Submission

to the

Inquiry into Palliative Care

to the

Joint Select Committee on Palliative Care in Western Australia

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1. Introduction

On 28 May 2020, a joint select committee of the Legislative Assembly and Legislative Council was established to inquire into palliative care in Western Australia.

FamilyVoice Australia is a national Christian advocacy group – promoting family values for the benefit of all Australians. Our vision is to see strong families at the heart of a healthy society: where marriage is honoured, human life is respected, families flourish, Australia's Christian heritage is valued, and fundamental freedoms are valued and enjoyed.

Submissions are due **10 July 2020**.

2. Terms of reference

The committee has the following terms of reference:

> *(1) That a joint select committee of the Legislative Assembly and Legislative Council into palliative care in Western Australia be established.*
>
> *(2) That the joint select committee inquire into and report on —*
>
> *(a) the progress in relation to palliative care, in particular implementation of recommendations of the Joint Select Committee into End of Life Choices;*
>
> *(b) the delivery of the services associated with palliative care funding announcements in 2019–2020;*
>
> *(c) the delivery of palliative care into regional and remote areas; and*
>
> *(d) the progress on ensuring greater equity of access to palliative care services between metropolitan and regional areas.*
>
> *(3) That the joint select committee consist of six members, of whom —*
>
> *(a) three will be members of the Assembly; and*
>
> *(b) three will be members of the Council.*
>
> *(4) That the standing orders of the Legislative Council relating to standing and select committees will be followed as far as they can be applied.*
>
> *(5) That the joint select committee report to both houses by 19 November 2020.*

3. Palliative care

Ageing population

The Royal Commission into Aged Care Quality and Safety has highlighted how significantly Australia's population will age over the coming years:

> *Australia's population is ageing. On average, we are living longer in greater numbers than ever before. Older Australians represent a steadily increasing proportion of our total population and we continue to have one of the longest life expectancies in the world. The proportion of people aged 65 years or over in the total population is projected to increase from 15% at 30 June 2017 to between 21% and 23% in 2066.*[1]

There will obviously be a corresponding increase in demand for the provision of palliative care, especially with an ageing population. This demand will be felt by government and private providers, both for institutional care (in hospitals, hospices, etc.) and for home-based care.

Exploring similar challenges interstate, a Victorian Auditor-General's report into palliative care found that:

> *palliative care in Victoria is delivered by skilled and dedicated staff who specialise in caring for people with a terminal illness. Indeed, Victoria has a strong palliative care sector and DHHS [the Department of Health & Human Services] has set a clear and ambitious agenda for what remains a relatively new area of health provision. However, a number of areas for further improvement remain.*
>
> *Demand for home-based care is increasing and some metropolitan community palliative care services have struggled to meet this demand, resulting in waiting lists to access services. This can place additional stress on patients and carers, and can mean that some people who have chosen to die at home cannot spend their last days there. DHHS has committed to better forecasting demand for services and to work with palliative care services to better understand how to support carer needs and respond to unmet demand.*
>
> *More also needs to be done to support carers and families. While there has been progress in some areas, improving respite provision and access to psychosocial support remain major priorities. Notably, 'support for carers' and 'engaging with the community' were two key priorities of DHHS's Strategic Directions that have not been met.*
>
> *Going forward, it is imperative that DHHS sets clear expectations for service delivery across the state and provides sufficient and appropriate funding to health services and community organisations.*[2]

Those are common sense findings which likewise deserve support in Western Australia. It is imperative that they be followed by practical support to meet growing demand.

Palliative care-related hospitalisations are increasing rapidly across the country, according to the Australian Institute of Health and Welfare:

> *Between 2011–12 and 2015–16 the number of palliative care-related hospitalisations increased by 28.2%, from about 57,600 to almost 74,000. The number of all hospitalisations increased by 14.6% over the same period. The population rate of palliative care-related hospitalisations trended upward from 25.6 to 30.8 per 10,000 population between 2011–12 and 2015–16.*[3]

However, Australia is under-provisioning palliative care services in homes when compared to other Western nations. This adds unnecessary pressure to health budgets and impedes patient and carer choice and comfort. In 2013 it was reported that just over half of Australians (54%) die in hospitals with the rest dying in residential aged care (32%) and their own homes (14%).[4] Home and other non-institutional deaths are about half as prevalent in Australia as they are in New Zealand, the United States, Ireland and France.[5]

Recommendation 1

In palliative care service provision, greater consideration should be given to home-based care and to the needs of carers and families.

Health literacy

The Australian Bureau of Statistics conducted an Adult Literacy and Life Skills Survey (2006) and found that 60 per cent of Australians have less than adequate levels of literacy and health literacy. The survey also found that only 6 per cent of the Australian population has 'high' health literacy levels.

What is health literacy?

> *Health literacy describes the ability of a person to understand essential health information that is required for them to successfully make use of all elements of the health system (preventive, diagnostic, curative and palliative services). Health literacy lies at the heart of a person being able to take control of their own health care through making informed health decisions, seeking appropriate and timely care and managing the processes of illness and wellness.*[6]

Recommendation 2

Increase public understanding of palliative care to ensure all patients have early and appropriate access, as access in early stages of a diagnosis may improve remaining quality of life, mood, resilience, symptom management and allow death in the patient's preferred location.

Cost savings

CEO of Hammond Care Dr Stephen Judd has estimated significant cost savings across Australia through funding more palliative care hospice beds, upskilling residential aged care staff to co-ordinate with palliative care specialists, and increasing appropriate palliative home care services.[7]

> *If we don't think about changing where we die – if we continue to predominantly die in hospitals – then, with the annual death rate in Australia projected to double to more than 300,000 in the next 40 years, we'll need the equivalent of an extra 9 New Royal Adelaide Hospitals, or 15 new Northern Beaches Hospitals in the next 40 years – JUST for people to die in...*
> *Opening the back door of a public hospital – and having palliative patients supported in a more suitable and less expensive environment – frees up resources for the front door. If 5% of annual deaths were in hospices/sub-acute hospitals rather than in acute hospitals (7,500) we would save $100m a year. What does that require? Fewer than 400 additional hospice beds nationally…*
> *If, we actually did [improve palliative care in nursing homes], the resulting net benefits from inappropriate hospital admissions would be about $27m per annum. More importantly, it enables people to die safely and well in familiar environments… If we focus on providing appropriate palliative home care services so that 28% of deaths occurred at home we can save about $175m per annum.*[8]

In 2016, compared to other states, Western Australia had the lowest ratio of palliative care doctors per capita. The state had 0.57 full-time-equivalent (FTE) palliative care specialists per 100,000 residents. This compared with others states' figures of QLD (0.9), Victoria (0.7), New South Wales (1 per 100,000) and South Australia (1.1)[9].

At that time, only the Northern Territory and the Australian Capital Territory with 1.9 specialists per 100,000 were near to Palliative Care Australia's benchmark of 2 per 100,000[10].

In October 2019, Premier Mark McGowan announced an increase in funding as part of an "end of life choices and palliative care services package" over a four year period of $41 million.[11] While the funding is an increase, it is still at least about $60 million shy of the $100 million needed as detailed by the Honourable Jim Chown speaking in support of his palliative care motion in the WA Parliament which was unanimously supported.[12,13] It is also not clear what amount of the $41 million package will be spent on euthanasia.

More recently, a landmark report by KPMG found that a significant investment in palliative care would deliver a net saving of about $100 million in national health care costs.

The report, titled *Investing to Save – The economics of increased investment in palliative care in Australia,* concluded that decades of reports and inquires have failed to mount the economic argument for broad reforms in palliative care.

> *Despite considerable reform over the past 30 years, palliative care has remained an optional extra rather than 'core business' within our health and aged care systems, which defaults to extending life, rather improving the quality of time we have left.* [14]

The report found that there are significant savings to be made in emergency visits, transport, length of hospitalisation and ICU care.

> *The majority of Australians die in hospital when most would prefer to spend more time at home. Talking about death can be difficult and seen as something to avoid.*
>
> *Government funded palliative care services are predominantly delivered over the last days and hours of life.* [15]

The recommendations in the report would save governments $460 million annually, if annual palliative care funding was boosted by $365 million. The social benefits of an improved quality of death are incalculable.

The report made a number of recommendations, including: boosting community- and home-based palliative care, expanding palliative care services in residential aged care and boosting early and integrated palliative care services in hospitals and the appointment of a national palliative care commissioner.

Critically, the report comments that "too many Australians with life-limiting conditions miss out on appropriate palliative care."

Dr Chris Schilling, KPMG Health Economist and report author, noted that:

> *Our report shows that increasing the provision of palliative care services not only improves health and social outcomes for people experiencing life-limiting conditions, but also helps to lower end-of-life costs to Government.*[16]

Recommendation 3

That Western Australian palliative care services receive proper funding to meet current and expected demand.

Recommendation 4

The Western Australian government work with other state and territory governments for the establishment of a national palliative care commissioner.

Provision of palliative and psychiatric care

The practice of euthanasia has been found to have serious flaws in terms of patients seeking access to palliative care or psychiatric treatment.

The radical step of ending or taking a life would surely be considered only after all other avenues have been explored – yet the Belgian experience shows this is not the case. Disturbingly, a majority of euthanased patients were not previously visited by a palliative care team.

Barely a fraction of euthanased patients received a visit from a palliative care specialist or a psychiatric consultation, as a 2015 Belgian study documents:

> *When analysing the latest data provided by the Belgian Federal Euthanasia Commission (years 2012–2013), we see that only 40 percent (1,283 out of 3,239) of the euthanized patients had a visit by a palliative care team, barely 12 percent (396 out of 3,239) had a visit by a palliative care specialist, and just 9 percent (307 out of 3,239) were consulted by a psychiatrist (Commission Fédérale de Contrôle et d'Évaluation de l'Euthanasie 2014). Thus almost 40 percent of the patients who received euthanasia did not see a palliative care specialist nor interacted with a palliative care team.* [17]

Given that pain and suffering are frequently-cited arguments in favour of euthanasia, it is concerning that experience shows euthanasia to be a first resort, rather than professional pain management. Likewise, considering the likelihood of depression and other mental health issues in such cases, it is alarming that appropriate care has been supplanted under a euthanasia regime.

It is entirely foreseeable that a similar situation could develop in Western Australia given the legalisation of euthanasia. This is especially the case with an ageing population creating greater demand for palliative care and other health services. It is appalling that the legalisation of euthanasia was given priority over rectifying the inadequate funding of palliative care in Western Australia.

Recommendation 5

Given the legalisation of euthanasia in Western Australia, rectifying the inadequacy of funding for palliative care should be made a priority.

4. Conclusion

There is considerable pressure on the health system and this is especially so when it comes to services such as palliative care. With demand set to soar over coming decades, it is vital that greater resources be planned for and allocated – and a better diversification of services be included. Good physical and mental health outcomes must be centred on a desire to uphold the dignity and worth of patients.

5. Endnotes

[1] "Navigating the Maze: An overview of Australia's Current Aged Care System", Royal Commission into Aged Care Quality & Safety, https://agedcare.royalcommission.gov.au/publications/Documents/background-paper-1.pdf

[2] Victorian Auditor-General's Report into Palliative Care, p. vii.

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[5] *Ibid*

[6] Health literacy, 7 February 2011, Australian Government Department of Health, https://www1.health.gov.au/internet/publications/publishing.nsf/Content/womens-health-policy-toc~womens-health-policy-key~womens-health-policy-key-literacy#:~:text=The%20Australian%20Bureau%20of%20Statistics,'high'%20health%20literacy%20levels.

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[8] *Ibid*

[9] *Palliative care workforce tables 2016*, Table Workbook 3, Australian Institute of Health and Welfare, https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/palliative-care-workforce

[10] "Palliative Care 2030 - Working towards the future of quality palliative care for all", p. vi, Palliative Care Australia, https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2019/02/Palliative-Care-2030-public.pdf

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[12] WA Parliament Hansard, 3 April 2019, https://www.parliament.wa.gov.au/Hansard/hansard.nsf/0/e8b52e22212cb3fb482583d3002b3412/$FILE/C40+S1+20190403+p1894e-1910a.pdf

[13] "WA: Assisted suicide rejected by palliative care specialists", FamilyVoice Australia, 8 July 2019, https://familyvoice.org.au/news/wa-assisted-suicide-rejected-by-palliative-care-specialists

[14] KPMG, "Investing to Save – The economics of increased investment in palliative care in Australia", May 2020, https://palliativecare.org.au/kpmg-palliativecare-economic-report

[15] *Ibid*

[16] KPMG, "Investing to Save – The economics of increased investment in palliative care in Australia", May 2020, https://palliativecare.org.au/kpmg-palliativecare-economic-report

[17] Tom Mortier, René Leiva, Raphael Cohen-Almagor & Willem Lemmens, *Between Palliative Care and Euthanasia*, Journal of Bioethical Inquiry, 22 April 2015.