

12th June 2018

Hon Matthew Swinbourn MLC
Chair of the Environment & Public Affairs Committee
Legislative Council
WA Parliament – Harvest Terrace
West Perth WA 6005

Dear Sir

Submission in support of Petition 067 – Access to Specialist Palliative Care

Thank you for inviting me to submit additional support for Petition 067, which concerns limited or no access to Specialist Palliative Care for hospitals in Joondalup, Midland, Peel, Fremantle and Bentley.

This petition only addresses Specialist Palliative Care, as distinct from non-specialist palliative care which can be delivered by GPs and other primary health providers with additional training. Specialist Palliative Care is considerably more complex than non-specialist palliative care, and it is particularly relevant for patients with co-morbidities. A Specialist Palliative Care physician has undergone a considerable amount of extra training beyond the additional training for non-specialist palliative care delivery by GPs and other primary health providers.

Recently, the WA Department of Health released its *WA End-of-Life and Palliative Care Strategy 2018-2028*, which provides details of Specialist Palliative Care in the Perth metropolitan area on page 30. It will be observed that only Joondalup appears on this map. At this hospital, direct care is not delivered to dying patients in an inpatient setting. Rather, patients might get a visiting Specialist Palliative Care physician, but there is no guarantee.

It will be further observed that none of the other aforementioned hospitals appear on page 30. This is because they do not have any Specialist Palliative Care services. Undoubtedly these hospitals can provide good end-of-life care from their existing staff given their experience and skillset. However, if a dying patient required Specialist Palliative Care, then they would have to decide on whether to continue non-specialist palliative care or be referred to another health service that does have a Specialist Palliative Care team. It is unacceptable to place WA's most vulnerable residents, already confronted with feeling unwell and anxious, in a situation where:

1. their pain and symptoms cannot be managed by a specialist with the particular training to do so, and
2. their questions cannot be fully answered to help them make considered decisions about their death.

In order to maximise quality of life, palliative care is best delivered at diagnosis. It is adjustable to the changing needs of the patient as death approaches, including being

ratcheted up to Specialist Palliative Care as needed. The rational choice is a comfortable and peaceful dying experience. The concern therefore is that such a death may be denied certain patients for want of Specialist Palliative Care. These deaths have no place in a compassionate civilised society, and leave an indelible painful memory for us left behind.

In addition, based on my understanding from a recent conversation, Palliative Care WA has observed an increasing number of calls about difficulties in accessing both non-specialist and Specialist Palliative Care. These calls come from both patients and carers who are experiencing real challenges negotiating an increasingly complex system. This is made even more difficult if there are no Specialist Palliative Care services in their region.

Furthermore, data published in the *Palliative Care Outcomes Collaboration* 2014 from the Australian Health Services Research Institute strongly suggests there is reduced access to non-specialist palliative care for: Aboriginal peoples, culturally and linguistically diverse peoples, the homeless, refugees, and people from the lesbian, gay, bisexual, transgender, intersexual and queer communities. It is a **grave social injustice** that Specialist Palliative Care is not accessible to people who are already marginalised. Given the limited data from such groups, I ask, for example, whether the views of Aboriginal peoples have been invited?

The first priority of the WA Department of Health's *WA End-of-Life and Palliative Care Strategy 2018-2028* is that "care is accessible to everyone, everywhere" (page 2) such that any individual person can state "I have access to good quality end-of-life and palliative care, regardless of who and where I am, or how I live my life" (page 6). Currently this priority is not being met at Joondalup, Midland, Peel, Fremantle and Bentley hospitals.

This petition has not been brought to the Parliamentary Commissioner for Administrative Investigation because there are no systems in place for the Ombudsmen to investigate whether they are properly administrated. Therefore, I respectfully ask the Committee:

1. Why are Specialist Palliative Care services not currently being provided in at least these metropolitan hospitals? and
2. Given that no specific funding announcements have been made to implement the WA Department of Health's *WA End-of-Life and Palliative Care Strategy 2018-2028* plan, what is going to be done about this? and
3. How will access to Specialist Palliative Care be improved for marginalised groups who already have compromised access to non-specialist palliative care?

By your indulgence, I am prepared to present for a hearing to give further evidence.

Yours faithfully



Mr Warwick D'Silva