



HEALTH CONSUMERS'
COUNCIL

Inquiry into Palliative care in Western Australia

Submitted to the Joint Select Committee of the Legislative Assembly and
Legislative Council on Palliative Care in Western Australia



palcare@parliament.wa.gov.au

Contact: Executive Director Pip Brennan
Pip.brennan@hconc.org.au

Tel: 9221 3422
GPO Box C134 Perth WA 6839
www.hconc.org.au

Introduction and Background

The Health Consumers' Council (WA) Inc. (HCC) was established in 1994 with the purpose of ensuring the lived experience voice is heard at all levels of service and policy design, implementation and evaluation.

We have been involved in many palliative care initiatives, including the Palliative Care Summit held in August 2019, at which we presented, the World Café Conversation on Palliative Care in December 2019, as well as regular attendance at the Advanced Care Planning Consortium meetings. We are on the National Goals of Care Project which interfaces closely with Advanced Care Planning, and we are on the Project Control Group for the WA Country Health Service's Palliative Care project. More recently we have joined the Reference Group for a time limited research project undertaking an independent review of patient and carer perspectives of palliative care service models in Western Australia via a survey.

In short, there is a significant amount of work happening, and while it is an important area and HCC is pleased to see that the attention on Voluntary Assisted Dying Legislation has led to a focus on Palliative Care, we have the same concerns we always have – that the lack of coordinated, privileged lived experience voice into the many palliative care initiatives will mean we will not achieve the aims of the *My Life My Choices* Report. Nowhere are we seeing anything approaching co-design. The current survey of patient and carer perspectives is going to be key, BUT there has to be some way to include a 50/50 voice between those with lived experience and those that deliver services in the long road to iterative service design, implementation and review. On the continuum below from the Mental Health Commission's Engagement Framework¹, activities to date have sat at the consult/involve level, where the system is still "doing for" the community.



We have advocated for more community engagement in scoping, design and planning of palliative care services, and to allow for extra time for that engagement with this topic given many people's reluctance to talk about it. We have suggested grass roots initiatives such as the Kitchen Table Discussion approach (where a community leader brings together up to 15 people into their home or community space to discuss a topic and collate responses back to the decision maker). We had hoped to ensure conversations were taking place in the heart of communities. In the absence of time and resources to do this, we offer this Submission as a distillation of the conversations we have participated in and witnessed in the last eighteen months in relation to palliative care services.

¹ <https://www.mhc.wa.gov.au/media/2532/170876-menheac-engagement-framework-web.pdf>

A consumer story

In the period of time since the My Life, My Choices report was handed down, HCC has tried unsuccessfully to assist a woman with terminal breast cancer, aged 54, whose relationship has broken down, and with no immediate family supports. She had reached out to HCC for assistance when her condition was considered “stable” rather than “deteriorating”, and Silver Chain discharged her from all clinical and home care services. At the time she had not long moved into a new home and suburb as her previous tenancy had ended, and had also suffered a significant bereavement.

Despite HCC’s advocacy attempts, Silver Chain did discharge her. Within the limits of the system it may well have been the right decision, as at the time her condition had stabilised. But it did not seem to be a compassionate or ethical service response to discharge someone so unsupported. In several phone calls with Silver Chain, she had been promised their help until new supports were in place, but this did not happen.

She had been advised to apply for NDIS and had been trying for some time. The mental health impact of her illness, separation and other bereavements did not assist in this task, which anyone who has attempted will tell you it takes concentration, focus, a thick skin and persistence. The application was not successful, and a Regional Assessment Service Assessor has assessed her for an Aged Care Package which has been dribbling out several supports. It is impossible to know whether she would be better off sticking with the Aged Care Package or try again for NDIS. The system is even more opaque than when trying to choose a phone plan.

Much of her other assistance is through her network of friends and purchased home care services from drawn-down superannuation funds. She talks about playing a balancing act of not living too long that she runs out of these reserves.

Further tumours have appeared in the base of her spine now, but despite this when HCC last spoke to her, Silver Chain had rejected her as a patient, and she is supported clinically by her GP and the Palliative Care Team at Fiona Stanley Hospital. She has been given a current prognosis of 12-18 months, and the chances are, much of this will be spent in ever decreasing circles of paperwork, trying to navigate a system built on funding models, not patient need.

“death, dying and loss is an enormous public health problem... poor bereavement has really poor outcomes in terms of morbidity and mortality, including suicide, depression, chronic ill health and all that comes from social isolation and loneliness...”

Dr Julian Abel, UK Palliative Care Physician (<https://www.youtube.com/watch?v=ubhyr5-GoS8&feature=youtu.be>)

Compassionate Communities

Recommendation 3 of the Minority Report submitted by Nick Goiran MLC notes that “The Minister for Health should assess the recommendations made by Western Australia’s peak body for palliative care and report to Parliament with a plan to...b) progress the Compassionate Communities model.”

People who are dying or grieving spend only about 5% of their time in front of health professionals. The rest of the time, they’re with family, friends, work colleagues or other people in their communities.

“Compassionate Communities are really about... how do we provide equity of care for all people who are dying?” from [this video](#) by Julien Abel

This video from Allan Kellehear is very compelling about the benefits of compassionate communities
<https://www.comcomhub.com/about>

It's not the dying or the grieving that are the issues – as these will affect us all at some point – but the co-morbidities that come with them – mental health conditions, social isolation, lost work and school days and suicides. All other areas in healthcare recognize that there is a community role in preventing ill-health – compassionate communities is one approach to support the community role in end of life care. We strongly advocate for support to allow this community based model to flourish and grow.

Cultural Security

The *My Life My Choices Report* has key inputs from the Aboriginal Health Council of WA and the Aboriginal Legal Service of WA and we agree with the points noted in the Report. We would also like to draw the Panel’s attention to a significant relevant current project by the Langford Aboriginal Association (LAA) to develop a culturally secure Aged Care Hub. This project has been many years in the development and has strong support from community and the many stakeholders. We believe that this project would allow for Aboriginal community to have a safe, culturally relevant facility that is both designed by and controlled by the Aboriginal community and we strongly recommend Government support this project. LAA is an important stakeholder in end of life and palliative care services implementation.

In this, as in all areas of health, there is a pressing need for clinicians and services to keep improving on and learning about Aboriginal Cultural beliefs around dying and death, including the need to appreciate that Aboriginal staff may also have Cultural obligations of their own that require different HR responses.

Recently HCC was asked to assist an Aboriginal woman who was caring for her grandchild. This child had been discharged from Palliative Care and sent home to the Kimberley and the care of the local hospital. It became very clear that there was no plan explained properly to the family, that the service hadn't explained either the condition or prognosis and that there was not an agreement that the prognosis was even correct. This led to enormous distress and feeling of isolation and helplessness for the Nan and unnecessary pain and suffering for the child. Through Advocacy and the support of both the WACHS and the local Aboriginal Community Controlled Health Organisation, the family was able to be supported and their urgent needs met. This incident highlighted both the need for accessible, timely and sensitive independent advocacy, and a system willing to listen, understand and work with their patients and to collaborate quickly and productively with other agencies and NGOs

We would like to note that there are no findings or recommendations relating to culturally secure care for Culturally and Linguistically Diverse People. In 2018 we hosted a Diversity Dialogue on the topic “Difficult conversations: Talking about Advance Care Planning (ACP) with people from culturally and linguistically diverse backgrounds.”

Some key learnings from this session in terms of culturally secure care and culturally appropriate approaches to education included:

- Death and dying is viewed differently by different cultures. In some cultures (e.g. Sudanese) it is not appropriate to talk about.
- Family has an important role to play in many cultures – perhaps elders having the final say over patients, perhaps family members having the medical information about the impending death of an elderly person over the patient themselves etc.
- Religion may have an important role to play particularly in regards to Voluntary Assisted Dying and what is acceptable and what is not.
- It may be inappropriate for a young person or person from outside the community / family to discuss death with a patient.
- Language is important. Ask communities what they want to call ACP – make it relevant to them. Some people may wish to talk in terms of principles, values and dignity rather than ‘planning’.
- Dementia may not be well understood / accepted in some communities.

Ableism in Healthcare

While HCC welcomes the introduction of Voluntary Assisted Dying (VAD) legislation, we are aware through our work with People With disabilities WA and other key disability networks, that the introduction of VAD legislation has caused fear and distress through some parts of the disability community. This is based on the experience of ableism within society that is often felt in health services most painfully. Recently, during the COVID-19 crisis, patients with disability who access home based oxygen and other respiratory services were receiving “routine” check-up calls. During these calls, unsolicited Advance Care Planning conversations were being inserted into the script along the lines of “would you want to be resuscitated?”

Disability awareness education should be happening in services to ensure the disability community’s point of view is understood. The judgement of “a good life” which is so often made by people without disability in the medical system is often flawed as it does not understand this demographic or their views of “a good life”. For many disabled people, the need for someone to provide personal care (feeding, toileting, communication support, other activities of daily life) is a regular and typical part of their life, and doesn’t lessen or negate their intrinsic value as a human being, or their ability to be productive, contributing and highly valued members of community. Doctors, clinicians and the system need to be aware of their own language and attitudes toward disability and how that plays out when treating disabled patients and consumers.

As much of the evidence to the current Royal Commission shows, hospitals can be very unsafe places for many disabled people and their families. The health system needs to listen to community and address these urgent and valid concerns. The “burden of care” narrative is very ingrained and does influence peoples’ decisions. It is vitally important to encourage and support this community to be proactive in advance care planning. We are currently embarking on a project with People With disabilities WA and Palliative Care WA to support this aim.

Recommendation 7 Inpatient specialist palliative care hospice northern suburbs

It is our understanding that North Metropolitan Health Services are planning a tender to be issued in August for specialist inpatient hospice beds. There is no clarity for HCC to know if the specifications for those beds have been developed with community input. It's not even clear as to whether this tender relates to this recommendation because the specifications aren't yet available. We urge coordination and clarity in relation to implementing new services, to ensure there is a partnership approach with consumers and carers to develop the right kind of service.

It is important to note there are no children's hospice services – the group Hannah's House have long had the ambition to build a standalone hospice, but they are providing in-home support to ensure some choice for parents in the dreadful position of losing their child.

Recommendation 8 Palliative Care Services – community providers are adequately funded

Our understanding is that it is now harder for people to access the practical care they need than it was 10 years ago. While families were once able to access emergency in-home respite care for up to three days to support exhausted carers, this is now no longer available. The current system means that people have access to information and are regularly "assessed" but that it's hard to access practical hands-on support.

The appalling situation for people under 65 who are required to go through the process of applying for NDIS funding support to access support, for example when their condition stabilizes and they are discharged from Silver Chain, they face lack of services and a huge administrative burden of trying to get an NDIS application through.

There needs to be direct referral options for consumers from their hospital palliative care team to home services, without the labyrinthine processes of having Regional Assessment Services. People's needs always stretch well beyond clinical and while the funding streams are siloed, people are not.

As noted in our opening case study however, it is important that all services have a range of effective and accessible feedback processes to ensure safety and quality is always at the fore. We strongly recommend the mandating the use of Care Opinion for all WA services who are funded by the WA government to provide health and human services. We would further note that this should be facilitated by the WA government by purchasing subscriptions to the platform and providing one single, moderated place for people to provide their feedback.

Recommendation 9 Palliative Care Services – that WA Health do a review from a patient's perspectives of three models of pall care:

- *Inpatient*
- *Consultative*
- *Community*

This has always been a concern for HCC – that there is an assumption that these are the three models. How grounded is this in what people actually want? Why aren't hospice services also considered?

Recommendation 10 - Palliative care services – WA Health determine the level of unmet demand

Recommendation 11 – Palliative Care services

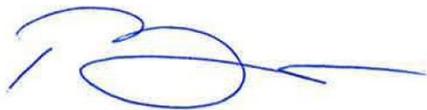
- *Establish consistent definition*
- *Education for professionals and community*
- *Palliative care info and community hotline*

While it's challenging that people think of palliative care as only being about end of life – which stops some people taking it up or being willing to be referred to it – that it's likely this may always be some people's perception and so we need to work with that. HCC has often advocated for a different term such as comfort care.

There is also a need for education of community members about what happens when people die, to help people develop their understanding of a good death and what is required. While people may want to look after their loved ones at home, it is not widely understood that this is not sustainable for most people beyond a couple of weeks, and their loved one may linger for weeks or months. People also fear pain but have little understanding of the distress caused by breathing difficulties, which can be better supported in hospital than in the home, for example.

Please contact the undersigned for any clarification or further information.

Kind regards



Pip Brennan
Executive Director

Prepared by HCC Engagement Staff members Pip Brennan-Executive Director, Clare Mullen-Engagement Manager, Tania Harris-Aboriginal Engagement Coordinator, Nadeen Curran-Cultural Diversity Coordinator.