PalliativeCare QUEENSLAND
PALLIATIVECAREQLD.ORG.AU

23 December 2021

Committee Secretary
Health and Environment Committee
Parliament House
George Street
BRISBANE QLD 4000
hec@parliament.qld.gov.au

Dear Secretariat and Committee Members,

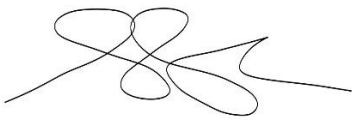
Re: Submission to the Queensland parliament Inquiry into the provision of primary, Allied and private Health Care, Aged Care and NDIS care services and its impact on the Queensland public health system

Thank you for the opportunity to provide a submission to the **Health and Environment Committee.**

Palliative Care Queensland (PCQ) is the peak body for palliative care in Queensland. Our 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 stage of life, and have the choice of quality palliative care.

Please find attached our submission, including recommendations regarding the Inquiry into the provision of primary, Allied and Private Health Care, Aged Care and NDIS care services and its impact on the Queensland public health system.

Sincerely yours,



Shyla Mills
CEO, Palliative Care Queensland

Email- [redacted]

EXECUTIVE SUMMARY

Palliative Care Queensland (PCQ) believes that the way we care for our dying is a significant indicator of the kind of society we are.

Our organisational 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 stage of life and have the choice of quality palliative care

Palliative Care Queensland submits the following recommendations in relation to this Inquiry:

Palliative Care Queensland's recommendations regarding Aged Care:

- General practitioners are central to the palliative care continuum wherever their patients are, to ensure that care is coordinated (e.g., primary care, acute care, aged care and all other services in community). Remuneration should be appropriate to the services provided.
- Build capacity and capability for aged care workforce training and resources (including improved technology) that are specific to palliative care needs of people living in aged care settings (from diagnosis to bereavement).
- Embed a culture of quality palliative care in aged care. Develop strategies to respond to the high workforce turnover in aged care to ensure provision of consistent and high-quality palliative care.
- Support people to stay socially connected throughout the palliative care journey, recognising the important role of family, carers, and community in aged care.
- Enhance psychosocial, spiritual and bereavement care to those receiving aged care support, their families, and the workforce.

Palliative Care Queensland's recommendations regarding NDIS:

- Fund a consultation regarding the role of disability care and palliative care in Queensland, to understand the current situation and identify key recommendations for improvements.
- Support a pilot implementation of the Talking End of Life ...with people with intellectual disability (TEL) toolkit across Queensland.

Palliative Care Queensland's recommendations regarding Private Health Care:

- Fund a consultation regarding the role of private health care and palliative care in Queensland, to understand the current situation and identify key recommendations for improvements.
- Strengthen the coordination of care between private and public care settings in relation to palliative care.

Palliative Care Queensland's recommendations regarding Primary Care:

- Strengthen the coordination of care between care settings (i.e., hospitals, GPs and community palliative care providers and networks). Empower GPs to coordinate their patients' care in community (including aged care) and to ensure the flow of information about patients across multiple settings. Support GPs to begin the conversations about care and care coordination early in the palliative care journey.
- Increase primary care funding, including appropriate remuneration and resourcing to enable primary care providers to respond to patients' and carers' needs (particularly in their home).
- Map generalist and primary palliative care services to assist with system navigation, coordination and integration of patient care throughout the palliative care journey (i.e., from diagnosis to bereavement).
- Fund generalist and primary care services and supports to be mobile and rapidly responsive to patient care needs (such as 'Last Days' Packages).
- Equip and train frontline health staff to understand the diverse range of palliative care needs, and to ask their patients what matters most (i.e., advance care planning and care planning).
- Work with communities (they have the answers) through consultation and raise awareness of palliative care.
- Map assets and social capital to further the reach of palliative care through asset hunting, and partnership and engagement building between services, civic community and social networks (including Aboriginal and Torres Strait Islander peoples and culturally and linguistically diverse communities).

Palliative Care Queensland's recommendations regarding Allied Health Care:

- Fund a consultation regarding the role of allied health care in palliative care across Queensland, to understand the current situation and identify key recommendations for improvements.
- Increase access to allied health practitioners in regional and rural areas.

Introduction

"Palliative Care is everybody's business"
Palliative Care Queensland's Policy Guiding Principles (appendix 1)

In 2016, there were 29,690 deaths in Queensland and 90% occurred in people aged 50 years or older (7). Palliative Care Queensland estimates that approximately 75% of people who die would benefit from access to palliative care.

The state's population is highly decentralised with more than 40 % of residents aged 65 years or older living outside of major cities. This includes over 10,000 people living in remote areas and a further 6,400 living in very remote areas across Queensland (8). There is a strong expectation that all communities across Queensland have access to services 24 hours a day, seven days a week and 365 days a year. Sadly, access to services at a local level is often problematic, particularly for Queenslanders in regional, rural, and remote communities.

To have better coordinated care arrangements for supporting people experiencing a serious illness, dying, death and grief, there is a desperate need to streamline support and involve the community.

The six guiding principles of the Australian Government Department of Health's National Palliative Care Strategy (2018) are:

- 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

"Palliative Care is for every age and every stage"
Palliative Care Queensland's Policy Guiding Principles (appendix 1)

Palliative care needs to be considered across all health, social and community systems. Research highlights that death is often not discussed. Health professionals are uneasy about discussing death and dying with patients, which consequently obfuscates the likely treatment outcomes and overestimate the chances of recovery (3).

"Palliative Care is care for the carer"
Palliative Care Queensland's Policy Guiding Principles (appendix 1)

Carers play a critical role in palliative care. Research highlights that support for carers and end-of-life services are fragmented, and sufficient palliative care is often not available. In 2010, informal carers provided 1.3 billion hours of home care. However, informal carers are under pressure. They carry financial, emotional and time costs which needs to be considered as part of palliative care (3).

Palliative Care Queensland believes the following recommendations would improve the quality of life of Queenslanders experiencing a serious illness, dying, death or grief.

Palliative Care Queensland's recommendations

Palliative Care Queensland's recommendations regarding Aged Care

RECOMMENDATIONS:

- General practitioners are central to the palliative care continuum wherever their patients are, to ensure that care is coordinated (e.g., primary care, acute care, aged care and all other services in community). Remuneration should be appropriate to the services provided.
- Build capacity and capability for aged care workforce training and resources (including improved technology) that are specific to palliative care needs of people living in aged care settings (from diagnosis to bereavement).
- Embed a culture of quality palliative care in aged care. Develop strategies to respond to the high workforce turnover in aged care to ensure provision of consistent and high-quality palliative care.
- Support people to stay socially connected throughout the palliative care journey, recognising the important role of family, carers, and community in aged care
- Enhance psychosocial, spiritual and bereavement care to those receiving aged care support, their families, and the workforce.

WHY THIS IS IMPORTANT?

Palliative Care is core business in aged care. Many residents in residential aged care are living with life-limiting illness (including dementia) and/or they may be nearing the end of their life and are in need of a palliative care response.

The capacity of primary health care providers to be able to visit and treat residents in aged care facilities is widely recognised in the palliative care sector as integral to quality care for aged care residents. While there have been some measures to support providers to utilise the Medicare Benefits Schedule (MBS) in care provision there is scope for further work.

The MBS needs to be funded to support GPs and other appropriate primary health care providers to undertake longer consultations for palliative care patients, undertake advance care planning discussions and attend residential aged care facilities (including time for travel, planning and follow-up work).
Palliative Care Australia Submission Primary Health Reform Discussion paper – July 2021 (13)

Also see appendix 2: Palliative Care Australia Palli8

The recommendations above related to Aged Care were sourced from the Priorities for Palliative Care in Queensland 2021 publication (14).

Palliative Care Queensland's recommendations regarding NDIS

RECOMMENDATIONS:

- Fund a consultation regarding the role of disability care and palliative care in Queensland, to understand the current situation and identify key recommendations for improvements.
- Support a pilot implementation of the Talking End of Life ...with people with intellectual disability (TEL) toolkit across Queensland.

WHY THIS IS IMPORTANT?

To have better coordinated care arrangements for supporting people with terminal illness and disability there is a desperate need to streamline support and delivery of services through Pathways and service navigation support for health care providers and consumers/carers, where key points of contact (supports coordinators, key service providers) in the disability sector who understand navigation pathways act as a link to navigate and connect with the system and services as needed (1).

Projects such as **TEL** are a national initiative, not yet adopted in Queensland (11).

> Talking End of Life ...with people with intellectual disability (TEL) shows you how to teach people with intellectual disability about the end of life.
>
> TEL is a resource that shows you how to teach people with intellectual disability about end of life. It is designed for disability support professionals (DSPs) but is also helpful for families, health professionals and educators. With assistance, people with intellectual disability might also find the TEL information helpful. TEL reflects 10 years of Australian research on end of life and people with intellectual disability. TEL is an online version of the Dying to Talk project, an Australian Research Council funded partnership between The University of Sydney, Keele University in the UK, and Unisson Disability.
>
> TEL comprises 12 Modules. Modules include activities, case studies, videos, resources and links to the research. TEL also offers a set of additional website resoruces. Videos from the "Dying to Talk" research project give extra information. TEL is funded by the Australian Government Department of Health under the Public Health and Chronic Disease Grant Program.
> *Wiese, M. Y., Stancliffe, R. J., Wagstaff, S., Tieman, J., Jeltes, G., & Clayton, J. (2018). TEL Talking End of Life [website]. https://www.caresearch.com.au/TEL/*

Palliative Care Queensland's recommendations regarding Private Health Care

RECOMMENDATION:

- Fund a consultation regarding the role of private health care and palliative care in Queensland, to understand the current situation and identify key recommendations for improvements.
- Strengthen the coordination of care between private and public care settings in relation to palliative care.

WHY THIS IS IMPORTANT?

The evolving health service landscape across Australia has a mixed public-private system, and there is potential for 'cream skimming' where the private sector selectively provides high profit services such as radiotherapy, chemotherapy and surgery, and transfers complex patients back into the public sector (4).

Private funds (in the main) are not funding in the home care services and there is often a significant out of pocket expense for the consumer. For instance, if a person accesses palliative care in a private hospital, Medicare and private health insurance rebates apply, with the Australian Government paying 75 per cent of the Medicare Benefits Schedule (MBS) fee for private hospital palliative care patients, and the remaining 25 percent, as well as any gap, may be required to be paid by the patient or their health insurance provider (2).

There are however some trial Private Health Palliative Care programs which appear to be having a positive impact in relation to palliative care. For example, Medibank at home (Palliative Care at Home) and bereavement care follow up for families and carers is a trial program for eligible patients and clinically appropriate customers to provide them more choice when it comes to where they receive care (10). In addition, Queensland Hospices have access to Private Hospital funding which is creating increases in care options for Queenslanders.

A greater understanding of Palliative Care in relation to private Health care across Queensland is required.

Palliative Care Queensland's recommendations regarding Primary Care

RECOMMENDATIONS:

- Strengthen the coordination of care between care settings (i.e., hospitals, GPs and community palliative care providers and networks). Empower GPs to coordinate their patients' care in community (including aged care) and to ensure the flow of information about patients across multiple settings. Support GPs to begin the conversations about care and care coordination early in the palliative care journey.
- Increase primary care funding, including appropriate remuneration and resourcing to enable primary care providers to respond to patients' and carers' needs (particularly in their home).
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- Equip and train frontline health staff to understand the diverse range of palliative care needs, and to ask their patients what matters most (i.e., advance care planning and care planning).
- Work with communities (they have the answers) through consultation and raise awareness of palliative care.
- Map assets and social capital to further the reach of palliative care through asset hunting, and partnership and engagement building between services, civic community and social networks (including Aboriginal and Torres Strait Islander peoples and culturally and linguistically diverse communities).

WHY THIS IS IMPORTANT?

Most older people (95%) continue to live in their own homes – known as ageing in place (5). It is also likely that people will continue to prefer to remain in their own homes as they age (5, 6).

> The primary health care system will have limited ability to respond to challenges including the growing number of Australians with chronic illness, mental health needs and frailty, workforce development, resourcing, regional service integration and futuristic models of care. Palliative care providers are at the forefront of seeing (and responding to the implications of) the increased numbers of people living with often multiple chronic illnesses (and often living for longer). The ability and incentive for primary care providers to facilitate inter-disciplinary case management for these patients is also currently limited.
> *Palliative Care Australia (2021) Discussion Paper to inform the development of the Primary Health Reform Steering Group recommendations on the Australia Government Primary Health Care 10 Year Plan (15)*

The recommendations above related to Primary Care were sourced from the Priorities for Palliative Care in Queensland 2021 publication (14).

Palliative Care Queensland's recommendations regarding Allied Health Care

RECOMMENDATIONS:

- Fund a consultation regarding the role of allied health care in palliative care across Queensland, to understand the current situation and identify key recommendations for improvements
- Increase access to palliative care allied health practitioners in regional and rural areas

WHY THIS IS IMPORTANT?

The role of allied health in palliative care is recognised by the national peak body Palliative Care Australia and has been described in the literature for individual professions. However, inclusion of palliative care in undergraduate curriculums and support for upskilling of qualified allied health professionals is needed.

This support should include consideration of the role of Allied Health Professional within residential aged care facilities. Improved data collection on supply and demand for allied health services across settings and in the palliative care context is also needed to inform future planning.

The limited availability of MBS funding streams for the large number of allied health professionals operating in the private sector may be a barrier to greater involvement. Finally, support for improved integration of allied health professionals into palliative care teams and earlier referral for services is also likely to encourage increased engagement with palliative care.

Many of these findings represent opportunities to increase awareness and support upskilling and networking among allied health professionals specifically and across palliative care teams more generally.
Gravier S, Erny-Albrecht K. Allied health in Australia and its role in palliative care. Adelaide: CareSearch; 2020.

A greater understanding of Palliative Care in relation to allied health care across Queensland is required.

Conclusion

Society (and the health system) can tend to avoid discussions, plans and preparations around death. Queenslanders want an open and streamlined access to health care and to experience serious illness, dying, death and grief in a place of their choice, surrounded by their community. Without systematic policy change and amalgamation of commonwealth and state health resources, it is unlikely that this is possible.

Collaborative efforts (includes Local Government Agencies (LGAs), Hospital and Health Services (HHS), Primary Health Network (PHNs), Peak Bodies, other state and commonwealth health entities), a shift in care focus to home-based models and transparent funding arrangements can reduce the hospital and institution admission and care costs.

Undoubtedly, supporting people at the end stage of life takes planning and community support, along with significant investment and community engagement. While there has been some investment in the Queensland palliative care system by the Queensland Government, it is unlikely to make the significant impact required to respond to the needs of Queenslanders.

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Attachment 1: Palliative Care Queensland's policy guiding principles

Attachment 2: Palliative Care Australia's Palli8: Ensuring Palliative Care is core business for Aged Care

https://palliativecare.org.au/campaign/palli8-core-business-in-aged-care/