

08/19

3 April 2008

Mr Peter Hallahan
Committee Secretary
Senate Legal and Constitutional Affairs Committee
Department of the Senate
PO Box 6100
Parliament House
CANBERRA ACT 2600

Dear Mr Hallahan

Thank you for providing the Australian Medical Association (AMA) with the opportunity to make a submission to the Senate Legal and Constitutional Affairs Committee's Inquiry into the *Rights of the Terminally Ill (Euthanasia Repeal) Bill 2008*.

Our understanding of the intent of this Bill is that it will repeal the *Euthanasia Laws Act 1997* and then restore the Northern Territory's *Rights of the Terminally Ill Act 1995*.

The AMA does not support the provisions of the *Rights of the Terminally Ill (Euthanasia Laws Repeal) Bill 2008*.

The AMA will limit its comments specifically to the issue of euthanasia and physician-assisted suicide and will not comment on whether or not it was appropriate for the National Parliament to overturn the Northern Territory's *Rights of the Terminally Ill Act 1995* (which has been the subject of debate in the past).

Yours sincerely

Dr Rosanna Capolingua
President

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D08/2334

Australian Medical Association Submission to the Senate Legal and Constitutional Affairs Committee's Inquiry into the *Rights of the Terminally Ill (Euthanasia Repeal) Bill 2008.*

The AMA recognises the divergence of views regarding voluntary euthanasia and physician-assisted suicide in Australia. Indeed, the range of views, from those who fully support voluntary euthanasia to those who totally oppose it, is reflected within the medical profession itself.

AMA position on euthanasia and physician-assisted suicide

The AMA believes that medical practitioners should not be involved in interventions that have as their primary intention the ending of a person's life (this does not include the discontinuation of futile treatment).

This position was recently reaffirmed in the AMA's *Position Statement on the Role of the Medical Practitioner in End of Life Care 2007* (see attached). This position statement resulted from a long consultation process. As recognised above, we received the full range of views on euthanasia and physician-assisted suicide from our members and others. The majority of opinion, however, was to reaffirm our policy opposing medical practitioners' involvement in euthanasia and physician-assisted suicide.

The AMA feels very strongly that medical practitioners participating in euthanasia or physician-assisted suicide undermines the trust that is the cornerstone of the doctor-patient partnership. The public trusts medical practitioners to care for patients (and their families and carers) throughout the course of their disease or condition and to advocate for their health and well-being.

We cannot confuse the role of the medical practitioner as someone who supports life with someone who takes life.

In consultation with the patient (or their advocate), medical practitioners apply the most appropriate therapeutic means to treat their patients. Where death is inevitable and when treatment that might prolong life will not offer reasonable hope of benefit or will impose an unacceptable burden on the patient, death should be allowed to occur with dignity and comfort. For medical practitioners, this means using their skills to care for the patient by making them as comfortable as possible, free from unnecessary suffering. It does not mean deliberately taking the life of the patient.

The AMA absolutely recognises that for most patients in the terminal stage of illness, pain and suffering can be alleviated by therapeutic and comfort care; however, there are still currently instances where the satisfactory relief of suffering cannot be achieved.

We must, therefore, ensure that all patients have access to appropriate palliative care and advocate that greater research must go into palliative care so that no patient endures such suffering. No one should feel that their only option for satisfactory relief of pain and suffering is to end their own life.

Definitions

It is important for any discussions on euthanasia and physician-assisted suicide to clarify the terminology.

The AMA defines euthanasia as:

the act of deliberately ending the life of a patient for the purpose of ending intolerable pain and/or suffering (from AMA Position Statement on the Role of the Medical Practitioner in End of Life Care 2007).

The AMA believes that if a medical practitioner 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:

- 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.

The AMA defines physician-assisted suicide as:

where the assistance of the medical practitioner is intentionally directed at enabling an individual to end his or her own life (from AMA Position Statement on the Role of the Medical Practitioner in End of Life Care 2007).

We advocate that patient requests for euthanasia or physician-assisted suicide should be fully explored in order for the medical practitioner to adjust the patient's clinical management or seek specialist assistance.

Again, we advocate that quality palliative care services must be available to everyone in need of such services. A patient should never feel that death is their only option for relief of pain and suffering because appropriate palliative care is not available.

Advance care planning

The AMA endorses advance care planning as a means for supporting patients' wishes in their end of life care (see *AMA Position Statement on the Role of the Medical Practitioner in Advance Care Planning 2006*). Advance care plans provide (competent) patients with the opportunity to express their goals and values in relation to their future health care should they lose decision-making capacity.

Some patients may fear that when they lose decision-making capacity, their goals and values in relation to their end of life care will be unknown or even disregarded by their families and/or the health care team since the patient can no longer actively participate in their own health care decisions. As such, this fear may lead some patients to consider undergoing euthanasia or physician-assisted suicide before they lose decision-making capacity.

An advance care plan, which may include an advance directive and/or an enduring power of attorney, provides patients with the reassurance that they can participate in future decisions regarding their health care by articulating their wishes and goals of care in their plan.

Concluding remarks

The AMA does not support the provisions of the *Rights of the Terminally Ill (Euthanasia Laws Repeal) Bill 2008*.

Whilst acknowledging the range of societal views on euthanasia and physician-assisted suicide, the AMA strongly reiterates that medical practitioners should not be involved in interventions that have as their primary intention the ending of a person's life.

Position Statement on the Role of the Medical Practitioner in End of Life Care

2007

1 Preamble

- 1.1 The AMA believes that 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 surrogate decision-maker.
- 1.2 Further, the AMA believes that good quality end of life care should:
 - 1.2.1 ensure the patient is always treated with respect, dignity, and compassion;
 - 1.2.2 ensure that the patient is free from unnecessary suffering;
 - 1.2.3 endeavour to facilitate care in the patient's environment of choice;
 - 1.2.4 ensure that the patient's goals and values for end of life care are respected;
 - 1.2.5 respect the patient's privacy and confidentiality, even after death;
 - 1.2.6 support not only the physical needs of the patient but also the psychological, emotional, religious, and spiritual needs of the patient and their family members and carers;
 - 1.2.7 empower patients and, where appropriate, their family members and carers to participate in managing their treatment;
 - 1.2.8 provide counselling and other support to patients, their family members and carers throughout the patient's condition, including support for family members and carers beyond the patient's death.
- 1.3 The AMA recognises and respects the intimacy of death. Death, dying, and bereavement are all an integral part of life; however, reflecting on and discussing death can be profoundly confronting and difficult. The AMA encourages open and frank discussion of death, dying, and bereavement within the profession and in the wider community.
- 1.4 The AMA supports a guidance framework rather than a legislative system to oversee end of life care. Where legislation does exist, the AMA supports uniform, flexible legislation that protects medical practitioners and allows them to undertake their clinical duties in line with good medical practice.

2. Terminology Used in This Document

Advance care planning (ACP) – A process that allows a competent individual to express their views in relation to future health care decisions when the capacity to express those views is lost. The outcome of an ACP process is an advance care plan that may include:

- (a) an Advance (Health or Care) Directive (AD) (or other similar instruments);
- (b) a Medical Enduring Power of Attorney (EPA) (or other similar instruments);
- (c) a letter to the person who will be responsible for this decision-making;
- (d) an entry in the patient medical record;
- (e) a verbal instruction or other communication which clearly enunciates a patient's view; or
- (f) any combination of the above.

Advance directive - A statement that allows patients who understand the implications of their choices to state in advance how they wish to be treated when they are no longer capable, as a consequence of physical or cognitive incapacity, of making such health care decisions in a particular circumstance.

Carers – This refers to family carers who provide unpaid, informal care to the patient. Whilst some family carers may be eligible for government benefits, this definition excludes those that are actually employed as carers.

Euthanasia – The act of deliberately ending the life of a patient for the purpose of ending intolerable pain and/or suffering.

The AMA acknowledges that some people prefer to categorise euthanasia in specific ways; for example, voluntary, non-voluntary, or involuntary euthanasia **and/or** active or passive euthanasia.

These are generally defined as¹:

- voluntary euthanasia – ending the life of a competent, informed patient at their request;
- non-voluntary euthanasia – ending the life of a patient with impaired decision-making capacity who cannot provide truly informed consent (this does not include murder);
- involuntary euthanasia – ending the life a patient against their will or consent (this may include murder or manslaughter);
- active euthanasia – giving a patient a treatment or action that directly and deliberately results in their death;
- passive euthanasia – not initiating or no longer continuing life-sustaining treatment that results in death as a direct consequence of the underlying disease.

The AMA believes, however, that if a medical practitioner 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:

- 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.

Futile treatment – Treatment is futile when it is no longer providing a benefit to a patient, or the burdens of providing the treatment outweigh the benefits².

Good medical practice – Good medical practice is practice that is consistent with:

- the current recognised medical standards, practices and procedures of the medical profession in Australia; and
- the current recognised ethical standards of the medical profession in Australia.

Life-limiting illness – An illness where it is expected that death will be a direct consequence of the specified illness. A life-limiting illness may be expected to shorten an individual's life.

Life-sustaining treatment - Medical treatment that supplants or maintains the operation of vital bodily functions that are temporarily or permanently incapable of independent operation. This includes assisted ventilation, artificial nutrition and hydration and cardiopulmonary resuscitation but excludes measures of palliative care.

Medical Enduring Power of Attorney (EPA) – A legal document that gives another person authority to make health care decisions on behalf of a person who has lost capacity. In relation to ACP, this attorney may have an important role in assisting in health care decisions that need to be made with the treatment team. It is important for both patients and practitioners to understand that relevant to State or Territory legislation, a person may appoint a single (or joint) attorney for all matters or different attorneys for different matters (eg., one for personal matters, one for financial matters, one for health matters).

Palliative care – 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 life³. Palliative care integrates physical, psychological, emotional, and spiritual care for patients, their families, and other carers.

Physician-assisted suicide – Physician-assisted suicide is where the assistance of the medical practitioner is intentionally directed at enabling an individual to end his or her own life⁴.

Surrogate decision-maker or ‘person responsible’ – The person legally responsible for giving valid consent to medical treatment, including its limitations on behalf of a patient who lacks decision-making capacity. The designation of such a person should be undertaken in accordance with legislation relevant to one’s jurisdiction (eg., state Guardianship Acts).

Terminal illness - An illness which is inevitably progressive, the effects of which cannot be reversed by treatment (although treatment may be successful in relieving symptoms temporarily) and which will inevitably result in death within a few months at most. Terminal phase of a terminal illness is defined as the phase of the illness reached when there is no real prospect of recovery, or remission of symptoms (on either a temporary or permanent basis).

3 Cultural and Religious Influences on Decision-making

3.1 In recognising the diversity of cultural and religious perspectives relevant to end of life care, the AMA advocates a culturally sensitive approach, acknowledging that culture-based and religious-based responses may vary, even within the same cultural and/or religious ‘group’.

3.2 Views may vary between cultures and religions on issues such as⁵:

- the preferred place of treatment;
- communication of diagnosis and prognosis. For example, in certain cultures it is not appropriate to inform the patient of a ‘terminal’ diagnosis;
- the role of family/relative/friends in caring for the patient. For example, the designation of a decision-maker for medical treatment. In certain cultures, it is not appropriate for a competent patient to make his/her own treatment decisions, particularly regarding life-sustaining treatment;
- the role of health professionals and volunteers, for example, whether or not they may be welcome in the home;
- attitudes to pain relief, whether certain medicines are taboo;
- attitudes to euthanasia;
- ‘taboo’ words. For example, in certain cultures it is inappropriate to use ‘cancer’ or ‘death’;
- handling of the body. For example, in certain cultures, only family members of the same sex as the deceased may handle the body;
- the expression of grief and bereavement.

3.3 Medical practitioners should be provided with education and support in cultural awareness to enable them to care for all their patients and family members in a sensitive and culturally appropriate manner. This includes timely access to support personnel such as trained translators, indigenous community members, and religious advisers.

3.4 Indigenous Australians have their own perspectives regarding death and dying. In addition, they may feel a lack of trust in government services, including health care services that may become even more apparent in relation to end of life care³.

3.5 Medical practitioners caring for Indigenous Australians at the end of life may benefit by working in partnership with the Aboriginal controlled health organisations, where they exist³.

4 Conscientious Objection

4.1 The AMA recognises that the diversity of cultural and religious views and practices regarding end of life care are reflected within the medical profession itself.

- 4.2 Medical practitioners caring for patients at the end of the patient's life should be under no obligation to recommend or participate in treatment to which they hold a conscientious objection related to the end of life management. In such a circumstance, the medical practitioner should explain to the health care team involved as well as the patient or the surrogate decision-maker, why they are not willing to recommend or participate in the treatment. Where possible, the practitioner may remove themselves from that aspect of care but continue to provide other necessary care.

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

- 5.1 The AMA strongly advocates for equity of access across Australia to intensive care, respite care, palliative care, bereavement support, carers' support, and other relevant services to patients undergoing end of life care and their families and carers.
- 5.2 Equity of access means that care must be available regardless of gender, age, ethnicity, race citizenship status, language, religion, mental health, medical condition, disability, location, place of residence, or ability to pay.
- 5.3 Different patient groups including neonates, children and young people, older persons, and persons with mental health problems may have specific care requirements.
- 5.4 Regardless of where a patient lives, appropriate support services for family members and carers should be available, including respite care and grief and bereavement support.

6 Resource allocation

- 6.1 The AMA advocates that medical practitioners, governments, independent, and voluntary agencies must work together to ensure that limited resources are utilised in the most effective way in order to provide patients and families with physical, psychological, social, domestic, financial and spiritual support⁶.

7 The role of good communication within end of life care

- 7.1 The AMA promotes the patient-practitioner relationship as a partnership, where patients and practitioners work together to achieve informed and mutually agreed goals of health care. An essential component of this partnership is good communication between the patient, their family members and carers as appropriate, and the practitioner and health care team. Good communication in end of life care is timely, open, informative, provides opportunities for questions, and where possible and relevant, allows patients and/or their family members and carers time to come to terms with the patient's condition.
- 7.2 Good communication between the patient, their family members and carers, and the health care team may help alleviate fear, confusion, and guilt over the patient's condition, assist decision-making, and reduce the potential for conflict over the patient's care.
- 7.3 Good communication within the health care team itself is important in reducing any confusion, stress and anxiety that may be experienced by team members over the patient's condition and/or treatment.
- 7.4 It is important that the process for decision-making along with the outcomes should be made clear to all participants involved and documented accurately.

8 Competent patients and decision-making

- 8.1 The AMA supports the right of a competent patient to make fully informed health care decisions, including the right to refuse treatment. The AMA recognises that this may include life-sustaining treatment as well as palliative care.

8.2 The AMA strongly promotes advance care planning as a process of supporting patient self-determination, including the development of advance directives and the identification of surrogate decision-makers such as Enduring Powers of Attorney (EPA) (or similar), as a means to ensure that the patient's values and goals of care are known. ACPs are prepared by the competent patient to assist in decision-making if he/she loses the capacity to make treatment decisions in the future.

9 Patients who have impaired decision-making capacity

- 9.1 The AMA recognises that patients with impaired decision-making capacity may include:
- those who were competent before losing decision-making capacity and had previously expressed their goals, values, and/or wishes around end of life care;
 - those who were competent before losing decision-making capacity and did not express their goals, values, and/or wishes around end of life care;
 - those who never had decision-making capacity;
 - patients with a mental illness resulting in permanent or fluctuating impairment of decision-making ability;
 - patients with decision-making capacity for some, but not all, decisions.
- 9.2 For many patients, the loss of decision-making capacity is progressive rather than immediate and may fluctuate over time. Such patients should be encouraged to participate in treatment decisions consistent with their level of capacity at the time a decision needs to be made.
- 9.3 Situations may arise where a patient has impaired decision-making capacity and a surrogate decision-maker must make health care decisions on behalf of the patient, including decisions to no longer continue or not to commence life-sustaining treatment. This should be undertaken in collaboration with the practitioner.
- 9.4 Where a known and valid advance directive exists, it should be used in decision-making.
- 9.5 Where a surrogate decision-maker is required, the patient's known values and goals regarding end of life care should be used to guide a care plan and treatment decisions.
- 9.6 The surrogate decision-maker, or 'person responsible', for a patient lacking decision-making capacity should be identified in accordance with relevant legislation (eg., guardianship acts). Ideally, a surrogate decision-maker should be familiar with the patient and able to represent the patient's values and goals regarding end of life care.
- 9.7 Children and young people
- 9.7.1 Children and young people may be considered to have limited rather than impaired (unless otherwise relevant) decision-making capacity.
- 9.7.2 The continuing physical, emotional and cognitive development of children and young people sets them apart from adults and influences all aspects of their care.
- 9.7.3 Children and young people experiencing end of life care should be involved as much as possible in clinical decision-making as appropriate to their mental and emotional maturity as determined by a medical practitioner.
- 9.7.4 Developmental influences through infancy, childhood, and adolescence may impact upon³:
- the experience of illness;
 - the understanding, reporting, and management of symptoms;
 - psychological/emotional distress; and
 - the understanding of death and dying.

9.7.4 Guidance should be offered to parents about how to communicate with their child and their siblings, where appropriate, regarding the child's condition.

10 Good medical practice and the relief of pain and suffering

- 10.1 The AMA believes that while medical practitioners have an ethical obligation to preserve life, death should be allowed to occur with dignity and comfort when death is inevitable and when treatment that might prolong life will not offer a reasonable hope of benefit or will impose an unacceptable burden on the patient.
- 10.2 Medical practitioners are not obliged to give, nor patients to accept, futile or burdensome treatments or those treatments that will not offer a reasonable hope of benefit or enhance quality of life.
- 10.3 All patients have a right to receive relief from pain and suffering, even where that may shorten their life.
- 10.4 While for most patients in the terminal stage of an illness, pain and other causes of suffering can be alleviated, there are some instances when satisfactory relief of suffering cannot be achieved.
- 10.5 The AMA recognises that there are divergent views regarding euthanasia and physician-assisted suicide. The AMA believes that medical practitioners should not be involved in interventions that have as their primary intention the ending of a person's life. This does not include the discontinuation of futile treatment.
- 10.6 Patient requests for euthanasia or physician-assisted suicide should be fully explored by the medical practitioner in order to determine the basis for such a request. Such requests may be associated with conditions such as a depressive or other mental disorder, dementia, reduced decision-making capacity, and/or poorly controlled clinical symptoms such as pain. Understanding and addressing the reasons for such a request will allow the medical practitioner to adjust the patient's clinical management accordingly or seek specialist assistance⁷.
- 10.7 If a medical practitioner 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:
- 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.
- 10.8 Medical practitioners are advised to act within the law to help their patients achieve a dignified and comfortable death.

11 Artificial nutrition and hydration

- 11.1 The AMA recognises that in Australia, artificial nutrition and hydration, or medically administered nutrition and hydration, may legally be considered 'medical treatment'. Like all treatment limitation decisions, decisions to not offer or no longer continue artificial nutrition and hydration must be undertaken in accordance with good medical practice.

12 Resuscitation orders

- 12.1 The AMA recognises that limitations on resuscitation orders constitute treatment limitation decisions that must be undertaken in accordance with good medical practice. Good medical practice may include, as well as override limitations on resuscitation orders.

13 Grief and bereavement

- 13.1 The AMA affirms that grief and bereavement are a natural part of the dying process, experienced by the patient, family members, and the health care team. The expression of grief and course of bereavement is unique to each individual.
- 13.2 The morbidity associated with grief and bereavement is a major cost to healthcare³.
- 13.3 The health care team can play a vital role in reducing the impact of grief and bereavement on family members and carers by attempting to alleviate the burden and guilt associated with having to make treatment-limiting decisions.
- 13.4 Counselling can help an individual to accommodate their loss and grief and assist in reducing the associated morbidity for the patient, their family members and carers. Counselling should be available to the patient throughout their end of life care and to their family members and carers, as well as the health care team, before and after the patient's death.

14 Carers

- 14.1 The AMA recognises that carers play an important and integral role in working with the health care team to support the patient's health care.
- 14.2 All carers are entitled to the same rights, choices, and opportunities as other Australians in order to enjoy optimum health, social and economic wellbeing and to participate in family, social and community life, employment and education⁸.
- 14.3 There are a diverse range of carers including young carers, aged carers, culturally and linguistically diverse carers, gay men and lesbian carers, rural and remote carers and others. Some carers may have special requirements to assist them in their care situation.
- 14.4 Carers experience associated physical and emotional stress, anxiety, social isolation, financial stress, and other difficulties that may adversely affect their own health and well-being.
- 14.5 The health and well-being of carers is linked to the availability, quality, responsiveness and cost of support from health and community services^{8,9}.
- 14.6 Appropriate respite care and other support services should be accessible for patients and carers.
- 14.7 Carers should be offered appropriate training to support the management of the patient, including 'hands on' skills development for their carer role.

15 Workforce

- 15.1 The AMA advocates that medical practitioners should have appropriate ongoing training in end of life care, including palliative care and grief and bereavement counselling, to support both patients and their family members.
- 15.2 Medical practitioners should also have reasonable access to relevant end of life care specialists for advice, including advice regarding ethical dilemmas.
- 15.3 Whilst caring for patients at the end of life, junior doctors should be:
- appropriately trained in communication with patients and their families;
 - supervised and supported by senior practitioners within the health care team; and
 - made aware of their legal and ethical obligations to the patient and the patient's family members.

16 Clinical settings

- 16.1 Some 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. Support should be given to the development of services that will meet the changing requirements in patient care and streamline movement between clinical settings.
- 16.2 Where possible, the patient should be cared for in the environment of their choice.

17 Palliative care

- 17.1 Palliative care provides not only physical support but also psychological, social, emotional and spiritual support for patients, their families and friends^{3,9}. This includes grief and bereavement support.
- 17.2 Quality palliative care services should be available to everyone in need of such services.
- 17.3 Adequate funding for quality palliative care services should be provided.
- 17.4 Adequate funding for appropriate palliative care research and projects should be provided.

See also:

AMA Code of Ethics 2004. Editorially Revised 2006.

AMA Position Statement on the Role of the Medical Practitioner in Advance Care Planning 2006.

*Please note that the Position Statement on Care of Severely and Terminally Ill Patients - 1997 has been revised and is now the Position Statement on the Role of the Medical Practitioner in End of Life Care - 2007

Reference:

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- ¹Kerridge I, Lowe M, McPhee M. *Ethics and law for the health professions. 2nd edition*. The Federation Press, Australia, 2005.
- ²Adapted from White B and Willmott L. *Rethinking Life-Sustaining Measures: Questions for Queensland*. QUT, February 2005.
- ³Palliative Care Australia. *Standards for Providing Quality Palliative Care for All Australians*. 4th edition. PCA, Canberra, May 2005.
- ⁴World Medical Association Statement on Physician-Assisted Suicide. Adopted by the 44th World Medical Assembly, Marbella, Spain, September 1992 and editorially revised at the 170th Council Session, Divonne-les-Bains, France, May 2005.
- ⁵Taylor A and Box M. *Multicultural Palliative Care Guidelines*. Palliative Care Australia, 1999.
- ⁶Australian Medical Association (Queensland). *Options for Dying With Dignity*. AMAQ, February 1994.
- ⁷Australian and New Zealand Society of Palliative Medicine. *Guide to Ethical Principles on Voluntary Euthanasia. Ethical Guidelines #4*. ANZSPM, 6 May 1998.
- ⁸Carers Australia. *Federal Budget Submission 2007-2008. Building Choices for Carers*. Carers Australia, November 2006.
- ⁹Palliative Care Australia. *The hardest thing we have ever done. The social impact of caring for terminally ill people in Australia, 2004*. PCA, Canberra, May 2004.

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The Role of the Medical Practitioner in Advance Care Planning

2006

1. Preamble

- 1.1 The AMA recognises that Advance Care Planning (ACP) plays an important role in patient self-determination. ACP provides a competent individual with a means to articulate their current health care goals and values. This may be done through the preparation of an advance directive (AD) (or similar instrument), which may include the designation of a surrogate decision-maker such as an Enduring Power of Attorney (EPA), to assist in health care decision-making in the event that the individual loses decision-making capacity in the future.
- 1.2 The AMA believes that ACP is likely to become more prevalent as the population ages, the ability to maintain life following a catastrophic event improves, and as more people want the ability to record in advance their views on their future health care.
- 1.3 While providing patients with a means to participate in future health care decision-making, the AMA considers that ADs, in particular, pose ethical and legal challenges to the health care team.
- 1.4 As such, the AMA recommends that all States and Territories enact legislation that establishes advance directives as legally enforceable, whilst ensuring that the same legislation provides statutory protection for doctors who comply with an AD, or who do not comply if they have reasonable grounds to believe it is inconsistent with good medical practice or advances in medical science, thereby preserving doctors' clinical judgement and discretion.
- 1.5 The AMA will lobby State and Territory governments accordingly.
- 1.6 The AMA's position statement on ACP is an extension of the AMA position statement on Care of Severely and Terminally Ill Patients, and serves to complement rather than replace that position.

2. Definitions

- 2.1 The AMA defines **Advance Care Planning (ACP)** as a process that allows a competent individual to express their views in relation to future health care decisions when the capacity to express those views is lost, and believes it can play a critical role in reducing the stress to families that participation in health care decisions can cause.
- 2.2 The outcome of an ACP process is an **advance care plan** that may include:
 - a) an **Advanced (Health or Care) Directive (AD)** (or other similar instruments);
 - b) an **Enduring Power of Attorney (EPA)** (or other similar instruments);
 - c) a letter to the person who will be responsible for this decision-making;
 - d) an entry in the patient medical record;
 - e) a verbal instruction or other communication which clearly enunciates a patient's view
or
 - f) any combination of the above.
- 2.3 The AMA defines an **AD** as a statement that allows patients who understand the implications of their choices to state in advance how they wish to be treated when they are no longer capable, as a consequence of physical or cognitive incapacity, of making such health care decisions in a particular circumstance.

- 2.4 In this context, an **EPA** is a legal document that gives another person authority to make health care decisions on behalf of a person who has lost capacity. In relation to ACP, the attorney may have an important role in assisting in health care decisions that need to be made with the treatment team.
- 2.5 **Terminal illness** is defined as an illness which is inevitably progressive, the effects of which cannot be reversed by treatment (although treatment may be successful in relieving symptoms temporarily) and which will inevitably result in death within a few months at most (from AMA Position Statement on Care of Severely and Terminally Ill Patients 1997). **Terminal phase** of a terminal illness is defined as the phase of the illness reached when there is no real prospect of recovery, or remission of symptoms (on either a temporary or permanent basis).¹
- 2.6 The AMA defines **life sustaining measures** as medical treatment that supplants or maintains the operation of vital bodily functions that are temporarily or permanently incapable of independent operation. This includes assisted ventilation, artificial nutrition and hydration and cardiopulmonary resuscitation but excludes measures of palliative care.²
- 2.7 **Palliative care** is defined as measures directed at maintaining or improving the comfort and dignity of a patient who is, or would otherwise be, in distress.³ 2.8 **Good medical practice** is defined as having regard to:
- The recognised medical standards, practices and procedures of the medical profession in Australia; and
 - The recognised ethical standards of the medical profession in Australia.⁴

3. The Doctor-Patient Relationship and ACP

- 3.1 The AMA upholds the (competent) patient's right to make health care decisions, including withholding and/or withdrawing life-sustaining measures (AMA *Code of Ethics 2004*, AMA *Position Statement on Care of Severely and Terminally Ill Patients 1997*) and supports the premise that the competent patient can have a role in anticipatory decision-making should he/she lose decision-making capacity in the future.
- 3.2 The AMA recognises that some individuals will prefer not to make decisions about the future, but rather make decisions about their health care as the need arises.
- 3.3 The AMA respects cultural diversity and encourages health care professionals to be sensitive to cultural and religious perceptions of how health care decisions are to be made and by whom.
- 3.4 The AMA endorses ACP as a process of reflection, discussion, and communication of health care preferences that respects the patient's right to take an active role in their health care, in an environment of shared decision-making between the patient and doctor. ACP can be part of a health care discussion with patients of all ages within the primary care environment or hospital setting.
- 3.5 The AMA endorses the key role of the doctor in providing guidance, advice and in discussing treatment issues related to incapacitating conditions and/or future health care options with patients, as part of the therapeutic relationship. This process may involve family members, religious advisors, friends and other people the patient feels should be involved in the process.

1 Submission from Palliative Care Western Australia on Medical Treatment for the Dying. July 2005. pp4.

2 Submission from Palliative Care Western Australia on Medical Treatment for the Dying. July 2005. pp3.

3 Submission from Palliative Care Western Australia on Medical Treatment for the Dying. July 2005. pp3.

4 B White & L Willmott (2005), Rethinking Life-Sustaining Measures: Questions for Queensland: An Issues Paper reviewing the legislation governing withholding and withdrawing life-sustaining measures pp. 58-59.

- 3.6 When engaged in developing an ACP, doctors have a responsibility when possible to ensure that patients:
- are competent to do so;
 - 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;
 - understand and appreciate the information, including medical concepts and terminology contained in the advance care document;
 - have the capacity to understand the decisions they have made; and
 - are acting voluntarily (as best as the doctor can determine this).
- 3.7 Advance care plans should be reviewed as the patient's condition, and possibly preferences, change. Accordingly, it is important to update plans on a regular basis with defined review points to ensure currency, and to encourage patients to explore all ACP options, including the appointment of an EPA.
- 3.8 The AMA would expect that ADs would be particularly useful in the following clinical settings:
- The patient is in the terminal phase of a terminal illness or condition that is incurable and progressive and is likely to die within a few months at most; or
 - The patient is in a persistent vegetative state or coma, or
 - The patient has an illness or an injury of such severity that there is no reasonable prospect that he or she will recover to the extent that his or her life can be sustained without the continued application of life-sustaining measures, and/or has no reasonable prospect of regaining decision-making capacity.
- 3.9 It is the responsibility of the patient or advocate to make the contents of an AD known. Patients should be encouraged to give a copy of their documents to their doctor, the attorney, to a trusted family member or friend, and to their solicitor. It is important for staff in all health care settings to be aware that the patient has made an advance care document, and where it can be obtained. The patient may therefore wish to carry notification on their person, stating that they have made a document or directive, and where it can be found.

4. Dilemmas in Patient Care

- 4.1 The AMA recognises that ADs may play an important role in the ACP process and enhance patient self-determination, however, the direct application of an AD under certain circumstances may pose the following serious ethical, clinical challenges to the health care team:
- The circumstances that existed at the time the AD was made may have changed. It may then be impossible to determine the extent to which the AD may still apply. Health care decisions arising from an AD are based on the information relevant to the medical condition (if any) and treatment options available, as well as the patient's attitude and values around health care, at the time the AD was made;
 - Patients may use ambiguous terms in ADs such as 'heroic measures' or 'extraordinary treatment' that make interpretation and application of the AD difficult. The patient's view of what constitutes 'extraordinary treatment' may be quite different to that of their family members, surrogate decision-makers, and/or the health care team;
 - When preparing an AD, a patient cannot predict and account for every relevant future health care scenario; therefore, a patient's AD may not be directly applicable to the actual circumstance at the time of losing decision-making capacity.
- 4.2 As such, the AMA is concerned that legally enforceable ADs may lead the doctor into a situation that he or she believes does not reflect good clinical care. Therefore, doctors should be under no absolute legal obligation to follow an AD which is not consistent with Good Medical Practice.

- 4.3 The AMA respects the rights of doctors to hold differing views regarding ADs. Doctors should be under no obligation to follow an AD to which they hold a conscientious objection. In such a circumstance, the doctor should explain to the medical team involved, and any appointed surrogate decision maker, why they are not willing to follow the AD, and, where possible, the doctor may remove themselves from the treatment team.

5. AMA lobbying

- 5.1 Given that there are currently jurisdictional differences in the law pertaining to advance care documents between each State and Territory, the AMA calls for **all** States and Territories to enact consistent legislation that establishes ADs as legally enforceable.
- 5.2 The AMA calls for greater consistency across all State and Territory legislation. All legislation should provide clear, consistent directions on:
- a) determining the validity of an AD;
 - b) providing for an Enduring Power of Attorney (EPA) (or similar surrogate decision-maker); and
 - c) providing for the recognition of a valid AD from another State or Territory;
 - d) under what clinical circumstances an AD comes into effect;
 - e) the establishment of appropriate protection for health professionals who:
 - i) comply with a valid AD;
 - ii) do not comply with an AD that they consider is not valid;
 - iii) do not comply with a valid AD where the existence of the AD or the revocation of the AD was unknown;
 - iv) do not comply with a valid AD where the health professional determines the direction in the AD is not consistent with Good Medical Practice or where the circumstances have changed so that the terms in the direction are inappropriate;
 - v) through conscientious objection, refer the patient's care to another health professional.
- 5.3 Further, the AMA calls for the development of clear, nationally consistent guidance for:
- a) the preparation, notification, and storage of ADs, including consistent pro-formas; and
 - b) the establishment of procedures for identifying an appropriate decision-maker when there is no AD or EPA and the patient's medical circumstances are relevant (e.g. patient is in terminal phase of terminal illness; permanent vegetative state; or illness or injury where unlikely to regain decision-making capacity; etc).
- 5.4 The AMA encourages doctors to familiarise themselves with the relevant law and practice in their jurisdiction.