Palliative Care Queensland
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ABN 49 047 803 923 | ACNC - CH1825

26 June 2020

Ms Meegan Fitzharris
Chair, Reform Planning Group
E: reformplanning@health.qld.gov.au

Dear Ms Fitzharris,

Re: The Inclusion of Palliative Care in the Queensland Reform Roadmap

Thank you for this opportunity to provide input into the development of a Reform Roadmap. COVID-19 has come with enormous challenges, and along with the Reform Planning Group, it is our hope that our Queensland health system can use the lessons we have learned to improve and transform healthcare.

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 and about the challenges the sector faces and the opportunities those challenges can bring.

During the COVID-19 crisis, Palliative Care Queensland (PCQ) initiated the development of a 'Queensland Palliative Care Response to COVID-19 Working Group' which included representatives from statewide palliative care health services, Queensland Specialist Palliative Care Directors' Group, and Palliative Care Queensland.

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. Palliative Care Queensland 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 in the palliative care realm, COVID-19 emphasized what most in the healthcare system already know: **our health system needs to be restructured and adequately resourced to support Queenslanders who are dying.**

Though it may sound obvious, our hope for the Reform Roadmap is that it will layout how our health system can better support Queenslanders who are dying, in both times of disaster/outbreak and also during 'ordinary' time. Dying is a universal health outcome.

During COVID-19, many frameworks were developed, including those to guide diagnosis and triage, ethical frameworks to help Queensland clinicians make difficult decisions around ICU admission and discharge in a time of resource scarcity, and protocols on handling the bodies of patients who died with COVID-19. Disaster plans focused on surge capacity for workforce (especially ICU), equipment, and alternative service locations should hospital capacity be overwhelmed.

Each of those components and frameworks are vital. Yet, in most cases, 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. This is of great concern to us. People were dying during COVID-19 – a few with COVID-19, but the vast majority without this virus – and yet there was little to no planning for supporting the process of dying during the crisis.

We were much more fortunate than other countries; however, feel that we are still vastly underprepared in the palliative sector (generalist and specialist) for a 'second wave'.

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.

As we learn the lessons from COVID-19 and look ahead, we respectfully request that you add palliative care to your agenda for reform. Please plan and provide support for the needs of Queenslanders who are dying and their families who are grieving. We suggest two priorities for inclusion in the roadmap.

First, include palliative care specialist teams at the planning table, 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. Though PCQ believes that dying is everyone's business, not everyone is skilled in providing palliative care. This must be a priority; there is no second chance in palliative 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. These 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.

Second, please review funding and its demarcation for specialist palliative care. 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 etc.). 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[1] tabled to the Queensland Parliament on 31 March 2020.

Finally, as the Reform Planning Group looks at innovations, do 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 volunteer village. With volunteer roles and appropriate training which can be scaled up in times of disaster to support people experiencing loss, ageing, 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).

[1] 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]. https://www.parliament.qld.gov.au/Documents/TableOffice/TabledPapers/2020/5620T466.pdf

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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 requests. We appreciate the enormity of the task before you and thank you for your efforts to make life better for Queenslanders.

Please contact me if you have any questions or comments.

Sincerely yours,

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CC:
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