1 General Submission

The *Joint Select Committee into End of Life Choices* process, its final report, the report of the *Ministerial Expert Panel* and finally WA's *Voluntary Assisted Dying Act (2019)* constitute a long and profoundly disturbing journey for many West Australians who must struggle with new realities in the human experience of dying and of death.

As an ethicist I hold clearly articulated views on assisted dying / euthanasia, while as a Minister of Religion I must engage regularly – sometimes daily – with these realities.

As a reflective and pastorally caring person, I am conscious that my engagement in the tragic journeys of others inevitably shapes my own journey and illuminates my own interior struggle to negotiate the realities of ageing, illness and death.

It matters a great deal to me, and to many West Australians, that our journey into voluntary assisted dying should not advantage those who wish to end their own lives without bringing benefit to the much greater majority who hope we can achieve better end-of-life care, including palliative care, for all West Australians.

However, neither the State Government nor the media have provided us with much comfort in this regard.

Despite Government promises of more funding for palliative care throughout the State, we have no evidence of any material gains in terms of numbers of dedicated inpatient palliative care beds, numbers of palliative care specialists, or more equitable access to palliative care services for West Australians in outer metropolitan, rural or remote regions.

The present Parliamentary Inquiry should ensure that

- ***the State Government is held to account for the funding announcements it makes by demonstrating substantial material gains in all of these areas, by identifying and publicising those gains accurately and without delay;***
- ***the Government is held to publish a timeline of other planned improvements to palliative services;***
- ***the Government addresses structural barriers to better palliative care services for all West Australians.***

In the following sections I focus on specific areas for the Inquiry's attention.

2 Scope of this Inquiry

The Terms of Reference of this Inquiry are limited effectively to two matters:

- whether or to what extent the Health Department has delivered on recommendations regarding palliative care in virtue of State funding announcements in 2019-202; and
- the equitable delivery of adequate palliative care services in metropolitan, rural and remote areas.

The TOR make no distinction between hospital, hospice and community deliver of palliative care, nor between services provided by nurses, by general trained doctors and by specialist palliative care physicians.

These distinctions are material to the Inquiry: services provided in specialist hospice care are very often qualitatively different from services provided in home settings; and it is reasonable to assume that services provided by specialist physicians will be qualitatively different from services provided by nurses.

Since the intention of this Committee is to inquire into what improvements, if any, have been made in palliative care delivery in WA in 2019-2020, the Committee's conclusions must be based on robust evidence.

Therefore the Committee should

- ***ensure that only like-for-like comparisons are made over time; and***
- ***define at every point which care settings and levels of medical professional are being compared.***

3 Definition of Palliative Care

The Joint Select Committee into End of Life Choices made the following recommendations:

Recommendation 11 Page 79

To improve understanding of palliative care in Western Australia, WA Health should establish a consistent definition of palliative care to be adopted by all health professionals;

Recommendation 14 Page 91

Once a consistent definition of palliative care has been established by WA Health in accordance with Recommendation 11, the Minister for Heath should appoint an independent reviewer to audit:

- *The level of palliative care activity actually provided in Western Australia's hospitals and compare it against the level of recorded palliative care activity.*
- *The actual spend by WA Health on palliative care on a year-by-year and like-for-like basis, across all aspects of palliative care provision, including community service providers, area health services (including WA Country Health Services) and delineating between inpatient, consultancy and community care.*

Has WA Health established a consistent definition of palliative care?

Has the Minister for Health conducted an audit of the matters noted in Recommendation 14?

When will the Minister for Health make public the outcomes of these actions?

4 Visibility of relevant information

It is extremely difficult to obtain precise data on

- numbers of dedicated palliative care beds in different facilities and regions of WA at different times in the period under review;
- levels of care available in each region (since these are dependent on the expertise of the providing medical professionals); and
- progress toward attaining the outcomes to be funded by State Government. For example,
  - how far advanced is planning or building of the proposed new aged care and palliative care facility in Carnarvon?
  - when will this come online?
  - how many of the proposed 38 beds will be dedicated palliative care beds?

The Committee should obtain and publish, for the start and end points of the period under review (1 January 2019 and 30 June 2020),

- ***exactly how many dedicated palliative care beds were available in which public and private acute hospital settings, in dedicated hospices, and in other settings;***
- ***exactly how many hours of palliative care specialist time were available in each region of the State, preferably expressed as 'hours per 1000 population';***
- ***exactly how many persons having conditions that would be responsive to palliative care were and were not able to access appropriate levels of palliative care in each region of WA (see Finding 14 and Recommendation 10).***

5 From the *Joint Select Committee into End of Life Choices* Report:

a) Recommendation 7 Page 67
The Minister for Health should facilitate the establishment of an inpatient specialist palliative care hospice providing publicly funded beds in the northern suburbs of Perth.

This Recommendation relates to Finding 10 of the End of Life Choices Report.

The Committee should disclose where this inpatient hospice is to be established, who will operate it, current expected completion cost, and progress to date on its completion.

b) In relation to paragraphs 3.40-3.42 and Finding 9 of the End of Life Choices Report

The Committee should discover and disclose any improvements or deterioration in service provision for each of the hospitals and health campuses noted in paragraph 3.41 and 3.42, and the costs incurred in obtaining improvements (if any).

c) Recommendation 8 Page 68
The Minister for Health should ensure that community palliative care providers, such as Silver Chain, are adequately funded to provide for growing demand.

This Recommendation relates to paragraphs 3.43-3.45 of the End of Life Choices Report which disclose that Silver Chain routinely delivers 50% more episodes of palliative care services than it is funded to deliver.

The Committee should discover and disclose whether there has been any increase in funding to Silver Chain for palliative care services, the size of any increase, and its effect on service delivery.

6 Funding for Palliative Care in WA

a) I note that

- Western Australia has the lowest number of publicly funded inpatient palliative care beds per head of population (Finding 17);
- In 2015-16 WA had the lowest rate of palliative care related public hospital admissions at 14.3 per 10,000 population (AIHW);
- In the same period WA had the highest rate of palliative care related private hospital admissions at 9.3 per 10,000 population, six times the rate in NSW (AIHW).

Why does WA have such low rates of publicly funded palliative care beds and palliative care public hospital admissions, yet such high rates of palliative care private hospital admissions?

What is the significance of these data?

b) I note that in 2015-16, 44.7% of palliative care related hospital admissions in WA were funded as public patients.

What is the impact on the private hospital sector of this arrangement?

c) The Committee may be aware that palliative care is funded differently depending on whether care is provided at acute hospitals or in aged care facilities: palliation in an aged care setting attracts substantially less funding then the same service provided in a hospital setting.

The Committee should promote more affordable and more equitable access to palliative care for all West Australians by seeking ways to equalise funding for the same services delivered often by the same medical professionals in different settings.

d) I note that

- Finding 19 of the Report is "*There is limited access to palliative care medical specialists in regional Western Australia*";
- Recommendation 13 of the Report is "*The Minister for Health should ensure regional palliative care be adequately funded to meet demand*".
- There are only 20 FTE palliative care specialists working in WA (Report 3.26) or ***less than 1 per 100,000 population***;
- Palliative Care Australia's 2018 *Service Development Guidelines* adopted a recommended ratio of ***2 palliative care specialists per 100,000 population***.
- Finding 21 of the Report is "*There are insufficient numbers of primary care workers providing palliative care in Western Australia*."
- Appendix 1 of the PCA 2018 *Service Development Guidelines* discloses the recommended ratios of nursing and allied health professionals to provide palliative care per 100,000 population.

The Committee should ask: when does the State Government expect West Australians to have equal access to the recommended levels of palliative care services?