



# 2021-22 Pre-Budget Submission Queensland Requirements for New Investment to Transform Palliative Care in Queensland

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[palliativecareqld.org.au](http://palliativecareqld.org.au)



**PalliativeCare**  
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## 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

## 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.<sup>1</sup> 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

<sup>1</sup> 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 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<sup>2</sup>

## National Palliative Care Strategy 2018

### Endorsed by all Australian Health Ministers

The National Palliative Care Strategy<sup>3</sup> 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:

- 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-based<sup>2</sup>

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

<sup>3</sup> Australian Government, Department of Health. *National Palliative Care Strategy*, 2018

## Context for this submission

Queensland's population is rapidly increasing and an increasing proportion of it is ageing. Queensland's 2020 population of 5.1 million is expected to increase to over 6.22 million by 2036 – a jump of over 20%. By 2041 that is forecast to rise to somewhere between 6.5 million and almost 8 million people with the current proportion of over 65's expected to jump from around 16% of the population (2019) to over 20% by 2036.<sup>3</sup> By 2050 almost 8% of the population are projected to be receiving aged care.<sup>4</sup>

Analysis by KPMG in a report conducted for Palliative Care Australia *Investing to Save: The Economics of Palliative Care*, highlighted that investing in better care for those experiencing life-limiting illnesses will reduce rather than increase public sector costs. KPMG estimated that the cost of death in Australia is \$7.8 billion per year, with more than half, \$4.0 billion, in hospital costs. It outlined interventions around health and palliative care presented here can 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.<sup>5</sup>

In 2020-2021, the Palaszczuk Government invested almost \$22 Billion in Queensland Health.<sup>6</sup> But currently, the palliative care sector receives only \$110 Million per year in funding, around half a percent of the total annual state budgets reported in the Queensland Parliament *Health Committee Report into Aged Care, end-of-life and palliative care*, many health organisations supported PCQ's urgent call for increased funding for the sector. The Committee made several recommendations regarding Queensland Government funding for palliative care – both in amount and transparency of reporting. Recommendation 54 proposed “that the Queensland Government increase its funding for palliative care in Queensland and Recommendation 55 supported it by proposing that “the Queensland Government examine options to ensure that palliative care funding is not diverted to other sub-acute areas.”<sup>7</sup>

The Queensland Premier Anastacia Palaszczuk announced during the Queensland election campaign (October 18, 2020) that her government would invest \$171 million in palliative care **over six years**. PCQ then welcomed the Premier's commitment of a further investment of **\$28.5 million per year** over six years, but noted that it fell “significantly short of being able to provide universal access to care for all Queenslanders.”<sup>8</sup> During the campaign, PCQ as the peak body, launched its *Requirements for New Investment to Transform Care*<sup>9</sup> – a fully costed funding request which was created in partnership with the Australian Medical Association Queensland and representatives from the Queensland Specialist Palliative Care Medical Directors' Group. That funding submission forms the basis of this current Pre-Budget Submission which calls for a new annual investment of \$275 million per year.

It is PCQ's strong contention that the election commitment by the Queensland Government will do very little to change or improve the current sub-standard access (by other Australian state's standards) by all Queenslanders seeking palliative care which is highly inequitable and is very much determined by where you live in the state.

### VAD and palliative care

PCQ continues to advocate for the separation of palliative care and Voluntary Assisted Dying (VAD) and we remain neutral regarding VAD in that we do not advocate for, nor argue against the introduction of VAD, having among our membership, people who strongly support and just as strongly oppose VAD. PCQ does however argue that the lack of access to high quality palliative care should never be the reason to consider VAD in Queensland to end 'intolerable suffering'. Our submission to the Queensland Parliamentary inquiry highlighted recommendations to improve palliative care systems (as does this submission), as well as recommending some principles and safeguards to consider in the development of VAD legislation.

### COVID-19 and palliative care

The emergence of the COVID-19 pandemic highlighted the fact that palliative care is an essential service and as such has been an essential component of the frontline response to the pandemic. Palliative care can help manage physical symptoms and distress, and provides personal support for people who are seriously ill or dying, and their families. The President of the European Association for Palliative Care (EAPC), Prof Christoph Ostgathe pointed out in a statement on 20 March, 2020: “We need to make it clear that in a pandemic like this palliative care is not a luxury, it is a human right!”<sup>10</sup>

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

Palliative care is a recognised human right, which provides a holistic approach to improving the quality of life for terminally-ill people at all stages of life - from in utero to geriatric - that should be available from the day of diagnosis until death, as well as providing bereavement support for loved ones.

Though many Queenslanders receive timely and high-quality palliative care, this care is not available to all. At present, access to palliative care for Queenslanders is a lottery based on where they live, their age, their illness, their culture and even the way their local Hospital and Health Service allocates its funding.

To address the critical shortages and gaps in palliative care for Queenslanders, Palliative Care Queensland, as the sector's peak body, is proposing new investment to create a purpose-built palliative care system that provides timely and high-quality care when and where Queenslanders need it.

This request for funding has been created together with AMA Queensland and representatives from the Queensland Specialist Palliative Care Medical Directors' Group as well as through regular consultation with communities from across the state. As a result, this funding request is truly representative of the needs of all Queenslanders from specialist health practitioners to carers of those approaching their end of life.

This funding proposal seeks to address the significant system challenges faced by the palliative care sector in Queensland. These challenges are identified by Reports No. 33 and 34, 56th Parliament – Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying.<sup>11</sup>

In response, the Queensland Government has committed to increasing investment for the delivery of palliative care.<sup>12</sup> To bring about this system transformation, we propose that Queenslanders need \$385 Million per year of dedicated funding to palliative care.

Palliative care is universal, touching all Queenslanders directly and indirectly. Yet the current Queensland Budget of \$110 Million per year is grossly inadequate to meet the care needs of dying Queenslanders, their carers, families and front-line medical professionals upon which the sector relies.

Palliative Care Queensland proposes an additional investment of \$275 Million with a two-pronged approach to new funding:

- The first prong focuses on improving palliative care health service delivery (with new investment of \$241 Million per year)
- The second prong builds community capacity (with new investment of \$34 Million per year)

The proposed investment provides a roadmap for systematic, positive and balanced transformation of palliative care for all, directly improving the quality of life for terminally-ill Queenslanders at all stages of life - from in utero to geriatric.

An increase in funding of \$275 million per annum, equates to less than \$53 per capita per annum,<sup>13</sup> a small investment to meet a universal need and address a human right.

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

<sup>5</sup> 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

<sup>6</sup> KPMG *Investing to save: The economics of increased investment in palliative care in Australia*. Palliative Care Australia and KPMG. May 2020

<sup>7</sup> Queensland Health. 2020-2021 Queensland Budget. December 2020.

<sup>8</sup> 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>

<sup>9</sup> Palliative Care Queensland Media Release 20 October, 2020

<sup>10</sup> Palliative Care in Queensland Requirement for New Investment to Transform Care, November 2020

<sup>11</sup> Ostgathe, C. (20 March 2020). Start thinking about palliative care in times of a pandemic: The case of Corona. EAPC Blog.

<sup>12</sup> Queensland Parliament (2020). Reports No. 33 and 34, 56th Parliament - Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying. Retrieved 30 September 2020. <https://www.parliament.qld.gov.au/work-of-committees/committees/HCDSDVPC/inquiries/past-inquiries/AgedCareEOLPC>

<sup>13</sup> \$275 million divided by 5,160,023 persons. Queensland's preliminary ERP as at 31 March 2020 - Queensland Treasury <https://www.qgso.qld.gov.au/statistics/theme/population/population-estimates/state-territories>

# Funding: Prong 1

<b>What are we investing in?</b>	<b>Palliative Care Service Delivery</b>	
<b>What does this mean for every Queensland?</b>	<b>Care for you and your support network when and where you need it</b>	
<b>New investment required?</b>	<b>\$241 Million per year</b>	
<b>What new investment is needed per year?</b>	<b>Summary</b>	<b>Details (inc. amount per year)</b>
<b>Palliative Home Care Packages (Flexible funding packages)</b>  <i>Total: \$117 Million</i>	<b>Last Days Packages:</b> Provide flexible funding coordinated by the local specialist palliative care service to fund additional nursing care needs during their terminal care phase	10,000 packages/year: \$70 Million
	<b>Palliative Care Community Packages:</b> Provide flexible funding coordinated by the local specialist palliative care service for the last 6 months of life and to support the transition of children with palliative needs to adult care	14,000 packages/year: \$42 Million
	<b>MASS Statewide palliative care patient equipment and syringe driver program:</b> Provide essential equipment supplies to people's homes in a timely manner for the last 6 months of life	\$5 Million
<b>Specialist palliative care workforce</b>  <i>Total: \$72 Million</i>	<b>Palliative Medicine Physicians</b> including Consultants, Registrars & Resident Medical Officers	40 FTE: \$20 Million
	<b>Palliative Care Nursing Specialist workforce</b> including Nurse Practitioners, Clinical Nurse Consultants & Clinical Nurses	130 FTE: \$25 Million
	<b>Palliative Care Allied Health Specialist workforce</b> including bereavement counsellors & spiritual care coordinators	65 FTE: \$10 Million
	<b>Palliative Care Administrative Support Staff</b> including volunteer coordinators	40 FTE: \$5 Million
	<b>Palliative Care Clinical Educators</b>	35 FTE: \$7 Million
<b>Targeted Palliative Care Service Delivery Programs</b>  <i>Total: \$50 Million</i>	<b>Advance Care Planning Facilitators</b>	25 FTE: \$5 Million
	<b>First Nations Palliative Support:</b> Statewide specialist palliative care support and a Centre for Excellence	\$9.5 Million
	<b>Hospice and Specialist NGO Support Program:</b> Hospice and Specialist NGO specialist support and care model expansion	\$10 Million
	<b>SPARTA (Queensland's Specialist Palliative Rural Telehealth Service):</b> Regional, rural and remote hub and spoke support and education	\$5 Million
	<b>PallConsult:</b> Statewide specialist medical, nursing and allied health telephone support for adult generalist and primary care providers	\$2 Million
	<b>Office of Advance Care Planning:</b> Statewide Advance Care Planning information, support and tracking service	\$1 Million
	<b>Statewide Paediatric Palliative Care Collaborative Outreach Service:</b> Expand children's services to include telehealth outreach and a 24-hour paediatric support phone line	\$2 Million
	<b>Aged Care Palliative Support:</b> Provide specialist palliative care support and consultation services for residential and community aged care	\$12.5 Million
<b>Technology investment</b>  <i>Total: \$2 Million</i>	<b>Statewide Bereavement Support Program:</b> Counselling services, bereavement support groups and telephone advice for generalist services	\$5 Million
	<b>Statewide Spiritual Care Program:</b> Spiritual care support and advice for generalist services	\$3 Million
	<b>ICT:</b> 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)	\$2 Million

## Funding: Prong 2

What are we investing in?	<b>Palliative Care Capacity Building</b>	
What does this mean for every Queensland?	Your community and services are equipped to care for Queenslanders experiencing life-limiting diagnoses, dying, death and grief. Queensland is a compassionate community where palliative care is everyone's business.	
New investment required?	<b>\$34 Million</b>	
What new investment is needed per year?	<b>Summary</b>	<b>Details (inc. amount per year)</b>
Specialist Palliative Care Training and workforce development programs  <i>Total: \$13 Million</i>	Specialist Palliative Medicine Training and Support program	25 places \$5.5 Million
	Specialist Palliative Care Nursing Training and Support program	40 places \$5 Million
	Specialist Palliative Care Allied Health Training and Support program	20 places \$2.5 Million
Invest in Workforce, Research, Quality Improvement and Innovation  <i>Total: \$11 Million</i>	<b>Palliative Care Database Registry:</b> A Queensland fit for purpose data registry system which builds profiles of palliative care teams, operations and service delivery as well as mapping service delivery. This registry will also share progress measures, tracking capacity and reach, ultimately providing a statewide report card for palliative care	\$8 Million
	<b>Centre for Palliative Care Research and Education:</b> Including research grants, fellowships and scholarship funding	\$3 Million
Policy, Engagement, Awareness Raising and Last Wishes  <i>Total: \$1 Million</i>	<b>Palliative Care Queensland:</b> Provide advice regarding palliative care strategy and policy issues. Ongoing engagement and consultation with stakeholder groups and community awareness initiatives for National Palliative Care Week & World Hospice and Palliative Care Day	\$600,000
	<b>Ambulance Wish Queensland:</b> Establishment of 3 sites across Queensland, expanding reach to the regional areas	\$400,000
Community Capacity Building, Engagement and Development  <i>Total: \$9 Million</i>	<b>Statewide Palliative Care Volunteering Program:</b> A statewide 'Volunteer Village' to support palliative care services (specialist and generalist) and community groups, based on existing programs in NSW, VIC and ACT	\$4 Million
	<b>Queensland Compassionate Communities:</b> Build community capacity through community development, engagement and awareness initiatives, including community education, community signposting and community support for underserved populations (including homeless, diverse population groups and prisoners). This approach utilises Public Health Palliative Care models.	\$5 Million

*“We believe that the way we care for our dying is a significant indicator of the kind of society we are”*

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