



**Bereavement
During
COVID-19**

**Summary Report and
Recommendations**

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The Bereavement during COVID-19 Study

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This report contains quotes which may be confronting. Their inclusion is balanced against the need for the voices of the bereaved to be heard.



Main messages

Context

The COVID-19 pandemic changed how we live, die and grieve. During the first two years of the pandemic 334,700 Australians died in these circumstances, including 2,251 from COVID-19.^[1]

Australians faced some of the strictest COVID-19 public health measures globally. End-of-life care and bereavement practices were significantly disrupted due to community fears of contracting the virus, public health measures introduced to reduce infection rates and protect healthcare workers, and the re-deployment of frontline workers to other roles. The burden of such strict public health orders was experienced differently by States, regions and cultural groups.

Many families and friends were left to grieve alone and in isolation, unable to visit their dying person, and unable to either receive or give physical support to each other. Many face-to-face support services closed or switched to online delivery, and mental health support services were overwhelmed by general demand within the community. The cumulative impacts of these circumstances on end-of-life care and bereavement responses raise the potential of significant negative mental health costs for the person themselves, the health care system, and society.

The Bereavement during COVID-19 Study documented the experiences of Australians bereaved, from any cause, during the first two years of the COVID-19 pandemic. The aim was to hear their stories, establish their mental health and support needs, and inform policy planning for future pandemics. In doing so the study also identified a range of pre-existing cracks within the system

Interviews were also held with multicultural health care workers. Recommendations based on the findings were developed in collaboration with consumers, key stakeholders and community organisations.

Over 2000 people responded to an online survey and 100 of these participated in additional interviews

Multicultural health workers were interviewed about the experience of their communities

Recommendations were developed in collaboration with consumers, key stakeholders and community organisations.



Conclusions

The COVID-19 pandemic introduced extraordinary challenges for individuals, society and for end-of-life and bereavement care, and simultaneously exposed significant pre-existing gaps within healthcare, administrative and support systems.

The lessons learned from this pandemic can help us better prepare and coordinate our approach to death and dying to minimise negative consequences of public health measures and fragmented systems.

Specific patterns of intense and chronic grief reactions are associated with negative long-term health outcomes that can be reduced through specialist interventions.



Bereavement care must be elevated within **pandemic planning and health care processes** to address the gaps exposed by this study.



Basic bereavement outreach should be implemented to prepare families for the death of their loved ones and supporting them afterwards is essential.

To achieve this, a **National Pandemic Bereavement Preparedness Plan**, created in collaboration with relevant stakeholders (i.e., consumers, grief and loss professionals, health, funeral, coronial services, government and support services) is required.

This is essential to mitigate poor bereavement outcomes and better support people who are dying and the grief of their families.



**Bereavement
During
COVID-19**

Key findings



Many bereaved people experienced **high levels of grief, depression and anxiety**, indicating the pandemic and related restrictions were associated with adverse impacts on bereavement.



Disruptions to the ability to care for the dying person and the experience of **social isolation and loneliness** were linked with worse mental health outcomes



Inconsistent and changing rules across States, Territories and health settings were a **source of confusion, fear, frustration, anger, guilt, stigma, and despair** for the bereaved



Services and supports **were often not available, not offered**, or varied in their quality. This was a source of distress



Although high quality resources have been developed, there was a **lack of provision of information** about grief and support services



Many reported **unmet needs for social, community and professional supports**



There were **long waitlists for accessing support** from mental health professionals and mixed experiences with the consultations. Experiences with telehealth, support lines, and self-help resources were also mixed



Interactions with many government services and administrative processes were experienced as **lacking in compassion or an understanding of grief and bereavement**



Executive summary

The Bereavement during COVID-19 Study

In March 2020 the World Health Organisation declared COVID-19 a global pandemic. Australia, like many countries, introduced a range of national and jurisdictional (State/Territory) “COVID-safe” measures, to slow the spread of the virus (“flatten the curve”), reduce deaths, and protect frontline workers, vulnerable members of the community, and essential industries. Measures varied across jurisdictions as circumstances changed and knowledge of the virus increased, but included social distancing and general mask wearing mandates, stay at home orders, limits to gathering in public, mandated industry shutdowns, quarantine requirements, curfews, and State and international border closures. Across health settings and aged care facilities there were also requirements for personal protective wear, visiting restrictions and periodic lockdowns, and frontline staff were relocated to other roles including contact tracing, vaccination and testing centres. Together with the widespread community fear of contracting COVID-19, there was significant disruption to culturally expected end-of-life-care and bereavement practices.

During the first two years of the pandemic 334,700 Australians died^[1], with many families and friends left to grieve alone and in isolation, not able to visit the dying person and unable to either give or receive support. Coming only weeks after the Black Summer east coast bushfires and on the back of a prolonged droughts and flooding, many Australians were facing multiple and ongoing challenges at a time when community and professional support services were closed or moved to online formats.

The Bereavement during COVID-19 Study was established to document their experiences.

Aims

- To provide an evidence-base to inform bereavement planning and policy development in future pandemics; and
- To identify ongoing supports needs for those bereaved during the COVID-19 pandemic of 2020-2022.

Methods

The project employed a mixed-methods approach comprising four studies. Initially, over 2000 Australians, bereaved between 2020-2022, volunteered to complete an online survey about their bereavement experiences and mental health functioning; Of these, 100 volunteers were purposefully selected for an in-depth interview, and over 340 volunteered to completed up to three further surveys across the first 15 months of their bereavement. Additional interviews were conducted with multicultural health workers to document the experiences of under-represented populations. The study protocols were approved by the University of Technology Sydney Human Research & Ethics Committee (HREC) Ref ETH20-5447 and ETH21-5923.

Findings

Mental health

We observed high rates of grief-related distress. While grief is a normal human response to loss and is not of itself indicative of a mental health concern, specific patterns of intense and chronic grief reactions are associated with negative long-term health outcomes that can be reduced through specialist interventions. This makes identifying people experiencing intense chronic grief or those with Prolonged Grief Disorder (PGD) increasingly important^[2, 3]. Over one third (39%) of our participants who were bereaved for more than 12 months had levels of grief in the range suggestive of a prolonged grief reaction. Pre-pandemic population estimates sit at 7-10%. While caution is required before generalising from our study to the Australian population, our figures are consistent with international data showing elevated levels of grief distress during the pandemic.^[4, 5]

Participants also reported high rates of depression and anxiety. Almost half (45%) reported depressive symptoms within the suggested clinical range, and a third (32%) reported clinical levels of general anxiety. For comparison, this is 10-20% above rates reported in surveys of the general Australian population during the first year of the COVID-19 pandemic (excepting from Victoria, where rates were equivalent).^[6, 7, 8]

Almost 20% of participants reported concurrently high levels of grief, depression, and anxiety. Difficulties providing care and social isolation and loneliness were associated with greater bereavement distress. People bereaved from deaths due to COVID-19 did not have worse mental health outcomes in this study.

Multicultural health workers described additional stressors impacting the mental health of their clients, including an inability to travel to relatives and friends, stigma and blame associated with media coverage, and challenges accessing accurate information in language.

End-of-life care

Two thirds (65%) of the participants reported the decedent as dying in hospital (e.g., specialist palliative care unit, intensive care unit (ICU), emergency departments (ED), acute hospital wards) or at home with or without community palliative care support.

Just over a third (37%) of participants receiving palliative care services (PC) indicated that the public health measures had driven their decision for a home death. They also perceived a health care system under strain, with a lack of practical home care support and information provided about the dying process.

Regardless of whether a death with PC occurred at home or in hospital, however, more than 80% of responsible person participants felt the patient had been well cared for at the time of the death. Significantly fewer participants were asked by health professionals about their stressors prior to the death (29.3%). This was significantly greater for hospital deaths (25.2% vs 38.2%). However, the rate in home PC deaths remains concerning as compared to hospital PC deaths, these participants reported greater grief-related impairment, and comparable rates of possible prolonged grief (41.5%) as the hospital death group (38.6%) 12 months after the bereavement. Those who experienced a home death had a greater likelihood of being offered information about grief support and literature before the death.

Of the third (33%) of participants who reported a **death in a hospital without PC**, almost half reported reduced contact with their close person at end-of-life, were unable to say good-bye, unable to spend time as a family, and unable to provide care as they would have liked due to the COVID-19 public health measures. This was a source of distress.

Participants who were the patients' nominated visitors as part of the COVID restrictions, felt the additional burden of being the conduit of information and bearing witness between the patient/health system and the rest of the family/community. While some participants were granted exemptions around visiting hospitals in the last days of life, not everyone was afforded this opportunity, raising issues of equity and causing confusion.

Those who experienced sudden or unexpected deaths in hospital described a lack of follow-up care or information.

Residential aged care

During COVID-19, many residential aged care facilities (RACF) went into complete lockdown, closing their doors to all visitors. Almost one in five (19%) of participants reported a death in RACF. More than 60% reported that the public health measures impacted their ability to provide care, spend time together as a family, and have contact with their close person in the last days of life. Participants were concerned that residents were not getting the care and socialisation they needed. Their inability to enter to provide care was a main worry and related to poorer outcomes.

Deaths outside of health services or RACF

Participants who experienced a **death outside of a health facility**, which was often traumatic, reported having limited or no health care support, lack of follow-up by police and the coronial system, and in some cases inability to move from the place of death due to the lockdowns.

Participants unable to leave their State or the country to visit dying family and friends described their sense of hopelessness, anger, and confusion around navigating border rules.

Many participants also reported difficulties completing practical, financial and legal requirements, which compounded distress.

Information and Support

Participants reported unmet needs for information about the dying process, grief, managing practical matters such as bank accounts and Centrelink, and support options. Over 70% of participants whose family/friend died in a RACF received no information on grief, bereavement, or support services, despite this information being readily available through existing centralised hubs such as palliative care (CareSearch) and aged care (palliAGED and ELDAC).

Most participants' main source of support was family and friends, virtually and in-person when allowed. Many of these said this was the most helpful support (63%), but others found family and friends to be unhelpful (21%). General practitioners and psychologists were accessed by about 20% of participants, respectively. Over 50% reported unmet need for social, community and/or professional support.

For those who pursued it, accessing professional (mental) health supports was often difficult as available appointments were limited or delayed and associated with out-of-pocket expenses.

Participants' perceptions of professional supports and telehealth varied; for some it was too impersonal and of little help, while for others it was a lifeline and highly valued. The majority expressed a preference for face-to-face appointments.

“ I hope that we didn't go through all of this without learning and leaving some learnings for the next generation. Because it would be very sad to see that. ”

– multicultural health worker 5

Discussion

This Project identified multiple impacts on end-of-life and bereavement care experiences related to the COVID-19 pandemic and also revealed multiple pre-existing gaps in related health, government and support systems.

Health professionals were working extraordinarily long hours in difficult conditions, with reduced staffing, and balancing multiple needs involving protection of patients, families and staff.

Given this reality, the bereavement needs of patients' families were not a key priority for Services. Yet, responding to anticipatory grief and preparing families/friends for the persons' death can do much to alleviate longer-term bereavement distress.

Recognising that future health crises may be associated with a range of challenges, there needs to be national agreement on processes to facilitate safe and compassionate visiting for people at the end-of-life, inclusive of:

- redesigned spaces to enable visiting while maintaining the safety of the patient, visitors and staff (see also^[9])
- telehealth initiatives to enable real and virtual visiting
- strategies to limit burdens placed on individual family members and individual health professionals implementing the public health measures
- consideration of individual grief risk factors for adverse outcomes
- Residential Aged Care Facilities need to devise strategies to enable family members and friends to continue providing practical care and support for residents. If visiting is restricted, family/friends virtual communication link(s) need to be established and readily available (e.g. phone chargers, internet (wi-fi and data), mobile devices (e.g., tablets) lent out to patient/resident and family/friends

While bereavement care needs are multifaceted, National Palliative Care Standards require palliative care services to provide, at a minimum, information on grief and bereavement and information about available support services and pandemic responses.^[19]

Health services must be supported with clear direction and staffing capacity to ensure sustainable implementation of standards

Grief and bereavement information should be stored in a central repository and be made available beyond specialist palliative care services so that organisations interacting with bereaved people can disseminate and tailor the material according to the bereaved person's support needs. Operationalising this will require investing in workforce training initiatives to increase health professionals' understanding of the potential impacts of bereavement and increase their confidence to facilitate grief and bereavement conversations. Staff in institutions that regularly interact with the bereaved also need greater grief literacy training.

Our study reinforces the need for bereavement care to span community and mental health services. Both avenues of support are vital. Despite the small proportion of bereaved individuals requiring specialist mental health care, this need appeared to increase during the pandemic. Bereaved people with prolonged grief need primary care referral and care pathways to trained mental health professionals. There is currently a lack of awareness and training for professionals across such interventions. Operationalising this will require that loss, grief, and bereavement content is embedded into all medical, nursing and allied health curricula.

The strengths of community-based services, groups and activities are of relevance during pandemics and should be fostered outside of these circumstances. Community leaders, particularly in culturally and linguistically diverse and LGBTQIA+ communities could ensure appropriate messaging and act as conduits for information and support. Drawing on public health and Compassionate Community initiatives, neighbourhood centres, Men's Sheds, cultural and community centres, faith organisations or even sporting clubs could assist, acting as avenues to increase death literacy and grief literacy^[10], provide information on grief and bereavement and link bereaved people to social

support to mitigate high levels of social isolation and loneliness reported in this study. This may require additional financial or technical support to "go virtual" if restrictions are required. Feedback from co-design workshops identified a need for cemetery and funeral workers to be familiar with pandemic infection control measures.

Strengths and limitations

This Project represents one of Australia's largest and most comprehensive bereavement studies which has documented decedents' families and friends and experience of bereavement during the COVID-19 pandemic, capturing a significant moment in time. However, participants were predominantly female, English-speaking, tertiary educated adult volunteers, so may not reflect the experiences of other genders, cultural groups or younger Australians. Further, the study was widely advertised via community organisations, partners, and newsletters, however, most recruitment occurred online, primarily through Facebook; as such, people with limited digital literacy and limited access to the internet or Facebook may also be under-represented in the data. Thus while our study has provided evidence across cities and rural areas and included deaths within Australia and overseas, further research is required to understand the experiences of these under-represented populations.

We also note that convenience samples may be subject to a volunteer effect^[11] which might have resulted in over-representation of people with negative experiences. Nevertheless, in open-ended questions people reported a range of experiences, including positive experiences.

It is regrettable that the Aboriginal and Torres Strait Islander component of the study could not proceed. Timelines and budgets did not allow for National consultation and whilst the Protocol for a smaller local study was approved by the University of Technology HREC, after consultation, the Aboriginal Health & Medical Research Council Ethics Committee did not consider it representative of the views and experiences of Aboriginal and Torres Strait Islander peoples throughout Australia. We are pleased to report that the Aboriginal and Torres Strait Islander investigators took ownership of this sub-study and appointed a project officer to complete the study as a quality improvement project in South Eastern Sydney Local Health District.

Conclusions

It is critical that governments take heed of the lessons learned here, and respond to the gaps identified by this Project when planning for responses for future pandemics. During pandemics, health systems need to include in their focus the implementation of basic bereavement outreach to prepare families for the death of their loved ones and support them afterwards.

Bereavement care must be elevated within the national pandemic planning processes to reduced long-term dysfunction. This will require initiation of a National Pandemic Bereavement Preparedness Plan developed in collaboration with relevant stakeholders (consumers, grief and loss professionals, health, funeral, government, and support services). This is needed to better support people who are dying, and their families, to minimise unmet needs and mitigate poorer bereavement outcomes associated with required public health measures and community responses to health pandemics.

“ I was so angry and felt incredibly let down by the government, my only need was to be allowed to travel. I'm certain that my grief would have been manageable then. My plan had always been to be with my mother at that time. Just 24 hours away. I am desperately sad and have lost the will to participate in life. I don't think that anyone could help with that. It happened; I cannot change that. I have to somehow manage to live with the anger and guilt. ”

– 3757 home death, no palliative care

Recommendations emerging from our report

Recommendations in relation to public health measures, health care and bereavement

The COVID-19 pandemic resulted in widespread impacts to the delivery of end-of life care, funerals, and bereavement care and support. To facilitate future pandemic preparedness, organisations need to be supported to develop systems that:

- formally recognise the central role families play in providing end-of-life care in their pandemic planning
 - recognise the potential for enduring negative impacts that can result from restrictions to visiting during end-of life-care and at the time of the death and seek to ameliorate these impacts
 - enable caring at end-of-life to be shared amongst family members to reduce carer burden
 - adjudicate visiting exceptions in a transparent and equitable manner to avoid discrimination in family access and additional strain on the clinical team relating to decision-making/policing of policies
 - when visiting must be restricted,
 - o ensure there are communication link(s) to family/friends
 - o ensure virtual communication equipment is available and accessible e.g. phone chargers, internet (wi-fi and data), tablets to patient/resident and family/friends
 - o include systems to provide support for isolated family/friends involved in care provision
 - consider facility re-design to allow for safe visiting during periods of restriction e.g. single entry and exit visiting, entry/exit away from public areas
 - adjust PPE requirements and pandemic restrictions in line with evidence
 - allow for PPE adjustments for people who have hearing or cognitive impairment
 - revise definitions of essential workers to include in-patient bereavement support workers in acute settings and community settings (e.g. social workers)
- The Clinical Communities of Practice (COPs) which were established and continue to meet across key clinical specialities in NSW and other States to support the response to COVID-19 provide a useful model to address many of these recommendations. The purpose of a COP was to: support clinicians to network and share strategies, identify local solutions and issues with respect to pandemic preparedness; prioritise and escalate issues and solutions related to COVID-19. It is recommended these COPs be expanded to include grief and bereavement experts who can identify and disseminate evidence-based supportive and end-of-life care resources to health workers for their patients and clients.
- hospital and aged care facilities could utilise trained volunteers to undertake a “check-in and chat” follow up for isolated grieving families. Volunteers could work from home but the volunteer co-ordinator at the facility can provide training and supervision/de-briefing
 - when face-to-face services are reduced (e.g., outpatient clinics), clinical staff could be re-allocated to provide clinical updates for families on patients; provide psycho-social support and information
 - include training in loss, grief and bereavement as an essential component in medical, nursing and allied health curricula, and for residential aged care facility staff to facilitate understanding and compassionate responses to implementation of any necessary restrictions
 - include a clear and compassionate process with access to high level decision makers to facilitate people to leave the country where friends and family are dying. Individuals should be permitted to make informed decisions to leave the country and accept any requirements for re-entry
 - funeral company services review costs for “hybrid” or virtual funerals as bereaved participants commented on the extra costs involved

Recommendations on communication of public health measures and bereavement

Confusion around communication of public health measure restrictions was identified as a significant stressor. To facilitate future pandemic preparedness it is recommended that organisations be supported to develop systems that:

- facilitate communication across local health districts (or equivalent) of locally relevant and consistent communications regarding implementation of public health restrictions. This could be achieved through a Communities of Practice model
- provide clearer definitions around “compassionate visits” that are widely distributed to bereaved family/friends and easily accessible
- utilise Community leaders in culturally and linguistically diverse and LGBTQIA+ communities to be conduits for information and social support
- provide assistance for navigating travel and quarantine restrictions to visit dying family/ friends and family/ attend funerals

Recommendations for multicultural communities

We recognise that data saturation was not reached in our interviews with multicultural health workers so firm recommendations cannot be made. However, this quote from a participant suggests a way forward, particularly, the importance of community networks and connection. We recommend:

- Providing support to CALD community leaders, faith leaders, and multicultural health workers as they are the link between Government, health services, and CALD communities. Supporting these key stakeholders will help ameliorate confusion around government messaging and facilitate equitable access to culturally appropriate bereavement supports.
- Involving CALD community representatives in decision-making and governance structures to respond to the needs of CALD communities and reduce stigmatisation.

“ But I think that the message is – have we learnt anything to be better prepared for disasters... that we don’t allow the system to break down so badly. And we might have to have a stocktake of what happened and what should have been done differently or better. And I think that we have learnt how important networks are. How important to be connected as a health service with communities, and NGOs, and community. ”
– multicultural health worker 5

Recommendations in relation to provision of information about grief and bereavement support at end-of-life

- Establish a virtual information and support hub for family and friends to access existing evidence-based bereavement resources in multiple formats and languages for easier access for a wide range of audiences
- Location of this information should be documented for relevant agencies to access
- Existing mechanisms and systems should be leveraged to disseminate end-of-life and grief information e.g. Services NSW; Services Australia; My Gov website
- Health care professions be trained to provide evidence-based information on grief and support services that can be built on/tailored to individual needs and accessed from multiple access points (e.g. QR Codes)
- Information on the police and coronial process needs to be centralised and made available to family and friends immediately a sudden death is reported

Recommendations on provision of bereavement support

Project findings identified multiple organisations and agencies as being relevant to bereavement support and highlighted the significant challenges to bereaved families and individuals that arise when systems are shut down. To facilitate future pandemic preparedness, governments and organisations need to be supported to develop systems that:

- allow for multiple points of provision of information to increase the likelihood of family/ friends receiving the information and support they require including:
 - o health services and aged care facilities consider a concierge model to help families navigate different health, support and government services when face to face contact is not available during pandemics
 - o funeral industry services provide information on supports and the coronial process and timelines (for where health services had no or minimal involvement in the death)
 - o consider establishment of community link worker roles to link bereaved people to community services e.g. neighbourhood centres, Men’s Sheds, cultural centres as places of information and support

- incorporate a public health approach to providing bereavement support which include a role for informal, community (e.g., Compassionate Communities, “Death Cafes”), and specialist care services in pandemic preparedness plans and for usual bereavement care
- increase support services provided by the coronial process to keep families informed and ensure follow-up is provided in pandemic preparedness plans, and for usual bereavement care
- that staff in government services such as Centrelink and banks receive training to increase grief literacy and awareness about the emotional, legal and financial support needs of bereaved people; such modules are available through CareSearch, palliAGED or Grief Australia

Further recommendations to improve bereavement supports

- greater bereavement leave (i.e., more than 2 days) and for bereavement leave to be granted for the death of family members as well as friends
- provide an opportunity to acknowledge the deaths that have occurred during the pandemic with a recognised National Day of Mourning

Recommendations on professional health support use

COVID-19 resulted in elevated rates of mental health distress, including suicidal ideation, and many respondents reported difficulties accessing the care they were seeking. This is significant as specific patterns of intense and chronic grief reactions are associated with negative long-term health outcomes that can be reduced through specialist interventions.

To facilitate future pandemic preparedness, governments and organisations need to be supported to develop systems that:

- identify pathways of bereavement care through primary health care systems
- include documented systems to identify people who are at risk of, or experiencing a complex response to bereavement to avoid people getting lost between services when services may be closed during pandemics; GPs were the most used health service and as such could play an important role in primary care and triage to appropriate grief supports
- train the workforce to facilitate referrals to services and organisations that can meet identified needs and are matched with the required levels of expertise maintain flexible delivery options, including face-to-face grief counselling where possible

- address the lack of training for psychologists and mental health professionals in delivering interventions for prolonged grief disorder

This will require:

- broader recognition and understanding among health professions of the links between bereavement and mental health outcomes, including Prolonged Grief Disorder
- training in loss, grief and bereavement to be an essential component in medical, nursing and allied health curricula
- pandemic preparedness bereavement education to be an essential component of the medical, nursing and allied health curricula.



Partners

