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3 July 2020

Mr Aaron Harper MP
Chair
Health, Communities, Disability Services and
Domestic and Family Violence Prevention Committee
E: health@parliament.qld.gov.au

Dear Mr Harper,

Re: Inquiry into the Queensland Government's health response to COVID-19

Thank you for this opportunity to provide input into the Inquiry into the Queensland Government's health response to COVID-19 (COVID-19 Inquiry). COVID-19 has come with enormous challenges, and along with the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee (Committee), it is our hope that Queensland's health system can use the lessons we have learned to improve and transform healthcare into the future.

As you are aware, Palliative Care Queensland (PCQ) is the peak body for palliative care in Queensland. PCQ has been operating for over 30 years, has over 300 members and is a founding member of 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 about the challenges the sector faces and the opportunities those challenges can bring.

In the first instance, I would like to acknowledge the work undertaken by the Queensland Government in these unprecedented times, in responding to emerging community needs and preparing the health system. However, we were concerned that planning for palliative care could have been started early and still could be significantly improved. PCQ strongly believes that Queensland is still vastly underprepared in the palliative care space for a 'second wave'. People do die from COVID-19, and they need access to both specialist and generalist palliative care.

In some countries and jurisdictions, when they planned for a COVID-19 surge in ICU, they prepared for a corresponding surge in the palliative care. **We did not see this done in Queensland.** Palliative Care is needed during a pandemic for Queenslanders who are dying without the virus, ensuring that care can still be provided to them and their family. Palliative care is also needed during a pandemic for Queenslanders who are dying with the virus. Bereavement care needs to be included in the palliative care for both cohorts as well.

Specialist palliative care teams are specialists in alleviating suffering at the end phase of life, including symptoms such as dyspnoea, cough, fever, shortness of breath, that affect COVID-19 patients. They are trained to manage complications that may affect COVID-19 patients at the end of life. They are trained to provide holistic support to the dying person and their family. They are trained to breaking bad news compassionately. And they are trained to support general health care teams to provide generalist palliative care.

In response to the COVID-19 pandemic, PCQ initiated the development of a 'Queensland Palliative Care Response to COVID-19 Working Group' (Working Group) which included representatives from statewide palliative care health services, Queensland Specialist Palliative Care Directors' Group, and PCQ. The Working Group met (and still meets) regularly to identify the pressing state and national issues faced by Queensland palliative care providers as they planned for a potential surge of COVID-19 deaths, and as they cared for dying patients in the midst of the COVID-19 uncertainties. PCQ also facilitated the Queensland Compassionate Communities Peaks Network, which included regularly meeting with Council on the Ageing Queensland (COTA Q), Carers Queensland and Health Consumers Queensland (HCQ). This network met (and still meets) regularly to identify the pressing issues related to Queensland citizens experiencing loss, ageing, dying and grief amid the COVID-19 uncertainties.

As these group tackled the many challenges that COVID-19 presented for our members, we watched as the response to COVID-19 provided further evidence that our health system needs to be restructured and adequately resourced to support Queenslanders who are dying, in both times of disaster/pandemic and also during 'ordinary' time. Attention was not given to creating the infrastructure needed to care for those who will die and ensuring that there will be as least suffering in their deaths as possible.

As we learn the lessons from COVID-19 and look ahead, the importance of palliative care, the need to respond to people who are dying, and the requirement for support for families who are grieving must be added to the reform agenda, including future disaster preparedness. Palliative can make an important contribution to the health, social and community sectors.

We are aware that dying was not a discussion people wanted to have during the pandemic; however, people do die from COVID-19, and a good death is possible with the appropriate planning in place.

Thank you for considering our attached brief submission. We appreciate the enormity of the task before you, and thank you for your efforts. While we acknowledge the need for a rapid response by the Committee to the COVID-19 situation, our ability to provide a more detailed submission was limited as our focus was on supporting the palliative care sector, our members and the Queensland community. To this end, I would like to highlight your Committee's Inquiry reports released during the COVID-19 period, which demonstrates the existing gaps in the Queensland palliative care system, which were highlighted during the pandemic.

Please contact me if you would like to receive further information or have any questions or comments.

Sincerely yours,

Shyla Mills
CEO
Palliative Care Queensland
[redacted]

CC:
John Haberecht, President, Palliative Care Queensland
David Harmer, Senior Director, Strategy, Policy & Legislation, Queensland Health
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Submission to the Inquiry into the Queensland Government's health response to COVID-19

Death is not unusual or restricted to a crisis. In 2018 in Queensland, there were 30,860 deaths, the majority of which were aged over 65 years.[1] Early estimates of the coronavirus outbreak were that without urgent measures, 30,000 people could have died in the first three months of the pandemic.[2]

Before COVID-19, the importance of palliative care was gaining recognition within the Queensland Government, due in part to the 2019 Palliative Care Service Review and the Queensland Parliamentary Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying.

During COVID-19 attention has focused on increasing the health systems capacity and decreasing demand (especially ICU), equipment, and alternative service locations, where many frameworks have been developed Nationally and within Queensland, including:

- those to guide diagnosis and triage,
- to help clinicians make ethical decisions around ICU admission and discharge in a time of resource scarcity,
- to guide residential aged care facilities regarding lock-down and safeguard residents, and
- protocols on handling the bodies of patients who died with COVID-19.

It appears that less planning and resourcing has been directed to ensuring the infrastructure needed to care for those who will die, from COVID-19 or otherwise, during the pandemic. PCQ has had representation from a number of members that specialist palliative care teams focus has been on getting 'in the door' or 'at the table' for pandemic planning meetings rather than being invited to attend and add expertise to the plans.

To highlight this, PCQ were not engaged to participate at the 10 March 2020 forum convened by Queensland Health to enable critical hospital planning to ensure preparedness for COVID-19, despite the matters considered at this forum being "…complex, wide-ranging and impacted on all of parts of the health system in Queensland, with focus on hospital capacity (particularly ED and ICU), health system funding and the health workforce" (p.13) [3]. While the **Queensland ethical framework to guide clinical decision making in the COVID-19 pandemic (The Ethical Framework)** acknowledges the 'highly crucial' role of palliative care team and incorporates referral to palliative care services, many other essential policy documents did not even mention palliative care. While the Ethical Framework does acknowledge the role of palliative care, yet the palliative sector had limited capacity (and resourcing) to develop the important next steps of this framework, which would be to prepare the palliative care sector for the surge response that would be required.

Another example is that there was no representative from Specialist Palliative Care on the Pandemic Health Response Implementation Advisory Group (PHRIAG). PCQ and several palliative care specialists presented to this group on the 15th June but were not engaged prior to that.

[1] State of Queensland (Queensland Government Statisticians Office) 'Deaths Queensland, 2018' released 25 September 2019 [accessed online]
[2] State of Queensland (Department of Premier and Cabinet) 'Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee Inquiry into the Queensland Government's health response to COVID-19 - Department of the Premier and Cabinet briefing on matters as requested by the Committee' 15 June 2020 [accessed online]
[3] State of Queensland (Queensland Health) 'Inquiry into the Queensland Government's health response to COVID-19 Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee Queensland Health written submission to Committee' 17 June 2020 [online].

This enquiry provides an opportunity to address this and include palliative care expertise in future planning and responses, as well as any review process as a result of COVID-19. The following examples are provided for the Committees' reference where palliative care should have been included:

The **Australian Health Sector Emergency Response Plan for Novel Coronavirus**[4], which was designed to guide the Australian health sector response, noting:

- "A major outbreak will increase the demand on specialist expertise, particularly in acute care, such as intensive care nursing, emergency medicine and ambulance services. It may also increase the demand on specialist equipment, some of which requires specialist training to implement and is of limited availability, such as extracorporeal membrane oxygenation (ECMO). Demand on primary health care will also increase, exacerbated by the need to attend to patients affected by the changes in availability of services at hospitals". (p.10)
    - It is important to highlight that for most practitioners, the provision of end-of-life care is an unfamiliar and often challenging role, and COVID-19 planning and responses have left many with roles and tasks outside their scope of training. This not only relates to pain and symptom management, but also communicating at the end of life with an individual and their families, and even in awareness of and options for situations of withdrawal of clinically non-beneficial treatment, or where intensive treatment for COVID-19 is unavailable.

- "As clinical severity increases, the following will also increase: the demand for high-end services, such as Intensive Care Unit (ICU), paediatric and respiratory care (associated with this will be increased demand for specialised equipment and health care professionals, such as ECMO and ICU nurses). High end services are areas likely to increase the demand on support services, such as laboratories, much more than increased demand in general wards; the demand for services associated with management of the deceased; the importance of informing and supporting at-risk groups…" (p.10)
    - PCQ believes that specialist palliative care should have been included as a 'high-end service' in this context. As people do die from COVID-19.

- Scenario three – "If clinical severity is high widespread severe illness will cause concern and challenge the capacity of the health sector. Areas such as primary care, acute care, pharmacies, nurse practitioners and aged care facilities will be stretched to capacity to support essential care requirements. Heavy prioritisation will be essential within hospitals to maintain essential services and mortuary services will be under pressure. The demand for specialist equipment and personnel is likely to challenge capacity." (p.13)
    - The pandemic has brought a challenge unique to both ICU and specialist palliative care services as they both needed to balance the need to manage their current patient-load with the possible surge of patients who need their specialist care due to COVID-19. However, the planning was not parallel.

[4] Australian Government (Department of Health) 'Australian Health Sector Emergency Response Plan for Novel Coronavirus (COVID-19)' February 2020 [accessed online]

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The **National Mental Health and Wellbeing Pandemic Response Plan**[5] which responds to the mental health and wellbeing needs of all Australians during the response and in recovery from the COVID-19 pandemic. In this essential Plan there is only notional reference to support for grief, where:

- "Clear, concise and sustained public communication across a range of media platforms likely to be accessed by different demographics is essential to foster preparedness, increase knowledge and provide outreach for those most affected. Public communication should: Promote positive thoughts and behaviours related to self-care, wellbeing and resilience to maintain mental wellbeing. Normalise messages about mental health impacts such as fear, anxiety, grief, loss and stress." (p.31)
    - Dying alone in an ICU setting or within a Residential Aged Care Facility (RACF) without family present is difficult on anyone and their loved ones in any instance. During COVID-19, or any future situation where isolation is required, the risks for complicated grief of surviving family members who were not allowed to be with their loved ones is high.

The **Queensland Health response to this Inquiry**[6] does not make mention of palliative care, even though it states that "Queensland has had time to consider and develop our health system to be able to respond to any outbreaks, to meet the needs of unwell Queenslanders…(p.6)" and Further, PCQ notes from the Queensland Health submission:

- "The pandemic health response include but is not limited to the health systems capacity to support the public health response, and surge planning ensure capacity to treat and manage cases and to ensure continued delivery of essential health services, including emergency care, cancer treatment and obstetric services. (p.6)"
    - PCQ believes that specialist palliative care should have been included as an essential health service

- "To further specific clinical workforce capacities across the Queensland HHSs, including the utilisation of the Pandemic response sub-register, a series of options papers were produced for consideration and utilisation of the respective Clinical Chief… (p.18)"
    - These did not include a palliative care specific workforce surge options paper unlike 'Nursing and Midwifery', 'Pharmacy, Physiotherapy and Diagnostic Imaging', 'Aboriginal and Torres Strait Islander Health workforces', 'ICU nursing' and 'Aged Care nursing'.

- Palliative care was not identified as "employees who have critical skills and experience to respond to COVID-19, including employees who have worked in ICUs, emergency services, aged care services and PHUs" in the system-wide workforce dashboard to support workforce management during the COVID-19 response (p.20).

PCQ also notes the Department of Communities, Disability Services and Seniors is the functional lead agency for community recovery, including emotional, social, and psychological health and wellbeing[7], and to this end have undertaken a number of important activities.

The Seniors COVID-19 strategy to support the wellbeing of seniors during COVID-19 was implemented through the Community Recovery Hotline, expansion of the Seniors Enquiry Line and establishment of the volunteer Care Army. PCQ worked closely with COTA-QLD to keep updated regarding the Care Army and liaised with Volunteering Queensland to inform them of opportunities

[5] Australian Government (Department of Health) 'National Mental Health and Wellbeing Pandemic Response Plan' May 2020 [accessed online]
[6] Op.Cit(3) State of Queensland (Queensland Health)
[7] Op.Cit (2) State of Queensland (Department of Premier and Cabinet)

for volunteers to support people who are palliative, such as provide bereavement and spiritual support. However due to capacity issues within the palliative care sector and PCQ, we were unable to 'instantly develop and implement' the Statewide Volunteer Village to support palliative care volunteering during the pandemic. PCQ has previously recognised a statewide volunteer palliative care program (as funded in several other states and territories) as a significant gap in Queensland. This was included this in our 2020-21 Pre-Budget Submission Queensland, submitted to the Queensland Government in January 2020[8]. In addition to our previous recommendation of creating a Statewide Palliative Care Volunteer Village (Village) to benefit Queenslanders who are experiencing loss, dying and grief. PCQ believes an additional benefit of this Village, could be to provide training to additional volunteers with the specific skills required for bereavement support, spiritual support and as compassionate connectors[9]. This cohort of trained volunteers could then be mobilised to respond in a disaster or emergency.

PCQ liaised with the Queensland Hospices regularly throughout the pandemic and an issue regularly noted was regarding volunteers. The fact that they had to put their highly successful volunteer programs on hold during the pandemic mostly due to the majority of their volunteers being with in the vulnerable population age group. The Hospices also noted that they often 'fell through the gaps' of the systems during the pandemic as they are not Queensland Health Service, therefore issues such as how to order Personal Protective Equipment (PPE) was noted as a significant a challenge.

While we have highlighted the gaps in this submission, it is important to note that: there were some successful collaborations forged during the COVID-19 pandemic in relation to palliative care; PCQ and our members were involved in many discussions with various stakeholders throughout the pandemic (including nationally, statewide and locally); and in some regions integration of palliative care within the planning did occur. Yet due to the inconsistent nature of this and the timeframe of these submissions, we have chosen to highlight the gaps.

PCQ was delighted to be successful during the COVID-19 in funding for the COVID-19 Immediate Support Measures. These funds will support us to:

- Continue our Queensland Compassionate Communities activities including networking peak bodies, community groups and individuals
- Develop a spiritual support network to support access to quality spiritual care in Queensland during COVID-19 and identify opportunities to continue this network for future disaster responses.
- Develop a bereavement support network to support access to quality bereavement care in Queensland during COVID-19 and identify opportunities to continue this network for future disaster responses.
- Continue our organisational operations during COVID-19, including purchasing ICT equipment to support a virtual office and improve our risk and quality management.

8 https://palliativecareqld.org.au/wp-content/uploads/2020/01/PCQ_pre-budget-submission-.pdf

9 Compassionate Connectors is a concept developed and proposed by the PCQ team during COVID-19 for volunteers who are specialty trained to work with the aged care facilities lock-down teams to connect residents to their families either via phone, videoconferencing or move them closer to the window to see their family. We believe this role would improve the capacity of the staff to respond to the health needs, while providing loved ones the reassurance and connection they need to the resident.

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Recommendations:

- Ensure Palliative Care is included in the whole of government planning, preparedness and response to the COVID-19 health emergency.

- Include palliative care specialist teams in future planning *across portfolios*, to map the patient journey and the changing needs of the dying person and their loved ones at each stage and the training required for generalist health professional to 'break bad news compassionately', discuss ceilings of care, understand the palliative supports they can provide and practice self-care. With this skillset in alleviating suffering – and especially given the profound impact that COVID-19 had on mental health – these specialists are a tremendous resource in a time of crisis. Palliative medicine specialists, who work in both acute care and community care, can speak to the system infrastructure that needs to be scaled up, regarding both specialist and generalist palliative care services and supports.

- Review funding and its demarcation for specialist palliative care as there is a lack of transparency and accountability in palliative care funding, where allocated funding is often diverted to other directorates that fund general end of life care, terminal care, care of the aged and frail. This is in line with recommendations made by Queensland Parliament's Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee Report No. 33 on Aged Care, End-of-Life and Palliative Care[10] tabled to the Queensland Parliament on 31 March 2020.

- Commission the analysis of palliative care learnings from international countries where COVID-19 death rates were high to ensure these are integrated into future pandemic disaster management plans.

- Consider the role that community can play in providing assistance. The response to the Care Army initiative identifies there is an appetite to care, however most charities and NGOs do not have the capability or capacity to activate these volunteers in a serge-style response. We recommend a consideration of a statewide palliative care volunteer village. With volunteer roles and appropriate training which can be scaled up in times of disaster to support people experiencing loss, dying and grief – for example bereavement care volunteers; spiritual care volunteers and compassionate connectors (volunteers for aged care disability facilities who can connect the residents with their families).

- Review the recommendations within the Queensland Parliament's Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee Report No. 33 on Aged Care, End-of-Life and Palliative Care tabled to the Queensland Parliament on 31 March 2020, to consider if these recommendations were in place prior to the pandemic, how this may have improved the Queensland response to the pandemic.

As the Queensland Government shifts its focus from the planning, preparedness and immediate COVID-19 response to the recovery phase, PCQ requests that consideration is given to those Queenslander living with a life-limiting illness, of any age, who are among our most vulnerable populations. This must include engagement with the palliative care sector in the work undertaken with the Roadmap to Easing Restriction and in review of the Queensland's State Disaster Management Plan and Queensland Health Disaster and Emergency Incident Plan.

[10] 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].