - Online 1:1 support (8.8% to 83% (OR 50.3)
  - Online facilitated group meetings (4.1% to 56%, OR 30.48)
  - Online specialist intervention (3.4% to 36%, OR 16.01)

# Access

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- 67.3% reported there were groups with unmet needs not accessing their services before the pandemic:
  - people from BME communities (49%)
  - sexual minority groups (26.5%)
  - deprived communities (24.5%)
  - men (23.8%)
- Compared with before the pandemic, 3.4% of services were seeing more people from BME groups, 52% were seeing the same proportion, 6.1% were seeing fewer
- 38% didn't know/didn't collect this data

## Challenges – huge shift to online/ telephone support

- Emotional impact on staff/volunteers – increased supervision
- Volume of clients and complexity of needs, higher risk, grief + anger
- Implementing staff training e.g. in provision of online support
- IT use – working from home, client access/familiarity
- Financial challenges (52%) – including cancellation of fundraising events
- Lack of volunteers able to work
- Access to appropriate facilities e.g. COVID-secure space

## Positive changes – reported by over 93% of services

- Widening access/reach
  - those unable to attend f2f
  - some prefer online support e.g. young people
- Introduction of new services
  - bereavement support calls
  - walking groups
  - online relaxation/meditation, remembrance services, bereavement cafés
- Embracing digital technology e.g. enabling “goodbyes”
- Initiatives to coordinate services (47%)
- Changing future practice

# Conclusions & recommendations

- Rapid, major shifts in bereavement support provision
  - Notable challenges – impact on staff/volunteers, operational & financial difficulties
  - But almost all services report positive changes
  - Over two thirds recognise inequity in who accesses support – BME groups most frequently recognised
  - During pandemic proportions of BME clients did not increase despite disproportionate impact
- Carry forward the positives (e.g. coordination) while alleviating the challenges
  - Invest in training, staff/volunteer support, digital provision
  - Crucial to consider whose needs are not being met
  - Assess and respond to unmet needs for formal bereavement support among disadvantaged groups
  - Routinely collect client data to determine and ensure equity

# UK Commission on Bereavement

- Launched 15 June 2021
- Review of evidence, report 2022
- Policy roundtable, Oct 2021

## UK Commission on Bereavement

A major independent commission exploring issues and recommendations on how to better support bereaved people.

LATEST: Translations of [our survey](#) now available



# Commissioners



Chair: The Right Reverend and Right Honourable Dame Sarah Mullally DBE,  
the Bishop of London

## The Commissioners

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The Right Honourable Prof. Paul Burstow

Lesley Goodburn

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Dr Donald Macaskill

Professor Anand Menon

Zara Mohammed

Dame Barbara Monroe DBE FRSA

Patrick Vernon OBE

Dr Marilyn Relf

Professor Nichola Rooney

Julia Samuel MBE

Dr Catherine Millington Sanders



# Calls for evidence

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- Written calls for:
  - Professionals and organisations (including researchers)
  - Individuals bereaved in the last 5 years
  - **Close 31 Dec 2021**
- Alternative engagement methods for children and young people, people with learning difficulties – available on website in coming weeks
- Oral evidence sessions: Dec 2021, Jan 2022

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**Study website:** [www.covidbereavement.com](http://www.covidbereavement.com)

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