

1 September 2021

**Community Support and Services Committee**

Parliament House  
George Street  
BRISBANE QLD 4000

Dear Secretariat and Committee Members,

**Re: Community Support and Services Committee Inquiry into Social Isolation and Loneliness 2021**

Thank you for the opportunity to provide a submission to the Committee for the inquiry into social isolation and loneliness.

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 following our submission, including recommendations regarding the Inquiry into social isolation and loneliness.

Sincerely yours,



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## 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 seven recommendations in relation to this Inquiry:

**Recommendation 1:** Support the statewide Queensland Compassionate Communities Peaks Network to showcase **World Compassionate Communities Day**, through a variety of initiatives, to promote and build compassionate communities throughout Queensland

**Recommendation 2:** Develop a **Statewide Palliative Care Volunteer program** across Queensland to support people experiencing a serious illness, dying or grief, their carers and particularly those with limited access to family and friends

**Recommendation 3:** Fund a **public 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

**Recommendation 4:** Increase **social and community sector workforce capacity and capability** to communicate, understand and support people and their families experiencing serious illness, dying, death and grief

**Recommendation 5:** Work with health, social and community agencies to identify barriers and mitigate risks related to incorporating exemptions for **access to their own pets or companion animals** in hospitals or residential care locations for people experiencing serious illness, dying, death and grief

**Recommendation 6:** Ensure **Compassionate Communities and health promoting palliative care** techniques are included in social and community planning

**Recommendation 7:** When restrictions occur in hospitals, facilities or group homes (including for COVID, gastro or flu outbreaks) ensure specific **exemptions** are in place and clearly articulated in relation to people in the last weeks and months of their lives

**Recommendation 8:** Utilise agencies such as Palliative Care Queensland, when developing and implementing intervention strategies and activities to combat **loneliness to ensure it includes support** for people experiencing a serious illness, dying, death or grief and their carers, families and community

## Introduction

The Australian Psychological society has highlighted the concept of 'Power of Human Connection', that reflects on the prevalence of loneliness and its effects on holistic physical and mental wellbeing of Australia.<sup>2</sup> Correspondingly, the evidence highlighted that nearly 55% of the Australian population feel the lack of companionship at least sometimes and one in every 4 Australians experience loneliness and a high level of social interaction anxiety consequently leading to poor psychological wellbeing and poorer quality of life.<sup>2, 4</sup> These feelings and emotions of loneliness and isolation have been made worse by the COVID-19 pandemic, with one in two Australians indicating they feel lonelier since the pandemic.<sup>4</sup> Australian Bureau of Statistics (2020) reported that the loneliness was the most prominent personal stressor as experienced by Australians during the COVID-19 pandemic.<sup>1</sup>

***"Loneliness acts as a fertilizer for other diseases."***<sup>12</sup>

Loneliness is epitomised by lower levels of community connection which is more prevalent among those dying or suffering from serious illness.<sup>5</sup> Social isolation and loneliness is a major health issue among older adults and those suffering from any form of life-limiting condition.<sup>3, 11</sup> The economic cost of loneliness in Australia is likely to be substantial, although no current estimate of this cost is available.<sup>1</sup> Therefore, innovative and creative initiatives are required to enable communities to connect with those feeling lonely or lacking social ties especially for those approaching or currently experiencing serious illness, dying, death or grief.

***"Social connection is everyone's business, and is vital for physical, psychological and social wellbeing."***<sup>7</sup>

Socially and culturally appropriate care at the end stage of life can positively impact people's comfort and dignity and is responsive to psychological and spiritual needs.<sup>9,10</sup> Hence, social interaction for people experiencing a serious illness, dying, death or grief is critical to providing care and support, and reduces loneliness and social isolation.

***"Death is not the opposite of life, but a part of life".***<sup>8</sup>



## Palliative Care Queensland's recommendations

### **Palliative Care Queensland's recommendation 1:**

#### **RECOMMENDATION:**

Support the statewide Queensland Compassionate Communities Peaks Network to showcase **World Compassionate Communities Day**, through a variety of initiatives, to promote and build compassionate communities throughout Queensland

#### **WHY THIS IS IMPORTANT?**

Compassionate Communities are networks of support which surround people experiencing serious illness, dying death and grief. World Compassionate Communities Day is a new international initiative (founded in 2021) to promote and build compassionate communities. The Queensland Compassionate Communities Peaks Network is a network hosted by Palliative Care Queensland, involving several Queensland Peak bodies who support the principles of Compassionate Communities (see appendix 1).

The Queensland Government supports NGOs with similar initiatives on Grandparents Day, such as 'Time for Grandparents Program'

*In partnership with Uniting Care, Queensland Government operates 'Time for Grandparents Program' that provides an opportunity to have well-earned time for grandparents to attend activities and enjoy with their children. Correspondingly, through programs such as 'Grandparents Day' is a brilliant initiative to acknowledge the contribution of older Australians in building communities and providing them a platform to re-engage which is further helpful for their own mental health and well-being.*

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.<sup>13</sup> For more information about World Compassionate Communities Day:

<https://palliativecareqld.org.au/compassionate-communities-day/>

### **Palliative Care Queensland's recommendation 2:**

#### **RECOMMENDATION:**

**Develop a Statewide Palliative Care Volunteer program** across Queensland to support people experiencing a serious illness, dying or grief, their carers and particularly those with limited access to family and friends

#### **WHY THIS IS IMPORTANT?**

Compared to Victoria and New South Wales, Queensland has a very small number of palliative care volunteers. Volunteers can make a huge difference at the end stage of life, to support the person with a life-limiting diagnosis, their carer, their family and their community. Volunteers are often referred to as the 'backbone' of palliative care. There is a desperate need to mobilise volunteers across Queensland to make a difference in people's life when it is needed the most.



Volunteers can positively influence the quality of life and quality of care for people experiencing serious illness, dying, death or grief by providing a link to the community and to “what matters most”. Volunteers provide a feeling of ‘someone being there’ and fill in the domain between the professional and family.

Although the eight Queensland hospices in south-east Queensland have wonderful volunteering programs, there is need of enhancement and re-integration of volunteers through the development of a Statewide palliative Care volunteer program, similar to NSW, ACT and Victoria.

International programs such as “no one dies alone” in aged care services demonstrate the value of volunteers for people and their families experiencing serious illness, dying, death and grief in reducing loneliness.

### **Palliative Care Queensland's recommendation 3:**

#### **RECOMMENDATION:**

**Fund a public 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

#### **WHY THIS IS IMPORTANT?**

“If I only had known that before, it would have helped me when my aunt died.”- participant Last Aid course <sup>15</sup>

In most communities, knowledge about palliative care is sparse or totally absent.<sup>15</sup> Communities across Queensland lack knowledge about Palliative care and end-of-life care, and there is an urgent need to educate the non-professionals about serious illness, dying, death and grief which can reduce fear and open discussions about supporting each other.

Last Aid is an international basic-level community education program, founded in Europe and available in Queensland.

*“Just as everyone is likely to experience the need to be a first responder at an accident or emergency at some point in their lifetime and therefore need to know the basic knowledge and skills of first aid. Everyone will likely know someone who is experiencing serious illness, dying, death or grief at some point in their lifetime and need to know the basic knowledge and skills of last aid.”* Palliative Care Queensland

Last Aid can be seen as an educational foundation of Compassionate Communities.<sup>15</sup> Last Aid courses were well accepted and assist in narrowing the gaps and deficits in information on care of dying.<sup>20</sup> For more information on Last Aid: <https://palliativecareqld.org.au/lastaid/>



#### **Palliative Care Queensland's recommendation 4:**

##### **RECOMMENDATION:**

**Increase social and community sector workforce capacity and capability** to communicate, understand and support people and their families experiencing serious illness, dying, death and grief

##### **WHY THIS IS IMPORTANT?**

Social and Community sector workers often care and support people who are experiencing serious illness, dying, death or grief, yet because they experience no (or minimal) training in this space they often miss the opportunity to socially connect and have conversations about 'last wishes' and 'what matters most' to them. If undertaken professionally and ethically, serious illness and end-of life conversations can empower patients to make informed decisions in addition to subsiding consequences of loneliness.

Increased workforce capacity and capability of social and community sector staff and volunteers would increase awareness, understanding and confidence within the staff to have meaningful conversations and connect people with formal and informal supports.

#### **Palliative Care Queensland's recommendation 5:**

##### **RECOMMENDATION:**

Work with health, social and community agencies to identify barriers and mitigate risks related to incorporating exemptions for **access to their own pets or companion animals** in hospitals or residential care locations for people experiencing serious illness, dying, death and grief

##### **WHY THIS IS IMPORTANT?**

Companion animals (pet dogs and cats) can assist in countering social isolation.<sup>1,3</sup> Pets can facilitate social relatedness, friendship formation, getting to know people and building social support networks.<sup>17</sup> Companion animals can also serve as a catalyst for incidental social interaction, getting to know people, through formation of social relationships and friendships in the neighborhood. Evidence shows that dogs reduce anxiety in hospitals, but this statement is counter-productive towards convincing hospitals to allow pets in the hospital facilities.<sup>18</sup>

Many hospitals and residential care facilities (where people live out their end stage of life) prohibit animals (such as pets) visiting, out of concern for the health of their patients/residents. Many hospitals and services are allowing service or therapy dogs under strict standards which include vaccines, being house-trained, clean and healthy. However, for many people at the end stage of life, their pet is a companion that they have built a 'personal-bond' with, and their last wish is to reconnect.

#### **Palliative Care Queensland's recommendation 6:**

**RECOMMENDATION:**

Ensure **Compassionate Communities and health promoting palliative care** techniques are included in social and community planning

**WHY THIS IS IMPORTANT?**

Social and community plans are regularly being developed and reviewed but often people experiencing a serious illness, dying, death or grief are not included or have limited inclusion. Generating awareness about loneliness and social isolation as a public health initiative and wellness issue, along with the development of targeted government and community support programs in Queensland for those affected by loneliness and isolation could prove beneficial to build capacity and generate awareness, thus extending the quality life .<sup>1, 3, 6</sup>

**Palliative Care Queensland's recommendation 7:**

**RECOMMENDATION:**

When restrictions occur in hospitals, facilities or group homes (including for COVID, gastro or flu outbreaks) ensure specific **exemptions** are in place and clearly articulated in relation to people in the last weeks and months of their lives

**WHY THIS IS IMPORTANT?**

Visitor restrictions during an outbreak have complicated the ability of hospital or residential facilities to support patients and residents through the end stage of life journey and create ongoing bereavement issues for families. Ensuring that clear exemptions are in place related to people in their last weeks and months of life when a hospital or residential facility is experiencing an outbreak is critical to ensure people are not socially isolated while dying.

**Palliative Care Queensland's recommendation 8:**

**RECOMMENDATION:**

Utilise agencies such as Palliative Care Queensland, when developing and implementing intervention strategies and activities to combat **loneliness to ensure it includes support** for people experiencing a serious illness, dying, death or grief and their carers, families and community

**WHY THIS IS IMPORTANT?**

Recognising that dying is a natural part of life and incorporating this aspect into social and community planning and policy is critical to ensure that people experiencing a serious illness, dying, death or grief are not socially isolated. Organisations such as Palliative Care Queensland are available to collaborate with and support the development of strategies, plans, policies and activities.

Some international countries have developed specific social and community plans related to this area and palliative care is available to work with the social and community sector to develop similar plans. For example, the UK has developed a community plan 'Each Community is Prepared to Help' Ambitions plan (Partnership 2015, UK)<sup>19</sup> which highlights that society as a

whole can participate to support the dying, those important to them and those who are bereaved. This community plan is based on a co-design model that involves social capital of compassionate and resilient communities, public awareness, practical support, and the role of volunteers. Combining professional care with local knowledge of communities could have a significant impact in supporting the ones who are dying and grieving alone.

## Conclusion

Serious illness, dying, death and grief is difficult to discuss, but ignoring this natural stage of life can create social isolation, loneliness, unnecessary suffering and prolonged grief.

***“We all have a responsibility to proactively reach out to those who aren’t in the room and to encourage people to reach out for help in a timely manner.”***



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Attachment 1: What are Compassionate Communities

## What are Compassionate Communities?

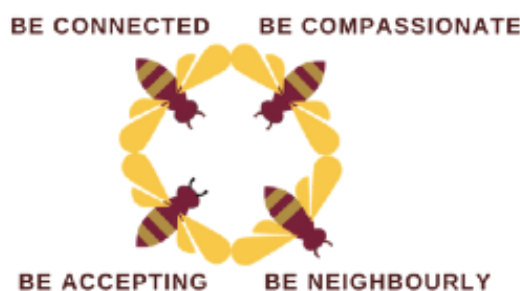
*"A city is not merely a place to work and access services but equally a place to enjoy support in the safety and protection of each other's company, in schools, workplaces, places of worship and recreation, in cultural forums and social networks anywhere within the city's influence, even to the end of our days".* Compassionate city charter, A Kellehear.<sup>1</sup>

Compassionate Communities are communities where everybody recognises that we all have a role to play in supporting each other in times of loss, ageing, dying and grief. Everyone is ready, willing and confident to have respectful discussions to support each other in emotional and practical ways.

Compassionate Communities are a core part of public health approaches to palliative care, end of life care and bereavement. Compassionate Communities are derived from the World Health Organisation concept of 'Healthy Cities' or 'Healthy Communities' and is based on the 'New' public health idea that health is more than mere absence of illness and that it is everyone's responsibility—not just their doctors and their health services.<sup>2</sup>

Compassionate Communities "publicly encourage, facilitate, support and celebrate care for one another during life's most testing moments and experiences, especially those pertaining to life-threatening and life-limiting illness, chronic disability, frail ageing and dementia, grief and bereavement, and the trials and burdens of long term care."<sup>3</sup>

### Be a part of a compassionate community



For more information about the Queensland Compassionate Communities program  
visit: [palliativecareqld.org.au/qcc](http://palliativecareqld.org.au/qcc)

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Attachment 2: What is palliative care

*Palliative Care Queensland's policy guiding principles*

<p>Palliative Care is</p>	<p>about the whole person</p> 	 <p>for the entire dying journey</p>
<p>for every age and every stage</p> 	 <p>about the community of care</p>	<p>about choice, autonomy &amp; dignity</p> 
 <p>about living</p>	<p>not 'one-size fits all'</p> 	<p>Everyone's business</p> 
<p>care for the carer</p> 	<p>a Human right</p> 	 <p>Palliative Care <i>It's more than you think.</i></p>

palliativecareqld.org.au

