

Health Consumers Queensland submission

Queensland Health Palliative Care Services Review

24 August 2018

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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 carers. 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 MISSION, VISION AND STRATEGIC DIRECTION

OUR MISSION

Health Consumers Queensland empowers consumers to lead and drive better health outcomes.

OUR VISION

Consumers and community partnering with the health system to get the healthcare we want.

STRATEGIC THEMES

- 1 Build capacity towards consumer-focused co-design and transformation of the health system**
 - Education for consumers and health service staff.
 - Building systemic advocacy skills that enables consumers to take leadership in co-design.
- 2 Growing a strong, responsive and sustainable organisation**
 - Develop, strengthen, build, measure, learn.
 - Utilise the passion, energy and vision of our people.
 - Strong governance, culture, accountability and compliance.
 - Sustaining diverse income sources.
- 3 Building profile and research**
 - Research excellence and partnering with universities nationally to inform policy and practice.
- 4 Sought after source of strategic advice to key influencers**
 - Long term relationships to promote development of a consumer-centred health system.
- 5 Partnership with sister organisations and networks**
 - Building effective and efficient networks of health consumer organisations to leverage engagement with key influencers and decision makers.
 - Working alongside sister organisations to strengthen the consumer voice.
 - Shared development of consumer advocacy.

VALUES



Introduction

Our organisation welcomes the opportunity to provide an organisational response to this inquiry, particularly focused on these 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 treatment and management options
- Participation - patient involvement in health policy to ensure that they are designed with the patient at the centre¹.

How we consulted

We welcome the recognition in the Queensland Health Discussion Paper that:

It is critical that the health system works better for consumers, their families and communities by tackling funding, policy and service delivery barriers. This includes seeking a balance of options across the delivery of palliative care services directed by consumer choice in relation to hospital, in home and hospice care settings.²

And that:

The views of palliative care service providers, patients and their carers, and the Queensland community will be integral to the development of future palliative care service arrangements that are evidence-based, practical and relevant to stakeholder requirements and preferences.

Therefore, as such, in addition to drawing upon the organisational knowledge of our staff and Board members, we have based our organisational response on feedback from consumer and carer members of our state-wide Network.

We undertook in-depth telephone interviews with consumers and carers from a variety of backgrounds including people who are living in rural and remote Queensland, Aboriginal, culturally and linguistically diverse, living with chronic/life threatening conditions and those who have cared for a child with a life-limiting condition.

Each of these consumers and carers have broad consumers networks. Some undertook consultation of their own to inform their contribution.

¹ International Alliance of Patients' Organizations (2006) Declaration on Patient-Centred Healthcare (IAPO: London) <https://www.iapo.org.uk/sites/default/files/files/IAPO%20Declaration%20on%20Patient-Centred%20Healthcare%20Poster.pdf>

² Queensland Health Palliative Care Services Review Consultation paper (June 2018) https://www.qld.gov.au/_data/assets/pdf_file/0016/14272/consultation-paper.pdf

Consumer/carer responses to consultation questions

Question 1: How well are palliative care services meeting the demand and service setting preferences for patients and their carers and families in your local area?

Consumer feedback clearly demonstrated **variability** in the provision of palliative care services in Queensland that meets the needs of consumers and their families, including a choice of care in hospital, hospices, residential aged care facilities and at home. Some are very happy with options available to them, and others want greater choice.

The following are quotes from carers and family members in North-West remote Queensland:

Well serviced with ability to provide services locally with advice and supervision from (regional public hospital). Families contacted were very happy with the service. Some complex conditions may need to be managed at larger centres. Palliative Care built by funds raised by community, donations allows family members to stay 24 hours. Is unable to provide chemotherapy services locally.

We have needed to use Palliative Care in (town 1700kms from Brisbane - population 500), we have nothing but praise for the staff and service our family member was given and I am would be surprised if this is not always the case. What happens to other communities who don't have the support ours has to fund this service? I am talking beds, curtains, linen etc.

To give quality end of life care many people want to be at home with family for their final days, many want to "Die on Country." (But there is):

- *Lack of suitable equipment to loan to families*
- *(Regional public hospital) palliative care service receives no funding for this to happen.*
- *Very difficult to be taken home to country when extra support is needed in remote areas*

The following is from a Brisbane-based carer-consumer:

We do need more established palliative care services, there's no doubt about that. The population is aging, baby boomers are going to be demanding these options for them. They're not meeting the demands. Euthanasia and improving palliative care services has to go hand in out with that debate.

Question 2: What changes could be considered to palliative care service delivery in your area that would improve the experience of patients and their carers and families?

Participants identified the need for us as a community to **change how we view death and dying, and how we provide and receive care at the end of life:**

The need seems to be to talk about dying and make it an allowable thing to do. We need to cut across the expectation of 'living forever' and being forever fixed up by the health system.

Resources aimed at stimulating community conversations need to be co-designed, fit-for purpose, widely disseminated and evaluated for impact. One consumer we spoke to asked about the recently created Queensland Health resources for care at the end of life³, asking how widely used and effective they were.

(There can be a) lot (of) not talking/ sharing with the next lot and everyone misses out in the end or is doubling up and wasting time and resources?

Clinicians needing to have good communication skills was identified as vital. It was recognized that conversations need to happen with consumers and their families earlier than they are now, and handled sensitively:

Who is available to have conversations with carer and patient when they are moved from active medical service delivery to palliative care? It's critical that patient (and carer) needs to be informed and supported through this process. We acknowledge this is difficult conversations to have – we need to put in place services or processes so that emotionally intelligent conversations about the terminal state of patient is discussed with carer and a patient and this should lead to and advance care plan with their involvement, discussion and the empowerment of the patient.

At (large metro hospital) they are employing facilitators who can do this work. They talk to the patients about their choices. However, there is no money. Resources need to be provided for secondary services after oncology so that facilitators are available to provide these services.

Hospital palliative care did not deal with feelings that might have arouse in moving to community based palliative care services. They did not have the conversation – acknowledging and hearing what it means emotionally for a person to be palliated. (They should have been) working closely with that person – so that a staff member/palliative care worker who is emotionally intelligent who can partner with the person who is dying. This is difficult work – they need to be really good listeners.

Consider having some conversations away from patients. Shouldn't even be done in the presence of patient (ie. conversations about end of life choices in front of unconscious patients). When people are in the same room family members are very hesitant to discuss impending death issues – when other extended family members are there. All discussions should be always with privacy and with immediate family.

³ <https://www.health.qld.gov.au/news-alerts/campaigns/care-at-the-end-of-life>

Doctors need to be very very clear – to explain that I cannot terminate or turn switch off until I have your permission and have explained very clearly that the person has NO chance of survival. Family members are not medical experts and also there is no burden of guilt.

If a person is dying and there is no chance of survival then we support turning power off. Doctors ask us what we want to do – we don't know – we are not experts. (In our culture) we don't want to take the blame and what if they survive but my choice affects that and ends their life.

A common suggestion for improvement was **community education about the benefits, availability and appropriate timing of palliative care**, so that people are aware of local services. Consumers said:

The concept of Palliative Care is still very misunderstood, and many see it as the last days of life care, were it really starts well before that. I think the general community needs education (TV ad or similar) about the timing and stages of Palliative Care. The person has time to formulate their wishes and make plans that meet their personal needs and can be discussed with Palliative Care Services and implemented.

It's hard to comment on palliative care services because they are not visible. People tend not to know about palliative care services until they need them.

My main response would have to be that this is not 'common' knowledge in the sense that it is anything that we know about here in advance of needing it. It is not familiar or widely understood. Compare this to parents of young children. They easily know where the local childcare centres and schools and sports clubs are for their kids and develop expectations of the way forward easily. By contrast as we approach chronic and final stages of life in debilitating ways, we have few if any ways to prepare expectations in advance that can provide us with a sense of safety and security and knowing what ways forward can be planned for.

I have no idea where I'd start to find out what palliative care services are available. My observation is that people are steered in the direction when the health system decides somehow that they need it, but they don't tell you anything beforehand.

Palliative care services are not meeting the needs – a lot of people don't know, where to reach them. It's very difficult also because palliative care is a last minute thing, you don't normally know you're going to need it. That's a real problem we have, (a lack of) empty beds, and people waiting and queuing to get in.

Service provision is highly variable (across geographies and disease groups) and the appropriate training of staff to start having the conversation with patients is lacking. For example, in the cardiology space, cardiologists rarely have the discussion with patients and keep actively treating them, often with expensive devices – which would make the patient and their family assume they are not on the road to palliation! It is also often left to the nurses to start this conversation and they have little training. As such, we need better pathways to palliative care, but also training for non-specialised staff to help have the conversation.

Overall, patients with some cardiac conditions, such as heart failure, have had difficulty accessing palliative care services, as they were viewed to live too long. While more recent Palliative Care Plans (federally and in Qld) have recognised that there are numerous 'trajectories to death', this patient cohort (and some other chronic disease groups) still have difficulty accessing palliative care services.

Another suggestion was the need for universal access to palliative care services not only to the patient, but for the **benefit of family and loved ones**:

Each hospital should have palliative care services so that they are available in each local area for availability for the patient, and their loved ones. Access for loved ones is especially important as they are the ones who meet the emotional and spiritual needs of the patient. Loved ones emotional and spiritual needs cannot be met without access to local services where they have ready access to their dying loved one.

Respondents also identified the need for palliative care to be **considerate of individuals/family circumstances**, including for those from culturally and linguistically diverse backgrounds, LGBTIQ people and more.

Discrimination is very real. Services need to be sensitive to marginalized groups. A nurse encouraged the life partner to be with her partner, to climb into bed and still be loved, and stay overnight. This provided great comfort for the dying partner and the surviving partner. Palliative care services are not only here for the dying but also the surviving. We need to consider the surviving partner too and their needs. Apart from the LGBTI aspect of this, but all partners, that notion of intimacy and physical connection close to death is important to acknowledge. They're actually still living breathing human beings who need love and care and comfort and support, compassion from the person who loves them the most. Must be willing to follow the advanced care directives and respect the person and their partner.

We know that diversity is changing in Australia. All cultures have their own way of dealing with palliative care. (The health system) needs to link in and partner with the CALD communities so they can develop appropriate palliative care for the diverse groups that present to different hospitals. Existing services are good but they of course don't have enough funding. The community based and hospital based services need to partner with the CALD groups in their catchment area to provide culturally inclusive services.

Partnering with CALD people is really important. What they want, may not seen as ok by hospital. Treat and deal with and tap into the wisdom – that consumers all have their own unique ways of dealing with death. It may not be cultural- sometimes – staff need to think wider and broadly and ascertain if it is cultural or unique to a family and not make assumptions.

Staff need to always ask immediate family member, never make assumption all people from one culture or religion are the same.

At (public hospital palliative care service) – very good services, and allowed for family and religious leaders to come to be with the patient. They provided space – created a private space. Blocked off space.

Could the hospital provide extra bed for family or maybe a convertible or sofa chairs so carers can be with patient? In the same room is essential. I know of a patient who had a fall as family member was not allowed to stay with patient.

In our community we always have lots of visitors – it would great to have another space so that visitors can leave for a short while and be there. Allocated space for them to be in. Lots of people come to visit and hospital should know and understand that we culturally we come give moral support to family in big numbers. Extended family and community feel morally obliged to come and support the family. So the hospital staff should be aware of this and not be daunted by this but

facilitate this. If the suggestion comes from hospital (to leave) it is easily listened to and obeyed by people. When we say it as family it is hard and people may not listen and we fear we will lose their support.

The need for an **increase in adequate staffing levels** in order to provide good care was identified:

Our Nursing Care Annex does provide a good Palliative Care service with input from (regional public hospital palliative care service) however I personally found that the big nursing home Mum was resident (in Brisbane) to be wanting due to poor staffing. So I think more needs to be done to increase trained staffing levels in Aged Care Institutes across the state.

Consideration also needs to be given to what **supports and funding** are provided to small NGOs providing palliative care, so they can take care of their staff, who in turn provide good care to consumers and their families:

My experience of (small NGO provider) was good but I saw staff was treated very badly. Small community based organizations need help - they need to get support and funding in how to run an organization so that the services are resilient.

Staff not taken care of well by the organization cannot do their job well. This kind of work is relationships based and sensitive. Resourcing is an issue – care for patient and their carer was affected.

Where services do exist, particularly in regional areas, there needs to be **improvements to how services are designed and delivered** to be able to maximize the ability for people to remain close to home and have their complex health issues managed in a holistic, clinically safe care way. Consumers said this includes having the right staffing mix, access to supervision (eg. telehealth), protocols to provide medications (eg. chemotherapy) and ensuring there are reliable processes for sharing information between clinicians and services providing care:

Care plans being available to all staff at all times is a must. We had a care plan in place, but when we went into the hospital, none of our regular staff were there, so the staff who were on had no idea we had a plan and could not access it. This was a breakdown in communication, and was a real problem.

Implementing models that ensures that there is **coordination of care** by an identified staff member is seen as vital. The following are quotes from parents of a young person with a life-limiting condition:

Not a lot of services for young people. I had to initiate the coordination between paediatrician and palliative care team myself. I was informed and confident enough to do this, but many people would not be able to. The palliative care team at LCCH were very good – they worked with us to meet our needs.

Much of the coordination happened by phone. Once again, this was by my initiation. The clinicians were happy to work in this way, and all paedists stuck to our plan.

A key worker to help navigate the system would have greatly improved our experience. We managed because I had the skills and energy to do that, to act in a coordination role. Many people will not be able to do that, for a variety of reasons (grief, inexperience, low health literacy, lack of confidence).

Innovative ideas for models and locations of service delivery included locating them in local communities and building in **peer support**:

My personal wish would be for 'caring centres' to be as ubiquitous as childcare centres around our suburbs. Places where carers and those needing care in the community could go as a sort of support centre. This would make it much more visible, and people could learn from and help each other locally. Having an on-demand mini-bus to bring relatives to the centre would be a help.

Consumers understand that increasing consumer access and satisfaction with coordinated and integrated palliative care services must include consumers being involved in the **co-design** of these:

Palliative care for young people available in local areas...needs to be created in a wholistic way, with paediatricians, specialists, medication, equipment, therapy all available in the one place. The services at Caboolture were moved around, so that in order to get everything we needed I had to travel to North Lakes, Redcliffe, and Aspley during the few hours of respite care I was getting. There was no consumer consultation when this "streamlining of services" happened, so consumers being involved in all aspects of service planning is essential. I was only able to access some services after the "streamlining" by contacting our Federal MP.

Further development and growth of the Nurse Navigator role for child, adolescent and adult palliative care patients. Having well informed clinical staff to provide signpost options for the patient and their carer as they navigate the health system can reduce carer fatigue, acute admissions and foster greater collaboration between hospital and community services.

The need for investment into specialist outreach education opportunities to build clinical confidence of the local health care providers. The development of pop up clinics where specialist and local clinicians can share knowledge, develop skills and build confidence and trust between patients and clinicians. Pop up clinics in rural and remote settings can provide for joint patient review, education of local staff, networking opportunities between local and specialist care services.

Consumers raised the issue of needing to **review palliative care funding mechanisms** to ensure equitable access to services across the State for staffing in general and support for people to die at home if they wish.

I have not confirmed but heard that some regions do have specific funding, this should be across the board and I believe more so when there is extremely large multi-cultural diverse region as ours.

There is no specific funding to enable people to go home to die on country. The only way home is to fly and even worse there is no extra money to help the often stretched hospitals they go home to, needing to employ extra staff to assist with these special needs people whose family may not be in any situation to deal with the situation for many reasons although, they want their family member, if at all possible to die on country.

The need for **better coordination around funding between the State Government and Commonwealth** was recognised:

I think it also probably needs Commonwealth buy in for those marginal grey areas between aged care and supported dying at home. The PHNs probably have a strategy around it as well.

There needs to be support and encouragement for collaboration between Queensland Health and not-for-profit services enabling greater access to and coverage of care. This could include and is not

limited to pathways being developed to enable streamlined care between the hospital and community services; joint funding submissions for both government and philanthropic grants; data capture and research opportunities.

Question 3: What types of palliative care services do you think will be required in your local area or across the state to meet future demand? Will different services be needed in the future to those provided today?

Consumers identified that palliative care services will need to be responsive to an increase in chronic disease and numbers of those ageing and dying. This includes **appropriate staffing, equipment and location of services in all local communities:**

As the population ages, we will need more services, particularly those with dementia issues as a secondary factor. More funding for equipment, to assist families in their homes. The need for portable hospital type beds to be loaned to families that fit through the house doors.

If more people are wishing to die at home (and most I know still go to hospital for the final days / stages), then we will need more home care services and carer support services available. Small communities can't provide that amount of service intermittently, so many will still need hospital admission. Obviously staying at home is cheaper for the government, the patient would be happier to be at home (now that pain relief is not an issue) but it does make it very hard on the family.

Along with the great population increase in SEQ, the need for palliative care services will increase. This care needs to be dignified, connected care. At home services, and support for at home care, should be increased. This should be available at all times, despite public holidays and weekends. People need to be able to die in peace and dignity, which just cannot happen in an emergency department.

Residential palliative care that patients can choose to go to should be an option. A nice, peaceful, non-clinical space, that is homely. Perhaps like some birthing facilities are now.

A model that's worth considering is that that was instigated by AIDS Councils around Australia, care teams of volunteer support workers. I was part of a group/ movement that set up home based care through the AIDS epidemic. A roving network/squad of trained people would come out to people's homes, provide basic nursing care, clean the house, do the shopping and pay the bills, as well as comforting and supporting the person who was very sick. There were shifts each day and the person could be at home with their families. When the person became more sick, there was increase in care. There is no need to be tied to the notion of palliative care buildings, we can provide mobile palliative care mobile. Opportunity and use of resources, rather than empty pal care beds, that no one wants to go into, or people waiting to get in and dying at home. There's a disconnect there between supply and demand. Could be attached to a hospital in some cases. These are the hard lessons learnt in the AIDS movement.

(Private hospital palliative care service) blew us away in terms of accommodating of us and our culture. They made us feel welcome. Lot of moral support. Distance and amount of traveling we had to do was difficult with a family. Something closer would have helped up as a family. There could have been something more accessible. There needs to be one in every HHS closer to home. There is more aged care – there is lack of palliative care regionally and accessible for us in south side. We missed days, if it was closer we would have gone everyday. It was hard. (This is) discouraging for people in care as there is less visits people. Spending quality time – but 2 hours traveling puts strain on day to living for entire family – inter generational.

Conclusion

One of our respondents shared this quote, which we feel reflects the wishes of consumers and carers to have equity of access to quality, consumer-centred palliative care services across the State:

We want to improve health for all patients by ensuring that the quality of clinical outcomes and access to care are not affected by deprivation, geography or demographic profile. Value based healthcare will drive quality and sustainability by continually focussing on, and measuring, outcomes that matter to patients and carers alongside understanding the true cost of care.

Prof John Moxham, Clinical Director, King's Health Partners (Presented to the Senate a few years ago).

In order for this to happen in Queensland, consumers and carers must be centrally involved in influencing not only this policy phase of palliative care services in Queensland but also the co-design, delivery, governance, monitoring and evaluation of models and services at a Departmental, HHS and NGO level.