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The Principal Research Officer
Select Committee on End of Life Choices
Legislative Assembly
Parliament House
PERTH WA 6000

By email: eolcc@parliament.wa.gov.au

Dear Dr Purdy

Inquiry into the need for laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices

Thank you for the opportunity to provide input into the Joint Select Committee's inquiry into the need for laws in Western Australia regarding end of life choices.

Avant is Australia's largest medical defence organisation, providing professional indemnity insurance and legal advice and assistance to more than 75,000 medical and allied health practitioners and students around Australia, including Western Australia.

In addition to assisting members in claims and complaints under our insurance policies, Avant has a medico-legal advisory service (MLAS) that provides support and advice to members when they encounter medico-legal issues. Our members have contacted us for advice about issues relating to end of life care and we have assisted our members in various matters in which end of life issues have been raised.

Avant's experience

Practitioners are often uncertain about their obligations when treating patients at the end of life. The calls we have received from our members include issues such as who is the appropriate substitute decision-maker when a patient lacks capacity and there are several family members, and how to proceed in the face of an advance directive where it conflicts with their clinical judgment, or where there is conflict.

Based on our experience of assisting members, the key concerns we have identified in this area are:

- Lack of understanding of medical practitioners about their legal obligations regarding advance care directives and substitute decision-making, including identifying who is the appropriate substitute decision-maker.
- Lack of consistency of the law across jurisdictions in Australia, leading to uncertainty and confusion.
- Difficulty dealing with situations where there is disagreement among or between family members, the patient and the treatment team about treatment options.

Practitioners worry about getting it wrong. In our experience, practitioners are often challenged by the implications of an advance care directive. Some practitioners can feel very uncomfortable about proceeding on the basis of a refusal of treatment. On the other hand, some practitioners express concern about providing increasing pain relief and sedation in the terminal phases of illnesses because of the concern that they may be subject to prosecution. The doctrine of double effect is often not well understood.

In light of this experience, our submission provides some general comments on three key areas relating to the end of life decision-making and the terms of reference of this inquiry:

1. National consistency.
2. Substitute decision-making.
3. Voluntary assisted dying.

1. National consistency in the legal framework

As a national organisation we support national consistency of approach in legislation and national consistency of terminology.

Each state and territory in Australia has a different legal framework for end of life decision-making. As a result there are different terms for similar concepts.

In the context of advance care planning, although advance care directives (ACDs) are used in all states and territories, the terminology, format, documentation requirements, the application of ACDs in practice and even the hierarchy of substitute decision-makers, differ markedly from state to state.[1]

In Western Australia, there are statutory ACDs ("advance health directives" under the *Guardianship and Administration Act* 1990) that have particular technical requirements, as well as common law ACDs.

Lack of consistency between states and territories and legal uncertainty impacts upon the ability of doctors to provide appropriate care at the end of life, and exposes doctors to medico-legal risk including criminal and civil claims and disciplinary or coronial proceedings. The intricacies and varied legal requirements across states and territories surrounding advance care directives and substitute decision-making cause confusion and have significant implications for doctors and patients.

In 2012, the Senate Community Affairs References Committee's report, *Palliative Care in Australia*, found that differences in state and territory legislation and complexities with advance care planning were hampering greater take-up. The Senate Committee recommended that "national model legislation for advanced care planning be developed, and that all governments pursue harmonisation of legislation as a high priority".[2]

[1] See Carter R, Detering K, Silvester W and Sutton E "Advance care planning in Australia: what does the law say" *Australian Health Review* 2016, 40, 405-414. See also QUT End of Life Law in Australia https://end-of-life.qut.edu.au/

[2] Senate Community Affairs References Committee. Palliative Care in Australia. 2012. See also Deeble Institute "Improving end-of-life care in Australia" Issues brief no. 19, 14 December 2016

Avant supports the development and use of consistent terminology across Australia as a matter of priority. We believe that the legislation around Australia that impacts on end of life choices should be harmonised.[3]

The legislative framework should be clear in its application and should facilitate appropriate end of life decision-making. The National Framework for Advance Care Directives (National Framework) released in 2011[4] and the Australian Commission on Safety and Quality in Health Care's National Consensus Statement: Essential elements for safe and high-quality end of life care are a useful start towards a nationally consistent approach to end of life care.

2. Substitute Decision-Making

Determining who is the appropriate substitute decision-maker for a patient who lacks capacity (in the absence of a valid advance care directive) is an important legal role that practitioners play in decision-making at the end of life.[5]

In our experience, the person responsible hierarchy and the provisions relating to making treatment decisions within the *Guardianship and Administration Act* 1990 are reasonably clear. However, a lack of knowledge among medical practitioners of the existence of the hierarchy and how it applies in practice reduces its effectiveness. Different definitions of decision-makers in other legislation can also cause confusion for practitioners, patients and their families.

There is also a lack of knowledge about the distinction between enduring powers of attorney and enduring powers of guardianship. Some practitioners are unsure of which instrument applies in a healthcare setting. We would support more education and information for those working within a healthcare setting about the application of both instruments, as well as the decision-making hierarchy within the *Guardianship and Administration Act* 1990.

In our experience many practitioners believe that a patient's next of kin or power of attorney is the appropriate substitute decision-maker for medical treatment decisions. "Next of kin" has no legal status at common law. However, "senior available next of kin" or "next of kin" is used in the *Human Tissue and Transplant Act* 1982.

Again, this differing terminology can lead many practitioners to believe that in general the next of kin has legal status and is the correct substitute decision-maker in all scenarios.

We recommend that all legislation that contains provisions regarding to substitute decision-makers use the same definitions and terminology.

[3] Avant Position Paper: *Advance care planning and end-of-life decisions making* 26 November 2015
[4] The Clinical, Technical and Ethical Principal Committee of the Australian Health Ministers' Advisory Council. A National Framework for Advance Care Directives. September 2011: 1-76
[5] White B et al. The legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment: Part 1 (New South Wales). *Journal of Law and Medicine* 2011; 18: 498-522

3. Voluntary Assisted Dying

While voluntary assisted dying (VAD) is not specifically referred to in the terms of reference, media reports suggest that VAD will be considered by the Committee. If VAD is under consideration during this inquiry, Avant makes the following points.

As a membership organisation, Avant recognises that our members hold a range of views on VAD. Because of this, we do not take a position on the substantive issue of whether or not VAD should or should not be permitted at law.

However we recommend that:

1. Any legislative framework for VAD must incorporate sufficient protections for those doctors who choose to participate, and those who choose not to participate.

2. Any legislation needs to provide a clear framework within which patients and doctors can operate.

    a. As a matter of general principle, legislation should balance the need for clear and unambiguous wording with the need to leave sufficient scope for the exercise of clinical judgment, consideration of the patient's individual circumstances and changing standards of medical practice.

    b. If legislation is too prescriptive, compliance will be difficult and may leave limited room for clinical judgment and increase medico-legal risk. Legislation that is too flexible may be open to interpretation and retrospective criticism.

3. The following protections should be included in the legislation:

    a. That a doctor is not required or compelled to comply with a patient's request, or to be involved in assisted dying at all.
    b. That a doctor should not face any criminal, civil, administrative or disciplinary action for refusing to participate, or for choosing to participate.
    c. That doctor is immune from criminal and civil liability, and disciplinary action for providing treatment that causes death if they have acted in accordance with the requirements of the legislation in good faith and without negligence.
    d. That this immunity be extended to a doctor being present when the patient takes the medication.

4. Any legislation should not include a prescriptive requirement for referral in the case of conscientious objection. Issues relating to conscientious objection and referral should be dealt with under current ethical guidelines.

If the Committee makes recommendations that VAD legislation be considered in Western Australia, Avant would welcome the opportunity to provide further comments on any proposed legislative scheme.

Additional matters

Avant believes appropriate and continued funding of end-of-life care, including supporting the process of advance care planning and palliative care services, will raise awareness of end-of-life choices, support high quality decision-making, improve patient outcomes and further contribute to a health care system that is person-centred.

We **attach** our position paper *Advance care planning and end-of-life decision making* which provides further information about issues under consideration by the Committee.

Please contact me on the details below if you require any further information or clarification of the matters raised in this submission.

Yours sincerely

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