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# Submission in response to the Senate Community Affairs References Committee Inquiry into Palliative Care in Australia

The AMA welcomes the Senate Community Affairs References Committee Inquiry into palliative care in Australia.

Our health care system must give people the opportunity to die with dignity and without avoidable suffering. Access to medical practitioners is a fundamental factor influencing access to and choice of appropriate palliative care that meets the needs of the population. The demand for quality palliative care in all health care settings is increasing with an ageing population. Inefficient palliative care services and poor communication about advance care directives can have a significant impact on the whole health care system, through unnecessary pressure and counter-productive utilisation of acute services.

## 1. Factors influencing access to and choice of appropriate palliative care

'Palliative care' is care provided for people of all ages who have a life-limiting illness, with little or no prospect of cure, and for whom the primary treatment goal is quality of life.<sup>1</sup> Palliative care integrates physical, psychological, emotional, and spiritual care for patients, their families, and other carers. This includes respite care, grief and bereavement support. Medical practitioners play an instrumental role in all aspects of palliative care.

### *Equity and access*

There is evidence that the current access to palliative care services across Australia is not equitable<sup>2</sup>. People dying with cancer are more likely to access palliative care than people dying of other conditions<sup>3</sup>.

The AMA advocates for equity of access across Australia to palliative care, carers' support, and other relevant services to patients undergoing end of life care and their families and carers.

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<sup>1</sup> Palliative Care Australia (May 2005), 'Standards for Providing Quality Palliative Care for All Australians', 4th edition, p 10.

<sup>2</sup> Australian Government (2010), 'Supporting Australians to Live Well and the End of their Life: National Palliative Care Strategy', p 1-2.

<sup>3</sup> Palliative Care Australia (2009), 'Is access to quality palliative and end-of-life care equitable for all Australians?' EoL- Towards quality care at the end of life, Vol 1, No 2 (Spring edition), p 3.

Equity of access means that quality palliative care services should be available to everyone in need of such services, regardless of gender, age, ethnicity, race, citizenship status, language, religion, mental health, medical condition, disability, location, place of residence, or ability to pay.

The AMA advocates that if the present inquiry determines that the inequities across Australia and across disease or patient groups are disproportionate, that consideration be given to recommending targeted funding.

*Medicare rebates for medical services provided to patients, including time spent with family and carers*

To improve the delivery of medical palliative care in a range of private settings, the AMA recommends the introduction of specific Medicare rebates for the medical care provided to people at the end of their life. These rebates would recognise the holistic services provided by medical practitioners, including providing clinical treatment.

Medicare rebates should cover the time that medical practitioners spend:

1. with the patient's family and carers, which is often considerable and complex; and
2. organising and coordinating palliative care services.

Medicare rebates should also support case conferencing between medical practitioners who provide medical care.

The Medicare telehealth items could be extended to patients in urban areas. Given most palliative care patients are immobile, their medical care could be enhanced by video technology. This could allow rapid assessment and care decisions when a patient's condition changes quickly and the medical practitioner is not immediately available to attend the patient in person.

The Productivity Commission has recognised the costs of providing palliative care in the aged care context, suggesting that the costs to aged care providers of supporting GPs, geriatricians, and other specialist teams (such as palliative care specialists) be taken into account in the costs of delivering care<sup>4</sup>. The Commission recommended that the Government ensure residential and community care providers receive appropriate payments for delivering palliative care<sup>5</sup>.

*Education of our community and health professionals*

Our community needs to be educated about the reality of death and dying. Similarly, health care professionals need to be upskilled and supported to provide quality palliative care. There should be training in palliative care and grief and bereavement counselling available to all health practitioners, to support both patients and their family members.

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<sup>4</sup> Productivity Commission (2011), *Caring for Older Australians*, Volume 2, p. 224.

<sup>5</sup> Ibid, p. 224.

## 2. Advance care planning

The AMA supports advance care planning, through the use of advance care directives (ACDs), as important to patient self-determination. ACDs benefit patients by providing them with a means of informing health care decisions, including the withholding and/or withdrawing of life-sustaining measures, in the event of losing decision-making capacity in the future. ACDs also benefit surrogate decision-makers (SDMs), medical practitioners, and other health care providers by alleviating the stress and anxiety they may face in trying to make treatment decisions that reflect the person's wishes. ACDs can also advance the rational use of health resources and encourage the provision of care in the most appropriate environment.

### *National consistency in law and policy*

The AMA supports the work undertaken by the Australian Health Ministers' Advisory Council in setting out the principles that should underpin a National Framework for Advance Care Directives<sup>6</sup>. This Framework should guide development of nationally consistent legislation. Medical practitioners practicing in multiple jurisdictions would be able to confidently carry out an ACD without fear of inadvertently contravening the law.

Legislation should protect the right of the patient to specify future health care treatment preferences while they still have the capacity to do so. The legislation should also provide equal protection for medical practitioners and other health care providers who follow that advance direction or who do not follow it to the letter due to clinically valid circumstances.

Medical practitioners are in the front line of having to make judgments about whether they should strictly follow a directive or whether the clinical circumstances in which the directive was given are no longer appropriate and the directive should not be followed. In making decisions medical practitioners are conscious that they potentially face the possibility of criminal action, civil action or disciplinary proceedings.

The AMA suggests that if ACDs are to attain widespread acceptance then medical practitioners and other health care providers need to have:

1. *Quick access to legal certainty.*

Where there is doubt about the validity or appropriateness of an ACD, a health care provider or substitute decision maker should have access to a legal body, such as a tribunal, which can quickly make advisory rulings on whether an ACD ought to be followed.

2. *Protection from criminal and civil liability and from disciplinary proceedings.*

Such protection should apply where a medical practitioner provides medical treatment or withholds medical treatment in reliance on an ACD made by the patient and the medical practitioner:

- is acting in good faith;
- on reasonable grounds; and
- the ACD, on its face, appears properly given; or
- there has been an advisory ruling from a tribunal in relation to the directive.

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<sup>6</sup> The Australian Health Ministers' Advisory Council (September 2011), 'A National Framework for Advance Care Directives'.

It is imperative that medical practitioners and other health care providers are protected from civil or criminal prosecution if they choose to provide life-sustaining measures in an emergency situation where the SDM is not immediately available and it is unclear whether the person intended the direction to apply to the current clinical circumstance.

*Avenues for communication about end of life care*

Medical practitioners play a key role in assisting patients to develop an ACD by discussing treatment issues related to incapacitating conditions and/or future health care options. Such discussions are an accepted part of good clinical care and the doctor-patient relationship.

Where engaged in developing an ACD, medical practitioners have a responsibility to ensure that patients:

- a) are competent to do so;
- b) are fully informed and have had an adequate opportunity to receive advice on various health care options pertaining to their current and possible future condition/s;
- c) understand and appreciate the information, including medical concepts and terminology contained in the advance care document;
- d) have the capacity to understand the decisions they have made; and
- e) are acting voluntarily (as best as the medical practitioner can determine this).

Despite being a clinically relevant professional service, there is currently no financial assistance to patients for such discussions. The AMA believes it is important for the Medicare Benefits Schedule (MBS) to provide patients with a rebate for the time that it takes for medical practitioners to undertake consultations to assist patients in preparing ACDs. This could be either through an explicit change to current MBS explanatory notes to clarify which existing MBS items can be used in respect of these consultations or through the addition of a specific new MBS item.

*Scope for including ACDs in personal electronic health records*

The AMA also recommends that ACDs be included in the Personally Controlled Electronic Health Record.

Patients may be treated in more than one clinical setting through the course of their illness, including intensive care (including neonatal intensive care), inpatient hospital care, aged care facilities, palliative care facilities, and at home. A shared electronic medical record that links reliable and relevant medical information across healthcare settings would provide treating medical practitioners with the information required to inform clinical decisions.

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