

23 January 2020

The Honourable Aaron Harper
Chair Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee
Parliament House, Queensland 4000

Dear Mr Harper and Committee Members,

Re: Inquiry into Aged Care, End-of-Life and Palliative Care and Voluntary Assisted Dying

We commend the intensive and extensive work done by the Committee during the *Inquiry into aged care, end-of-life and palliative care, and voluntary assisted dying*.

As you are deliberating your recommendations, Palliative Care Queensland (PCQ) would like to reiterate our position, as the peak body for palliative care in this state representing more than 400 members, including nearly 70 leading organisations.

Every Queenslanders must have access to quality palliative care

Death is the great equaliser. Rich or poor, young or old, LNP, Labor or Greens voter – we will all die one day. But not all deaths are equal.

As the Inquiry has heard in horrific detail, some Queenslanders are dying in terrible circumstances, which contributes to prolonged grief and social challenges that have a huge cost to our community and our economy.

Palliative care is an evidence-based strategy that prevents and relieves suffering through the early identification, assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.⁽¹⁾

It 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 and beyond to bereavement support for loved ones.

But as the Inquiry has heard, palliative care to the standard set by the World Health Organization is **NOT** available to all Queenslanders.

Access to palliative care is a lottery based on where you live, your age, your illness, your culture and even the way your local Hospital and Health Service (HHS) allocates its funding.

People fear death and they fear growing old

The *Royal Commission into Aged Care Quality and Safety* interim report also highlighted some shocking stories of neglect and abuse.

Growing old, losing autonomy and dying alone is now something people actively fear, even though ageing and death are a part of the natural cycle of life.

1. **World Health Organization.** Palliative Care. [Online] February 2018. <https://www.who.int/news-room/fact-sheets/detail/palliative-care>.

This is a significant concern given the number of people aged 65+ is expected to double by 2026 and we will reach ‘peak death’ - when more people will die in Queensland than ever before (post WWII) – within two decades.

We believe this fear is fuelling the debate about Voluntary Assisted Dying (VAD), which people may see as the solution to a painful or lonely death.

To be clear, PCQ does not advocate for, nor argue against, VAD.

Just as palliative care can coexist with curative treatment, every terminally-ill person who might choose VAD could benefit from palliative care along their journey.

However, Queenslanders should **NEVER** choose VAD to end “intolerable suffering” without first being able to access excellent palliative care when and where they need it.

Interstate and overseas experience tells us less than 1% of people with a terminal illness are likely to access VAD but palliative care could improve the lives and the deaths of 100% of people who die.

The way we care for our dying is a significant indicator of the kind of society we are.

People are dying while they wait for change

In 2012, the Queensland Parliament Health and Community Services Committee held an inquiry into palliative care and delivered **63 recommendations** to improve this vital sector.

In 2015, the *Statewide Strategy for end-of-life care* was delivered and the *Care at end-of-life: Implementation Plan 2015-2025* was developed. In 2018, we received the *National Palliative Care Strategy* and in 2019 the *Queensland Health Palliative Care Services Review – Key findings* and the *Royal Commission into Aged Care Quality and Safety* interim report.

In the past eight years alone, there have been hundreds and hundreds of pages of reports from these Inquiries, Royal Commissions and reviews – yet little has changed.

During that time around 200,000 people have died in Queensland.

About 75% of these deaths were expected, so 150,000 people – *our mothers, our fathers, our siblings, our children, our neighbours* – could have benefited from palliative care.

How many of those people actually received quality palliative care?

How many died with intolerable suffering without access to quality palliative care?

Frustratingly, the data does not exist to give us those exact numbers but the stories and submissions before the Inquiry paint a shameful picture.

Despite the many reviews and reports, and the commitment of our caring and competent health care professionals, the sector has not received the funding needed to transform the palliative care system.

Too often, recommendations have been lost in a blame game between state and federal agencies, the HHSs, the private sector vs public sector, or they have just taken far too long to action.

We urge the committee to demand accountable, equitable and transparent funding, requesting that resources are allocated immediately to reshape the palliative care sector into a fit-for-purpose model for all Queenslanders.

People are literally dying while they wait for these improvements.

What do we need?

To transform the palliative care system to ensure adequate support and services are available for all Queenslanders, we propose changes in three key areas:

1. Access
 - a. Invest in specialist and generalist palliative care services; build flexible funding packages; invest in hospital avoidance programs; engage technology; target services to underserved populations; and activate communities via volunteer networks, service mapping and care navigators.
2. Accountable and equitable funding
 - a. Develop annual, publicly available reports to track all funding and service outputs.
3. Awareness
 - a. Create a compelling and ongoing campaign to educate the community and health professionals about the value of palliative care, the importance of advance health care planning and death literacy.

For more details please see the Appendix, which summarises PCQ's 2020-21 State Budget submission for \$200 million on behalf of the palliative care sector to urgently expand Service Delivery and Capacity Building.

This would provide the foundation for the changes needed to address the issues that have been raised before the Inquiry.

We appreciate your consideration of this letter and look forward to the delivery of the Inquiry reports, which we anticipate will point the way forward to transform care for all Queenslanders with life-limiting conditions.

Yours sincerely,



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Mr David Harmer, Queensland Health
Mr Rohan Greenland, CEO Palliative Care Australia

Appendix

Palliative Care Queensland 2020-21 Pre-Budget Submission Queensland



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.

<i>What are we investing in?</i>	Palliative Care Service Delivery	Palliative Care Capacity Building
<i>What does this mean for every Queensland?</i>	<i>Care to you and your support network when and where you need it.</i>	<i>Your community and services are prepared to care. Queensland is a compassionate community.</i>
<i>How much new investment is needed?</i>	\$150 Million per year	\$50 Million per year
<i>How would this be delivered?</i>	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
<i>What are the key elements of this model?</i>	<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>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>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> <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>