



Palliative Care in Queensland 2021: Bereavement Care

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PalliativeCare
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We are inclusive.

We celebrate multiple approaches and points of view. We believe diversity drives innovation and connects us closer to our members, clients and our communities. We're building a culture where difference is valued. We take a holistic approach. We foster both a top-down and grassroots approach. When we say Palliative Care is Everybody's Business, we mean everybody.

Acknowledgements

Our organisation acknowledges the Traditional Custodians of the lands and seas on which we live and work, and pays respect to Elders - past, present and emerging.

This publication is an initiative of Palliative Care Queensland's Bereavement Care project, which was conducted in 2020-2021. PCQ wish to thank all of our stakeholders, carers and consumers who have given their valuable time and expertise to help guide the development of this publication. In addition we wish to thank the Queensland Government for holding an inquiry into palliative care, everyone that took their time to make a submission into that Inquiry and the members of the Health, Committee, Disability Services and Domestic and Family Violence Prevention committee and their staff for the Inquiry hearings, briefing and the Inquiry report. We greatly appreciate the contributions everyone has made in sharing experience, knowledge and time with us.

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About Palliative Care Queensland

Palliative Care Queensland (PCQ) is an independent not-for-profit peak body with charitable status representing the people who care for Queenslanders experiencing serious illness, dying, death and grief.

- **Our belief:** The way we care for our dying is a significant indicator of our society's values
- **Our mission:** Quality care at the end of life for all
- **Our vision:** To hear Queensland community members say:
"I live in a community where everybody recognises that we all have a role to play in supporting each other in times of loss, ageing, dying and grief. We are ready, willing and confident to have conversations about living, ageing, dying and grieving well, and to support each other in emotional and practical ways."

Our priorities are that all Queenslanders:

- are able to live every day until their last
- are able to have a dignified death, regardless of their illness, age, culture or location
- have access to a supportive social network at the end phase of life and have the choice of quality palliative care

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CONSULTATION AT A GLANCE

Our Aim

The aim of this consultation was to gain an understanding into the following core questions in relation to bereavement care in palliative care:

- What are the needs?
- What is currently happening?
- What are the opportunities and priorities for improvement?

Relevance

“ Provision of bereavement support is an essential component of palliative care service delivery.¹ ”

“ Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual. Addressing suffering involves taking care of issues beyond physical symptoms. Palliative care uses a team approach to support patients and their caregivers. This includes addressing practical needs and providing bereavement counselling.² ”

What we did



Palliative Care in Queensland 2021: Bereavement Care

CONSULTATION AT A GLANCE

There is a process of grieving and through bereavement care this can be remedied by helping them through that process. Having that support system in place to allow them to have that grief and work through it
(Consumer)

... bereavement care isn't just post-death. So, it's about the preparation, anticipatory grief and working with people who not only are the patients or the people with an illness, a life-threatening illness, but their families, carers and people around them, to invest time in helping them understand and grieve people while they're still here and alive
(Consumer)

... we live in a society that's not very death literate, particularly an Anglo-Saxon culture, and Western culture. So, a lot of family and friends don't know what to do or to say to a family whose child has died. And so, it can leave families feeling very isolated in their experience
(Stakeholder)

This support for people facing life threatening illness and "existential things that arise out of death, dying, anticipatory grieving, and bereavement care" is absolutely essential
(Stakeholder)

Palliative care teams must include services for bereavement and grief support
(Inquiry submission)³

A bereavement advocacy service would also be helpful on diagnosis to assist with all the services, processes, and preparations necessary for bereavement care. It could also reduce secondary complications such as stress related illness that might develop from these high-stress and traumatic experiences in bereavement
(Consumer)

Genuine bereavement support could have helped ease the deep trauma of watching a loved one die
(Consumer)

Bereavement care brings a strong calming effect, and inner peace to the dying person
(Consumer)

Grieving is not the same for all people and it can take a long time. Having support during this time is very important especially for those who do not have family or close friends around them
(Consumer)

For Aboriginal and Torres Strait Islander families bereavement care 'shows a sense of belonging'
(Consumer)

As soon as a person enters palliative care there should be a service dedicated to supporting the patient and their families during and after their death for up to 12 months. If they are getting the right service, it will help them move through that grief process a lot better than not having the service
(Stakeholder)

Your support networks and your connections are such a strong buffer for warding off mental health challenges, developing complex grief and so forth so, yeah, it's definitely got a valued place
(Stakeholder)

Recommendations

1 Recommendation 1: Undertake a service audit and gap analysis to support the development of a resource that can provide a central hub for bereavement service and supports, information and referrals

2 Recommendation 2: Review the processes used to identify people who need specialist bereavement care

3 Recommendation 3: Support health professionals and services providing bereavement care in Queensland to have greater access to the latest research, training and information about contemporary models of bereavement and bereavement care

4 Recommendation 4: Support policy and service development in relation to bereavement care for disaster and pandemic management, conduct a Statewide survey of the general public to understand more about the experience of grieving during COVID-19

5 Recommendation 5: Provide ongoing public education and awareness in relation to bereavement care

Next Steps

Our hope is the information contained within this consultation report will spark conversations about bereavement care in Queensland and inform policy development and organisational strategy and operations.

CONSULTATION OVERVIEW AND RECOMMENDATIONS

About the consultation

Background

In 2020 the COVID-19 pandemic resulted in border shut downs, house and facility lockdowns, vulnerable population age groups self-isolating and volunteers being restricted from palliative care services, Palliative Care Queensland identified that the COVID-19 had highlighted the need for bereavement care services, as people were often distant or isolated from their loved ones at the end phase of their life and unable to attend funerals or other post death rituals. The Queensland Government funded Palliative Care Queensland through their COVID-19 Immediate Support Measures funding to conduct a bereavement care project. This report summarises the consultation aspect of this project. The conclusions reached and recommendations made are Palliative Care Queensland's, they do not necessarily reflect the views of Queensland Health and are not Queensland Government policy.

Why the consultation was needed

Bereavement care is an essential aspect of palliative care. Bereavement is the state of loss, and grief is the response that follows this change or loss. Grief is the process of coming to terms with change and loss, it is profoundly personal. Grief is a challenging experience for individuals, families and their communities.⁵ In 2019, there were 32,473 deaths recorded in Queensland. If on average each death impacts 6-8 people, this may suggest at least 250,000 close family and friends are grieving for a significant other each year in Queensland.⁴ As a result, bereavement care is a substantial health concern.



Everyone at some point will experience the death of someone close to them. Grief is the normal emotional reaction to loss, but the course and consequences of bereavement will vary for each individual. Palliative care integrates the psychological, spiritual and cultural aspects of care, and offers a support system to help carers and families cope during the person's illness and in bereavement.⁵



Between 2018 - 2020 the Queensland Government conducted the Queensland Palliative Care Inquiry 2020³ into palliative care which involved a large number of submissions from across Queensland, yet anecdotally minimal referenced bereavement care.

In 2020 the COVID-19 pandemic resulted in reduced access to bereavement care in palliative care.

The aim of this consultation was to gain an understanding into the following core questions in relation to bereavement care in palliative care:

- What are the needs?
- What is currently happening?
- What are the opportunities and priorities for improvement?

How the consultation occurred?

There were three aspects to the 8-month consultation process:

- Consumer hosted consumer discussions (Kitchen Table Discussions),
- Qualitative stakeholder interviews
- Queensland Palliative Care Inquiry³ key word search

These findings were then collated and analysed to produce 5 recommendations and key focus areas.

Limitation of the consultation

The goal of this consultation was to compile a snapshot of bereavement care services and supports in Queensland. Given this scope, this report is to focus on the voices of people at the coalface rather than provide a literature review or services mapping. It is important to acknowledge that community consultations and the subsequent reporting that occurs as part of the process is a snapshot in time of the view of a small number of people and organisations. While all care was taken to ensure representation and participation from a variety of people, we acknowledge the limitations inherent in such a consultation.

Our hope is the information contained within this consultation report will spark conversations about bereavement care in palliative care in Queensland and inform policy development and organisational strategy and operations.

Recommendations

1

Recommendation 1: Undertake a service audit and gap analysis to support the development of a resource that can provide a central hub for bereavement service and supports, information and referrals

Key focus areas:

- Develop understanding of the issues and barriers related to the cost of bereavement services, geography-based funding, the digital literacy of providers and clients, and internet services also need to be considered
- Develop a resource that can provide a central hub for bereavement services and supports, information and referral pathways

2

Recommendation 2: Review the processes used to identify people who need specialist bereavement care

Key focus areas:

- Provide training and professional development opportunities to develop this specialist bereavement workforce
- Establishment of a practitioner network for bereavement coordinators/counsellors that includes private practicing practitioners
- Examination of the interface between the role of bereavement counsellors and spiritual care practitioners
- Identify the barriers to accessing specialist bereavement care

3

Recommendation 3: Support health professionals and services providing bereavement care in Queensland to have greater access to the latest research, training and information about contemporary models of bereavement and bereavement care

Key focus areas:

- Include screening tools in clinical settings and public health approaches to bereavement care
- Adapt and align bereavement services more closely to client needs, including consideration of a review of funding structures. Also includes considering the role of the public health bereavement models of service delivery

4

Recommendation 4: Support policy and service development in relation to bereavement care for disaster and pandemic management, conduct a Statewide survey of the general public to understand more about the experience of grieving during COVID-19

Key focus areas:

- Conduct a Statewide survey of the general public, include questions about pre-death support (i.e., in palliative care and aged care settings); pre death access to dying family member/friend; post death support; access and changes to participation in death care; cultural rituals and funeral rites such as viewings, body disposal and even inability to transport bodies across state or internationally
- Ensure feedback includes First Nations and culturally and linguistically diverse (CALD) communities

5

Recommendation 5: Provide ongoing public education and awareness in relation to bereavement care

Key focus areas:

- Focus on initiatives that support and build grief literacy in the general community
- Focus on initiatives that normalise death, dying and bereavement
- Include vulnerable populations (i.e., older and isolated) and disenfranchised grief (suicide, child deaths) or specific disease experiences such as MND, and First Nations and CALD communities

Invitation to action

The Palliative Care in Queensland 2021: Bereavement Care consultation report was created by the sector, for the sector. These recommendations were developed following a consultation with a variety of key stakeholders.

They provide direction for the sector in relation to this important aspect of palliative care.

To become involved in promoting these recommendations, please consider the following possibilities for action:



CONSUMER CONSULTATION SUMMARY

What was the purpose of the Kitchen Table Discussions?

The purpose of the Kitchen Table Discussions was to provide community members who may not normally have a say, an opportunity to have their voice heard in an informal, friendly and safe setting. Kitchen Table Discussions are an engagement tool that provide the information and guidance needed to support individuals and small group participation in discussions at a place and time of day that suits them, and which are led by a community member (the Kitchen Table Discussion Host). The Kitchen Table conversations consisted of three consumers and carers chosen to host sessions within tight timeframes in five Queensland locations. A total of 18 consumers were consulted. The outcomes of each discussion were collated by the hosts and provided to Health Consumers Queensland for inclusion in this report.

What were the key findings?

1. Bereavement care is important

Participants considered bereavement care to be most important to support families during and after their loved one's passing. This was equally true for Aboriginal and Torres Strait Islander families. Bereavement care was identified as support that could include mental, spiritual, physical and emotional. This reflects the varied experiences of and responses to grief different people have. Variables include: how traumatic the death was, how long people grieve for and if they have family or close friends around them. Other factors can be feelings of helplessness to assist in caring for a loved one, or the impact of life medically extended beyond natural life expectancy.

The support needed after a death can include: pressures such as notifying friends and relatives and responding to their condolences, legal obligations such as funeral arrangements and financial details, depression from losing a loved one, life adjustments and coping with day-to-day life.

Bereavement care support was particularly valued by participants for its capacity to assist the patient and their family to accept that death is imminent and be comfortable and peaceful in the final days.



There is a process of grieving and through bereavement care this can be remedied by helping them through that process. Having that support system in place to allow them to have that grief and work through it. (Kitchen Table Discussion participant)



2. Service provision and access

Trust in relationships with health professionals was valued. This was particularly important for First Nations participants, who spoke about the importance of staff knowing cultural protocols and having access to Aboriginal and Torres Strait Islander Liaison Officers. Some participants were unaware of any local bereavement support and services and mentioned they were very much needed. [Palm Island].

Support identified included family, counsellors, psychologists, social workers, funeral services, the local GP, hospital and hospice chaplains, and the local pastor. First Nations participants mentioned Aboriginal and Torres Strait Islander pastors who offered assistance beyond spiritual care to include practical care such as food parcels.

Participants identified a range of needs in QLD. This included service based and practical needs such as bereavement follow-up, accommodation for families, access to low-cost funerals and to meaningful and culturally appropriate funerals, complementary therapies, and increased awareness and information about grief and loss for community members. A number of participants identified the need for services and supports to extend to rural and regional areas.



As soon as a person enters palliative care there should be a service dedicated to supporting the patient and their families during and after their death for up to 12 months. If they are getting the right service, it will help them move through that grief process a lot better than not having the service. (Kitchen Table Discussion participant)



3. Impacts of COVID-19

Some participants had traumatic experiences due to not being allowed to visit family members in hospital. Lockdowns and border closures contributed to this situation. For some, this blocked the intimacy of families grieving together and supporting one another during bereavement. Reduced attendance at funerals also caused trauma, including the difficult choice of who would be invited to attend. Funerals are important and sacred for Aboriginal and Torres Strait Islander people, who have large families and often funerals are attended by up to or more than 500 people.



If the sick person knew who wasn't there, it would make them more upset. Others unable to go to the funeral have suffered a lot more because they could not grieve with the rest. And they're still grieving in their own way, possibly. (Kitchen Table Discussion - First Nations participant)



Finally, it was acknowledged that care was made more impersonal by use of masks and gowns, and telehealth appointments. Isolation was a problem, which was exacerbated by this degree of remove.

STAKEHOLDER CONSULTATION SUMMARY

What was the purpose of the stakeholder interviews?

The purpose of the stakeholder interviews was to gain a qualitative understanding of the sector's perspectives in relation to the core questions pertaining to this consultation. Approximately 400 minutes of qualitative data were collected from 11 different stakeholders identified by Palliative Care Queensland. The stakeholders included those people working in identified bereavement care positions in hospitals, hospices and bereavement care services. The interviews were conducted via Zoom and typically lasted between 30-60 minutes. The interviews were undertaken, analysed and reported on by an external contractor, the Death Literacy Institute.

What were the key findings?

Acknowledging discomfort with grief and death

The stakeholder interviews highlighted the significant impact a death-denying culture has on the bereavement experience for individuals and families and service providers. They noted that community members, health systems and health professionals are influenced by societal norms about loss and death and the fear of talking about death. As such, bereavement care can play an essential role in normalising and validating the experience of grief and loss. Importantly, care must be taken to ensure that health professionals or the health system does not pathologise grief.

COVID-19: a challenge and an opportunity for learning about capabilities and capacity

While challenging, there was considerable learning and adaptation through COVID. The key issues identified were:

- 1) We can learn from the work and experiences of practitioners responding to natural disasters.
- 2) Online support was a lifeline and part of the quick response.
- 3) Additional workload - bereavement support workers needed training in Zoom, and they also needed to support clients with technology issues and the broader impact COVID-19 has had on their services as a whole.
- 4) Online support resolved many issues to do with access, and this has improved broader challenges to access. While valuable, technology cannot replace physical touch and intimacy for families.
- 5) Delayed impact. Stakeholders expressed a concern about grief being delayed. One reason for this was the interruption of and change in rituals at the end of life and funeral care.

Creating awareness about bereavement services



... I would love our state to develop some sort of mechanism to ensure that we could somehow identify specialist bereavement counsellors throughout the state. It is something we really, really struggle to do. (Stakeholder 1)



Stakeholders identified a range of services and programs that offer bereavement support, both pre- and post-death. These services were being provided via telephone, online, face to face, in groups, with peers, volunteer led and provided by specialist bereavement services. A lack of communication between services meant that most stakeholders felt services across Queensland were not well coordinated.

Community education and professional development



When someone's going through it, yeah it can be scary, but once they have ... the information it's not so scary, it's not so scary. (Stakeholder 2)



Education about grief and loss, and death and dying was discussed throughout the stakeholder interviews. Two key ideas emerged:

- 1) Professional development is needed to convert generalists to specialists.
- 2) Stakeholders also identified low death and grief literacy as a barrier for community members to access support.

**QUEENSLAND INQUIRY
SUBMISSIONS, REPORT AND
RESPONSE KEYWORD
SEARCH SUMMARY**

Inquiry Submissions: What was the purpose of the Queensland Palliative Care Inquiry submissions keyword search?

The purpose of the key words search of the Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying,³ (abbreviated to the Queensland Palliative Care Inquiry submissions for the purposes of this consultation report) was to identify key messages in relation to bereavement care in palliative care that emerged through these submissions and to consider how often bereavement care featured in this large Statewide government inquiry.

In November 2018, the committee was ordered by the Legislative Assembly to undertake a major inquiry into the delivery of aged care, end-of-life care and palliative care, and community and health practitioners' views on voluntary assisted dying. The committee's terms of reference required it to inquire into and report on the delivery of end-of-life and palliative care in Queensland.⁶ The Queensland Palliative Care Inquiry 2020 report⁶ presents the committee's findings and recommendations covering aged care, end-of-life care and palliative care.

The committee announced the call for submissions on 14 February 2019 with a closing date of 15 April 2019. In total, the committee accepted 4,719 written submissions for the inquiry. The committee conducted 34 public and private hearings and briefings for the inquiry and heard evidence from 502 invited witnesses. These included public hearings across regional centres along the east coast of Queensland as well as Mount Isa, Longreach, Mossman and Palm Island. The report was tabled in March 2020; it contained 77 recommendations.⁶

2500 submissions are publicly available on the Queensland Parliament website. These PDFs were converted to Word documents, and a keyword search was completed (see below) to focus on submissions in the five areas of focus. Dedoose software was used to conduct searches and review the data manually. Segments of data were then extracted from the submissions and a thematic analysis completed. For quality assurance, sections of the submission were reviewed for each keyword and phrase. A comprehensive search was conducted for the following keywords and phrases: bereavement care, bereavement, grief, loss, mourning. (27 references found)

Summary of the findings of the keyword search of the Inquiry Submissions

The fear of prolonging the grief or suffering of family and loved ones left behind after an illness was the primary theme identified. Submissions spoke directly of concern for the grief of family members. Submissions that supported assisted dying laws argued that VAD laws would make it easier for families: 1) at time of death 2) preparing for death and reducing the impact of grief:

““ Until the law is changed, there is a terrible legacy for suffering individuals; and for their loved ones who face a complicated grief process. (unnumbered, submissions 157-236)

I do not want my family to suffer unnecessary grief and sadness due to a decline in my health over an extended period of time. I would rather have the choice to end my life in a dignified way than have my family have to suffer and focus on my pain and suffering. The inevitability of life ending will always be there. (Submission E443) ””

This included, Voluntary Assisted Dying having a role in reducing a sense of helplessness for the bereaved:

““ It is so difficult to put into words the emotions that we both felt, the sense of loss and complete helplessness. We talked about euthanasia, but it was not an option. Had it been an option, difficult as it would have been, I would have gladly injected him to let him go peacefully and with dignity. (Submission 001) ””

And the profound impact traumatic memories of dying have had on the grief experience for people who wanted to end the suffering of their family members:

““ And now, amidst my profound grief, there is a raging anger. It is almost 4 years since my beautiful mum died. I cannot remember her beautiful face and soul. Instead, all memories of her are tarnished by the manner of her death and her dying face. I have sought grief counselling, I have tried so hard, albeit in vain, to learn strategies that will diminish the horrific images that are persistently lurking in the forefront of my mind. Now I have similar images of my father. Their deaths taught us that death is something very much to fear. We considered mum and dad's condition to be so distressing that we denied grandchildren the chance to say goodbye, a decision approved by all. The children had already witnessed enough suffering, enough suffering to ensure that their final images of their grandparents would haunt them forever. (unnumbered, submissions 294-370) ””

And expressed frustration about how the current end of life laws are contributing to pain and suffering:

““ The last thing I want would be to cause my loved ones such grief, so I would be forced to die alone under the current Queensland law. (I emphasise that I have no thoughts, or need, of suicide right now, and my views are based entirely on my experience of dying patients!). I feel that it is only fair that, if I can ensure myself a peaceful pain-free death, my patients also should have this option. It is unfair that some people in our community (medical and veterinary practitioners) should have legal access to pharmaceuticals to assist dying while the rest of the community does not. (unnumbered, submissions 157-236) ””

Report Findings: What did the Aged care, end-of-life and palliative care findings and recommendations (report No 33.)⁶ state regarding bereavement care?

A keyword search was conducted for the term 'bereavement' in the Inquiry report (459 pages) and 23 matches were found. It is important to note that only one recommendation mentioned bereavement care (Recommendation 44).



44. Revision of the 2015 End-of-Life Strategy

The committee recommends that the Queensland Government revise and update the Statewide Strategy for End-of-Life Care 2015 in conjunction with the Australian Government, Primary Health Networks, Palliative Care Queensland and other peak bodies, consistent with the Clinical Services Capability Framework, to:

- specify what palliative care services and end-of-life care services are to be provided and in what form by government and non-government providers, including: specialist care services, telephone support, access to pharmacy services, grief and bereavement support, the delivery of awareness programs for health professionals and the general public, and interactions with aged care^{6 (p.2)}



Response Findings: What did the Queensland Government response state regarding bereavement care?

The Queensland Government Response – Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee Report No. 33: Aged care, end-of-life and palliative care was tabled on the 30th September 2020.⁷

A keyword search was conducted for the term 'bereavement' and one match was found.

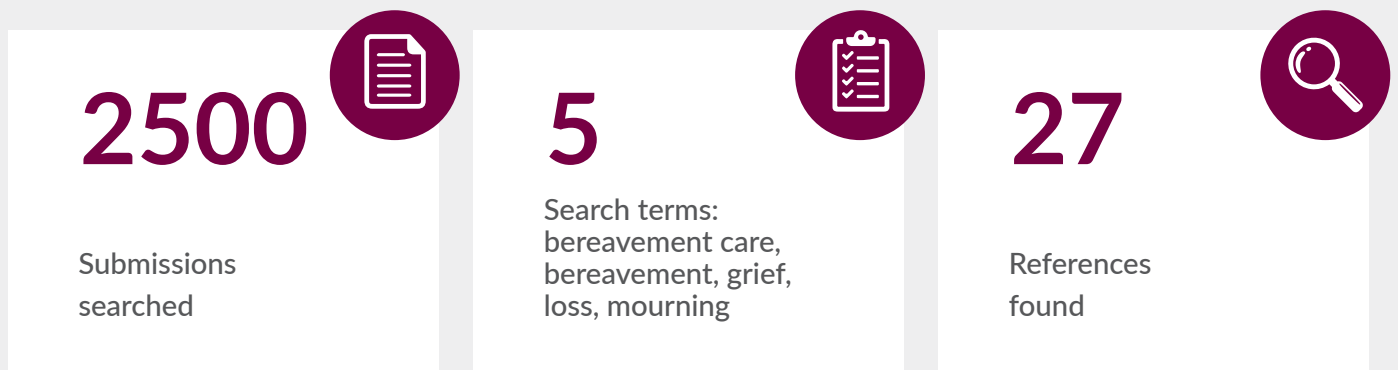
Bereavement is mentioned under the *Education, awareness and carer support initiatives* area.



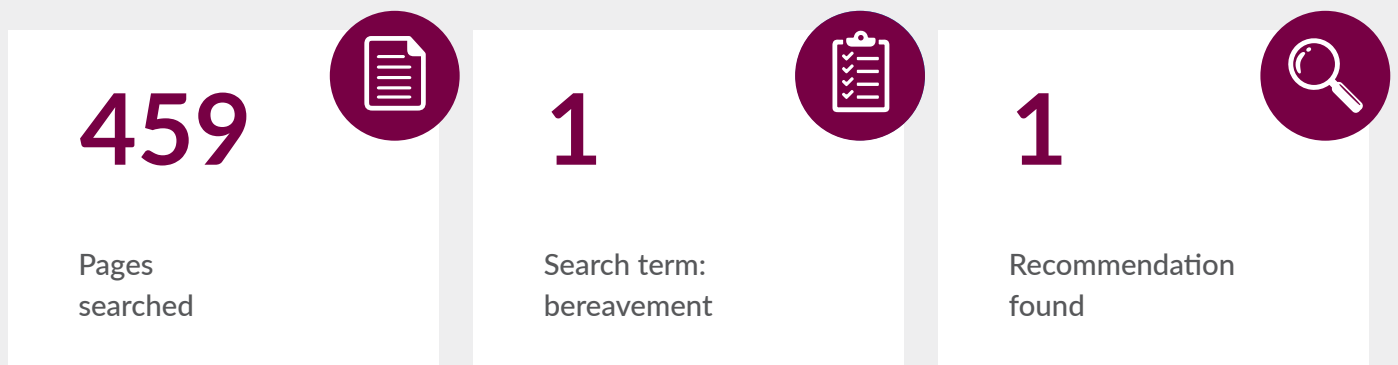
The needs of people providing informal end-of-life care to family and friends within the community are also important. Queensland Health has developed a range of bereavement resources that provide useful information about preparing for the end-of-life of a family member or friend.^{7 (p.7)}



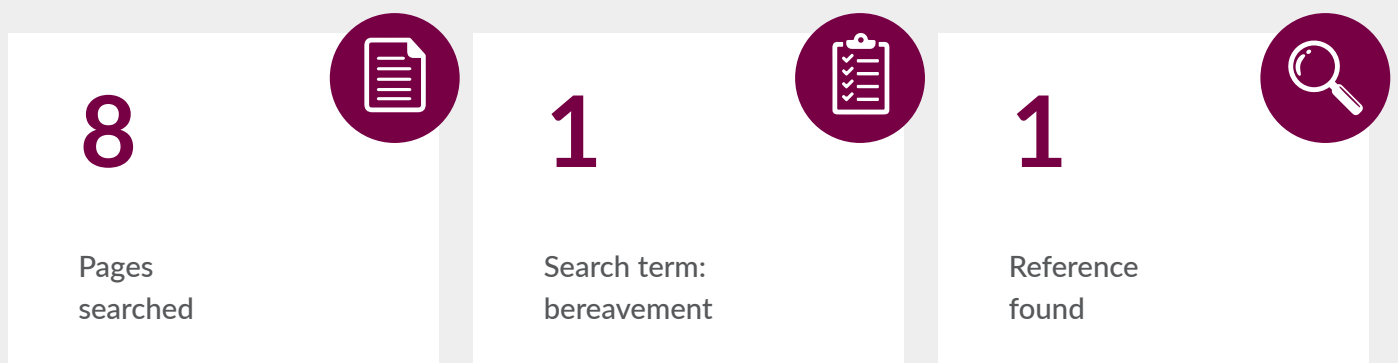
Submissions: Queensland Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying (2019-2020)³



Report findings and recommendations: Aged care, end-of-life and palliative care findings and recommendations (2020)⁶



Queensland Government Response – Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee Report No. 33: Aged care, end-of-life and palliative care (2020)⁷



Further information and supports in relation to bereavement care

Palliative Care Queensland

Provides information, links and education in relation to bereavement care, supports and services.

www.palliativecareqld.org.au/bereavement

Australian Centre for Grief and Bereavement

Provides a statewide specialist bereavement service for individuals, children and families who need assistance following the death of someone close to them. Their website also has useful information sheets you can download about grief, supporting a person who is grieving, children and grief, and grief anniversaries and significant events.

www.grief.org.au

Queensland Health – What to do after someone dies

Provides links to practical information about some of the things you will need to think about after someone dies.

www.qld.gov.au/health/support/end-of-life/after-death

Queensland Health – Bereavement resources

Provides a range of resources developed by the Care at End-of-Life project team to offer support and direction for people who are bereaved.

www.clinicalexcellence.qld.gov.au/priority-areas/service-improvement/improving-care-end-life-queensland/resources/bereavement-support

CareSearch – Bereavement and Grief

Provides evidence based information, resources and links regarding bereavement and grief.

www.caresearch.com.au

Compassionate Friends Queensland (Support family after a Child Dies)

An international self-help support organisation for bereaved parents, siblings and grandparents grieving the loss of child; offering friendship and understanding by reaching out to bereaved parents, to the surviving siblings and other family members to support them in the grief and trauma which follows the death of a child, through a range of support services and resources.

www.compassionatefriendsqld.org.au

PalliAged Bereavement support for older people

An online evidence-based guidance and knowledge resource about palliative care in aged care for use by health professionals and the aged care workforce.

www.palliaged.com.au

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*“If there ever comes a day where we can’t be together.
Keep me in your heart. I’ll stay there forever.”*

– A.A. Milne, Winnie the Pooh

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