

Health Consumers Queensland submission

Queensland Parliament

Health, Communities, Disability Services and Domestic and Family Violence Prevention
Committee

Inquiry into Aged Care, End-of-Life and Palliative Care, and Voluntary Assisted Dying

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About us

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 careers. Consumers may participate as individuals, groups, organizations of consumers, consumer representatives or communities.

Our priority focus is on consumer engagement that influences and leads improvements and delivers better health outcomes for all Queenslanders. We achieve this through our Queensland-wide health consumer network, tailored training and skills development programs, and maximising opportunities for consumer representation at all levels of the health system.

Consumer engagement is when health consumers actively participate in their own healthcare and in health policy, planning, service delivery and evaluation at service and agency levels.



Our Six Strategic Objectives

1. Enabling health consumers and healthcare staff statewide

We build consumer, staff and system capacity to design a health system together through collaborative, integrated and consumer-centred approaches by providing support, strategic advice, training and advocacy.

2. Acting as an agent of change for consumer-centred health care

In partnership with consumers and healthcare staff, we act as a strong voice on system wide issues to influence key decision makers, policies and models of care to deliver a high quality consumer-centred health care system for all Queenslanders.

3. Enhancing effective partnerships

We develop and grow effective organisational partnerships locally, nationally and internationally to achieve consumer-centred health care for all Queenslanders.

4. Building and using evidence

We support consumers and staff to be involved in co-creating the evidence base for health system development and transformation. We act on the evidence of the human lived experience of the health system to build capacity of consumers and to leverage system change.

5. Being transparent and enduring

We demonstrate transparency and responsiveness on behalf of consumers, community and our funders. We maintain strong leadership and governance to assure organisational sustainability and longevity. We support the passion, energy and courage of our staff and members of our Network.

6. Addressing the social determinants of health

We acknowledge that systemic reform of the health system requires recognising the social determinants of health and co-designing models of care that address them.

Areas of Focus

Our areas of focus in implementing our strategic objectives

In partnership with consumers (including vulnerable groups) and staff, we act as a strong voice on system wide issues such as:

- **Healthcare Rights:** Breaches of healthcare rights which prevent fair, just and affordable access to healthcare;
- **Quality & Safety:** Where quality and safety and/or consumer experiences are of concern;
- **Healthcare Standards:** Embedding healthcare standards around consumer engagement, comprehensive care and health literacy; or
- **Systemic Issues:** Complex, difficult or contentious systemic issues.

Introduction

Health Consumers Queensland along with COTA Queensland, Palliative Care Queensland and Carers Queensland have partnered with Clinical Excellence Queensland, Queensland Health to undertake consultation with consumers and carers on “*What matters to them in relation to ageing, end-of-life care and dying*”.

Our submission is based on the outcomes of the first stage of the consultation process involving 20 kitchen table discussions held across Queensland over a two-week period in March 2019 with 183 community members. The kitchen table discussions were hosted and facilitated by consumers and carers within their own community. Each host was provided with five key questions for their discussions.

Thirteen key themes emerged from the consultation with a consistency of feedback across the 20 sessions:

1. Staying at home (care in the home)
2. Access to quality and timely care and support
3. Better Information and knowledge, better navigation and choice
4. Voluntary Assisted Dying – Dignity and Choice
5. Care Choice (choice around what I need/individualized)
6. Informal Support System (family carers, volunteers, community)
7. Workforce (paid support workers/health professionals)
8. Palliative Care
9. Emotional Support, Burden and Risk
10. Financial Support, Burden and Risk
11. Communication
12. Transport
13. Housing

Our submission is also based on our Board’s input and consumer-focused principles of person-centred, integrated health care:

- Accessibility - safe, affordable and high quality services, treatments, preventative care and health promotion activities.
- Respect - healthcare that meets consumers’ unique needs, preferences and values
- Choice – a responsive health system which ensures consumer choices in prevention, treatment and management options
- Participation - patient involvement in health policy to ensure that policies are designed with the patient at the centre.

Recommendations

Recommendation 1:

Our consultation showed that the current aged care system is in urgent need of system reform and that the majority of consumers want to remain at home and be cared for at home.

Our recommendation is for an improvement and greater focus on access to quality and timely care, resources and support for people wanting to maintain their independence and remain in their own home or with their family through ageing and end-of-life stages. This includes:

- Access to home help and care packages appropriate to the individual's needs, with the necessary equipment and modifications to support being able to stay at home. Timelines and turnarounds for care packages should be based on 'need' and not the 'system'.
- Home care packages to be reviewed to take into consideration the social determinants of health, the need for intellectual stimulation, and be more socially inclusive and culturally appropriate i.e. visits to cattle sales as part of social engagement for rural and remote people.
- Quality and timely care is also reliant on systems working together and having in-home care services that are tailored to the person and respectfully provided.
- More qualified paid support workers, more opportunities for additional education for paid support workers to facilitate quality, respectful care to people in their own homes.
- Provide training and education opportunities and the necessary supports to enable family members to care for their loved ones at home.
- More knowledge of what supports are available to carers to keep their family member at home is required i.e. Palliative Care in the home and not in a facility.
- There needs to be a reduction in financial burden on family carers to enable more people to be cared for at home. Reduce the focus on the combined income of the home in determining care packages.
- There is a preference for community living for those in care or without families, clusters of share homes and facilities with a small number of beds. Care facilities within their existing community network is a preference.
- Facilities need to be less institutional in their structure and environment and more home-like environments for people to want to access these facilities.
- Reduce the requirement in rural and remote communities for people to be placed in care facilities often at a great distance from their local town, families and friends
- Increase in the use of telehealth for specialist appointments.
- Provide more culturally appropriate care with a focus on ethnically cultural in-home care with broader definitions around care activities to ensure cultural needs are being met.

Recommendation 2:

Choice of care and individualized care were another consistent message throughout the consultations. Consumers clearly indicated they want choice when it comes to care and end-of-life options, to know what choices are available to them and where care is delivered.

People should be supported to have the right to dictate their care and the location of that care.

- Provide care choices that enable integrity and preserve identity.
- Provide more clarity in relation to a person's rights and ensure their decisions are respected and acted on.

In relation to voluntary assisted dying (VAD) our consultation indicated that many wanted this to be made legal. Three aspects were particularly highlighted in discussions relation to VAD:

1. Choice to decide timing of death
2. Choice of VAD due to other options of care not being satisfactory (i.e. palliative care and nursing homes)
3. Current health system focus on "keeping people alive"

Many indicated they want to 'control the time of death' and 'decide when it is over'. For some life should be ended when it is no longer dignified. They ask for choice on how and when they die, if they want to be alone or with their family.

The preference of VAD in relation to current care options was highlighted.

We suggest there needs to be better/more flexible/more accessible palliative care services as people may be choosing VAD as their only alternative to sub-par palliative care services, rather than VAD being their preference regardless of services available.

Recommendation 3:

Reduce the emotional and communication challenges for both the patient and their family/carers by providing Queenslanders with better access to information and knowledge to make informed choices and decisions. They need 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 not only health literacy but 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 Advanced Health Directives. More consumer friendly forms are required and more consultation with consumers to develop the forms and promotion of Advanced Health Directives.
- Improve clarity and understanding of associated forms and their purpose i.e. Advanced Health Directives, Statement of Choices and Power of Attorney.
- Establishing a navigator role similar to nurse navigators with Queensland Health would 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. This would reduce the burden on both the patient and their family in making their choices, also helping them navigate the challenging paperwork requirements.

Recommendation 4

Our consultation identified the need for more education about what palliative care is, what is available to consumers and how to access palliative care. In addition, knowledge of where palliative care can/is provided (such as in the home) appeared to be limited, resulting in the need for better community education on the role of palliative care at the end stage of life.

- Provide increased access to equitable palliative care practice across Queensland
- Provide care packages, funding and workforce training to enable more palliative care at home and to increase palliative care beds close to a patient's home and community.
- For some people diagnosis is taking too long and this is impacting on their ability to access palliative care for their loved one.
- People with chronic conditions should have access to palliative care support.
- Improve and increase education opportunities for clinical staff caring for patients at the end stage of life.
- Provide personal care courses for family carers to better support their family member/loved one.
- Consider funding courses for family carers and their family members on grief and loss (including children) through the use of narrative therapy models.
- Support and fund Palliative Care Queensland's program to establish Compassionate Communities throughout Queensland.

Recommendation 5

Genuine ongoing consultation on Voluntary Assisted Dying to be undertaken with Queenslanders of all age groups and demographics, with particular consideration 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.
- Health Consumers Queensland in partnership with Palliative Care Queensland, COTA Queensland and Carers Queensland be funded 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.

Conclusion

Health Consumers Queensland strongly believes 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.

Health Consumers Queensland is undertaking a second phase of consultation on ageing, end-of-life care and dying during the months of April, May, June and July. This will inform our position on the Voluntary Assisted Dying aspect of the Parliamentary Inquiry.