



Australian Medical Association (WA)

**AMA (WA) Submission to
Joint Select Committee on
End of Life Choices**

AMA (WA) President's Statement

The Australian Medical Association (WA) welcomes the opportunity to provide its views on the need for laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices. The AMA (WA) is the State's peak medical representative body, and the only independent organisation acting on behalf of Western Australian doctors. We aim to better represent the medical profession to the government and to the community and advocate for the best interests of patients.

The AMA (WA) acknowledges that, within the medical profession and wider community, there is a need for open and frank discussion of death and dying including end of life options, approach to futile treatment, caring and bereavement. We support debate around end of life choices which addresses the broader societal issues with illness and death, including the adequacy of and gaps in palliative care, rather than focussing solely on the narrower topic of euthanasia. Any such debate should focus on the key issue of what is best for patients, learning from the experience of other jurisdictions that have had this debate or gone down this path, and understanding the reality of the end of life issues that face our community.

Our stance is consistent with the Federal AMA Position Statements on End of Life Care (2014)ⁱ and Euthanasia and Physician Assisted Suicide (2016)ⁱⁱ. The topic of euthanasia/assisted dying is a divisive one, including within the medical profession. The AMA believes that doctors should not be involved in interventions that have as their primary intention the ending of a person's life. However, decisions around the law are ultimately matters for our elected representatives and the community to determine. In the event of a Bill around assisted dying, the AMA (WA) strongly advocates for involvement of the medical profession in developing any legislation. We will ensure there are safeguards to protect vulnerable patients and those clinicians who choose to be involved.

Dr Omar Khorshid

President

Australian Medical Association (WA)

Assess the practices currently being utilised within the medical community to assist a person to exercise their preferences for the way they want to manage their end of life when experiencing chronic and/or terminal illnesses, including the role of palliative care

The primary role of the medical practitioner in end of life care is to facilitate the provision of good quality, patient-centred care that emphasises continuous, open, informed communication and collaboration between the patient, the health care team, and, where appropriate, the patient's carers, family members and/or substitute decision-maker.

Palliative Care

The demand for palliative care is growing, driven by an ageing population and a rise in the number of people living with chronic illnesses. Advances in medicine also mean that those with a life limiting illness are now living with the symptoms of their life limiting condition for longer. There is a strong, established evidence base for the benefits of palliative care in the end of life for patients, caregivers and the health system. Specialist palliative care physicians provide holistic care to the patient and their family, managing pain and other symptoms throughout the course of a life limiting illness and in the terminal phase. A significant proportion of palliative care is provided by General Practitioners, who may visit their longstanding patients at home, or within services such as Silver Chain. General Practitioners are key to end of life care in the residential aged care sector, such as nursing homes, which are increasingly centres for palliative care.

People receiving early specialist palliative care may have better quality of life, mood, coping ability, symptom management and death in the preferred place of choice. Effective delivery of palliative care can ease pressure on the acute hospital system and reduce the overall cost of care by increasing available bed numbers and limiting clinically futile treatments.ⁱⁱ

While evidence supports the value of palliative care, it is clear that more needs to be done to support individuals at the end of life. Although 68 per cent of Australians indicate a preference to die at home, only 14 per cent do so, with an increasing number dying in hospital (50 per cent) and residential care (30 per cent)ⁱⁱⁱ. Hospitalisation rates have increased in those over 85 years of age and patients in their last year of life experience an average of 3.5 admissions. In 2015/16, there were 2,811 deaths in Western Australia from conditions considered appropriate for palliative care.^{iv} Funding models that support a patient's regular GP in providing home visits would likely improve these figures. Additionally, 24-hour palliative care nursing services would provide support for patients in their own home at the end of life.

Equity of access to end of life care and other support services

As the need for end of life care continues to grow, existing services are under-resourced and unequally distributed. In particular, people in rural and remote areas, Aboriginal and Torres Strait Islanders and people from culturally and linguistically diverse (CALD) backgrounds experience inequitable provision of palliative care services. A major factor is the limited availability and distribution of the specialist palliative care workforce. Across Australia in 2012, specialist palliative medicine physicians made up 0.53% of medical specialists, 90% of whom worked mainly in major cities.^v

There should be equity of access to appropriate end of life care including respite care, palliative care, bereavement support, carers' support and other relevant services to patients at the end of life, their families and carers. The palliative care medicine workforce should align training numbers with workforce projections, including the expansion of aged care and chronic conditions. There also needs to be extended palliative care training to the rural generalist programme. Furthermore, better communication between hospitals and GPs could provide improved continuity of care, prevent hospitalisations for patients at the end of life, and decrease inappropriate treatments through sharing of advance care plans.

Practices and responsibilities of medical practitioners in end of life care

Medical practitioners have an ethical duty to care for patients so that death is allowed to occur in comfort and with dignity. All dying patients have the right to receive relief from pain and suffering, even where this may shorten their life. If a doctor acts in accordance with good medical practice, the following forms of management at the end of life do not constitute euthanasia or physician assisted suicide:^{vi}

- not initiating life-prolonging measures;
- not continuing life-prolonging measures;
- the administration of treatment or other action intended to relieve symptoms which may have a secondary consequence of hastening death.

A doctor responsible for the treatment or care of a patient in the final phase of a terminal illness is under no duty to use, or to continue to use, life sustaining measures which are of no medical benefit in treating the patient if the effect of doing so would be merely to prolong life. However, conversations and decisions around end of life remain difficult. We need greater emphasis on teaching training health professionals that a more balanced approach to death and dying is needed.

Consider what type of legislative change may be required, including an examination of any federal laws that may impact such legislation

The AMA (WA) believes that legislative change is not required in order to provide good end of life care, nor to achieve dignity in death. There are already have a number of practices and laws in WA to enable people to exercise choices at the end of life. Palliative care, paired with appropriate use of advanced care planning comprises quality, patient-centred end of life care to alleviate pain and suffering.

However, these are poorly understood and utilised both by the general community and health professionals. The reasons for this include, to name a few: under-resourcing of palliative care, inequitable access to palliative care based on diagnosis, location and other social-demographic factors; lack of education about advance care planning, AHDs and EPGs; and lack of appropriate GP remuneration for advance care planning.

Additionally, current ambiguity of legislation around end of life can lead to confusion and fear by doctors of being open to prosecution. This may in turn result in suboptimal symptom management or adherence to advanced care planning. Clarity and consistency of such legislation, in conjunction with focussed education of doctors and the public, would improve management of patients at the end of life.

The AMA (WA) supports nationally consistent legislation which holds that a doctor responsible for the treatment or care of a patient in the final phase of a terminal illness, or a person participating in the treatment or care of the patient under a medical practitioner's supervision, incurs no civil or criminal liability by administering or prescribing medical treatment with the intention of relieving pain or distress:

- a. With the consent of the patient or the patient's representative; and
- b. In good faith and without negligence; and
- c. In accordance with the proper professional standards;

Even though an incidental effect of the treatment may be to hasten the death of the patient^{tvii}

Legislation should support doctors and protect them from civil liability or criminal prosecution if:

- They have followed the terms in an Advance Health Directive (AHD) that they reasonably believed to be valid, in good faith, and without negligence;
- They provide life sustaining treatment to a patient in an emergency situation where there is significant uncertainty from the terms of the AHD whether it was intended to apply to the current circumstances and the SDM cannot be immediately contacted;
- They do not offer, refuse to provide, or choose to discontinue futile treatment in line with good medical practice.

Assisted Dying

As outlined earlier, the AMA does not support interventions whereby a doctor has as their primary intention to end a person's life. However, it believes that doctors must be involved in open conversations around and development of any legislation for physician assisted dying. The AMA (WA) will be holding a symposium in May 2018 to engage with its members on the issues of end of life and assisted dying, developing a set of recommendations around safeguards, eligibility, and training requirements for any such legislation.

There must also be consideration of the number of doctors who would realistically be involved in assisted dying, should it be introduced. In a 2016 survey^{viii} of our members, 62 percent stated they would not provide physician-assisted suicide were it to become lawful, while 25 percent believed that they would. However, experience in other jurisdictions indicates that in practice this figure is much lower. In Canada, where physician assisted dying has been introduced, approximately 1 per cent of doctors have taken up the practice.^{ix} This has major implications for access to doctors providing assisted dying, potentially increasing disparity of treatment for those in lower resourced settings.

Examine the role of Advanced Health Directives, Enduring Power of Attorney and Enduring Power of Guardianship laws and the implication for individuals covered by these instruments in any proposed legislation.

It is important that legislation surrounding decision-making responsibility is clear and straightforward, for all decisions towards the end of life.

Advanced Health Directives

An Advanced Health Directive (AHD) is a written document which formally records a person's plans for future healthcare in periods of impaired decision-making capacity.

The creation of Advanced Health Directives has added a degree of clarity when fulfilling the wishes of terminally ill patients, particularly when, in the context of the unclear and inadequate guardianship laws in Australia, they are unable or have difficulty in expressing their consent to treatment, or the withdrawal of that treatment.

It is important to recognise that AHDs are only one component of advance care planning and may be limited at times. For example, an AHD may be lost, unknown, invalid, the directions ambiguous, or not recognised by another jurisdiction. As such it is important for patients to take part in broader discussions to identify their wishes and preferences, communicate them with a range of people and record them in a variety of formats. AHDs should record values, life goals and preferred outcomes of care rather than medical interventions, which are best written by doctors in clinical care plans. There should be education of the public and clinicians on the use of advance care directives, their benefits and limitations.

Medical Enduring Power of Attorney and Enduring Power of Guardianship laws

A Medical Enduring Power of Attorney (EPA) is a legal document that gives another person authority to make health care decisions on behalf of a person who no longer has capacity.

There must be adequate training for medical professionals on all aspects of end of life care, including understanding the order of priority for substitute decision-makers (SDM) who can consent to or refuse, the commencement or continuation of any treatment on behalf of the patient.

There should be greater consistency in relation to legal recognition of ACDs. We need clear, consistent guidance for the preparation, notification and storage of ACDs as well as the procedures for identifying an appropriate SDM when there is no ACD or EPA. Furthermore, there needs to be a concerted effort in educating the community about AHDs and wider advanced care planning. This is a responsibility not only for medical professionals.

Implication in any proposed legislation

In the event that legislation is passed introducing assisted dying, the process should be initiated by the person themselves. Requests should not be initiated by others, including family and carers. A person's decision-making capacity in relation to assisted dying must be assessed. AHDs should not be involved in the process.

ⁱ AMA. Position Statement on End of Life Care and Advance Care Planning. 2014.

ⁱⁱ Australian Institute of Health and Welfare. Trends in Palliative Care in Australian hospitals. 2011.

ⁱⁱⁱ Palliative Care Australia. We need to talk about dying – survey. 2011.

^{iv} Government of Western Australia. ICD10 codes and separation due to death. 2017.

^v Australian Institute of Health and Welfare. Palliative Care Services in Australia 2014. 2014.

^{vi} AMA. Position Statement on Euthanasia and Physician Assisted Suicide. 2016.

^{vii} AMA. Survey to members on End of Life Care. 2016.

^{viii} <http://www.cbc.ca/news/canada/montreal/quebec-medical-assisted-dying-euthanasia-quebec-1.3452366>



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