



Australian Medical Association (WA)

Statement on End-of-Life Choices and Palliative Care

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Foreword

It is evident that end-of-life care in Western Australia cannot continue with the status quo. It is also clear that improving the care and experiences of patients at the end of life extends far beyond the narrow scope of a euthanasia debate.

The issues of end-of-life care and assisted dying are currently at the centre of debate in Australia. Voluntary Assisted Dying (VAD) will be legalised in Victoria from mid-2019, while the NSW Bill was narrowly defeated in late 2017. In Western Australia, a Joint Select Committee was established in August 2017 to inquire and report on the need for laws in our State to allow citizens to make informed decisions regarding their own end of life choices.

There are varying opinions on assisted dying among medical professionals, as in the wider community. The AMA (WA) supports dialogue around these issues, which address the broader societal concerns with illness and death, including the adequacy and gaps in palliative care.

To that end, the AMA (WA) held the End-of-Life Symposium, which aimed to:

- Understand more about the current state of end of life care in WA;
- Learn from the experiences of jurisdictions in Australia and overseas;
- Develop a set of recommendations in the event of proposed VAD legislation in WA; and
- Give members an opportunity to shape AMA (WA) advocacy

At the symposium, there was extensive discussion of the shortcomings and potential for improvement in the way palliative care is delivered in WA. AMA (WA) members also addressed the issues of Physician Assisted Suicide (PAS) and euthanasia, in an open and respectful forum.

As well as drawing on research and interviews from Australia and internationally, this statement is a result of discussions at the End-of-Life Symposium, which were voted on by the audience of over 150 AMA (WA) members. After being developed further, these statements were approved by AMA (WA) Council and subsequently presented to the WA Parliamentary Joint Select Committee on End-of-Life Choices.

The directions in this document are consistent with the Federal AMA Position Statement on Euthanasia and Physician Assisted Suicide (2016) and are not intended to supersede this policy. Rather the AMA (WA) wished to develop tangible, concrete recommendations for end-of-life care in Western Australia, both in the presence or absence of legislative change.

Current End-of-Life and Palliative Care

Community support for Voluntary Assisted Dying (VAD) stems largely from a negative perception of death and current end-of-life care: lack of autonomy, unbearable suffering, and unnecessary or unwanted medical interventions. The medical profession has undoubtedly played a role in this perception - for example, through a reluctance to accept death as an inevitability.

While resourcing and investment in services is certainly key to improving end-of-life care, there needs to be a focus on building capacity across the whole health system. This will involve education of both our health workforce and the public; integration of care between primary, community and hospital sectors; and better access to patient information.

The AMA (WA) sets out the following recommendations to improve palliative and end-of-life care within the current legislative framework:

1. There must be greater education in palliative care for all medical practitioners and healthcare workers

There should be better **training** and **education** for **doctors of all specialties** in **principles of palliative care**, conversations around end-of-life, and addressing broader psychosocial issues.

This should also involve improving awareness around what is required, in terms of **resourcing** and **collaboration** with other services, to **deliver** effective palliative care.

Specific strategies could include:

- Modules on end-of-life care, Advance Health Directives and negotiating 'the blue form' as part of the mandatory modules completed each year in public hospitals
- Training of ambulance services around alternatives to hospital for palliative patients, where appropriate and in discussion with the medical team

Patients and families are often focussed on treatment or cure, making conversations around palliative care or resuscitation difficult to initiate. The importance of **communication skills** cannot be overstated and should be instilled in medical student and junior doctor training – both through shadowing senior clinicians and formal teaching.

The needs of patients at the end of life or with a chronic, debilitating condition often extend beyond the physical and into existential or psychosocial suffering. This expertise lies outside of the medical profession. Therefore, we need consideration of how **multidisciplinary teams** can be best composed to help manage patients' needs.

2. Palliative care needs to be cemented in models of care, not confined to the end of life

Palliative care being should be available and discussed from the time of diagnosis with a terminal or debilitating condition. With improved education and training across medical specialties, symptomatic relief and broader psychosocial issues will be discussed early with the patient and family.

In cases of frailty and end stage disease, the answer lies in early **Advance Care Planning** through early Family Conference.

Goals of care discussions should be had as early as possible and potentially integrated into the hospital admission process.

3. The AMA (WA) advocates for a more holistic, integrated funding model that values end of life care, including Advance Health Directives, and consultative liaison services.

There must be recognition of the communication required between doctors and patients receiving palliative care. This should be reflected in the MBS schedule, for example with a specific item for Advance Health Directive completion and Advance Care Planning as part of an over 75 health check. Currently there is a lack of recognition of the time required to effectively communicate and engage with a patient, particularly for GPs.

4. Communication and integration between hospital, community and GP sectors is required to improve patient outcomes and achieve more effective care

Fragmentation of care is a major issue between General Practice, tertiary, secondary and community care, with families often left to navigate the complex interface. **Coordination of specialities and providers** involved in end of life care, such as GP, Geriatrics, Palliative Care, Psychiatry, NGO support agencies, is required.

Clinical leadership will be essential to improve collaboration between specialties and providers. Additionally, this will require **enablers** such as **IT infrastructure**, such as shared digital patient records, or a centralised AHD register.

This may also involve **realignment of funding** and **administrative processes** – for example, additional funding and support for GPs providing palliative care.

5. The role of Advance Care Planning needs to be better understood by the medical profession and wider community

It is widely acknowledged that current uptake of Advance Care Planning (ACP) and Advance Health Directives (AHD) is suboptimal.

There should be concerted efforts to inform the public about ACP: both formal AHDs and encouraging discussions about end-of-life issues. This could include a national or state media campaign, distribution of information leaflets at GP practices and hospitals, and community engagement events.

Adherence to AHDs is also variable. The reasons for this are complex, but include:

- Miscommunication between health providers or unavailability of an AHD upon presentation or admission,
- Diverging wishes and understanding on behalf of family or carers,
- Fear of litigation on the behalf of medical staff, and
- Misunderstanding of the AHD itself by the treating team

Other than greater awareness and education, potential strategies to improve uptake of and adherence to AHDs include:

- Delivering care that contravenes a patient's AHD to become a reportable clinical incident
 - Embedding AHDs into routine practice, such as discussions in General Practice and inquiry about Goals of Care/AHDs as part of the admission process to hospital
 - Availability of AHDs via a centralised register
6. There should be training for doctors to improve their understanding of medico-legal issues

Awareness and understanding of medico-legal issues by doctors varies across the profession.

Fear of sanction or litigation for not treating has been identified as a factor driving poor clinical decision-making. Increasing understanding of and confidence in medico-legal issues would not only better protect doctors, but would also improve care in the frail, elderly or chronically ill.

7. Any legislation to introduce assisted dying needs to be coupled with improved resources and training in palliative care.

It is widely recognised that access to timely, good quality end of life and palliative care varies throughout Australia, particularly in rural and remote areas, for Indigenous groups and CALD populations.

For diagnoses other than cancer, awareness of the role of palliative care and access to these services is limited. We must ensure that no individual requests VAD simply because they are unable to access this care.

Voluntary Assisted Dying

The AMA (WA) endorses the Federal AMA Position Statement on Euthanasia and Physician Assisted Suicide (2016) - that **doctors should not be involved in interventions that have as their primary intention the ending of a person's life**. This Position Statement also recognises the divergence of opinions within the medical profession and the broader community on these issues, and that legislative change around assisted dying is ultimately a matter for society and government.

It is apparent from the experiences of overseas jurisdictions that it is critical to involve the medical profession in any legislative process. Evidence from the Netherlands over its 20 years' experience of euthanasia must also be evaluated in the consideration of any future legislation to safeguard the integrity of our health system and society.

As well as enabling a service to be introduced, legislation sends a message to society. We must ensure that this message is the right one: focussed on autonomy and compassion for those with terminal and debilitating illnesses, and not that suicide is the logical solution to suffering, or for people in society who do not feel valued.

While our position on VAD is unchanged, the AMA (WA) acknowledges that legislative change around end-of-life choices is possible in the near future. Should there be consideration of VAD by WA Parliament, the AMA (WA) urges that the medical profession is involved in the development of relevant legislation, guidelines and regulations to protect:

- All doctors acting within the law
- Vulnerable patients – such as those who may be coerced or be susceptible to undue influence, or those who may consider themselves to be a burden
- Patients and doctors who do not want to participate; and
- The functioning of the health system as a whole

The following set of recommendations arose through the AMA (WA) End-of-Life Symposium, discussions with members, consulting local and overseas experts, and extensive research around the topic.

The AMA (WA) sets out the following directions **in the event that VAD is introduced in WA**:

1. The AMA (WA) supports its members regardless of their position on assisted dying

In the event of legislative change to introduce physician-assisted dying, the AMA (WA) will protect the rights of doctors not to be involved and support those doctors who choose to become providers.

2. There must be wide consultation and engagement in the development of legislation

One of the key lessons from the Canadian experience of assisted dying enactment was that wording and consequent interpretation of legislation is critical.

The AMA (WA) strongly urges **consultation** with experts within the medical profession in the development of legislation.

It is also essential to **engage more widely**, including with Indigenous communities and Culturally and Linguistically Diverse (CALD) populations.

Furthermore, the AMA (WA) proposes that there be education for the wider community on the impact such legislation has on the medical profession. This is a seismic shift in the attitude held by the medical profession for thousands of years and should not be underestimated. Such discussions should be had frankly and openly to increase public awareness.

3. Infrastructure and processes must be prepared before introduction of assisted dying

If VAD is introduced, **patient care pathways** must be established and clearly identified, for example: where no doctor is available, such as in rural locations or in faith-based institutions, or where a patient's doctor does not provide assisted dying.

Post-death processes would need to be clear, consistent and established prior to implementation. For example, the completion of death certificates:

- We suggest that *cause* of death would be the underlying condition for which a patient has sought assisted dying,
- The *manner* of death would then be VAD.

While not specified in legislation, there must be careful consideration of the **medication** to be used. The method of **dispensing and regulation** must also be established: for example, where drugs are prescribed and dispensed for self-administration, there must be safeguards in place to ensure that unused drugs (in cases where a patient dies of natural causes before using) do not fall into the wrong hands.

There needs to be a process and framework that is clear and provides sufficient **medico-legal protection** for doctors providing assisted dying. The impact of assisted dying on **patients' insurance** also needs to be clarified.

A high-quality assessment service and robust oversight process needs to be resourced and funded for the sufficient time and skill required for VAD. There would need to be commitment from the WA State government to adequately resourcing the service. A model of **funding and reimbursement** would need to be established to adequately reimburse doctors for the sacrifice to personal and professional commitments.

4. There should be specific mandatory training for physicians who opt in to provide VAD

If VAD were introduced, the AMA (WA) advocates for an **opt-in system** for any doctors electing to provide it. Only doctors who have agreed to be involved in VAD and have been certified under the legislation in medical aid in dying may exercise any medical role under the legislation.

There must be **training** on the legal, clinical and psychological aspects of VAD.

Physicians opting-in must be **appropriately qualified** to train as providers, for example 5 years post vocational registration.

Providers would then be **accredited** in VAD, which would need **oversight and governance** by a clinical regulation body.

The Victorian legislation is unique in requiring a **permit** to be issued by the Department of Health and Human Services before a case of VAD can be activated. The Victorian Ministerial Advisory Panel considered such a system would provide an opportunity for an independent check that the process had been complied with. This may also be considered by WA Health in the event of assisted dying being introduced.

It is also essential that, as well as professional training, **support structures** are in place for doctors involved in VAD. The psychological burden of providing VAD may be significant, and there must be professional support available for these doctors.

There must also be additional education of medical students and junior doctors around end of life and legislative issues if VAD were enacted in WA, as this represents a significant shift in the current ethical principles and curriculum taught to training doctors.

5. Doctors must not be compelled to provide or refer voluntary assisted dying

No medical practitioner should be obliged to refer a patient to a doctor certified under future VAD legislation.

However, in response to a query about VAD, we suggest that a doctor would need to provide information – such as a link to any website established by or on behalf of WA Health along the lines of the Victorian website:

<https://www.betterhealth.vic.gov.au/health/servicesandsupport/voluntary-assisted-dying>.

While the rights of doctors must be protected, lack of information should not be a reason for failure to access VAD.

An alternative option could be a centralised ‘transfer of care’ service for conscientious objectors.

6. AMA (WA) would advocate for a restrictive model of VAD should it be introduced: including a time proximity requirement and having high bar for assessment of competency

Any future VAD model in WA should include strict eligibility criteria and safeguards, as in the Victorian legislation and in Oregon. Eligibility criteria would need to include **all** the following:

- **Age** 18 or over.
- **Capacity** Legally capable of making decisions¹
- **Condition** A grievous and irremediable medical condition, where all the following are present:
 - The illness, disease or disability is serious, progressive and incurable
 - The patient is in an advanced state of irreversible decline
 - Natural death² due to the condition has become reasonably predictable, i.e.:

¹ See point 14: Assessment of capacity

² A *natural death* is one due to natural causes, i.e. not a *reportable death* under the *Coroners Act 1996*. A natural death is not defined under that Act, and certainly wouldn't require defining for the purpose of VAD legislation. From the doctor's perspective, it is a death that, should it come to pass, would present no impediment to the completion of a medical

- **Except for neurodegenerative disorders, prognosis must be under six months**
- The patient is enduring physical and/or psychological suffering that cannot be relieved under conditions acceptable to the patient.
- **Assessment** as to fulfilment of the above and other criteria has been carried out by two independent medical practitioners certified under the legislation in VAD.

7. Assessment of capacity and competence are key issues that need to be addressed in any legislation

The medical profession is not necessarily best placed to assess capacity. The reality and nuance of consent may be overlooked, particularly when issues around autonomy and psychosocial concerns are at play. It is important to consider capacity in context: the decisions made by someone experiencing suffering are by nature affected by that emotional experience. When we know this, and we know that suffering fluctuates depending on a multitude of factors, it is difficult to be sure that patients' decisions regarding VAD are consistent.

To account for fluctuation in wishes and ensure permanence of decision making, the AMA (WA) would propose a longer '**cooling off**' period between the first request and administration of VAD, where possible.

In the assessment of decision-making capacity, each of the two independent medical practitioners must separately assess and document the capability of a patient requesting access to VAD to comprehend the nature of the request, to understand the consequences if it is granted, and whether the decision to request VAD is an adequately informed one.

There may also be refractory mental health conditions at the end of life, including for patients who suffer mental health conditions that have not responded to treatment. This group may be particularly vulnerable in their end of life care. The AMA (WA) proposes that there be **exclusion of major psychiatric illness** for anyone requesting VAD. The patient must not be suffering from untreated major depression, anxiety or psychosis, and this must be confirmed in writing by a psychiatrist.

In the cases where capacity is in question, this could be determined by a third, objective party such as a tribunal. The pros and cons of such a system need to be considered: while this would be more objective, the added layers of bureaucracy could add unnecessary strain on the patient and family.

8. Where possible, assisted dying should be self-administered rather than euthanasia

Consistent with the notion of patient autonomy which has been central to the VAD debate, the method of self-administration would be preferred over voluntary euthanasia. This would also take some onus away from doctors involved in VAD.

certificate of cause of death. Authority: WHO Department of Health Statistics and Information Systems. See slide 7, https://unstats.un.org/unsd/demographic/meetings/wshops/Turkey/2015/docs/Presentations/Session8-Medical-certification_dmf.pdf.

The Victorian *Voluntary Assisted Dying Act 2017* permits injection by the doctor, but only where the patient is physically incapable of the self-administration or digestion of a lethal dose of oral medication (section 48(3)(a)).

The AMA (WA) contends that doctors do not necessarily need to be involved in the administration of lethal medication: where self-administration is not possible, another party could also be involved in this process.

9. There needs to be palliative care assessment as well as assessment of capacity for any patient requesting assisted dying

One of the key concerns around assisted dying is ensuring that in the future, decision makers do not view Euthanasia as more cost effective or 'more compassionate' than adequate provision of palliative care services.

Palliative care will continue to serve well most patients with terminal conditions, and VAD must never be discussed with a patient without proper consideration of palliative care and other management options. A doctor should never direct a patient towards VAD.

If legislated in WA, all patients requesting VAD must be assessed for their palliative care needs and the adequacy of any current management as part of the process.

10. Western Australia should closely monitor and evaluate data from cases of Voluntary Assisted Dying

Data will be essential for the evaluation of VAD, including monitoring trends and auditing practice. Methods and a system for robust data collection must be established prior to any assisted dying being implemented.

Accountability of medical practitioners will also be essential to maintaining public confidence in the operation of the legislation, and in refuting unfounded accusations of patients being pressured by doctors or others.

Each assisted death must be reported to a statutory authority to be appropriately reviewed, with all relevant documentation being retained and available for medical auditing purposes.



WESTERN AUSTRALIA

