

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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