

Palliative Care in Queensland 2021: Spiritual Care

palliativecareqld.org.au

Developed in collaboration with

Meaningful Ageing AUSTRALIA

Spiritual Health Association

An initiative of PalliativeCare QUEENSLAND
PALLIATIVECAREQLD.ORG.AU

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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 Spiritual Care in Palliative Care project, which was conducted in 2020-2021 in collaboration with Spiritual Health Association and Meaningful Ageing Australia. PCQ wishes to thank Health Consumers Queensland and the Kitchen Table Discussion hosts and participants, as well as Death Literacy Institute and 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."

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About Spiritual Health Association

Spiritual Health Association (SHA) is the peak body for spiritual care in the health sector. Our focus is on advocacy for and promotion of compassionate, person-centred spiritual care in health services. Since 1974 we have been collaborating with health services, faith communities and other key partners and stakeholders, to expand the availability and accessibility of spiritual care as an integral part of quality healthcare. We are informed by a growing body of evidence for the value and contribution of spiritual care and involved with international colleagues in the move towards professionalisation of the sector. We are committed to ensuring patients, carers and staff receive high-quality and safe spiritual care that is responsive to their spiritual needs.

03 8610 6327 **office@spiritualhealth.org.au** **spiritualhealth.org.au**

About Meaningful Ageing Australia

Meaningful Ageing Australia is the Australian leader in education and resourcing of evidence-based spiritual care for the ageing population in the context of health, aged care and community services. Our resources help bring person-centred care to life. We provide evidence-informed resources and engage with government and key agencies to enable access to integrated spiritual care.

1800 618 107 **admin@meaningfulage.org.au** **meaningfulageing.org.au**

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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 spiritual care in palliative care:

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

Relevance

The World Health Organisation views spirituality as inextricably linked to quality of life and that spiritual care is an essential aspect of palliative care.[1]

What we did

18
Consumers participated in Kitchen Table Discussions

3
Kitchen Table Discussions hosted

12
Stakeholders participated in qualitative interviews

600
Minutes of stakeholder interviews analysed

2500
Queensland Inquiry submissions searched[3]

8
Months consultation

5
Recommendations identified

16
Key improvement areas identified

Palliative Care in Queensland 2021: Spiritual Care

CONSULTATION AT A GLANCE

We are spiritual beings. Not everybody would claim that, but I do. But I think even those people who don't identify as a spiritual being I think would still benefit from spiritual care, partly because spiritual care overlaps things like ultimate questions and ethics frameworks, and those sorts of things are useful in a palliative care setting, either for patients, families, or staff, because they're a framework by which people make important decisions and sets a hope for the future. (Stakeholder)

Spirituality is extremely important in community because, without hope, people despair, and you see that without this hope people are unable to function. Spirituality gives hope and purpose and where this hope is present, people have belief in the next world. To do this journey to the next world in a comfortable way, people need hope and purpose in this life (Consumer)

Often the family do not know how to access spiritual care for the dying or for themselves, unfortunately. (Consumer)

Where it was possible to live stream funeral services from churches this was very well accepted. However, with dying patients in hospital, when there were strict visiting numbers allowed into the dying, that had a very serious negative impact on those present and their cultural norms. Whole families were told they could not go in together to see the dying person and this had a very negative effect. It was hard to accept. (Consumer)

I believe the community has a role. I don't believe that spiritual care is just an individual thing. I think, for example, we are part of the community, and spirituality is a communal act. So, I would personally say that they have a role. Then, I think that communities have a responsibility to provide practical support for people in bereavement, or people who are palliative. (Stakeholder)

Palliative care is a time to reach out for spiritual supports. Spiritual systems are there and should be available for free. (Consumer)

Recommendations

1 **Recommendation 1:** Create opportunities to raise awareness and understanding of the role of spiritual care and spiritual care services

2 **Recommendation 2:** Increase standardisation in training and supervision

3 **Recommendation 3:** Improve spiritual care in palliative care resourcing

4 **Recommendation 4:** Invest in best practice and evaluation

5 **Recommendation 5:** Promote the role of spiritual care in palliative care during a pandemic

Next Steps

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

Note that recommendations are NOT listed in any particular order

CONSULTATION OVERVIEW AND RECOMMENDATIONS

About the consultation

Background

In 2020 the COVID-19 pandemic resulted in border shutdowns, 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 response had resulted in the reduction of access to spiritual care supports available during this time, as the majority of Queensland spiritual care in palliative care is provided by volunteers, and many volunteers are in the vulnerable population age group that were self-isolating. The Queensland Government funded Palliative Care Queensland through their COVID-19 Immediate Support Measures funding to conduct a spiritual care in palliative care project.

In 2020 Palliative Care Queensland collaborated with Spiritual Health Association and Meaningful Ageing Australia to form a Collaboration which aimed to bring together leads in Queensland Spiritual Care in Palliative Care in networks; undertake a Queensland Spiritual Care in Palliative Care consultation activity; promote Spiritual Care in Palliative Care through education and awareness raising initiatives and consider opportunities to embed spiritual care in palliative care policy. This report summarises the consultation aspect of this collaboration. The conclusions reached and recommendations made are Palliative Care Queensland, Meaningful Ageing Australia and Spiritual Health Association's, they do not necessarily reflect the views of Queensland Health and are not Queensland Government policy.

Why was the consultation needed?

Spiritual care is an essential aspect of palliative care. The World Health Organisation defines palliative care as:

> *An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.*[1]

Spirituality is the way we seek and express meaning and purpose; the way we experience our connection to the moment, self, others, our world and the significant or sacred.[2]

Spiritual care is viewed as an essential service provided as part of palliative care services. In Queensland spiritual care is provided to support places (organisations, services) and the people (patients, family, staff) by supporting the meaning, purpose, rituals, ceremonies and much more associated with serious illness, dying, death and bereavement.

Between 2018 - 2020 the Queensland Government conducted an Inquiry[3] into palliative care which involved a large number of submissions from across Queensland, yet anecdotally minimal referenced spiritual care.

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

The consultation's aim was to gain an understanding into the following core questions in relation to spiritual 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 Inquiry keyword search

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

Limitation of the consultation

The goal of this consultation was to compile a wide and in-depth snapshot of spiritual care services and supports in Queensland. 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.

An attempt was made to broaden the consultation input through a sector survey however due to a small number of responses the results did not add any additional meaning to the existing data gathered.

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

Recommendations

1 Recommendation 1: Create opportunities to raise awareness and understanding of the role of spiritual care and spiritual care services

Key focus areas:

- Define benefits of spiritual care in palliative care (for both services and community), including clarification about how to access services within the community
- Develop a resource that can provide a central hub for bereavement services and supports, information and referral pathways

2 Recommendation 2: Increase standardisation in training and supervision

Key focus areas:

- Standardisation of roles and clarity of the skills and training required for the role (including cultural safety)
- Standardisation of practice in relation to the role (including linkage to health system-wide spiritual care)

Note that recommendations are NOT listed in any particular order

3 Recommendation 3: Improve spiritual care in palliative care resourcing

Key focus areas:

- Clarity on what resourcing is needed in what environment
- Detailed mapping and reporting of the current resourcing in palliative care
- Reduce the reliance on volunteers
- Ensure spiritual care is available in all palliative care services
- Ensure palliative care staff are trained in the basic principles of spiritual care and how to signpost them to more specialised support

4 Recommendation 4: Invest in best practice and evaluation

Key focus areas:

- Address the need to extend spiritual care
- Identify opportunities to highlight or showcase best practice initiatives
- Identify tools (and embed into practice) to demonstrate the benefit and access to spiritual care in palliative care
- Invest in research and evaluation of spiritual care in palliative care services

5 Recommendation 5: Promote the role of spiritual care in palliative care during a pandemic

Key focus areas:

- Detailed impact analysis of the palliative care sector in relation to spiritual care and Covid (with a particular focus on visitor restrictions)
- Explore the 'citizen spiritual care role'
- Identify opportunities for Statewide networks to support different regions

Note that recommendations are NOT listed in any particular order

Invitation to action

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



Individual Actions

- Inform your personal networks, local community and community groups regarding relevant recommendations
- Learn what is available or how you can support your local service and supports



Organisational Actions

- Consider how you can include these recommendations in your strategic and organisational plans, as well as policies and other systems.
- Create working groups to enact relevant recommendations



Government Actions

- Use these recommendations to guide strategy and policy development
- Ensure spiritual care is funded for all palliative care services

CONSUMER CONSULTATION SUMMARY

What was the purpose of the Kitchen Table Discussions?

The purpose of Kitchen Table Discussions (KTDs) 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. KTDs 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 is led by a community member (the KTD Host). The KTD 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. Spiritual care is important

- Spiritual care provides comfort and support for people who are dying and for people in bereavement.
- Spiritual beliefs of Aboriginal and Torres Strait Islander peoples, including the role of traditional healers, needs attention.

2. Accessing services can be challenging

- Health professionals need to know how spiritual care works in their settings so they can refer and/or enable access for patients and families. This is easier in some settings than in others.
- Specific groups such as First Nations, and some religions were identified as less catered for.
- Need for awareness in the community about available spiritual care in palliative care supports, services and people suggested a directory or an information hub might be helpful.

3. Covid changed practices at the end of life and included the adoption of technology. Many people did not receive spiritual care due to restrictions.

> *My father-in-law was a Community Elder, an Aboriginal man of that faith, and he expressed his oneness in very similar ways to that of the Buddhist faith. That was through connectedness to country/nature, family, culture and belief systems including the meritorious deeds of "Good" and acknowledging the impacts of bad deeds.*
> (Kitchen Table Discussion participant)

> *It would be beneficial to promote spiritual care and the accessibility of spiritual care to our community. It would be beneficial to have this information in general practice surgeries and not just at the pointy end. It would be necessary to have a database and update it regularly. This contact list could be put together and distributed widely and perhaps Palliative Care Queensland could assist us with that?*
> (Kitchen Table Discussion participant)

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 600 minutes of qualitative data were collected from 12 different stakeholders identified by Palliative Care Queensland, Spiritual Health Association and Meaningful Ageing Australia teams.

Stakeholders included those people working in identified spiritual care positions in both religious/spiritual organisations and public institutions. The interviews were conducted via Zoom and typically lasted between 40-60 minutes. The interviews were undertaken by the spiritual care coordinator for Palliative Care Queensland and then professionally transcribed, analysed and reported on by an external contractor, the Death Literacy Institute.

What were the key findings?

Spiritual care matters

Spiritual care is viewed as an essential service provided as part of palliative care services. Spiritual care is seen as a non-judgemental and supportive process provided to people, families and communities. Stakeholders were passionate in their beliefs that the spiritual dimension of being human ought to be valued and promoted in palliative and end of life care. Spiritual care provides support to the place (organisation, service) and the people (patients, family, staff) through pre and post death ritual and ceremony. Stakeholders expressed concern that the general public have a limited amount of awareness about spiritual care services offered in QLD, and they felt strongly that spiritual care provides a preventative function by easing suffering in dying and therefore supporting the short- and long-term bereavement process of individuals, families and communities.

Legitimacy and professionalisation

> *There's a need for us to be encouraging training, educating, clinical staff and non-clinical staff in spiritual care, in spirituality, because if the pandemic continues or we have another one, god forbid, the people who are allowed in the room need to understand that the person in that bed, if they don't understand holistic care, to help them to understand that their spirituality is vital as they approach the end of their lives.* (Stakeholder interviews)

As noted above, stakeholders expressed concerns about the lack of awareness of spiritual care and the role it has in palliative care. The call for improved awareness about spiritual care and access to spiritual care services and supports, was related to the need for competency and training guidelines, and a need for service-based screening tools. Stakeholders expressed concern and uncertainty about training, supervision and ongoing professional development in the field of spiritual care as a whole. Further, the lack of consistency was viewed as a potential barrier to both future resourcing and service development.

Frameworks to guide practice

Closely related to legitimacy and professionalisation is the need for a guiding framework to support the practice of spiritual care in palliative care. This includes training, supervision and support of any person practising in end-of-life or palliative care who may be in a position to provide basic spiritual care or refer to an identified position. Four levels of support were identified in the report.

1) **Identified positions - chaplains, spiritual carers, volunteers**

2) **Health professionals working with people at end of life**

3) **Service providers - aged care, care workers, teachers etc**

4) **Incidental Services - cleaners, food services**

Each of these levels of support have training and support needs that could be catered for in service planning and development. It was also noted that spiritual care frameworks need to support improved training in and awareness of cultural safety and cultural competency in spiritual care work.

Identifying tensions

> *I think there's barriers in the sense of it's the denominations that create the barriers, not so much the hospital.* (Stakeholder interviews)

> *Spiritual care is there for everybody not just for the ones who already own a faith. Well not own a faith but proclaim a faith. So, the person who's sitting in bed 2 who isn't on my list as a nominated denominational or faith-based person has just as much spirituality as the person on either side who may be a Catholic and an Anglican.* (Stakeholder interviews)

The interviews did identify an overall finding that relates to a tension about how spiritual care is delivered in Queensland. Three tensions are explored below: models of care, identified or general positions, and conceptual clarity.

Models of care

> *It gets down to a particular organisation's model of care, and their model of assessment.* (Stakeholder interviews)

There were two main ways that spiritual care is currently being provided - via identified positions (usually in a religious or spiritual organisation) or through the general workforce of a service provider. There was concern that neither were well funded or well resourced. In addition, services that relied on a volunteer workforce were significantly affected by COVID-19.

Identified positions or general?

Further to the pervasive belief that everyone will benefit from spiritual care, stakeholders generally held a belief that all health providers and services have the capacity to provide basic spiritual care. This was poorly done however, or it was given little emphasis. There was a need for more integration between spiritual care and the healthcare team. Spiritual carers practicing within an existing palliative care service, noted the benefits of having a close collaboration with social work and other health professionals. This was viewed as the optimum model of care.

Multiple concepts

This finding is based on a thread of ideas present throughout the stakeholder interviews. It is an attempt to summarise contradictory ideas and tensions that were expressed and discussed. First, stakeholders talked about new and old ways of practicing spiritual care (having a list of people with your faith versus visiting all those with identified spiritual needs). Further, this is related to the language stakeholders used to talk about their work; this includes spiritual care, chaplains, pastoral care and faith-based care. Through this use of interchangeable terms/phrases it was not always clear if stakeholders were referring to differing or similar roles and responsibilities. Finally, some stakeholders talked about distinctions between religious and spiritual beliefs and felt strongly that even people who identified as non-religious also had spiritual needs that should be attended to at end of life.

Resources and funding

> *I feel that if we had more resources, if we had more trained people, if we had more personnel, really, who would be in that position to do the role that I'm doing, so almost like a shared role, to establish where people are in their palliative care journey.*
> (Stakeholder interviews)

Lack of resources and funding for spiritual care in palliative care was a pervasive theme for the stakeholders. According to stakeholders, additional funding and resources would enable services to provide:

- Funeral care - being available to conduct funeral services for families when needed
- Bereavement support - including groups and participating more generally in bereavement follow-up services
- Support for pre and post death rituals - specific faith-based rituals and care that spiritual carers can provide to the dying person, their family and community.

There is a theme around how resources for spiritual care are used and allocated across the state. Smaller organisations with a spiritual or religious framework as core business were more confident about their impact within smaller geographic areas (hospitals or aged care facilities) but there were concerns about overall coverage in Queensland. While there was some non-denominational representation in the stakeholder interviews, many of the stakeholders had limited understanding of the resourcing needs for other spiritual or religious groups.

The COVID-19 pandemic

> *During Covid-19 restrictions, I had a Muslim aunt who was in Palliative Care. She was cared for at home with supports given by the hospital nurses and other visiting staff. The family also visited daily with up to 20 persons coming and going through the day. Hygiene practices were enforced and there was no fear or distress. The gathered family were able to share food and cultural practices and all rites were put in place. My aunt was able to participate in the process and direct some of the meals. She made an announcement one night that the family supper would be fish and chips and, this was orchestrated for her, much to her pleasure. More funding should be provided for in home palliative care when this can be offered as an alternative to hospital palliative care.*

> *There is something about that embodied presence, physical presence, that is really integral to what we do. It's not something that can just be taken fully online.*
> (Stakeholder interviews)

It is not surprising that stakeholders viewed the experience with COVID-19 as both a challenge and an opportunity. There were a number of changes to service delivery that meant that stakeholders had to develop new ways of working with clients and families, including the use of technology such as video conferencing. Access to patients in ICU and in other settings was often restricted unless a person was receiving palliative care. Volunteer positions were the most restricted. Being unable to touch, having to wear masks and protective clothing also made interpersonal connection challenging and certain rituals that involve touching the patient impossible. New opportunities arose however with the need for welfare checks that included spiritual care for people in quarantine. One of the key findings was an identified need to provide greater flexibility in the way spiritual care is provided.

> *People in hospital are tired, and it takes a lot of energy to ask spiritual questions. I think they're becoming more exhausted. They don't have the energy at the moment to answer them, or they've gone the other way and they really want to answer them. But my sense is, by and large, at the children's hospital more people are less open because they're so tired*
> (Stakeholder interviews)

There were both systemic and structural issues discussed by stakeholders and a call for a greater recognition and training for service providers who provide incidental spiritual care. One stakeholder used the term 'citizen spiritual carers' to describe the role. Closely related to this was the need to acknowledge the wide scope of the spiritual care role. Spiritual carers had a role in supporting other health care staff and other service providers. There was an overall sense for stakeholders that the pandemic has caused a greater awareness about spiritual issues, with people asking questions about meaning, purpose and connectedness. This has in turn created a strong need for spiritual carers to both practice self-care and to rely on each other for emotional and collegial 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 keyword search of the submissions to the Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying,[3] (abbreviated to Inquiry Submissions for the purposes of this consultation report) was to identify key messages in relation to spiritual care in palliative care that emerged through these submissions and to consider how often spiritual 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. The Queensland Palliative Care Inquiry 2020 report (abbreviated to Inquiry Report for the purposes of this consultatation report) presents the committee's findings and recommendations covering aged care, end-of-life care and palliative care.[4]

The committee announced the call for submission 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.[4]

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 thematic analysis completed. For quality assurance, sections of the submission were reviewed for each keyword and phase. A comprehensive search was conducted for the following keywords and phrases: spiritual, spiritual care, meaning. (30 references found)

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

The primary reference to "spiritual" and "spiritual care" in the submissions was in relation to the definition of Palliative Care. In particular, the World Health Organisation (WHO) definition.

A common example:

> *The term 'palliative care' describes an approach to care that improves the quality of life of people and their families who are facing the problems associated with a progressive illness. It does this by preventing and relieving suffering through early identification and assessment, by treating pain and other physical, psychosocial and spiritual problems and by addressing practical issues.*[1]

The next most common references were directly related to religion and then a "good death". These WHO concepts were used together:

As above:

> *A good death gives people dignity, choice and support to address their physical, personal, social and spiritual needs.* (Submission, 024)

And when directly referencing the spiritual/religious beliefs of the person writing the submission. For example:

> *I believe that we all have a moral obligation and responsibility before God, and before one another, to do what we can to maintain and promote good health for people of all ages. Every effort should be made to provide physical and mental/spiritual comfort to those who are going through times of discomfort or poor health. We do not, however, have any right to determine the time of death for any individual outside the context of just penalties for crimes committed by that individual.* (Submission, E347)

Following from this is the idea that spiritual suffering is a key contributor in situations where people request to die or requesting Voluntary Assisted Dying (VAD). This submission, for example, references an article from Palliative Medicine[10] that suffering at end of life would benefit from additional therapeutic support:

> *Requests for euthanasia and PAS may be altered by the provision of comprehensive palliative care. Suffering from physical symptoms can be alleviated, and psychosocial and spiritual care can improve well-being of patient and caregivers. Information about the available palliative care options may provide reassurance and diminish anxieties about the subsequent disease trajectory.* (Contained within submission 247-293, un-numbered)

In contrast another submission spoke to the connection between spiritual beliefs and the suffering associated with not having access to VAD:

> *Despite love from family and friends and on-going support from frequent, regular medical and psychological services, I no longer have the desire or will to live. It is not acceptable that an individual should be forced to remain alive despite their wishes, because another thinks they know best. I also believe that an individual's spiritual beliefs are not respected within the current laws and this has enormous impact on one's ability to live a quality life. It is my belief that we choose to come into this life. We should also have the right to choose when to leave it. This is all part of an individual's spiritual development. Even if this spiritual belief is not the general consensus, it remains that no other should have the right to determine an individual's life if that individual has a clear determination, wholly un-influenced by others, that they no longer wish to remain alive.* (Submission E138)

In general spiritual care was noted as an integral part of palliative care. Palliative care is not just about end-of-life but about the meaningfulness of that time as people near the end-of-life, for them and their loved ones.

> *Palliative care is not just about end-of-life but it is about supporting people to live with a life-limiting disease until the term of their natural life ends. Palliative care involves physical, mental, social, psychological and spiritual support. …Often people will say to me he's/she's taking a long time to die and my answer is 'what a special time in his/her life to share with him or her'. To me the final months, weeks, days of someone's life can be an incredibly meaningful time for not only the person but for all those around them. It has been my great privilege to have travelled the final journey with many people. I believe 'we should support people to live till they die, they should not need to wait in agony and despair to die'- it is a matter of perspective and good quality care. The most difficult area is the existential suffering that people have as they near the end of their life. Again, given appropriate support, this also can mean that their final days are meaningful and a time of acceptance of things resolved and those not resolvable and of healing for themselves, their families and their friends.* (un-numbered, Submissions 1-69)

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

A keyword search was conducted for the term 'spiritual care' in the Inquiry report[4] (459 pages). The following is a summary of the comments from the Committee, the submissions and the witness presentations highlighted in the report.

Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee comments

> *The committee acknowledges the important role of spiritual and pastoral care at end of life. The committee notes the calls for additional resourcing to ensure these services will continue to be delivered.*
>
> *Stakeholders highlighted the significance of supporting not only a person physically, but spiritually in the delivery of high quality, person-centred palliative care. Incorporating an individual's spiritual and pastoral care needs supports a holistic approach that integrates physical, social, psychological and cultural aspects in the provision of palliative care. Witnesses to the inquiry acknowledged the importance of providing this dimension of care in all settings.*[4 (p.323)]

14.2.1.2 Spiritual care

Spiritual care is an integral part of palliative care. A number of submitters and witnesses to the inquiry highlighted the importance of spiritual care as a component of the provision of palliative care.

A more detailed discussion of this can be found at 15.4 and discussion of the palliative care workforce in Queensland is contained in Chapter 17.

> Similarly the Anglican Church Southern Queensland called for a more integrated service provider model:
>
> *Bureaucratic red tape, for example, mires the path to palliative care for residents in regional Queensland towns, where the hospital provides a nurse practictioner who will pay limited visits to the local Anglicare aged care facility. But the resident GP must document that they want their involvement in care, and the nurse practictioner is located in and employed by another aged care facility. There is no education component with this service and it is not advisory, with the nurse practictioner taking over pain management from the GP.*
>
> *A more integrated service provider model is required to avoid situations for providers and patients where a split combination of cobbled-together funding from State and Commonwealth Governments is required to ensure a higher level of quality community in-home palliative care. Palliative care provision should be integrated and seamless for the patient/client, while minimising anxiety regarding how to leverage multiple health and aged care systems and programs to achieve a level of care. Our philosophy, holistic model of care and experience reinforces the fact that quality palliative care needs to also have as an integral part of the service, spiritual care which many Queenslanders currently miss out on due to the fact that spiritual care is unfunded.*[4 (p.268-269)]

14.4 Spiritual and pastoral care

A number of submitters and witnesses to the inquiry highlighted the importance of spiritual care as a component of the provision of palliative care.

> It was noted that the WHO definition of palliative care includes 'an emphasis on spiritual care.' The Most Reverend Dr Phillip Aspinall of the Anglican Church told the committee:
>
> *Spiritual Care or, as it is sometimes called, pastoral care provides a supportive, compassionate presence with people at times of significant transitions, illness, grief or loss. It is an integral part of holistic care intextricably linked with quality of life.*[4 (p.322)]

The Uniting Church in Australia Queensland Synod noted 'spiritual and pastoral care is fundamental to the delivery of high quality person centred care.' It further explained the important role of spiritual care at the end of life:

Whether a person affiliates with a religious tradition or not, they have spiritual care needs. We believe an approach that incorporates spiritual care holistically into our teams and services will deliver the best outcomes for the people and communities we work with. We define spiritual care as responding to the fundamental human need for meaning, purpose and deep relationships. These relationships include those with other people, self, those with creation, with the sacred or God. Spiritual care is offered to every person regardless of beliefs. It may include faith-specific support, exploring questions of meaning and purpose, enhancing relationships, reconciliation and healing, finding meaning and purpose in life stories, rites, rituals, mindfulness, meditation or prayer to enable people to experience life in all its fullness. Research increasingly demonstrates the importance of spiritual and pastoral care in health and aged care settings. This type of care plays a role in reducing distress and enhancing a person's ability to cope with illness and positively respond to changing life circumstances. Care that values spiritual elements such as faith, hope, meaning making, compassion and connections has been shown to promote health and quality of life.[4 (p.322)]

Similarly, Churches of Christ in Queensland submitted:

...we view spiritual care as being as important as physical care, and even more so at the end of life. Working as a team our nurses and chaplains along with family members are able to be attentive and listen to people as they near the end of life, offering them comfort and compassion. By doing this, we foster a sense of openness and spiritual wellbeing for those in our care, which is part of offering people dignity at the end of life.[4 (p.322)]

Stakeholders called for additional funding to support the provision of spiritual and pastoral care.

The Most Reverend Dr Phillip Aspinall of the Anglican Church noted:

Queensland Health also acknowledges the importance of this spiritual dimension of care, especially at the end of life, but Queensland Health does not fund this dimension of care. It relies entirely on churches and religious bodies to provide this care in public hospitals by properly qualified professionals without any financial contribution at all by Queensland Health. I submit that this committee should recommend to the Queensland government that it contribute to providing spiritual care as an indispensable dimension of palliative care, as do other Australian states.[4 (p.323)]

Reverend Linda McWilliam, Anglicare Southern Queensland suggested:

We would find it really helpful in community settings if we had some funding for that spiritual care component, because we seek to qualify them and train them professionally in all areas of palliative care, dementia and community care services. We really feel strongly that those spiritual practitioners can do some really good work in those circumstances.[4 (p.323)]

Mr Michael Hart, Chief Mission and Identity, Southern Cross Care agreed:

I take on board the idea of the provision of resources and funding around that. Whilst we do it because we believe it is integral to our faith tradition, it has a broader worth as well. That is something to be considered.[4 (p.323)]

Response Findings: What did the Queensland Government response state regarding spiritual 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[5] was tabled on the 30th September 2020.

A keyword search was conducted for the term 'spiritual care' and no matches were found. It is important to note that none of the Recommendations from the Inquiry Report specifically mentioned Spiritual Care.

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

2500

Submissions searched

3

Search terms: spiritual care, spiritual, meaning

30

References found

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

459

Pages searched

1

Search term: spiritual care

18

References found

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)

8

Pages searched

1

Search term: spiritual care

0

References found

Resources and Information

Palliative Care Queensland

Information, links and education in relation to holistic palliative care, supports and services.

www.palliativecareqld.org.au/spiritualcare

Meaningful Ageing Australia

Resources and advocacy for meaning, purpose and connectedness to be part of every ageing journey.

www.meaningfulageing.org.au

Spiritual Health Association

Creating more compassionate, person-centred health care.

www.spiritualhealth.org.au

CareSearch – Care of the spirit

Evidence based information and resources relating to spiritual care of people receiving palliative care, collated by CareSearch.

www.caresearch.com.au

Spiritual Care Australia

Professional association of practitioners in spiritual care, pastoral care and chaplaincy.

www.spiritualcareaustralia.org.au

Charter for Compassion

Promotes and cultivates the principle of compassion and the Compassionate Way of Life.

www.charterforcompassion.org

Self-Compassion

Tools and resources related to self-compassion, giving ourselves the same kindness and care we'd give to a good friend.

www.self-compassion.org

References

[1] World Health Organisation, “Palliative Care,” 5 August 2020. [Online]
Available: https://www.who.int/news-room/fact-sheets/detail/palliative-care

[2] Meaningful Ageing Australia, “adapted from California Lutheran Homes Centre for Spirituality and Ageing,” [Online]
Available: https://meaningfulageing.org.au/wp-content/uploads/2017/06/Meaningful-Ageing-Summary-of-Evidence-key-points-24.5.17.pdf#:~:text=Spirituality%20can%20be%20defined%20as%20%E2%80%9Cthe%20way%20we,National%20Guidelines%20for%20Spiritual%20Care%20in%20Aged%20Care

[3] Queensland Parliament, “Reports No. 33 and 34, 56th Parliament - Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying: Inquiry Overview,” 2019. [Online]. Available: https://www.parliament.qld.gov.au/work-of-committees/former-committees/HCDSDFVPC/inquiries/past-inquiries/AgedCareEOLPC

[4] Parliamentary Committees, “Aged care, end-of-life and palliative care, Report No. 33, 56th Parliament, Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee,” March 2020. [Online]
Available: https://www.parliament.qld.gov.au/Documents/TableOffice/TabledPapers/2020/5620T466.pdf.

[5] “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,” November 2020. [Online]
Available: https://www.parliament.qld.gov.au/Documents/TableOffice/TabledPapers/2020/5620T1686.pdf.

Notes

Notes

"You matter because you are you. You matter to the last moment of your life, and we will do all we can to help you not only to die peacefully, but also to live until you die."

– *Dame Cicely Saunders*

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