



2022-23 Pre-Budget Submission Queensland

Requirements for investment to improve palliative care for all Queenslanders

Date: March 2022
For: Queensland Government

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 and is a founding member of the national peak body Palliative Care Australia. Our 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 creates a community of care that holds tremendous knowledge and wisdom about the challenges the sector faces and the opportunities for improved care, education, and support for Queenslanders with a life-limiting illness, their loved ones and communities.

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

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.¹

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

¹ World Health Organisation <https://www.who.int/news-room/fact-sheets/detail/palliative-care>

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 - the principles of which apply to other paediatric chronic disorders - is as follows (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 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 homes²

National Palliative Care Strategy 2018

Endorsed by all Australian Health Ministers

The National Palliative Care Strategy³ 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.

Guiding Principles:

- 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-based³

New Queensland Palliative and End-of-Life Care Strategy

This is currently under development

² World Health Organisation, WHO Definition of Palliative Care [Online] December 21, 2019. <https://www.who.int/cancer/palliative/definition/en/>

³ Australian Government, Department of Health. National Palliative Care Strategy, 2018

Context for this pre-budget submission

The need for investment to improve palliative care for all Queenslanders

Queensland's population is rapidly growing, and an increasing proportion of it is ageing. From a base of 5.1 million in 2020, the state's population is expected to increase by over 20% to 6.22 million by 2036, reaching between 6.5 million and almost 8 million by 2041. As a proportion of the total population, over 65's are expected to jump from around 16% of the population (2019) to over 20% by 2036.⁴ By 2050 almost 8% of the population are projected to be receiving aged care.⁵

The results of the 2020 Queensland Parliament Health Committee report into Aged Care, end-of-life, and palliative care, identified several critical recommendations to improve palliative care.⁶

"There is no doubt palliative care plays an important role in our health care system."⁶

In 2021, Palliative Care Queensland welcomed an investment by the Queensland Government of \$171 million from 2021-22 to 2025-26 to lead reforms to palliative care, but noted it was approximately 25% of what PCQ's extensive research and consultation had identified as needed in their *Requirements for New investment to Transform Care report*⁷ which was created in partnership with the Australian Medical Association Queensland and the Queensland Specialist Palliative Care Medical Directors Group.

The case for investing in palliative care

Analysis by KPMG published by Palliative Care Australia in their report *Investing to Save: The Economics of Palliative Care*, highlighted that investing in better care for those experiencing life-limiting illnesses will reduce public sector costs. KPMG estimated that the cost of death in Australia is \$7.8 billion per year, with more than half, \$4 billion, accounted for in direct hospital costs. The report outlined interventions around health and palliative care that will significantly reduce the hospitalisation costs of dying by nearly 12 per cent, or \$460 million per year, while also improving the quality of death for the person and their loved ones.⁸

⁴ Queensland Government Statistician's Office 2019, Queensland Government Population Projections, 2018 edition (medium series); Queensland Regional Database.

⁵ 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

⁶ Queensland Government (2020). 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. <https://www.parliament.qld.gov.au/Documents/TableOffice/TabledPapers/2020/5620T466.pdf>

⁷ Palliative Care in Queensland Requirement for New Investment to Transform Care, November 2020

⁸ KPMG Investing to save: The economics of increased investment in palliative care in Australia. Palliative Care Australia and KPMG. May 2020

Palliative Care Queensland's Pre-budget submission 2022-2023 (Queensland)

What is desperately needed for palliative care in Queensland

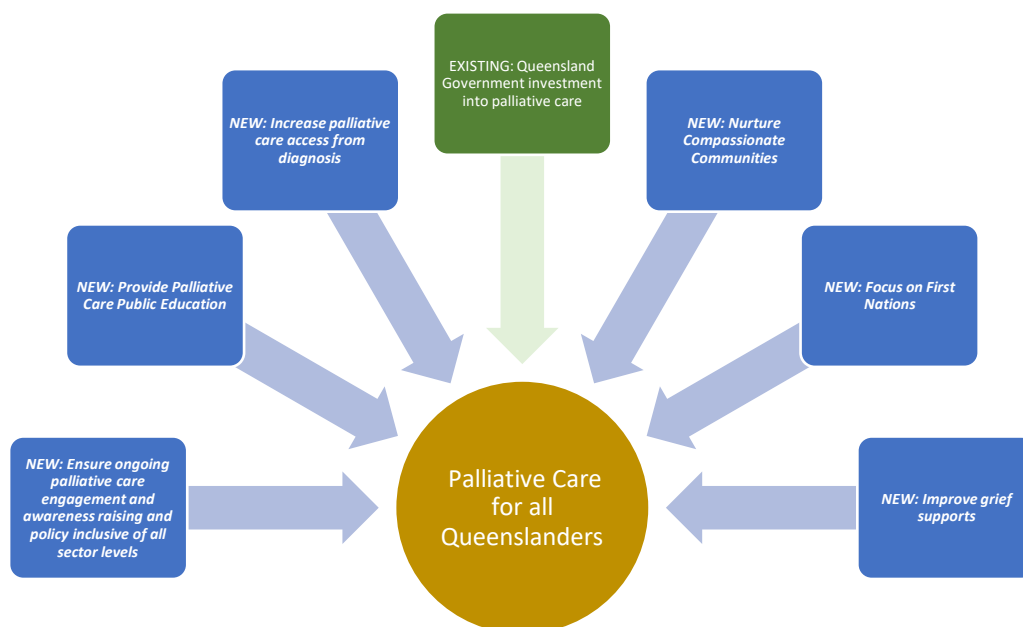
It is imperative that the state takes a critical and holistic view of the sector's needs and its ability to provide care and support to a growing population. Consequently, funding is required to:

- Bridge gaps in current care provision
- Build capacity across the healthcare sector to meet future needs
- Educate health consumers as to the role of palliative care, their options and supports available

In addition to roundtable discussions, community consultations and stakeholder engagement, this submission has taken into account:

- The 2020 inquiry report⁶
- The 2020 Requirements for New investment to Transform Care report⁷
- The 2021-2026 investment plan in palliative care by the Queensland Government⁹
- The additional burden the current pandemic has placed on the sector by significantly increasing the need for bereavement support¹⁰
- The fact that in 2023 voluntary assisted dying (VAD) will be available for Queenslanders with a life expectancy of 12 months or less, while access to specialist palliative care services and support is usually available for Queenslanders with a life expectancy of 6 months or less¹¹

Palliative Care Queensland's extensive research has identified six priority areas that are currently not funded but would transform care in Queensland and commence capacity building to meet the future needs of health professionals, practitioners and all Queenslanders. They are:



Financial modelling, undertaken in conjunction with service providers, peak bodies and stakeholders, has calculated the additional investment required at \$3.35 million in 2022-2023, or the equivalent of an additional \$0.65 per Queenslanders per annum¹², will assist in addressing the current gaps in the Queensland Government's Palliative Care Reform program and help to improve access to quality palliative care and support for Queenslanders from diagnosis to bereavement.

⁹ <https://www.health.qld.gov.au/system-governance/strategic-direction/improving-service/palliative-care-investment>

¹⁰ Palliative Care Australia (2021). Palliative care and COVID 19: Grief, Bereavement and Mental Health

¹¹ Palliative Care Queensland (2021) Submission into the Health and Environment Committee Inquiry into Voluntary Assisted Dying Bill 2021

¹² Based on Queensland's population of 5.269 million at 30 September 2021. <https://www.qgso.qld.gov.au/statistics/theme/population/population-estimates/state-territories/qld-population-counter>

Palliative Care Queensland's Pre-budget submission 2022-2023 (Queensland)

What does this mean for every Queenslanders?	Improved access to quality palliative care and support for Queenslanders from diagnosis to bereavement		
New investment required?	\$3.35 Million (in 2022-23)		
What new investment is needed	Summary	Relevant statements supportive of this investment from Qld Govt Palliative Care Inquiry report ¹³ said	Amount per year
Ensure ongoing palliative care engagement and awareness raising and sector policy inclusive of all sector agencies: Sustainable support for Palliative Care Queensland's PalliWellbeing program	PCQ's PalliWellbeing program recognises that dying is a normal part of life and it's everybody's business. The PalliWellbeing program using a wellbeing and public health approach to palliative care with an aim to increase understanding and acceptance, grow engagement and capacity, promote best practice, advise on policy and strategy, build social capital, enhance networks and nurture compassionate communities. This innovative program engages all levels of the sector including Local, State and Federal Governments, specialist and generalist palliative care services, compassionate communities, peak bodies, NGO's and civic agencies.	<i>Recommendation 67: Community understanding of death, dying and options for end-of-life care</i> "The committee recommends that the Queensland Government support Palliative Care Queensland and other stakeholders to increase the community's understanding of death, dying and options for end-of-life care."	\$350,000
Provide Palliative Care Public Education: PalliLearn and Last Aid	Support the statewide rollout of internationally recognised public education programs such as Last Aid and PalliLearn both online and face-to-face to community members.	"The committee considers public awareness and community involvement in palliative care vital in reducing fear and misconceptions about end-of-life and palliative care as well as providing better outcomes for patients and their loved ones. Education is needed across the community about palliative care and dying to enable the community to support those who wish to die at home."	\$200,000
Increase palliative care access from diagnosis: Serious illness conversation pilot project for specialist palliative care	Specialist Palliative Care choices should be included in <i>Serious Illness conversations</i> . Create a 2-year pilot to go out to tender for specialist palliative care service providers (level 2 or 3, NGOs and QHealth) to ensure palliative care is offered as part of high value care options and a valid care choice from diagnosis of neurodegenerative diseases and other life-limiting illness.	"It is simply not good enough that your postcode, your diagnosis or your place of residence could impact upon your ability to access palliative care."	\$200,000
Nurture Compassionate Communities: Local compassionate communities grants program	On World Compassionate Communities Day, provide ten (10) grants for \$10,000 each to ten (10) local communities groups with an aim to build community capacity through local community development, engagement, and awareness initiatives.	<i>Recommendation 68: Support for community initiatives</i> "[The committee] commented on the benefits that would flow from increased community awareness of palliative care and the importance of building compassionate communities"	\$100,000
Focus on First Nations: Clinical Centre of Excellence for First Nations Palliative Care	Create a world-leading Clinical Centre of Excellence for First Nations Palliative Care, with First Nations clinicians.	<i>Aboriginal and Torres Strait Islander people have different health profiles and rates of death to other Queenslanders, and this affects their demand for palliative and end-of-life care.</i>	\$1.5 Million
Improve grief supports: Statewide Bereavement Program	Create a Statewide Bereavement Program which supports the whole of sector and community by providing timely access to a statewide specialist bereavement counselling via phone/telehealth to individuals and groups, as well as supports the development of local bereavement support groups and provides easy to access bereavement education for both the community and health professionals.	<i>The WHO further explained that palliative care:</i> <ul style="list-style-type: none"> 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. 	\$1 Million

*The activities above are steps towards the ongoing investment required to transform palliative care in Queensland

¹³ Queensland Government (2020). 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. <https://www.parliament.qld.gov.au/Documents/TableOffice/TabledPapers/2020/5620T466.pdf>