AMA Victoria’s response to Victoria’s end of life care framework discussion paper.

18 December 2015

The Australian Medical Association (Victoria)

AMA Victoria welcomes the opportunity to respond to the framework for end of life care discussion paper.

Our submission identifies four key areas for change:

- Legislation
- Infrastructure and services
- Workforce
- Community information and awareness.

In this submission, the terms advance care plan, instructional health directive and advance health directive are interchangeable.

Area 1: Legislation

End of life care has legal implications for medical practitioners, other healthcare workers, and a patient's carer(s) and family.

Binding advance care directives

The discussion paper references "legally binding decisions". In 2012, AMA Victoria supported the Victorian Law Reform Commission's final report[1] into the Administrative and Guardianship Laws. In this report, the VLRC recommended binding instructional health directives, with a number of protections and exemptions in place.[2]

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.

Organ donation

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.

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.

AMA Victoria Recommendation 2

The enactment of legislation to enable an individual to detail their wishes about organ and tissue donation in an advance care plan.

Doctrine of double effect

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[1] The Victorian Law Reform Commission, Guardianship: Final Report, April 2012. http://www.lawreform.vic.gov.au/sites/default/files/Guardianship_FinalReport_Full%20text.pdf

[2] Refer to Appendix 2 for a list of VLRC's key recommendations on binding instructional health directives.

AMA Victoria's submission[3] to the Victorian Parliament's 2015 Inquiry into End of Life Choices called for legislation to provide legal certainty to medical practitioners on the:

- Doctrine of double effect, where the administration of treatment or other action intended to relieve symptoms may have a secondary consequence of hastening death; and
- non-provision of futile care, where medical practitioners are generally not obliged to provide treatments that are considered futile.

Legislative clarification will enable doctors to provide necessary care[4] to terminally ill patients, in the terminal phase of their illness, without the risk of prosecution. This is currently lacking and, in some instances, patients may not be receiving the care they want to have at end of life.

AMA Victoria Recommendation 3

The enactment of legislation to provide legal certainty to medical practitioners in connection with the accepted clinical practices of double effect and the non-provision of futile care.

Area 2: Infrastructure and services

The discussion paper refers to the need for "genuine choice" in end of life care. Significant investment in health infrastructure and services is necessary for improvements in end of life care in Victoria, and for greater patient choice.

General practice and the MBS

The discussion paper does not mention general practice. This is a significant oversight, as many GPs play a crucial role in end of life care. Any change in legislation needs to respect and facilitate the important clinical management role undertaken by GPs. Furthermore, for this to continue (and to increase), the MBS must recognise their service. While the MBS is a Commonwealth matter, the Victorian Government can raise this at COAG and also directly with the Commonwealth Government.

AMA Victoria Recommendation 4

For the MBS to include item numbers for end of life care provided in general practice. As this is a Commonwealth matter, the Victorian Government should lobby the Commonwealth Government to bring about this change.

Community services

As is detailed throughout the discussion paper, there is a significant desire for end of life care to be provided in the community. In end of life, patients' needs increase. For patients to die comfortably in the community, such as at home or in a residential aged care facility, services such as home visiting doctors and nurses, case workers and care co-coordinators, and other health professionals who provide valuable end of life services (from showering patients, to pain relief) must be accessible.

AMA Victoria Recommendation 5

Significant investment in community-setting end of life care services, which enable patients to die at home or in a residential aged care facility, rather than be admitted to a hospital for the end stage of end of life care.

Rural and regional areas

End of life care, palliative care (and access to palliative care services) must be available in rural/regional areas. This requires significant investment from the Victorian Government. For remote

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[3] AMA Victoria's submission to the Inquiry into End of Life Choices by the Victorian Legislative Council's Standing Committee on Legal and Social Issues, August 2015.
http://amavic.com.au/icms_docs/225566_Submission_to_the_Inquiry_into_End_of_Life_Choices.pdf

[4] AMA Victoria's submission to the Inquiry into End of Life Choices references "good medical practice". Please see Appendix 3 for relevant extract of *Good medical practice: a code of conduct for doctors in Australia* (published by the Medical Board of Australia, March 2014)

areas where this is not practical, concessions and support must be made available to patients to assist with the high out-of-pocket ancillary costs they experience in commuting or relocating for health services.

AMA Victoria Recommendation 6

Significant investment in rural/regional areas is needed to ensure rural Victorians have access to appropriate end of life care services.

Health IT

The health system must be connected. The digital communication between hospitals, general practice, private specialists, residential aged care facilities, and state and federally-funded community healthcare services needs to be integrated to enable patient information to be securely, legally and rapidly transferred between the various health sectors, when needed.

This is particularly important in end of life care. It is necessary that a patient's GP, residential aged care facility, and the treating hospital can access a patient's advance care plan in a timely manner (including whether they have a Refusal of Treatment Certificate).

AMA Victoria Recommendation 7

Significant investment in health IT and secure-messaging between health services. Patient records, including their advance care plans, must be accessible in a timely manner.

Residential aged care facilities

All residents in aged care facilities should have the opportunity to develop an advance care plan.

A common barrier preventing the system-wide implementation of advance care plan programs in residential aged care facilities is the associated time constraints.[5] The introduction of an advance care plan template, with a range of adaptable resources, is likely to reduce the time related barriers that are currently preventing the implementation of advance care plans in these facilities.

As outlined in Recommendation 6, IT infrastructure is needed so that residential aged care facilities can share a patient's advance care plan with hospitals.

AMA Victoria Recommendation 8

The Victorian Government to fund and provide support to residential aged care facilities to enable all patients (if desired) to have an advance care plan.

Area 3: Workforce

Workforce planning

In 2014, the Commonwealth Government disbanded Health Workforce Australia. Given this gap, it is imperative that the Department of Health and Human Services undertakes appropriate health workforce planning for Victoria.

There has been a significant increase in the number of medical graduates coming from Australian universities, which is in addition to the ongoing net importation of international medical graduates. Across Australia, there has been a 150% increase in medical school places since 2004,[6] unsurprisingly, this has led to a bottleneck pressure to train these junior doctors. Appropriate workforce planning could lead to increased training positions for junior doctors in specific areas of need. For example, it may be determined that due to Australia's ageing population and demand for

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[5] Rhee J, Zwar N & Kemp L 2012. 'Uptake and implementation of advance care planning in Australia: findings of key informant interviews'. *Australian Health Review*, vol. 36, issue 1, pp. 98-104.

[6] 'Medical School won't fix doctor shortage', *Australian Medicine*, 18 May 2015. https://ama.com.au/ausmed/%E2%80%98captain%E2%80%99s-call%E2%80%99-medical-school-won%E2%80%99t-fix-doctor-shortage

end of life care services, funding should be directed towards general practice, palliative care or geriatrics training. Workforce planning is necessary and will improve Victoria’s health system.

AMA Victoria Recommendation 9

The Department of Health and Human Services to undertake appropriate health workforce planning.

Area 4: Community information and awareness

More must be done to improve patient medical literacy and inform patients about their condition, the likely trajectory of their condition, and the treatment options (including the option of being entitled to refuse treatment).

AMA Victoria and the Department of Health and Human Service have developed the “Advance Care Planning: Have the Conversation”[7] resource for medical practitioners. This is an excellent resource, and the MBS must ensure that these conversations are able to occur with patients.

As outlined in Recommendation 3 of this submission, the MBS must recognise and support the doctor:patient relationship. Currently, GPs are limited in their ability to have thorough conversations with patients as MBS item numbers do not always reflect the realities of clinical practice, in particular the questions and counselling that accompanies conversations about a diagnosis, and often the need to engage a patient’s family or carer(s).

Promotion of advance care plans

The Victorian Government must increase public information about end of life care planning. Information (for example in the form of TV advertisements) on the importance of advance care plans are needed to ensure patients have detailed their desired end of life care to their GP and to their family.

Information should also be provided to patients on the options and services available for diverse groups, and where needed these services should be expanded. This may include translators, religious and/or ethnic customs in healthcare settings, non-denominational palliative care services etc..

AMA Victoria Recommendation 10

The Victorian Government to fund ongoing public information on end of life care and the importance of advance care plans. End of life care services for diverse groups should be made well known, and expanded where needed.

Support for family members and carers

It is important that family members and carers are not pressured or feel guilty if they are unable to follow all of a patient’s wishes as to their end of life care. For example, it will not always be possible for patients to die at home, as this requires support from a carer(s). This is particularly relevant for elderly and/or frail couples, where one partner is the primary carer and may not be able to meet the patient’s needs. The Government must ensure that family members and/or carers are counselled and supported through these difficult decisions.

AMA Victoria Recommendation 11
The Victorian Government to fund ongoing public information and awareness on end of life care for family members and carers.

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[7] AMA Victoria and the Victorian Department of Health and Human Services’ “Advance Care Planning: Have the Conversation” resource, November 2015.
http://amavic.com.au/page/Member_Services/Policy_and_Media/Current_Issues/Advance_Care_Planning_Have_the_Conversation/

Appendix 1 - Summary of AMA Victoria's recommendations

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.

AMA Victoria Recommendation 2
The enactment of legislation to enable an individual to detail their wishes about organ and tissue donation in an advance care plan.

AMA Victoria Recommendation 3
The enactment of legislation to provide legal certainty to medical practitioners in connection with the accepted clinical practices of double effect and the non-provision of futile care.

AMA Victoria Recommendation 4
For the MBS to include item numbers for end of life care provided in general practice. As this is a Commonwealth matter, the Victorian Government should lobby the Commonwealth Government to bring about this change.

AMA Victoria Recommendation 5
Significant investment in community-setting end of life care services, which enable patients to die at home or in a residential aged care facility, rather than be admitted to hospital for the end stage of end of life care.

AMA Victoria Recommendation 6
Significant investment in rural/regional areas is needed to ensure rural Victorians have access to appropriate end of life care services.

AMA Victoria Recommendation 7
Significant investment in health IT and secure-messaging between health services. Patient records, including their advance care plans, must be accessible in a timely manner.

AMA Victoria Recommendation 8
The Victorian Government to fund and provide support to residential aged care facilities to enable all patients (if desired) to have an advance care plan.

AMA Victoria Recommendation 9
The Department of Health and Human Services to undertake appropriate health workforce planning.

AMA Victoria Recommendation 10
The Victorian Government to fund ongoing public information on end of life care, patients' options and the importance of advance care plans. End of life care services for diverse groups should be made well known, and expanded where needed.

AMA Victoria Recommendation 11
The Victorian Government to fund ongoing public information and awareness on end of life care for family members and carers.

Appendix 2 – Summary of the VLRC's 2012 recommendations

The Victorian Law Reform Commission's final report[8] into the Administrative and Guardianship Laws identified 440 recommendations. The recommendations detailed below are particularly relevant to the framework's discussion paper and its reference to binding advance care directives.

VLRC Recommendation 134
An instructional directive should be able to provide:

(a) binding instructions or advisory instructions about health matters.
(b) advisory instructions about personal and lifestyle matters, other than health matters and financial matters, that should be taken into account and followed where reasonably possible but should not be legally binding.

VLRC Recommendation 139
The principal should be able to make instructional health care directives about future as well as current conditions.

VLRC Recommendation 140
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.

VLRC Recommendation 141
To avoid doubt, new guardianship legislation should specifically provide that an instructional health care directive allows the principal to give directions about requiring a life-sustaining measure to be withheld or withdrawn in particular circumstances.

VLRC Recommendation 142
New guardianship legislation should include a statement that an instructional health care directives cannot authorise, justify or excuse taking positive steps to assist someone to end their life unlawfully.

VLRC Recommendation 143
A health professional should be required to refer the patient or enduring personal guardian to another health professional if their personal views or beliefs prevent them from complying with lawful directions in a valid instructional health care directive.

VLRC Recommendation 148
The forms and any associated information and educational material should be available in a range of community languages. Translated forms should be in a bilingual format that includes both English and the community language.

VLRC Recommendation 151
A direction in an instructional health 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 instructional health care directive to the extent that the principal, if they had known of the change in circumstances, would have considered that the terms of the directions are inappropriate.
(b) the instructional health care directive is uncertain.
(c) there is persuasive evidence to suggest that the instructional health care directive is based on incorrect information or assumptions.

VLRC Recommendation 154
New guardianship legislation should provide the following protection for health providers:

(a) a health provider is not affected by an instructional health care directive to the extent that the health provider, acting in good faith, does not have actual knowledge that the person has an instructional health care directive.

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[8] Victorian Law Reform Commission's Guardianship: Final Report, April 2012. http://www.lawreform.vic.gov.au/sites/default/files/Guardianship_FinalReport_Full%20text.pdf

(b) a health provider who – acting in good faith and without knowledge that an instructional health care directive is invalid – acts in reliance on the directive, does not incur any liability to the principal or anyone else because of the invalidity.
(c) a health provider has a duty to determine whether an instructional health care directive is in place by checking the register before providing treatment. A health provider who fails to check the register and provides treatment that is inconsistent with the directive will not be protected from liability by the provisions providing protection for a lack of actual knowledge. A health provider is not required to check the register if emergency treatment is required.

VLRC Recommendation 155
If emergency treatment is required and the health provider is aware of an instructional health care directive but does not have time to apply to the tribunal to determine if it is valid or if a directive is operative, and they believe on reasonable grounds that one the following principles applies:
(a) circumstances, including advances in medical science, have changed since the completion of the instructional health care directive to the extent that the principal, if they had known of the change in circumstances, would have considered the terms of the direction inappropriate
(b) the instructional health care directive is uncertain
(c) there is persuasive evidence to suggest that the instructional health care directive is based on incorrect information or assumptions
then the health provider does not incur any liability, either to the principal or anyone else, if the health provider does not act according to the directive.

VLRC Recommendation 162
A principal who combines the appointment of an enduring personal guardian with an instructional health care directive should be able to specify if the instructional health care directive is binding for the matters it covers, or intended as a guide only.

Appendix 3 – *Good medical practice: a code of conduct for doctors in Australia*

The Medical Board of Australia's *Good medical practice* code pertaining to end of life care is detailed below.

Section 3.12

End-of-life care

Doctors have a vital role in assisting the community to deal with the reality of death and its consequences. In caring for patients towards the end of their life, good medical practice involves:

1. Taking steps to manage a patient's symptoms and concerns in a manner consistent with their values and wishes.
2. Providing or arranging appropriate palliative care.
3. Understanding the limits of medicine in prolonging life and recognising when efforts to prolong life may not benefit the patient.
4. Understanding that you do not have a duty to try to prolong life at all cost. However, you do have a duty to know when not to initiate and when to cease attempts at prolonging life, while ensuring that your patients receive appropriate relief from distress.
5. Accepting that patients have the right to refuse medical treatment or to request the withdrawal of treatment already started.
6. Respecting different cultural practices related to death and dying.
7. Striving to communicate effectively with patients and their families so they are able to understand the outcomes that can and cannot be achieved.
8. Facilitating advance care planning.
9. Taking reasonable steps to ensure that support is provided to patients and their families, even when it is not possible to deliver the outcome they desire.
10. Communicating bad news to patients and their families in the most appropriate way and providing support for them while they deal with this information.
11. When your patient dies, being willing to explain, to the best of your knowledge, the circumstances of the death to appropriate members of the patient's family and carers, unless you know the patient would have objected.

http://www.medicalboard.gov.au/Codes-Guidelines-Policies/Code-of-conduct.aspx