AMA Victoria's submission to:

Simplifying medical treatment decision making and advance care planning

(a position paper on a proposed *Medical Treatment Planning and Decisions Act*).

22 July 2016

INTRODUCTION.

The Australian Medical Association (Victoria) Ltd is the peak body representing doctors in Victoria. AMA Victoria and its members are committed to improving health services and the health of all Victorians.

AMA Victoria is pleased to make this submission in response to the position paper on *Simplifying medical treatment decision making and advance care planning* for which the Victorian State Government and the Victorian Department of Health and Human Services are currently seeking consultative feedback.

BACKGROUND TO AMA VICTORIA'S RESPONSE.

Much of this submission response re-states or is based upon established positions that have been previously been adopted by AMA Victoria and endorsed by the AMA Victoria Board in relation to previous policy development work by AMA Victoria.

In June 2011, Australian Medical Association (AMA) Victoria made a submission to the Victorian Law Reform Commission (VLRC) Review of Guardianship and Administration Laws in Victoria. AMA Victoria also gave direct oral evidence to the Commission and participated in a VLRC Working Group. AMA Victoria particularly supported the Commission's proposal that Victoria's various substitute decision-making laws be consolidated into one single Act.

AMA Victoria subsequently supported the Victorian Law Reform Commission's final report on Guardianship tabled to the Parliament in 2012. In this report, the VLRC recommended binding instructional health directives, with a number of protections and exemptions in place.

In 2013 AMAV hosted their Round Tables on Advance Care Planning, chaired by Professor Richard Larkins. The Round Tables were attended by many expert stakeholders from a range of sectors including aged and community care, emergency responders and the legal and medical professions. The objectives of the Round Table series were to identify an ideal model in Victoria for Advance Care Planning, and to further shape AMA Victoria's priorities in Advance Care Planning policy.

In 2015 AMA Victoria made a submission in response to Victoria's end of life care framework discussion paper, *Greater say for Victorians - Improving end of life care*. In this submission, AMA Victoria put as its first recommendation,

> *AMA Victoria Recommendation 1*
> *The enactment of legislation that reflects the VLRC's 2012 recommendations on instructional health care directives. We also seek clarification from the Victorian Government on the term "medical conditions" (as referenced in the discussion paper) and how this is to be defined in legislation.*

RESPONSE TO THE POSITION PAPER AND OUTLINE OF THE PROPOSED BILL.

The following is AMA Victoria's response to the Victorian Government's proposed positions on the legislation to be introduced by the prospective bill.

Response to Summary of Key Changes as put in Table 1.

Available legal instruments to make binding treatment decisions.

Advance care directive – with which a person may refuse or consent to treatment for current and future conditions and outline their values.

AMA Victoria supports this proposed position subject to the conditions that qualify the meaning given to "binding" as follows:

1. The binding nature of advance care directives

1.1 An advance care directive should be binding on health professionals if:

(a) it is valid; and
(b) the directive operates in the circumstances that have arisen.

1.2 An advance care directive does not operate if the maker would not have intended it to apply in the circumstances that have arisen. This occurs if one of the following applies:

(a) circumstances, including advances in medical science, have changed since the completion of the advance care directive to the extent that the maker, if they had known of the change in circumstances, would have considered that the terms of the advance care directive are inappropriate;

(b) the meaning of the advance care directive is uncertain; or
(c) there is persuasive evidence to suggest that the advance care directive is based on incorrect information or assumptions.

2. Emergency treatment

If emergency treatment is required and the health professional is aware of an advance care directive but does not have time to determine if it is valid or if a provision in the advance care directive is operative, and the health professional believes on reasonable grounds that one of the following applies:

(a) circumstances, including advances in medical science, have changed since the completion of the advance care directive to the extent that the maker, if they had known of the change in circumstances, would have considered the terms of the advance care directive inappropriate;

(b) the terms of the advance care directive are uncertain; or

(c) there is persuasive evidence to suggest that the advance care directive is based on incorrect information or assumptions

then the health professional does not incur any liability, either to the maker or anyone else, if the health professional does not act according to the advance care directive.

Substitute decision-makers.

A person may appoint a medical treatment decision maker and the tribunal may appoint a guardian. If no one has been appointed, a medical treatment decision-maker may be recognised. Each form of medical treatment decision maker will have the same powers.

AMA Victoria supports the broad proposal for people to appoint a medical treatment decision maker.

The position paper implies in the table of proposed positions, that in the absence of medical decision maker appointed by the person, the Victorian Civil and Administrative Tribunal would appoint a Guardian. Further, in the absence of either of these, and, if a person has not given a relevant instructional directive, the health practitioner would be required to identify as medical treatment decision-maker to consent or refuse treatment.

The position paper also outlines a proposal for capacity to be assessed.

Clarification is required as to how the consolidated framework for alternative medical treatment decision makers will work in relation to the existing legislation, particularly the Guardianship and Administration Act 1986 and the Powers of Attorney Act 2014, including substitute terminology for the purposes of consistency and avoidance of confusion. In order to gain this clarity as to the proposed legislative arrangements. AMA Victoria recommends that exposure draft legislation is put to Victorian community for consultation as soon as practicable.

It is also noted that the proposed Medical Treatment Planning and Decisions Act would provide a hierarchy for determining who the medical treatment decision-maker is in the absence of a relevant “instructional directive” (i.e. a sub category of the two types of advance care directive proposed, the other being a “values directive”).

AMA Victoria cautions codifying the suggested hierarchy into legislation, and that, instead, this hierarchy be only be applied as a guide. The diversity of human relationships and social circumstance, including the negative influences of relationship breakdown, family violence and elder abuse, generates a large margin for variation as to how such a hierarchy might apply practically and safely to all individuals across our population.

Considerations for making substitute decisions.

The proposed Act will contain a single test for all medical treatment decisions and medical research procedure decisions – that the decision is consistent with the person’s preferences, values and rights.

AMA Victoria supports a clear and well understood test for decision-making capacity, and recognises that codifying the criteria outlined on page 10 into legislation will require a supportive implementation strategy to educate health, social and legal and allied professions form these groups to be thoroughly and consistently familiar with these criteria.

Clarification is required as to how different capacity testing for alternative medical treatment decision making will be brought into alignment with capacity testing for other matters such as where or how a person should live such - as may also be in scope for other decisions made by an appointed Guardian.

Supported decision making.

The proposed Act will provide that a person should be presumed to have capacity and recognise that they should be supported to make their own decisions. The Act will also provide for the appointment of a support person.

AMA Victoria supports the intent of the proposed Act to uphold people's rights by assuming capacity and assessing decision capacity for each decision.

Given the recency of the Enduring Powers of Attorney Act (2014), and its provision for Supportive Attorney Appointments, it would seem practical to consider legislative alignment. In practical terms, significant-others often execute this role when attending health appointments and consultations. However, social welfare and community health workers also may perform this role as "health advocates" for their clients. It should be noted that Section 91 of the Enduring Powers of Attorney Act precludes a care worker, a health provider or an accommodation provider from being eligible to be appointed as a Supportive Attorney. For the purposes of medical decision-making, the legal standing of social welfare and community health workers, when they "*assist the person to make their own decisions by having access to medical records (if relevant, communicating on behalf of the persons and advocating for them*" therefore needs to be clarified.

The status of an expression of values.

As part of their advance care directive, a person will be able to complete a values directive. Health practitioners and medical treatment decision makers will be required to give effect to a values directive.

AMA Victoria notes that an advance care directive is proposed to take two forms, an instructive health directive and a values directive. Given that much of the intent of reform has been to establish the ability to enable Victorians to made decisions about their future medical treatment for both existing and future conditions, a values directive would provide an approach to guiding whether a person may or may not wish to pursue a treatment – whether this was a treatment as yet unknown for an existing condition at the time they documented their directive or for a condition that they did not presume themselves to have at the time of their documenting the directive.

It is noted that the position paper that medical treatment decision maker and health practitioners will be required to give effect to a values directive as far as reasonably possible when making treatment decisions. Caution needs to be prevail when the concept of a values directive is considered in its practical application for the fundamental issue of being able to interpret and apply any documented "views and values" in a given set of presenting health circumstances. The Victorian Government may need to consider how people will be assisted to practically formulate and document directives in a way which may assist people to coherently express their values and not create potential legal minefields. If for example, a person requests no treatment be given which has involved any animals in prior research development of the treatment – could this be taken to preclude all medical treatment? Would the person have been fully informed as to the extent of treatments that they might be excluding themselves from?

Legal obligations of providers.

The proposed Act will apply to all practitioners registered under the Health Practitioner Regulation National Law and paramedics. Non-compliance may constitute unprofessional conduct.

AMA Victoria supports this proposed position subject to the conditions that limit a finding of non-compliance. AMA Victoria proposes that the following conditions are to operate as to provide a protection for health professionals.

> **3. Protection for health professionals for non-compliance with an advance care directive**
>
> 3.1 A health professional is not affected by an advance care directive to the extent that the health professional, acting in good faith, does not have actual knowledge that the person has an advance care directive.
>
> 3.2 A health professional who acts in reliance on an advance care directive in good faith and without actual knowledge that the advance care directive is invalid or cancelled does not incur any liability to the maker or anyone else because of the invalidity or cancellation.
>
> 3.3 A health professional must take reasonable steps to determine if a patient has made an advance care directive and to obtain a copy of and read it before deciding on what treatment (if any) the patient is to be offered.
>
> 3.4 A health professional who fails to take reasonable steps to determine if a patient has made an advance care directive and provides treatment that is inconsistent with the advance care directive will not be protected from liability by the provision providing protection for a lack of actual knowledge in clause 3.1 above.
>
> 3.5 A health professional is not required to check on the existence of an advance care directive if emergency treatment is required.

AMA Victoria also proposes that protections are also assured for compliance in addition to non-compliance to operate as follows:

> **4. Protection for health professionals for compliance with an advance care directive**
>
> (1) A registered health professional or a person acting under the direction of a registered health professional who, in good faith and in reliance on a refusal of treatment certificate or an advance care directive, refuses to perform or continue medical treatment which he or she believes on reasonable grounds has been refused in accordance with the Act or is inconsistent with the advance care directive is not -
>
> (a) guilty of misconduct or infamous misconduct in a professional respect; or
> (b) guilty of an offence; or
> (c) liable in any civil proceedings-

Other responses to the Position Paper and Proposed Bill.

Non viable treatment or support.

It is foreseeable that the broader community response will be positive to laws that will provide Victorians with further and more robust avenues to avoid unnecessary suffering or futile

existence – to provide an assurity of preventing resuscitative attempts that might leave them in a vegetative state and/or distressing and painful state. However, it needs to be borne in mind that the bill will provide people with equally robust means to direct the treatments that they may wish to avail themselves of. This position was anticipated by the Victorian Law Commission's Report to the Victorian Parliament in 2012[1] who in Chapter 11 noted that,

> *an instructional health care directive not be used to demand particular medical interventions or treatment. The Commission agrees with the principle expressed in the National Framework for Advance Care Directives that 'health care professionals are not required to offer treatment that they consider neither medically beneficial nor clinically appropriate'… New guardianship legislation should include this limitation on the use of an instructional health care directive.* (p. 224 ibid).

Accordingly the Victorian Law Reform Commission made its recommendation, Recommendation No. 140 that,

> *The principal should be able to provide advance consent to treatment as well as advance refusal. However, a principal cannot demand treatment that is not offered.* (p. 224 ibid).

Medical treatment.
It should be noted that the position paper and the proposed bill refer to "Medical Treatment". With regard to those registered health professionals who are in scope of the proposed legislation, the bill may need to be clear about "Medical Treatment" as distinct from treatments that could be available through alternative health paradigms. This may be particularly important when people request a given treatment as part of their instructive health directive.

Organ and tissue donation.
AMA Victoria's response to the position paper remains consistent with the recommendation put by AMA Victoria in 2015 in its submission to Victoria's *End of Life Care Framework Discussion Paper*.

Victorian legislation is required to enable an individual to detail their wishes about organ and tissue donation in an advance care plan.

Provisions similar to those contained in Queensland legislation are worthy of consideration. Section 35 of the Powers of Attorney Act 1998 (Qld) allows an adult to give directions for his or her future health care in an advance health directive in relation to health matters and special health matters. Pursuant to schedule 2, sections 6 and 7, of that Act, by completing an advance health directive, an adult may authorise the removal of their tissue while alive for donation to someone else. The Transplantation and Anatomy Act 1979 (Qld) (section 22) governs the situation after the principal has died.

[1] Victorian Law Reform Commission (2012). Report 24 GUARDIANSHIP

By allowing Victorians to incorporate their wish to donate their organs or tissue in an advance care plan, individuals could clearly indicate whether they wished to donate and in doing so could effectively demonstrate his or her informed consent. This would also provide clear evidence of an individual's wish to donate to that person's family.

This wish might be able to be incorporated into the proposed *values directive*. This would lend greater flexibility to health care institutions in not being unduly compelled to attempt organ or tissue transfer if they were not viable at the time of the person's being in a fully terminal and moribund state.