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## Position Statement on End of Life Care and Advance Care Planning 2014<sup>i</sup>

### 1 Preamble

1.1 The primary role of the doctor (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 substitute decision-maker.

1.2 Good quality end of life care should:

- 1.2.1 ensure the patient is always treated as an individual, with respect, dignity and compassion in a culturally sensitive manner;
- 1.2.2 endeavour to meet the patient's care needs and uphold their care preferences which should guide decision-making and planning;
- 1.2.3 strive to ensure that the patient is free from suffering;
- 1.2.4 endeavour to facilitate care in the patient's environment of choice, where practical, recognising that a patient's health care needs may change in the course of their condition;
- 1.2.5 ensure that the patient's goals and values for end of life care are respected;
- 1.2.6 respect the patient's privacy and confidentiality, even after death;
- 1.2.7 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;
- 1.2.8 empower patients and, where appropriate, their family members and carers to participate in managing their treatment;
- 1.2.9 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;
- 1.2.10 ensure patients and their family members and carers have access to good quality palliative care resources such as educational materials as well as physical aids in a timely, easily accessible and coordinated manner;
- 1.2.11 recognise the role of doctors, allied health care professionals, carers and the wider community in working together to meet the needs of patients;<sup>1</sup>
- 1.2.12 facilitate continuity and coordination of care within and between medical, health and community services including when the patient transitions from medical care that is primarily focussed on curative treatments to care that is focussed on palliative treatments.

1.3 Death, dying and bereavement are all an integral part of life; however, reflecting on and discussing death can be profoundly confronting and difficult. Open and frank discussion of death and dying including end of life care options, approach to futile treatment, caring and bereavement should be encouraged within the profession and in the wider community.

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<sup>i</sup> This position statement does not address euthanasia and/or assisted suicide.

1.4 Doctors should be familiar with local (State and Territory) and Commonwealth laws relevant to end of life care and advance care planning.

## 2. Terminology

**Advance Care Directive (ACD)<sup>2</sup>** – An ACD is one way of formally recording an advance care plan (ACP). An ACD is a type of written ACP recognised by common law or authorised by legislation that is completed and signed by a competent adult. An ACD can record a person's values, life goals and preferred outcomes, or directions about care and treatment refusals, and can formally appoint a substitute decision-maker (SDM) in some States and Territories – or a combination of these. ACDs cannot be used to demand treatment that is not medically indicated or request treatments that are not legal. ACDs are not clinical care plans, however, clinical care plans should be informed by a patient's ACD.

A statutory ACD is authorised by legislation in most States and Territories. Legislation may also authorise various substitute decision-making options including the appointment of a Guardian to make medical decisions, a Refusal of Treatment Certificate, an Enduring Power of Attorney for health or personal decisions, a Medical Power of Attorney or a Health Direction.

Doctors should familiarise themselves with the law relevant to ACDs and substitute decision-making in their own State or Territory.

**Advance Care Plan (ACP)** - The outcome of planning for end of life decision-making is often an ACP that states preferences about the person's health and personal care and preferred health outcomes. They may be made by, with, or for the person. They may be made on the person's behalf and should be prepared from the person's perspective to guide decisions about care. There are different ways of recording an ACP including oral and written versions,<sup>2</sup> that may include, or entirely consist of:

- (a) an ACD (or other similar instruments);
- (b) a Medical Enduring Power of Attorney (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 Care Planning<sup>2</sup>** – A process of planning for future health and personal care whereby the person's values, beliefs and preferences are made known so they can guide decision-making at a future time when that person cannot make or communicate his or her decisions.

**Capacity<sup>2</sup>** – Having capacity to make a decision at common law means having the ability to:

- understand and appreciate information about one's own health condition and options for treatment including no treatment;
- make a free and voluntary decision regarding one's own health care; and
- communicate that decision.

**Carer** – A family member or friend, who provides unpaid, informal care to the patient. Whilst some carers may be eligible for government benefits, this definition excludes those that are actually employed as carers.

**Clinical Care Plan<sup>2</sup>** - A plan developed by the doctor in charge of the patient's care that sets out specific treatment directions at the end of life, such as decisions regarding resuscitation and the provision of palliative care, which should be followed by health professionals in a medical or aged care facility. When the patient has an existing ACD or ACP, this should inform the development of the clinical care plan.

**Competence** - A legal term used to describe the mental ability for an adult to perform a specific task. An adult is presumed at common law to be competent to make decisions about medical treatment unless the presumption is rebutted.<sup>3</sup>

**End of Life**<sup>4</sup> – That part of life where a person is living with, and impaired by, an eventually fatal condition, even if the prognosis is ambiguous or unknown. An eventually fatal condition, or terminal condition, is one that has no cure and where death appears imminent within the foreseeable future.

**Futile Treatment** – Treatment that no longer provides a benefit to a patient or treatment where the burdens of treatment outweigh the benefits. Doctors are not required to offer treatment options they consider neither medically beneficial nor clinically appropriate.<sup>2</sup>

**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-Sustaining Measures**<sup>2</sup> - Medical interventions that supplants, supports, or maintains the operation of vital bodily functions that are temporarily or permanently incapable of independent operation (such as mechanical ventilation, dialysis, and blood transfusions).

**Medical Enduring Power of Attorney (EPA)** – A legal document authorised in some States and Territories that gives another person authority to make health care decisions on behalf of a person who has lost capacity. In relation to advance care planning, 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 doctors 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 are living with, and dying from an eventually fatal condition, and for whom the primary treatment goal is quality of life.<sup>5</sup> Care focusses on reducing suffering through early identification, assessment, and treatment of pain, physical, psychological, social, cultural and spiritual needs.<sup>6</sup>

**Substitute Decision-Maker (SDM)**<sup>2</sup> – An SDM is a collective term for persons appointed or authorised by law to make substitute decisions on behalf of a person who no longer has the competence to make decisions about their medical care. A SDM may be appointed by the person, appointed for (on behalf of) the person, or identified as the default decision-maker appointed by a Tribunal or Guardianship Acts around Australia. More than one SDM can be appointed under an ACD. The SDM should make the decision the person would have made in the current circumstances, taking into account the person's life-goals, views, values and beliefs. The SDM should only base his or her decision on the person's best interests when there is no evidence of the person's preferences on care. The question of whether the guardian appointed by a person to refuse treatment on behalf of the patient is complex and is dependent on a number of factors including State legislation and if appointed by a Tribunal whether the guardian has 'full' (plenary) or limited powers.

**Supported Decision-Making**<sup>7</sup> - An approach to decision-making that involves providing a person with impaired decision-making ability the support they need to make their own decisions. It is often contrasted with substitute decision-making, where a decision is made on behalf of a person who is unable to make that decision.

**Supportive Care** - Symptom management while a person is receiving treatment to potentially cure his or her disease or extend life.

**Terminal Illness**<sup>4</sup> – A progressive condition that has no cure and that can be reasonably expected to cause the death of a person within the foreseeable future.

### **3. Palliative and supportive care**

3.1 Throughout the course of a person's illness, they will receive care that is focussed on symptom management and comfort. Curative treatments, those treatments that attempt to cure a life-limiting illness or extend life, are accompanied by supportive care which focusses on symptom management.

3.2 When curative treatments are no longer considered to be effective, the goals of care change from curative, or life-extending measures, to comfort measures. At this time, the patient transitions from curative care to palliative care.

3.3 Palliative care provides not only physical support to maximise quality of life but also psychological, social, emotional and spiritual support. This includes support for families and friends such as grief and bereavement support.

3.4 Adequate funding for palliative care services, research and projects should be provided.

3.5 All patients have a right to receive relief from pain and suffering, even where that may shorten their life.

### **4 Equity of access to end of life care and other support services**

4.1 There should be equity of access across Australia to appropriate care including respite care, palliative care, bereavement support, carers' support and other relevant services to patients undergoing end of life care and their families and carers.

4.2 Limited health care resources should be used responsibly, fairly and effectively to ensure all patients receive appropriate end of life care.<sup>8</sup>

### **5 Conscientious objection<sup>ii</sup>**

5.1 The diversity of cultural and religious views and practices regarding end of life care are reflected within the medical profession itself. Doctors caring for patients at the end of the patient's life should be under no obligation to recommend or participate in a legally-recognised treatment or procedure related to end of life care to which they hold a conscientious objection.

5.2 In such a circumstance, the doctor should explain to the health care team involved, as well as the patient or the SDM, why they are not willing to recommend or participate in the treatment and inform the patient of their right to see another doctor. The doctor must be satisfied the patient has sufficient information to enable them to exercise that right and take whatever steps are necessary to ensure the patient's access to care is not impeded.

5.3 A doctor should always provide medically appropriate treatment in an emergency situation, even if that treatment conflicts with the doctor's personal beliefs and values.

### **6 The role of good communication and end of life care**

6.1 Good communication between the patient, their family members and carers, and the health care team should occur throughout the course of patient's illness to help alleviate fear, confusion and guilt over the patient's condition, assist with decision-making and reduce the potential for conflict over the patient's care.

6.2 Communication between the doctor and the patient (and family members/carers) should start early, allow adequate time for the patient (and others) to come to term with their condition, and be ongoing to address changes in the patient's condition, treatment options and goals of care. The

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<sup>ii</sup> For more information, see *AMA Position Statement on Conscientious Objection 2013*.

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process for decision-making along with the outcomes should be made clear to all participants involved and documented accurately.

## **7 Medical futility**

7.1 Doctors should understand the limits of medicine in prolonging life and recognise when efforts to prolong life may not benefit the patient. In end of life care, medically futile treatment can be considered to be treatment that gives no, or an extremely small, chance of meaningful prolongation of survival and, at best, can only briefly delay the inevitable death of the patient.<sup>9</sup>

7.2 Whilst doctors are generally not obliged to provide treatments that are considered medically futile, where possible it is important that the doctor discuss their reasons for determining a treatment to be medically futile with the patient (and/or the SDM, carers, family members) before deciding the treatment should not be offered.

7.3 In some cases, a treatment may not offer a benefit in terms of curing a patient's condition, or significantly extending life or improving quality of life, but it may benefit the patient in other ways. For example, a 'medically futile' treatment may briefly extend the life of the patient so he or she can achieve their wish of saying goodbye to a relative who is arriving shortly from overseas.

## **8 Cultural and religious influences on decision-making**

8.1 Australia is a culturally, linguistically and religiously diverse nation. The basic values, principles and assumptions of Western medicine are themselves culturally determined and may not reflect the same values, principles and assumptions of patients from different cultural backgrounds.<sup>10</sup>

8.2. Aboriginal people and Torres Strait Islanders have their own perspectives regarding death and dying. In addition, they may feel a lack of trust in or ambivalence towards western health care, including government services, that may become even more apparent in relation to end of life care.<sup>11</sup> Doctors caring for Aboriginal people and Torres Strait Islanders at the end of life may benefit by working in partnership with the Aboriginal controlled health organisations, where they exist.

8.3 Views may vary between cultures and religions on issues such as:<sup>10</sup>

- 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 or to even discuss death;
- 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 customary for a competent patient to make their 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.

8.4 Doctors should receive education and support in cultural and religious 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 and spiritual advisers.

## **9 Considerations regarding decision-making capacity**

9.1 A legally competent person has the right to make health care decisions including the right to refuse treatment such as life-sustaining treatment.

9.2 Some patients may have limited or impaired decision-making capacity at the time a specific health care decision must be made.

9.3 Patients with limited or impaired decision-making capacity may include:

- those who never had decision-making capacity;
- patients with a mental illness or other condition resulting in permanent impairment of decision-making capacity;
- patients with decision-making capacity for some, but not all, decisions;
- patients with fluctuating decision-making capacity.

9.4 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. Some patients will have sufficient capacity to make a supported decision, where the patient makes the decision themselves with the assistance of a support person, while others with insufficient capacity will require a substitute decision, where a decision is made on behalf of the patient by an SDM.<sup>7</sup>

9.5 Decisions about withdrawal of life-sustaining treatment in the case of a patient who has impaired decision-making capacity are more complex and vary from state to state.

## **10 Children and young people**

10.1 Children and young people under the age of 18 may be considered at law to have limited rather than impaired (unless otherwise relevant) decision-making capacity.

10.2 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 doctor.

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

## **11 Advance care planning**

11.1 It is important that advance care planning become part of routine clinical practice so that patients' wishes and preferences for health care, particularly end of life care, are known and met. Advance care planning can be part of a health care discussion with patients of all ages within the primary care environment or hospital setting. The planning process 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. It may involve family members, religious advisors, friends and other people the patient feels should be involved.

11.2 While there is increasing public awareness of ACDs, it is important to recognise that ACDs are only one component of advance care planning which is not a single process nor does it consist of simply completing a form such as an ACD. Rather, it is a wider process of ongoing reflection, discussion and communication of health care preferences that may result in oral and/or written directives.

11.3 While ACDs are an important component of advance care planning, their utility may be limited at times. For example, an ACD may be lost, unknown, invalid, the directions ambiguous, not applicable to the circumstances at hand or not recognised by another jurisdiction (eg., an ACD in one State may not be legally recognised by another state). This is why it is so important for patients to undertake the advance care planning process, which involves broader discussions to identify wishes and preferences and to communicate those to a range of people (eg., doctor, family members, friends) and record them in a variety of formats.

11.4 As ACDs are recognised in common law or authorised by legislation in some States, it is preferable that they record values, life goals and preferred outcomes of care rather than listing medical interventions to which the patient consents or refuses.<sup>2</sup> Outcomes based ACDs reduce problems such as healthy adults writing medical directions for an unknown future; unanticipated new treatments; medical directions being



too specific, too non-specific or ill-informed.<sup>2</sup> There is a significant risk of potentially uninformed or inadequately informed medical directions binding a more informed substitute at a later time which could prove detrimental to the person's health in ways he or she had not envisaged when the ACD was written.<sup>2</sup> Medical directions are best written by doctors in clinical care plans, informed by the person's ACD or ACP.<sup>2</sup>

11.5 Legislation should support doctors, and protect them from civil liability or criminal prosecution, if:

- they have followed the terms in an ACD that they reasonably believed to be valid, in good faith, and without negligence;
- they provide life sustaining treatment to a patient in an emergency situation where there is significant uncertainty from the terms of the ACD whether it was intended to apply to the current circumstances and the SDM cannot be immediately contacted<sup>2</sup>;
- they do not offer, refuse to provide, or choose to discontinue futile treatment in line with good medical practice.

11.6 The doctor has a key role in providing guidance and discussing treatment options related to incapacitating conditions and/or future health care options with patients. Doctors have a responsibility to ensure that patients engaged in advance care planning:

- are competent;
- 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 ACDs and other relevant documents; and
- are acting voluntarily (as best as the doctor can determine this).

11.7 ACPs should be reviewed as the patient's condition, and possibly treatment preferences, change. Patients should be urged to communicate any changes in their ACP to their SDM and other relevant individuals (this may include updating any formal directives such as ACDs). Doctors should record relevant discussions with the patient and any changes to the ACD, the ACP, or the clinical care plan in the patient's medical record, including both the local health record (encompassing the practice as well as the hospital) and the national electronic health record.

11.8 Where a patient has a written ACP, it is the responsibility of the patient, or SDM, to make the contents of the ACP known. Patients should be encouraged to give a copy of any written documents such as an ACD to their doctor, the SDM, 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 ACP, and where any written directives can be obtained. The patient may wish to carry notification on their person, stating that they have made an ACP.

11.9 There should be greater consistency in relation to recognising at law ACDs across all States and Territories. For example,

- determining the validity of an ACD;
- providing for an EPA (or similar SDM);
- providing for the recognition of a valid ACD from another State or Territory;
- under what clinical circumstances an ACD comes into effect.

11.10 There should be clear, nationally consistent guidance for:

- the preparation, notification and storage of ACDs; and
- the establishment of procedures for identifying an appropriate SDM when there is no ACD or EPA and the patient's medical circumstances are relevant.

11.11 In circumstances where an ACD is reasonably considered invalid, treatment should be provided in the patient's best interests until a decision is made by a court or tribunal.

11.12 End of life decision-making and care should be based on a collaborative process between the health team and the patient and their family and carers, where patient autonomy is balanced with good medical practice. Where legislation does exist, it should bring clarity in supporting patient autonomy, particularly in the right to refuse treatment, while protecting doctors in undertaking their clinical duties in line with good medical practice, particularly in emergency situations where there may be ambiguity, and in regard to doctors not being required to offer treatment which would not be of benefit to the patient.

## 12 Artificial nutrition and hydration

12.1 For some patients, their ability to take in food or fluid by mouth reduces or becomes compromised as their condition progresses; for example, through diminished consciousness, difficulty in swallowing or simply through loss of interest in food and fluids.

12.2 Like any medical intervention, the provision of artificial nutrition and hydration, or medically administered nutrition and hydration, is associated with potential burdens to the patient, such as the insertion and replacement of tubes in the body, which should be carefully considered along with any potential benefits.

12.3 As with other life-sustaining medical treatments, artificial nutrition and hydration may be withheld or withdrawn as a part of appropriate palliative care and in accordance with good medical practice.<sup>12,13</sup>

## 13 Bereavement

13.1 Bereavement is 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 bereavement is a major cost to healthcare.<sup>5</sup> The health care team can play a vital role in reducing the impact of bereavement on family members and carers by attempting to alleviate the burden and guilt associated with having to make treatment-limiting decisions.

13.3 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 Carers play an important and integral role in working with the health care team to support the patient's care during the end of life.

14.2 The health and well-being of carers is linked to the availability, quality, responsiveness and cost of support from health and community services.<sup>14</sup>

14.3 Appropriate respite care and other support services should be accessible for patients and carers.

14.4 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 Medical education programs should include relevant education, and continuing medical education, to provide the knowledge and skills to provide safe, competent and effective care to support patients and their families at the end of life.<sup>15</sup>

15.2 Whilst caring for patients at the end of life, all doctors should be:

- appropriately trained in communication with patients and their families;
- trained and mentored in the decision-making processes at the end of life that are in line with good medical practice;
- trained in the provision of palliative and supportive care or treatment that maintains the comfort and dignity of patients as they die;



- 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.

15.3 A well distributed, accessible and appropriately trained and skilled specialist and primary health workforce is required to meet the needs of people at the end of life living throughout Australia.<sup>15</sup>

15.4 General Practitioners require support in working with primary care and specialist interdisciplinary teams. They should have reasonable access to relevant end of life care specialists for clinical and ethical advice.

15.5 Doctors working in end of life care require appropriate support to address their own emotional and spiritual issues and to promote their own health and well-being. This includes education on developing coping strategies to minimise the personal impact of working in end of life care, opportunities for debriefing, as well as, counselling services.<sup>15</sup>

15.6 Appropriate end of life care requires a corresponding increase in resources to those providing end of life care. New and more comprehensive requirements for end of life care cannot be simply added on to the existing workloads of busy clinical staff.

## 16 Clinical settings

16.1 Some patients may be treated in more than one clinical setting through the course of their illness including inpatient hospital care, aged care facilities, palliative care facilities, intensive care (including neonatal intensive care) and at home. Support should be given to the development of services that will meet the changing requirements in patient care and support continuity of care between clinical settings.

16.2 Where possible, the patient should be cared for in the environment of their choice.

16.3 There should be appropriate integration of General Practice and hospital care to improve patient outcomes through better clinical management, improved continuity of care and reduced readmissions. High quality continuity of care requires that the care provided by hospitals be well coordinated with a patient's General Practitioner and, where applicable, a patient's residential aged care facility.

## 17. Community awareness

17.1 There should be community awareness and education in relation to end of life care, the approach to futile treatment and the role of advance care planning. Community awareness and education should be undertaken by government through appropriate general and targeted initiatives. Community awareness is not, and should not be assumed to be, the responsibility of doctors.

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- <sup>2</sup> The Clinical, Technical, and Ethical Principal Committee of the Australian Health Ministers' Advisory Council. *A National Framework for Advance Care Directives*. September 2011.
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- <sup>12</sup> Brightwater Care Group v Rossiter (2009) WASC 229.
- <sup>13</sup> Gardner; Re BWV.
- <sup>14</sup> Palliative Care Australia. *Carers and End of Life*. Position Statement.
- <sup>15</sup> Palliative Care Australia. *Workforce for quality care at the end of life*. Position Statement.