

2020-21 Pre-Budget Submission Queensland

Palliative Care Queensland calls for
a purpose-built palliative care system
for all Queenslanders

January 2020



PalliativeCare
QUEENSLAND

About Palliative Care Queensland

Palliative Care Queensland (PCQ) is an independent not-for-profit peak body and leading palliative care charity representing the people who care for Queenslanders living with life-limiting conditions. Queensland Compassionate Communities (QCC) is the community arm of Palliative Care Queensland.

- 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."

PCQ has been operating for more than 30 years, has over 400 members and is a founding member of national peak body Palliative Care Australia. PCQ members include health professionals across all sectors of health, specialist and generalist palliative care services, aged care, disability care, peak bodies, as well as consumers and interested members of the Queensland community. Collectively, the PCQ membership body holds tremendous knowledge and wisdom about the challenges the sector faces and the opportunities those challenges can bring.

The PCQ key 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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What is Palliative Care?

World Health Organisation (WHO) Definition of Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the issues 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 symptoms, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

WHO Definition of Palliative Care for Children:

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a):

- palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- it begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- it can be provided in tertiary care facilities, in community health centres and even in children's homes.¹

National Palliative Care Strategy 2018

Endorsed by all Australian Health Ministers

Vision:

The National Palliative Care Strategy provides an overarching vision for palliative care in Australia: that people affected by life-limiting illnesses get the care they need to live well. People who require palliative care may be at different stages of an illness trajectory; they may be young or old, with different cultural, social, emotional, relational and spiritual needs; they may need palliative care for a short period of time, intermittently, or consistently over a period of months or years. Regardless of their circumstances, people affected by a life-limiting illness, including carers and families, may benefit from the varied support available through palliative care. Helping people to live as well as possible for as long as possible is ultimately what palliative care is seeking to achieve.



“People affected by life-limiting illness get the care they need to live well”

Guiding Principles:

Six guiding principles are identified as fundamental to ensure that all people experience the palliative care they need:

- Palliative care is person-centred care
- Death is a part of life
- Carers are valued and receive the care they need
- Care is accessible
- Everyone has a role to play in palliative care
- Care is high quality and evidence-based²

Current situation of palliative care in Queensland

Death is the great equaliser. Rich or poor, young or old, inner-city hipster or lillaroo in outback Queensland - we will all die one day. It is a natural part of the life cycle.

But not all deaths are equal.

The recent debate about voluntary assisted dying has highlighted the stark difference between a “good death” and a “bad death”, with many horrific stories presented to The Queensland Parliamentary Inquiry into aged care, end-of-life and palliative care, and voluntary assisted dying (The Inquiry).

It is clear, that some people die experiencing unnecessary suffering, which contributes to prolonged grief and social challenges. BUT there also is clear evidence that high-quality palliative care can eliminate or alleviate suffering and improve peace and comfort at the end of life for patients, for their families and their communities.³

AND, there is evidence that early access to palliative care can reduce high-cost hospitalisations and visits to emergency departments, shorten the length of hospital stays and reduce the use of Intensive Care Units.⁴

Palliative Care is the choice all Queenslanders deserve

But it is not currently a choice available for all Queenslanders.

The community want choice around dying. Palliative Care Queensland neither advocates for or against Voluntary Assisted Dying, however emphasises that everyone should have the choice of access to palliative care when and where they need it.

It is estimated that if Voluntary Assisted Dying became legal in Queensland, less than 2% of the population would be eligible⁵, but 100% of the population could benefit from quality palliative care

Each year, more than 30,000 Queenslanders die. 75% of those could benefit from palliative care, which is recognised internationally as a Human Right.

When palliative care is available to the level of the World Health Organisation definition... it is specialist and generalist care, it is holistic, it is needs-based, it is for all life-limiting conditions (not just cancer), it is available for all stages of life from in utero to geriatric, it is available when and where you live, it includes bereavement care and it is care for the person, their carers, their family and their community.

Palliative care is NOT just care during the last days or weeks of life.

But, as submissions to the Inquiry show, palliative care to the WHO standard is NOT currently available for all Queenslanders when and where they need it.

There are significant gaps around the state – particularly in regional and rural areas and underserved communities. Access to palliative care is limited by where you live, your age, your illness, your culture and even the way local hospital and health services allocate their funding.

Less than 0.78% of the Queensland Health budget is spent on palliative care.

In 2019-2020, the Palaszczuk Government invested more than \$19 Billion in Queensland Health.⁶ But less than \$150 Million will be spent on palliative care.⁷

A greater investment in palliative care is needed now for a purpose-built palliative care system for all Queenslanders

We are facing a silver tsunami with the number of people aged over 65 in Queensland projected to more than double by 2026 to 5.7 million.⁸

NOW is the time to invest in excellent palliative care for all Queenslanders.

Palliative Care Queensland (PCQ) seeks commitments in the forthcoming 2020-21 Queensland Budget to address two critical areas for this vital sector:

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| 1. Palliative Care Service Delivery | \$150 Million |
| 2. Palliative Care Capacity Building | \$50 Million |

Inclusive in the above, as the peak body for palliative care in Queensland, PCQ seeks an increase of current funding to expand core programs and new funding for two key initiatives to help improve much-needed access to palliative care, particularly in regional areas of the state.

Priority 1 Support Palliative Care Queensland core business	\$495,500
Priority 2 Support the Ambulance Wish Queensland program	\$200,000
Priority 3 Build capacity through a Queensland Volunteer Village for Palliative Care	\$575,500
Priority 4 Provide an innovative community focused education program: Last Aid	\$255,900

What does a purpose-built palliative care system for all Queenslanders look like?

1. Whole of sector investment:

To address the needs of all Queenslanders and provide the care they need in a place they want it in a timely and transparent manner, Palliative Care Queensland believes a significant new investment into palliative care is imperative.

We propose a two-pronged program of funding, developed in tandem, to improve health service delivery while building community capacity.

What are we investing in?	Palliative Care Service Delivery	Palliative Care Capacity Building
What does this mean for every Queensland?	Care to you and your support network when and where you need it.	Your community and services are prepared to care. Queensland is a compassionate community.
How much new investment is needed?	\$150 Million per year	\$50 Million per year
How would this be delivered?	Delivered through the Specialist palliative care services, with transparent reporting of outputs, outcomes and costs in a state-wide palliative care register	Delivered through projects and commissioning with transparent reporting of outputs, outcomes and costs in a state-wide palliative care register
What are the key elements of this model?	<p>1. Specialist Palliative Care Services Specialist teams in each Hospital and Health Service (HHS) funded to the equivalent level of the highest service provided within the HHS Clinical Services Capability Framework (CSCF); provided in block and activity based funding; inclusive of partnership models across the HHS to support smaller specialist teams; holistic teams and service models (including social, emotional, spiritual and bereavement care); all with transparent and accountable reporting, through a mechanism such as a Queensland palliative care registry.</p> <p>2. Flexible funding packages Introduction of three flexible care packages:</p> <ul style="list-style-type: none"> a) Terminal Care Packages: which provide flexible funding coordinated by the local specialist palliative care service to fund care needs during the last week/s of life. b) Palliative Care Community Packages: which provide flexible funding coordinated by the local specialist palliative care service, matching a level four aged care package, to fund the last 12 months of life. c) Palliative Child to Adult Transition Packages: which provide flexible funding coordinated by the local specialist palliative care service to fund the transition period between paediatric to adult care. 	<p>1. Queensland 'Volunteer Village' for palliative care Support the development of a state-wide Volunteer Village for palliative care to support specialist and generalist palliative care services (include standardised state-wide training, recruitment, administration and evaluation support); provide community education, navigation and information programs and support social care initiatives such as Ambulance Wish Queensland. Include a strong focus on a regional 'volunteer village'.</p> <p>2. Invest in Workforce, Research, Quality Improvement and Innovation Targeted investment in innovation, research quality improvement and both specialist and generalist workforce to promote leadership and mentorship, while demonstrating outputs, outcomes and showcasing innovation.</p> <p>3. Queensland Palliative Care Registry Create a Queensland Palliative Care Registry (based on the CAPC National Palliative Care Registry and mapping programs⁸) which builds profiles of palliative care teams, operations and service delivery as well as maps service delivery. Also sharing progress measures, tracking capacity and reach, ultimately providing a state-wide report card for palliative care.</p>

What does a purpose-built palliative care system for all Queenslanders look like? (Continued)

<p>What are the key elements of this model?</p>	<p>3. Hospital avoidance programmes Increase support of existing hospice and palliative Aged Care Support programs which prevent avoidable hospital admissions</p> <p>4. Technology investment Investment in technology solutions to complement service delivery and enable increased access to palliative care services 'in the home' or 'close to home', (particularly to regional, rural and remote clients).</p> <p>5. Underserved population programmes Targeted service delivery programs to underserved populations living with a palliative condition. Particularly Aboriginal and Torres Strait Islander populations, homeless populations and diverse population groups.</p>	<p>4. Queensland Compassionate Communities Invest in Queensland Compassionate Communities to act as an advocate, navigator and awareness raiser for palliative care throughout the state by promoting community engagement and partnerships between services and communities, mapping existing community assets and strengthening community networks.</p>
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How Palliative Care Queensland can be supported to build sector capacity

2. Palliative Care Queensland (PCQ) investment:

PCQ can be enabled to immediately support the capacity building aspect of the whole of sector capacity through the following investment priorities:

Priority 1	Support Palliative Care Queensland core business	\$495,500
Priority 2	Support the Ambulance Wish Queensland program	\$200,000
Priority 3	Build capacity through a Queensland Volunteer Village for Palliative Care	\$575,500
Priority 4	Provide an innovative community focused education program: Last Aid	\$255,900

Priority 1: Support Palliative Care Queensland core business

Palliative Care Queensland represents more than 400 members including 66 organisations involved in the delivery of palliative care services in this state. It provides advocacy for palliative care and delivers awareness raising and knowledge programs both for health professionals and the community.

There has never been greater focus on palliative care and with The Inquiry due to deliver its key reports this year, it is essential that PCQ has the capacity to support both the sector and the community through the anticipated necessary changes and growth, including the annual industry Summit, annual Awards, free community Good Life Good Death expo and symposiums to bring together thought leaders and innovators.

Investment: Increased ongoing annual funding of \$495,500

Priority 2: Support the Ambulance Wish Queensland program

Ambulance Wish Queensland is a charity program of Palliative Care Queensland delivering last wishes and creating lasting memories for dying Queenslanders and their loved ones. Since the launch in July 2019, it has generated almost unprecedented engagement with the community providing a powerful platform to start conversations about end-of-life planning, what matters most in life and the need to get your affairs in order.

The initial launch by the Minister for Health and Minister for Ambulance Services, Dr Steven Miles, garnered international attention with a social media reach of 4.25 million and media exposure with a potential reach of 146.03 million¹⁰. Our Ambulance Wish, for plane enthusiast Trevor Dawson on December 18, also achieved powerful engagement despite a low-key approach with no media present. The social media reach was 591,000 and the story was picked up by 40 media outlets with a potential reach of 27.4 million¹⁰. Over 125 volunteers have signed up to be involved in this program. While we are actively seeking corporate partners and fundraising support to expand the program to meet the community demand, it requires core funding to sustain the current operation.

Investment: Ongoing annual funding of \$200,000

Priority 3: Build capacity through a Queensland Volunteer Village for Palliative Care

Queensland is the most decentralised state in Australia and delivering health care to the geographically and culturally diverse population is a significant challenge. Even when funding is available, finding specialist palliative care practitioners and retaining well-trained general practitioners is an ongoing challenge.

A network of trained volunteers based in the community is a practical and cost-effective way to expand palliative care services across Queensland, particularly to areas outside of the south-east corner. It is a model already used in New South Wales, Victoria and the ACT, funded by the state and territory governments and run by the state Palliative Care peak bodies. Volunteers provide a range of functional support to patients and their carers including companionship, respite, transport, meals and assistance with daily living.

Investment: New ongoing annual funding of \$575,500

Priority 4: Provide an innovative community focused education program: Last Aid

The Last Aid course is an evidence based, population level course developed in Europe¹¹ and the PCQ Queensland Compassionate Communities program could implement this community focused education program in Queensland. The course includes four modules: Care at the end of life; Advance Care Planning and Decision making; Symptom management; Cultural aspects of death and bereavement. The course uses the compassionate community approach to stimulate people to talk about death and dying.

Investment: New ongoing annual funding of \$255,900

References:

1. World Health Organisation, WHO Definition of Palliative Care [Online] December 21, 2019. <https://www.who.int/cancer/palliative/definition/en/>
2. Australian Government, Department of Health. National Palliative Care Strategy, 2018
3. Statewide Health Service Strategy and Planning Unit, Health Commissioning Queensland, Department of Health. Statewide strategy for end-of-life care. Brisbane : State of Queensland (Queensland Health), 2015
4. Impact of a New Palliative Care Program on Health System Finances: An Analysis of the Palliative Care Program Inpatient Unit and Consultations at Johns Hopkins Medical Institutions. Isenberg, Sarina R, et al. 5, s.l. : J Oncol Pract. 2017 May;13(5):e421-e430. doi: 10.1200/JOP.2016.014860. Epub 2017 Feb 28.
5. Figure based on experience in other jurisdictions
6. Queensland Health. 2019-20 Budget. Queensland Health. [Online] June 11, 2019. <https://www.health.qld.gov.au/systemgovernance/health-system/managing/budget>
7. Figure based on details in the key findings report (7) and public presentations by Queensland Health officials
8. Strategic Policy and Legislation Branch, Department of Health. Queensland Health Palliative Care Services Review - Key Findings. Brisbane : State of Queensland (Queensland Health), 2019
9. Centre to Advance Palliative Care National Palliative Care Registry, Mapping Community Palliative Care and Palliative Care Leadership Centres [Online] December 21, 2019. <https://registry.capc.org/>
10. Figure provided by Meltwater, a media monitoring software used by Palliative Care Queensland
11. The last aid course - A Simple and Effective Concept to Teach the Public about Palliative Care and to Enhance the Public Discussion about Death and Dying. Bollig G and Heller A. : Austin Palliative Care, 2016, 1(2):1010

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