



Palliative Care Queensland, Health Consumers Queensland,
Council on The Ageing Queensland and Carers Queensland
joint submission for the
2019 Queensland Government Inquiry into aged care,
end-of-life, palliative care and voluntary assisted dying

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Executive Summary

Our organisations strongly believe there is a need to re-develop and re-think aged care, end-of-life and palliative care services in Queensland to meet the needs and expectations of the community.

There are approximately 29,500 deaths in Queensland each year and a recent Productivity Commission Reportⁱ suggests that up to 90% of people who die would benefit from palliative care.

The provision of end-of-life care can exacerbate the stress already experienced by carers^{ii iii}. Carers providing end of life care have repeatedly voiced concerns about:

- unmet needs for information and enhanced communication
- more flexible and responsive service provision
- uncertainty about the treatments offered
- fear about the availability and delivery of culturally safe services
- changing roles within the family
- lack of affordable and regular transport
- strained financial resources
- lack of social support and fear of the future.

The impact of this stress is evidenced in research: 46% of carers providing end of life care experienced increased anxiety and 39% increased depression^{iv} and older spousal carers who experienced heightened stress with their caring responsibilities were 63% more likely to experience earlier mortality.^v

Lack of social support and social integration and ‘caregiver burden’ has been cited by spousal carers of gay men with AIDS as the underpinning issues triggering suicidal ideation.^{vi} Similarly, the additional burden of stigma and the fear of discrimination and/or receiving poorer or lesser quality care was cited by some LGBTI people as the reason for delaying connection with the health and social services sectors. Stigma and marginalisation can cause ‘disenfranchised grief’ for many LGBTI carers.^{vii}

In 2017, PCQ created *Queensland Compassionate Communities* as its community arm, which focuses on building partnerships with local community groups to develop communities that respect and value living, ageing, dying and grieving well. The four organisations involved in this submission have partnered successfully in several projects linked to nurture compassionate communities throughout Queensland.

About the organisations

About Palliative Care Queensland

Palliative Care Queensland (PCQ) is an independent charity peak body representing the people who care for Queenslanders living with life limiting conditions. Queensland Compassionate Communities (QCC) is the community arm of Palliative Care.

PCQ has been operating for over 30 years, has over 400 members and is a founding member of Palliative Care Australia. These members include health professionals across all sectors of health, specialist and generalist palliative care services, peak bodies, as well as consumers and interested members of the Queensland community. Collectively, the PCQ membership body holds tremendous knowledge and wisdom about the challenges the sector faces and the opportunities those challenges can bring.

About Health Consumers Queensland

Health Consumers Queensland is the peak organisation representing the interests of health consumers and carers in the state. Health Consumers Queensland is a not-for-profit organisation and a registered health promotion charity and we believe in improving health outcomes for people in Queensland.

Consumers are people who use, or are potential users, of health services including their family and carers. Consumers may participate as individuals, groups, organizations of consumers, consumer representatives or communities.

About Carers Queensland

For almost 30 years, Carers Queensland has been working to advocate for equal rights, opportunities, and enhanced outcomes for caring families.

We work within and value our local community, responding to unmet need with care and respect, assisting those who are disconnected through high-quality personalised support.

Our objective is to ensure you achieve your goals, enhance your relationships, and can move forward with a life based on your own decisions and choices.

About Council on the Ageing Queensland

COTA (Council on the Ageing) Queensland is a statewide not-for-profit organisation that advances the rights, interests and futures of people as we age. Working in partnership with older Queenslanders, and groups, networks and organisations across Queensland, COTA Queensland seeks to hear the voices of older people and those who support them, and through this inform and influence decision makers in creating positive social change. COTA Queensland is committed to the fostering of age-friendly communities and our work is guided by the World Health Organisation's (WHO) Decade of Healthy Ageing.

About the collaborative

Our organisations have linked informally since our beginning however in 2018 we recognised our collective interest in Compassionate Communities and began to formally collaborate.

Our first formal collaboration was for National Palliative Care Week 2018 when we organised a **Compassionate Community Conversation** at the Translational Research Institute in Brisbane. This was attended by over 100 people and followed with a free afternoon tea and stalls sharing information about our organisations.

In 2018-2019 we have continued to collaborate on two projects:

- **Compassionate Communities Conversation Series**
 - A project lead by Palliative Care Queensland, in partnership with Health Consumers Queensland (HCQ), Council on the Ageing Queensland (COTA-Qld) and Carers Queensland, funded via a Department of Communities age-friendly Queensland grant
 - This project is currently underway and 15 free morning teas will roll out across Queensland from April to August 2019

- **'Talking about what matters to you in relation to ageing, end-of-life care and dying': Consumer and Carers consultation on ageing, end-of-life care and dying**
 - A project lead by Health Consumers Queensland, in partnership with Palliative Care Queensland, Council on the Ageing Queensland and Carers Queensland, funded via Clinical Excellence Queensland, Queensland Health.
 - The first stage of this project (Kitchen Table Discussions) has been completed and the report is with Clinical Excellence Queensland.
 - The second stage of this project (consumer focus groups) have commenced roll out in line with Compassionate Communities Conversation series from April to August 2019.

Key findings from the Kitchen Table Discussions

A summary of the key findings from the *Talking about what matters to you in relation to ageing, end-of-life care and dying*: Consumer and Carers consultation on ageing, end-of-life care and dying Kitchen Table Discussions (2019)

Core messages

- The core message from the consultation was that there was no evidence that people are in denial of dying and in fact, many spoke openly about their choices, for example: “when the curtain falls”.
- Although participant’s preference was to be at home, participants also noted that keeping them or their loved ones at home was not always possible and there was an acceptance of this fact.
- Voluntary Assisted Dying was often linked to the lack of aged care and palliative care and support.
- Ageing and palliative care support is everyone’s responsibility – the family carer is a key partner in care delivery and they need communication, navigation support and information to support the delivery of care.
- Palliative care and end-of-life care is not just a clinical matter.
- Time at the end stage of life is limited and you do not get a second chance. There are ongoing consequences if it is not done well.
- Nursing Homes/Residential Aged Care– there was discussion in various groups about nursing homes with many concerned (fear) about elder abuse, and stories in the media related to conditions and abuse in nursing homes. This was clearly identified for the ‘Forgotten Australian’s’ session where there is a distinct fear of institutionalization and the potential for abuse and bullying.
- For those who would go to a nursing home or care facility the request is for smaller facilities/community based living. Many of those who suggested going to a facility for care were without family or the support of family, or realization they would be a financial burden on their family.

Key themes

- Staying at home
- Access to quality and timely care and support
- Better Information and knowledge, better navigation and choice
- Voluntary Assisted Dying – Dignity and Choice
- Care Choice (choice around what I need/individualized)
- Informal Support System (family carers, volunteers, community)
- Workforce (paid support workers/health professionals)
- Palliative Care
- Emotional Support, Burden and Risk
- Financial Support, Burden and Risk
- Communication
- Transport
- Housing

Recommendations for the Inquiry

Recommendations regarding palliative care

People in the last phase of their life are amongst the most vulnerable members of our society. Quality care and social supports during this last phase of life and a ‘good death’ for people should be the aim of every health and social system.^{viii}

This collaborative has significant concerns regarding the current Queensland service and support systems for palliative care. Specifically, the current service proposition across the state does not meet the current needs of our community.

The role of carers in providing end-of-life care in the home is crucial. Carers require more support, education and engagement with health professionals, services and supports if they are to meet patient preferences for place of death. Improved quality of planning, communication and education for carers for end-of-life care may assist more people to die at home.

In the recent Kitchen Table discussions held throughout Queensland The preference for people to stay in their own home and be cared for at home was the most consistently repeated comment throughout the 20 consultations held, with the majority of participants requesting to do so with access to quality care and support.

“My husband and I have talked about this and we would ideally both like to die at home. I will not look at Aged Care until it is necessary.”

Many suggested they want to stay with their families and have their families care for them, or families suggested they want to care for their family member at home. However, they also said they would like their families to have the support and education to be able to effectively care for them at home. 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.

Given the number of people who wish to die at home identified in the Kitchen Table Discussions, it is clear that more open and honest whole of community discussion is required.

Recommendation 1:

Provide recurrent funding to Palliative Care Queensland for the continued rollout of a regular Compassionate Communities Conversations Series and Good Life Good Death expos annually.

Recommendation 2:

Promote recurring funding for our organisations to engage in community engagement strategies, including our members, schools, churches and community groups

Recommendation 3:

Promote recurring funding for the Palliative Care in Queensland Annual Summit which provides leadership and clear strategic direction across the sector including co-design palliative care priorities that can be adopted by all stakeholders

Recommendation 4:

Provide improvement funding to undertake a pilot activity that investigates the concept of reframing 'person-centred care' to 'network centred care', including:

- Individuals with a serious illness
- Carer /family
- Friends
- Community

Recommendation 5:

Demonstrate the value of palliative care. Create awareness and engagement campaigns targeting consumers, carers, community and service providers which promote quality palliative care, access to services and compassionate communities

Recommendation 6:

Provide statewide grants for palliative care services and community groups to promote Advance Care Planning during National Advance Care Planning Week

Recommendation 7:

Create a Statewide Palliative Care Consumer and Carer Advisory Group and Support Hub. This Advisory Group would provide advice to the National Palliative Care Advisory Group to ensure the collective Queensland voice is represented at both the state and national level. The Support Hub would be developed and monitored based on ongoing advice and feedback from the Advisory Group.

Recommendations regarding Health Consumers

Recommendation 8:

Establish a navigator role similar to nurse navigators within Queensland Health to provide a level of support to patients and their families that may not currently be available. This would support consumers to understand the decisions they need to make, the choices and options available to them towards the end stage of life. It would also reduce the burden on both the patient and their family in making their choices, also helping them navigate the challenging paperwork requirements.

Recommendation 9:

Improve access to better information to support consumers to make informed choices and care decisions. There is a need for better quality information, seamless communication and easier navigation to support their decision making in regard to ageing, end-of-life and palliative care, and dying.

- Provide programs and education towards improving death literacy of Queenslanders
- Information that is currently provided on care packages and options is deemed to be 'too complicated when already overwhelmed', as is the documentation for Advance Health Directives. More consumer friendly forms are required and more consultation with consumers to develop the forms and promotion of Advance Health Directives.
- Improve clarity and understanding of associated forms and their purpose i.e. Advance Health Directives, Statement of Choices and Enduring Powers of Attorney.

Recommendation 10:

This collaboration (Health Consumers Queensland, Palliative Care Queensland, COTA Queensland and Carers Queensland) be funded (recurrently) to continue to hear the voice of community on these important subjects through Kitchen Table Discussions which are led by consumers and carers consulting with their own community members. This provides an avenue for community members whose voice isn't always heard to have their say in a safe and supported environment.

This collaborative brings system and community knowledge and experience across health, ageing and aged care, dying, death and loss. And that the Queensland Disability Network be considered as an additional partner to include expert knowledge and understanding of the disability system and community experience

Also, to consider the inclusion of the Queensland Disability Network be considered as an additional partner to include expert knowledge and understanding of the disability system and community experience.

Recommendations regarding Carers

Carers Australia conducted a survey of Commonwealth Respite and Carelink Centres (CRCCs) and similar providers in order to investigate reports from carers and other stakeholders that respite in residential aged care facilities is becoming increasingly difficult to access.¹ The survey indicated that:

- there is a very high demand for both emergency (74 per cent of survey respondents) and planned (88 per cent) residential respite care
- most services organising access to respite found both emergency and planned respite care difficult or very difficult to access
- only 3 per cent of respondents found planned respite very easy to access, while none found emergency respite very easy to access
- there are not enough planned or emergency respite beds, particularly for people with high care needs, including dementia
- the subsidies paid to residential care operators are significantly lower for respite than permanent care, even though there are increased administration and other costs for providers associated with respite care admissions
- around half the places that are recorded as respite care are used as an entry to permanent care, rather than for genuine respite
- as well as the need for places in residential aged care, where services are often only available in two-week blocks or longer, there is a high demand for, and a low supply of, overnight and weekend respite in more informal settings, such as respite cottages.

Although Residential Aged Care is predominately funded by the federal government, respite availability is critical to allow persons to stay in their own homes for as long as possible, and for carers to get a well needed break that allows them to continue to care.

Recommendation 11:

Development of a State based response to respite provision.

Marginalised Populations – the LGBTI Communities

Research conducted by Carers Queensland in early 2017 highlights that despite significant social changes in Australia people in the lesbian, gay, bisexual, transgender, intersex and queer communities still fear connecting with, or have had negative experiences of, health and social care providers.^{ix}

¹ <http://www.carersaustralia.com.au/storage/residential-respite-care-report.pdf>

Of the survey respondents:

- **80%** of gender diverse respondents and **39%** of sexually diverse respondents expect to be discriminated against and another **19%** are 'not sure' whether or not they will experience discrimination.
- **28%** of sexually diverse respondents have experienced difficulties accessing services because of prejudice about their sexual orientation.
- **36%** of the LGBTI respondents indicated that they prefer not to disclose their sexual orientation or gender identity.

Similarly, some respondents to the survey suggest that there remains significant homophobic, transphobic and queer-phobic attitudes in the health and social care sectors.

"I've worked in the aged care sector for two decades. The ill-conceived ideas of LGBTI folk in our communities is alive and well in the care industry. Elderly LGBTI folk are at risk of not accessing support they need because of it. One agency I worked for won awards for excellence and the owner confided in me that she could not ever care for an elderly lesbian couple. I won't repeat her ill-informed and harmful excuses as to why."

Many in the LGBTI communities will have non-traditional families; that is families made up of friends, former partners, biological family, and children from current and other relationships. Some LGBTI carers will choose not to be out so as to gain legitimacy as the carer, to ward off undesired reactions and to protect those they are caring for.^x

Marginalised Populations – Rural and Remote

The relative scarcity of palliative care services in rural and remote regions means that there are additional burdens placed on carers. Research has shown that the needs of carers providing end of life care in rural and remote areas are three times more likely not to be met when compared with the patient's needs.^{xi}

"My husband was granted respite care in (name of town) for a week. The only trouble was it would take me day and a half to drive there and back, and another day and a half to collect him. The cost of the petrol and the time, it wasn't worth it – for me that is."

Recommendation 12:

Palliative care service providers be encouraged and supported to refer carers to their local Carers Queensland office to access specialist support services including counselling to address their anxieties and fears, and carer mentoring to help build resilience and create social connection with other carers.

Recommendation 13:

Incentives are provided to community and aged care providers to obtain Rainbow Tick accreditation and or provide LGBTI inclusivity training to their staff.

Recommendation 14:

Wider access to travel subsidies for rural and remote communities.

Recommendations regarding Aged Care

The need for increased access to aged care packages was highlighted throughout the recent Kitchen Table discussions with carers and community members.

- Waiting times for older Australians to access support from a Home Care Package can be more than 18 months.
- Older people prefer to live independently, in their own homes, for as long as they are able.
- Under the Home Care Support Program there are four levels of funding to help older people buy support services, equipment and home care modifications to help them remain in their homes.
- The demand for lower level (1 and 2) Home Care packages is decreasing, while it is increasing for higher level (3 and 4) packages, creating long waiting lists, often in excess of 18 months, for appropriate levels of support.
- According to the National Aged Care Alliance (NACA), more than 125,000 older Australians remain in limbo while they wait for appropriate levels of home care with many yet to receive any support at all. Without a significant increase in packages at appropriate levels, these numbers will only increase.
- In the meantime, their level of health is likely to decline and their need for support increase, making it difficult for them to remain at home. Alternatively, family and friend carers may need to step in to provide the level of care required. If these carers are working, they may have to give up their jobs. If the carer is a partner, their own needs as they age may mean that they are not able to provide the level of care needed and are at risk of compromising their own health and wellbeing.

Recommendation 15:

That all levels of government and community take responsibility for, and take actions in, creating more age friendly environments including affordable, safe and appropriate housing and transport; community and health services which enable people to access the care, support and respite they need in a timely and appropriate way; employment and training opportunities for carers to maintain economic viability during and following their full-time caring role

Recommendation 16:

The Queensland Government provide recurrent funding for community education and information programs to build and maintain community knowledge on health, ageing, disability, dying, loss and grief

Recommendation 17:

That the programs are appropriately resourced and managed, including the program being co-designed, delivered and co-evaluated by and with community members

Recommendation 18:

That the true cost, and cost saving, of this community capacity building program is recognized and the program/s adequately resourced

Recommendation 19:

That the program is delivered through peak consumer and carer organisations which would work in close collaboration with local communities and organisations and networks which support diverse, vulnerable and hard-to-reach population groups; and with government and other agencies which have aligned missions and objectives

Recommendation 20:

That the formal support system (health professionals, care support workers and so on) are

- a. informed and knowledgeable in ageing, disability, dying, loss and grief
- b. skilled, knowledgeable and supported in communicating effectively with others across the person's informal and formal support systems
- c. recognise and value the person, their carers, family, informal advocates and trusted decision makers as partners in the delivery of care and support

Recommendation 21:

Continued lobbying of the Federal Government to release increased Home Care Packages to meet assessed need and demand.

General recommendations

Recommendation 22:

Support and fund Palliative Care Queensland's program to establish Compassionate Communities throughout Queensland. This program would act as an advocate, navigator and awareness raiser for community initiatives in this space.

Recommendation 23:

Genuine ongoing consultation on Voluntary Assisted Dying (VAD) to be undertaken with Queenslanders of all age groups and demographics.

- Particular consideration to be given to young people transitioning from paediatric palliative care services into adult services, and the carers of paediatric palliative care consumers.
- Establish a community reference group early on, with the necessary safeguards and protocols in place to ensure engagement on VAD legislation, implementation and oversight is meaningful.
- Engage high quality facilitators who can advise on the consultation questions and how to address the topic with consideration of the social and emotional determinants.

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