PalliativeCare QUEENSLAND
PALLIATIVECAREQLD.ORG.AU

4 February 2022

Mental Health Select Committee
Parliament House
George Street
BRISBANE QLD 4000

Email: mhsc@parliament.qld.gov.au

Dear Secretariat and Committee Members,

Re: Submission to the Queensland Parliament Inquiry into the opportunities to improve mental health outcomes for Queenslanders

Thank you for the opportunity to provide a submission to the Mental Health Select 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 opportunities to improve Mental Health Outcomes for Queenslanders.

Sincerely yours,

Anthony Herbert

A/Prof Anthony Herbert
Acting-President, Palliative Care Queensland
[redacted]

Ms Shyla Mills
CEO, Palliative Care Queensland
[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:

1. Increased psychosocial support for people with a serious and persistent mental illness (SPMI) who are also experiencing dying or grief
    a. Improve workforce capability in both palliative care and mental health specialities and improve the interface between the two specialities
    b. Ensure access to both palliative care and mental health support is available in a timely manner when and where people need it
        i. Particularly focus on reducing barriers to access to meet the complex mental health needs of the palliative care patients.

2. Increased palliative care support for people experiencing dying or grief, to assist with the prevention of complex grief disorder and other mental health conditions
    a. Increase state-wide palliative care funding to ensure that both specialist and generalist palliative care supports can be accessed from diagnosis when and where it is needed
    b. Fund a state-wide Bereavement and Spiritual Care Program (including counselling services, bereavement support groups and telephone advice, spiritual care support and generalist advice, with a focus on supporting health, social and community teams and the community)

3. Increased education and research opportunities for palliative providers in relation to mental health
    a. Pilot the Integrated Mental Health and Palliative Care Task (IMhPaCT) project in Queensland
    b. Provide trauma-informed care education and training to all specialist palliative care teams across Queensland
    c. Provide dedicated research funding to investigate the interface between palliative care and mental health, particularly in relation to specific population groups (i.e., Aboriginal and Torres Strait Islanders)

4. Build community capacity and knowledge regarding dying and death to help prevent psychosocial morbidity
    a. Invest in an innovative community education program (such as Last Aid) to promote awareness and understanding that serious illness, dying, death and grief are a natural part of life, thereby reducing fear and promote people's engagement and compassion for people experiencing a serious illness, dying or grief

b. Invest in Queensland Compassionate Communities (community focused arm of Palliative Care Queensland) 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
c. Support the state-wide Queensland Compassionate Communities Peaks Network to showcase World Compassionate Communities Day through a variety of initiatives, to promote and build compassionate communities throughout Queensland
d. Ensure Compassionate Communities and health-promoting palliative care techniques are included in social and community planning

Palliative Care Queensland's recommendations

WHAT IS NEEDED?

1. **Increased psychosocial support for people with a serious and persistent mental illness (SPMI) who are also experiencing dying or grief**

WHY THIS IS IMPORTANT?

"High Quality palliative care is an International Human right "[1]

There is a need to coordinate the care provided in palliative care and mental health settings through the deployment of a multidisciplinary and capable workforce. Palliative care not only supports patients with an advanced, incurable or terminal illness, but also supports their family and caregivers in challenging times of psychosocial and psychological distress.[4] Hence, comprehensive psychological and social support for bereaved family members is expected. However, it is difficult to claim the benefits the healthcare and mental health services in the state provide for caregivers through palliative care services, thus unmet needs prevail.[4,5,] Therefore, there is a need to coordinate the care provided in palliative care and mental health settings through deployment of multidisciplinary workforce.

In Queensland, palliative care has received attention with the increase of interventions, policy, practice and research. Yet, the general population in palliative care have received more attention as compared to specific groups experiencing severe mental illness or persisting psychological issues.[1] This group can be perceived as a 'vulnerable group' which deserves good and timely palliative care and specific attention to mitigate the mental health issues. Strong evidence highlights the tendency of people with severe mental illness to avoid professional healthcare or under report symptoms because mental illness serves as a barrier to recognise and report the experience to full extent.[2,3] Consequently, under detection and undertreatment of symptoms and diseases may lead to late access to services, especially in palliative care.[1,3] Besides that, elderly people at home or in Residential Aged Care Facilities (RACFs) have smaller support networks (carers, families, nurses or specialized health professionals) or have impaired communication skills, therefore leading to sub-optimal, minimal to zero communication with healthcare service providers (outside or within the facilities).

WHAT DO WE RECOMMEND?

a) **Improve workforce capability in both palliative care and mental health specialities and improve the interface between the two specialities**
b) **Ensure access to both palliative care and mental health support is available in a timely manner when and where people need it**
    i. **Particularly focus on reducing barriers to access to meet the complex mental health needs of the palliative care patients.**

WHAT IS NEEDED?

2. **Increased palliative care support for people experiencing dying or grief, to assist with the prevention of complex grief disorder and other mental health conditions**

WHY THIS IS IMPORTANT?

Palliative care provides specialised care to individuals with serious or terminal illnesses, with a primary focus on providing symptom relief, pain management, as well as relief from psychosocial distress, regardless of diagnosis or prognosis.[6] Ideally, the core role of palliative care is addressing the physical, emotional and spiritual suffering experienced by the patient.[6] Early integration of palliative care and provision of psychological support has been shown to provide improved outcomes in patients (with serious and persistent mental illness) and their families to reduce the impact of dying and grief.[6,7] 10%-20% of bereaved individuals experience a persistent, debilitating phenomenon called 'complicated grief' which could be relabeled as 'Persistent Complex Bereavement Disorder'.[8] Complicated grief is a prolonged or pathologic grief.[8] If the resulting syndrome of grief is left untreated or misdiagnosed it can lead to substantial distress, functional impairment, depression and post-traumatic stress disorder.[6,8] Therefore, early diagnosis and treatment of palliative patients can assist the family members to successfully adapt without clinical interventions.[9]

Studies related to pediatric palliative care indicate that parents of children with a life-limiting disease are at increased risk of post-traumatic stress disorder due to increased caregiving demand and have a perceived high risk of life threat.[10] Parents need early explanation from health professionals to prevent overstress and overburden.[10] Health care professionals can strengthen the resilience and prevent distress of the parents to a certain extent through proactive attitude and compassionate communication.[10]

Patients, their families and carers want to access the best palliative care when and where they need it and not have zone boundaries and rules dictate their service access and their quality of care. Therefore, optimize the end-of-life care especially for those struggling with mental health issues by reducing the barriers to identify patients in their last months of life, adequately train staff and health professionals to positively communicate with patients and families and generate links within the medical teams.

Additionally, the lack of access and quality of care issues are also supported by a national study which shows most patients in Australia are not getting suitable end-of-life care. A research study by Professor Imogen Mitchell, an Intensive Care Specialist based at Canberra Hospital, looked at nine hospitals across Australia and tracked 1,693 dying patients. It showed only 41 per cent of dying patients will ever see a member of the palliative care team and that at least 60 per cent of people who die in Australia will die in a hospital setting and are at risk of not receiving appropriate end-of-life care.[11]

WHAT DO WE RECOMMEND?

a) **Increase state-wide palliative care funding to ensure that both specialist and generalist palliative care supports can be accessed from diagnosis when and where it is needed**

b) **Fund a state-wide Bereavement and Spiritual Care Program (including counselling services, bereavement support groups and telephone advice, spiritual care support and generalist advice, with a focus to support health, social and community teams and the community)**

WHAT IS NEEDED?

3. Increased education and research opportunities for palliative providers in relation to mental health

WHY THIS IS IMPORTANT?

Most people will go through at least one traumatic event in their lives, but not everyone will respond in the same way.[12]Australian research suggests that the unexpected death of a close loved one is considered the most common traumatic event experienced by Australians.[12] As the population continues to age, it could be predicted that by 2050, approximately 40% of those experiencing traumatic injury will be older than 65 years.[13]However, people in this age group who experience trauma are at a greater risk of death due to multiple reasons.[13]

South Australia successfully piloted a palliative care and mental health education program: *Integrated Mental Health and Palliative Care Task (IMhPaCT)*[19]. This program uses cross-training modelling, self-directed learning packages and liaison roles to achieve improved outcomes in the care of individuals with SMPI and life-limiting conditions. This increased knowledge and collaborations.

Trauma informed care models can benefit palliative care service delivery as there is a need to understand previous experiences of loss, grief and psychological issues, which may compound peoples current palliative care experience. This is particularly relevant for First Nations, Veterans and other vulnerable populations. Emerging evidence also shows some people may experience psychological trauma due to intensive medical interventions prior to admission to palliative care due to lack of suitable psychological interventions or strategies for these populations.[14] Notably, in elderly adults trauma reactivation can cause resurgence in post-traumatic stress disorder symptoms.[14]Palliative care patients (not only veterans and First Nations people) are likely to have histories of psychological trauma which require the need for trauma informed care. It requires patient and staff/health professional collaboration for skilful understanding, assessment and palliation of patients' trauma symptoms.[14] However, trauma-informed care does not replace existing approaches to palliative care; rather it provides a new lens to assist and support patients holistically through all approaches to care.

Evidence and knowledge are an additional gap in this area. Queensland requires improved data collection, data quality and implementation of research to inform an evaluation framework for continued improvement in mental health services, end-of-life, grief and bereavement, policy and program review, and the development/promotion of best practice.[15]

WHAT DO WE RECOMMEND?

a) **Pilot the Integrated Mental Health and Palliative Care Task (IMhPaCT) project in Queensland**
b) **Provide trauma-informed care education training to all Specialist palliative care teams across Queensland**
c) **Provide dedicated research funding to investigate the interface between palliative care and mental health, particularly in relation to specific population groups (i.e., Aboriginal and Torres Strait Islanders)**

WHAT IS NEEDED?

4. Build community capacity and knowledge regarding dying and death to help prevent psychosocial morbidity

WHY THIS IS IMPORTANT?

To increase awareness and build capacity in indigenous families and communities regarding potential mental health issues, the Government provided $15 million over three years to the National Wellbeing Alliance Pty Ltd.[16] This funding complemented the $2.3 billion investment in mental health and suicide prevention initiatives to support the efforts to achieve 'Closing the Gap'.[16] The funding initiatives will support appropriate mental health courses to upskill participants and help assist families and other community members to find appropriate ways to seek support and assistance. Consequently, by training communities on mental health issues and individual resilience, it will increase knowledge and skills in recognising mental health symptoms and available referral pathways and supporting families and loved ones who are experiencing difficult times. Therefore, similar initiatives embedded in palliative care (including bereavement and grief services) will increase the ability of individuals to alleviate psychological stress, worries and frustrations through provision of resources and greater understanding of available assistance and government initiatives.

In parallel to mental health, knowledge about palliative care and end-of-life care (including bereavement and grief support) is sparce or totally absent in most communities.[17] Consequently, communities across Queensland lack knowledge about Palliative care and end-of-life care, and there is an urgent need to educate non-professionals about serious illness, dying, death and grief, which can reduce fear, anxiety and frustration (which can further escalate psychological issues) and open discussions about supporting each other.

"*If I only had known that before, it would have helped me when my aunt died*."- participant Last Aid course .[17]

Last Aid is an international basic public education program about palliative care. Last Aid can be seen as an educational foundation of Compassionate Communities which can further provide communities and families with a platform to re-engage, which is helpful for their own mental health and well-being.[17] The course uses the compassionate community approach to stimulate discussion about death and dying. Last Aid courses were well accepted and assist in narrowing the gaps and deficits in information on care of those in their final stages of life.[8]
Palliative Care Queensland is a Last Aid training provider but this not a funded program.
For more information on Last Aid: https://palliativecareqld.org.au/lastaid/

If undertaken professionally and ethically, serious illness and end-of life conversations can empower patients to make informed decisions .Likewise, the model of 'Compassionate Communities' could be expanded, through further engagement and support to the Queensland Compassionate Communities Peak Network who are currently not resourced to support compassionate communities' initiatives. For more information about World Compassionate Communities Day: https://palliativecareqld.org.au/compassionate-communities-day

WHAT DO WE RECOMMEND?

a) **Invest in an innovative community education program (such as Last Aid) to promote awareness and understanding that serious illness, dying, death and grief are a natural part of life, thereby reducing fear and promoting people's engagement and compassion for people experiencing a serious illness, dying or grief**
b) **Invest in Queensland Compassionate Communities (community focused arm of Palliative Care Queensland) 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**
c) **Support the state-wide Queensland Compassionate Communities Peaks Network to showcase World Compassionate Communities Day through a variety of initiatives, to promote and build compassionate communities throughout Queensland.**
d) **Ensure Compassionate Communities and health-promoting palliative care techniques are included in social and community planning{Taylor, 2012 #138}**

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Attachment 1: Palliative Care Queensland's policy guiding principles