

POSITION STATEMENT

Issues Arising at the End of Life¹

2023

This document outlines the AMA's position on palliative care, end-of-life care and advance care planning.

1. Preamble

- 1.1 Doctors have an ethical duty to provide their patients with quality end-of-life care that strives to alleviate pain and suffering, uphold individuals' values and preferences for care and allows them to achieve the best quality of life possible.
- 1.2 Australia is a culturally, linguistically and religiously diverse nation. It is important to acknowledge that 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.
- 1.3 Quality end-of-life care is patient-centred. It is based on continuous, open, informed communication and collaboration between the patient, the doctor, the treating health care team, and, where appropriate, the patient's carers, family members and/or medical treatment decision-maker.
- 1.4 Quality end-of-life care involves:
 - treating the patient as an individual, with respect, dignity and compassion in a culturally safeⁱ and sensitive manner
 - respecting the patient's autonomy, goals and preferences for end-of-life care
 - providing impartial advice and treatment recommendations based on the patient's care preferences

¹ According to Palliative Care Australia, 'end of life' is the period when a patient is living with, and impaired by, a life-limiting illness, even if the trajectory is ambiguous or unknown. This period may be years in the case of patients with chronic or malignant disease, or very brief in the case of patients who suffer acute and unexpected illnesses or events, such as sepsis, stroke or trauma. Palliative Care Australia's *National Palliative Care Standards for All Health Professionals and Aged Care Services*. March 2022.

- empowering patients and, where appropriate, their family members and carers² to participate in managing their care
- meeting the patient's care needs and alleviating pain and suffering to the best extent possible through optimal management or referral for pain and symptoms as well as continuous and uninterrupted access to appropriate palliative care
- supporting the patient's cultural, psychological, emotional, religious and spiritual needs as well as the needs of their family members and carers
- supporting patients and their family members and carers to access quality palliative care resources as well as bereavement support in a timely manner
- facilitating care in the patient's environment of choice, where possible, recognising that a patient's needs and preferences may change as their condition progresses
- recognising the role of carers, doctors, nurses, allied health care professionals, other professional bodies, Non-Government Organisations (NGOs) religious bodies and the wider community in working together to meet patients' end-of-life care needs
- facilitating continuity and coordination of care within and between medical, health, social and community services including when the patient transitions from medical care that is primarily directed at treating the condition itself to palliative and supportive care only
- respecting the patient's privacy and confidentiality, even after death.

1.5 Death, dying and bereavement are all an integral part of life; however, even for health care professionals, reflecting on and discussing death with patients and their families can be profoundly confronting and difficult. Open and frank discussion and education in relation to death and dying should be encouraged and normalised within the medical profession and the wider community, addressing issues including the role and purpose of palliative care, advance care plans, non-beneficial treatment and bereavement.

1.6 End-of-life care strategies and initiatives should be based on deep and broad community consultation that includes communities and groups with diverse needs who may already experience health inequalities (eg. Aboriginal and Torres Strait Islander populations, the elderly, disabled individuals, those from culturally and linguistically diverse backgrounds, LGBTQIA+³ individuals, those in rural and remote regions, those in prison and immigration detention and neonates/children/adolescents).

² As outlined by Palliative Care Australia, the term 'family' includes people identified by the person as family. This may include people who are biologically related, however it may not. People who joined the family through marriage or other relationships such as kinship, chosen family, street family for those experiencing homelessness and friends (including pets) may be identified by the person as family. The term 'carers' may include family members and other members of the person's community (such as close friends or neighbours) who the person agrees to being involved in their care. A person may also choose not to have their family or carers involved in their care, or a person may not have any family or carers. Palliative Care Australia's *National Palliative Care Standards for All Health Professionals and Aged Care Services*. March 2022.

³ 'LGBTQIA+' is an umbrella term that brings together a range of diverse identities. It stands for 'Lesbian, Gay, Bisexual, Trans and/or Gender Diverse, Queer, Intersex, Asexual', with the '+' representing people who identify as part of a sexuality, gender or sex diverse community but who do not identify with one of these specific identities. See *AMA Position Statement on LGBTQIA+ Health 2021* at <https://www.ama.com.au/articles/lgbtqia-health-2021>

- 1.7 While this position statement broadly applies to patients of any age, there are certain unique characteristics and additional considerations that differentiate end-of-life care for children from that of adults.^{ii,iii}

2. Access to End-of-Life Care Services

- 2.1 Everyone deserves access to timely, affordable, high-quality end-of-life care regardless of where they live in Australia. Access requires sufficient and adequate planning, funding, training, coordination and clinical governance of health practitioners and health and related services.
- 2.2 End-of-life care is provided in a range of settings including domestic homes, residential aged care facilities (RACFs) and supported accommodation, general practices, hospitals, neonatal units and paediatric services.
- 2.3 End-of-life care encompasses a variety of services that support patients and their family members and carers including palliative care, hospice, respite care, bereavement support, carers' support, social and home supports, religious and spiritual supports, trained interpreters, culturally and linguistically diverse and Aboriginal and Torres Strait Islander health workers and information resources.
- 2.4 End-of-life care also includes voluntary assisted dying (VAD) in those States and Territories which have established VAD programs. Doctors working in States and Territories where VAD is available should familiarise themselves with the relevant legal issues and referral pathways. VAD specific issues are considered in a separate position statement.^{4,5}

3. Groups with Diverse Needs

- 3.1 End-of-life care services serve the needs of all communities to deliver equitable access to quality care. Groups with diverse needs may already experience health inequalities and face additional barriers in accessing end-of-life care. Examples of at-risk groups include those from culturally and linguistically diverse (CALD) communities,^{iv} LGBTQIA+ people,^v those living with addiction and substance abuse disorders, people living with

⁴ Refer to AMA *Position Statement on Euthanasia and Physician Assisted Suicide 2016* for further information regarding AMA policy on voluntary assisted dying. <https://www.ama.com.au/position-statement/euthanasia-and-physician-assisted-suicide-2016>.

⁵ Broadly speaking, voluntary assisted dying refers to the assistance provided to a patient by a health practitioner to end their life; for example, prescription of a lethal substance that the patient consumes or administering a lethal substance with the patient's consent for the purpose of causing death. Definitions, eligibility criteria and processes for requesting VAD are different in each State as referred to in specific legislation. For more information, it may be useful to refer to Queensland University of Technology's End of Life Law in Australia for a summary of State-based legislation. <https://end-of-life.qut.edu.au/assisteddying>

dementia, people who are incarcerated, people in immigration detention, people living with a disability and those experiencing homelessness.⁶

- 3.2 Identifying and eliminating barriers to end-of-life care for all communities aims to ensure that all individuals can be afforded equity, respect and dignity at the end of life.

4. Aboriginal and Torres Strait Islander People

- 4.1 Aboriginal and Torres Strait Islander people^{vi} can face barriers to accessing end-of-life care services such as (but not limited to):

- a lack of awareness/understanding of palliative care
- reluctance to talk about death and dying
- poor health literacy
- language and communication issues
- lack of translated, culturally appropriate resources
- poor access to professional interpretation services
- mismatching cultural, religious and/or health beliefs and preferences between individuals and service providers
- fear or mistrust of 'Western' medicine and/or healthcare providers and services
- a preference for family-based or kinship determined decision-making
- difficulty accommodating cultural practices in palliative care settings
- lack of/late referral to, or initiation of, palliative care
- racism, discrimination (historical and current) and cultural stereotyping
- financial disadvantage.

- 4.2 These barriers can be reduced by undertaking initiatives such as (but not limited to):

- community awareness-raising
- engagement between services and communities
- culturally-appropriate and translated resources
- culturally-appropriate engagement with individuals and families
- access to appropriately trained professional interpreting services
- community capacity-building (for palliative care provision and support)
- cultural competency
- cultural safety⁷
- trauma-informed approaches to care
- patient navigator initiatives
- involving culturally appropriate health practitioners.

⁶ Refer to Palliative Care Australia's *National Palliative Care Standards for All Health Professionals and Aged Care Services*. March 2022 for detailed guidance on supporting people from communities with diverse needs.

⁷ Cultural safety is central to Aboriginal and Torres Strait Islander peoples and their interaction with the health system, particularly as many feel a lack of trust in or ambivalence towards mainstream health care including government services. As outlined in the AMA's *Position Statement on Cultural Safety 2021*, cultural safety describes a state, where people feel enabled to access health care that is appropriate to their needs, expect to receive effective, high-quality care, have trust in the service, and challenge personal or institutional racism when it is encountered. Cultural safety is based on shared respect, and also means that there is no denial or challenging of Aboriginal and Torres Strait Islander identities and knowledges. Refer to AMA *Position Statement on Cultural Safety 2021* for more information on relevant AMA policy.

5. Children⁸

5.1 Children have specific end-of-life care needs⁹ such as:^{ii,iii,vii}

- The patterns and causes of death in children are not the same as those of adults (eg. many children have rare or nonmalignant conditions specific to childhood)
- End-of-life care for children is family-centred, supporting the child and their family
- The family has an increased role in decision-making and care
- Children are still developing, growing and learning, requiring specific physical, social, emotional and spiritual needs (such as play and education)
- A child's ability to communicate and understand varies according to their age, stage of development and underlying condition(s).

5.2 The specific needs of children must be included in any assessment of a community's end-of-life care requirements including funding, workforce and infrastructure.

6. Decision-Making Capacity and Informed Decision-Making

6.1 Adults

6.1.1 In Australia, a legally competent adult has the right to make their own informed health care decisions including refusal of treatment. To be legally competent, a person must have the decision-making capacity to comprehend and retain the information needed to make a specific health care decision at the time the decision is required. Competency is a complex concept and competence to make medical decisions can be dynamic and vary with time and situation. Adults are presumed to be competent unless there is evidence to the contrary.¹⁰

6.1.2 Some patients may have limited or impaired decision-making capacity such as those:

- who never had decision-making capacity
- with a condition causing permanent impairment of decision-making capacity
- with decision-making capacity for some, but not all, decisions

⁸ The term 'children' or 'child' includes infants, children and adolescents. Palliative Care Australia. *Paediatric Addendum. Palliative Care Service Guidelines*. December 2018.

⁹ For a range of comprehensive information on palliative care needs specific to children, refer to Palliative Care Australia. *Paediatric Addendum. Palliative Care Service Guidelines*. December 2018, Palliative Care Australia and Paediatric Palliative Care Australia and New Zealand's *Policy Statement. Paediatric Palliative Care*. 2019 and the Australian Commission on Safety and Quality in Health Care. *National Consensus Statement: essential elements for safe and high-quality paediatric end-of-life care*. Sydney: ACSQHC, 2016.

¹⁰ As defined in the Australian Department of Health's *National Framework for Advance Care Planning Documents*. May 2021, 'competency' is a legal term used to describe the mental ability required for an adult to perform a specific task. Competency is recognised in legislation and in common law as a requirement for completing a legal document that prescribes future actions and decisions, such as a will or an Advance Care Directive. Capacity refers to the ability to make a decision for oneself. When a person has capacity to make a particular decision they can: understand and believe the facts involved in making the decision; understand the main choices; weigh up the consequences of the choices; understand how the consequences affect them; make their decision freely and voluntarily; communicate their decision.

- with fluctuating decision-making capacity.

6.1.3 For some patients, the loss of decision-making capacity is progressive rather than immediate and fluctuates 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 will require a substitute decision, where a decision is made on behalf of the patient by a medical treatment decision-maker (MTDM).^{viii}

6.1.4 Doctors should be supported to understand the relevant laws that apply to competency, capacity and medical decision-making in their local jurisdiction.^{ix,x}

6.1.5 To support informed decision-making, patients (and their family members, carer and MTDM, as appropriate) require timely, appropriate and easily understandable information and communication from the health care team regarding their clinical condition throughout the course of their illness. The process and outcomes of decision-making should be clear to all participants and documented in the patient's medical record.

6.1.6 Communication should be culturally safe, sensitive and linguistically appropriate. Interpreters and culturally appropriate supports such as Aboriginal and Torres Strait Islander Health Workers, CALD workers and spiritual persons should be involved as required.

6.2 Issues specific to children

6.2.1 Parents generally have legal responsibility for making health care decisions related to their child; however, decisions must be made in the child's best interests in accordance with relevant legislation in their local jurisdiction.ⁱⁱ

6.2.2 Children and young people under the age of 18 may be considered at law to have limited rather than legally impaired (unless legally relevant) decision-making capacity. As a child develops, the doctor may determine they have become Gillick competent or 'mature minors'¹¹ and have capacity to make certain treatment decisions for themselves.^{xi,xii} The determination of capacity should be recorded in the medical record.

¹¹ The legal test used to determine if a child is capable of giving consent is when he or she "achieves a sufficient understanding and intelligence to enable him or her to understand what is proposed." (Gillick v West Norfolk and Wisbech Area Health Authority [1986] AC 112). This is referred to as 'Gillick competent' or a 'mature minor.' Avant factsheet. *Children and Consent*. 16 August 2019. <https://www.avant.org.au/Resources/Public/Children-and-consent/> (accessed 31 August 2022).

6.2.3 A child should be supported to participate in their own health care decisions as appropriate to their capacity at the time a decision needs to be made.^{viii,12}

6.2.4 In Australia, a competent child may refuse health care treatment provided it is in their best interests; however, the Court may overrule a refusal that would have grave consequences, place a child's life at risk, or result in the child's death, if this is not in the child's best interests. The law in this area is complex and legal advice should be sought if there is any doubt.

7. Advance care planning

7.1 Definitions:¹³

- Advance care directives (ACDs)– ACDs are voluntary, person-led documents completed and signed by a competent individual outlining their values and preferences for future care decisions including preferred outcomes of care. ACDs are recognised by State and Territory specific legislation (statutory) or under common law (non-statutory) and come into effect when an individual loses decision-making capacity. ACDs can also appoint MTDMs who are authorised to make decisions about health or personal care on the individual's behalf. A MTDM may be appointed by the person, appointed for (on behalf of) the person, or identified as the default decision-maker within legislation.
- Advance care plans (ACPs) - ACPs are documents that capture a person's beliefs, values and preferences in relation to future care decisions, but which do not meet the requirements for statutory or common law recognition due to the person's lack of competency, insufficient decision-making capacity or lack of formalities (such as inadequate person identification, signature and date). While ACPs are not legally binding, they can serve as excellent tools to facilitate and document communication and assist in guiding decisions about the person's future care.
- Advance care planning – This is a voluntary process of planning whereby a person's values, beliefs and preferences are made known to guide health care decision-making at a future time when they cannot make or communicate their decisions.^{xiii,xiv}
- Comprehensive clinical care plan – A care plan (written or electronic) prepared by doctors together with the patient (where possible), their family and carers (where appropriate) and other health professionals describing agreed goals of care and planned medical, nursing and allied health activities (for example, resuscitation plans).¹⁴ These plans can be put in place whether or not the person has an ACD or

¹² There are limits on whether a parent, guardian or mature minor can consent to 'special medical procedures' on a child. This involves situations where there is a significant risk of a wrong decision being made, the treatment involves grave consequences, it is irreversible and invasive, and there may be conflicting interests amongst a child, their parent and treating practitioners. In many cases involving these treatments, Court approval will be required. There are also additional laws relating to treatment of minors in South Australia, Victoria and New South Wales. In essence, these clarify when and how the mature minor test operates. If you are working in a public hospital, there may also be policies and protocols in place around when treatment can be given to minors without parental or guardian consent. There can be situations where a Court would overrule a mature minor's refusal if it is not in their best interests. These situations may include decisions which would lead to a child's death or have other very serious consequences. MIGA. *Consent for minors*. Accessed 1 June 2022. <https://www.miga.com.au/education/resources/Consent/Consent-for-Minors>

¹³Definitions from the Australian Department of Health's *National Framework for Advance Care Planning Documents*. May 2021, unless otherwise indicated.

¹⁴ As defined by NSW Health, a resuscitation plan is a medically-authorised order to use or withhold resuscitation measures and document other aspects of treatment relevant at end of life. Decisions to withhold cardiopulmonary resuscitation (CPR) and other resuscitation measures seek to avoid unwanted,

ACP; however, the care plan should complement and be informed by the person's ACD or ACP, if available.

- Goals of care – These describe what a patient wants to achieve during their care and may include clinical as well as personal goals.¹⁵ Goals of care are completed by doctors but should align with the patient's preferred health outcomes and treatment decisions.
- Medical treatment decision-maker (MTDM) – A person appointed to make medical treatment decisions on behalf of a patient who does not have decision-making capacity. The MTDM's legal authority only comes into effect when the person does not have capacity to make the medical treatment decision at hand.¹⁶

- 7.2 The key purpose of end-of-life planning is to support future decisions which are consistent with patients' values through respectful dialogue involving the patient, family and carers.
- 7.3 Consistency across jurisdictions with respect to legislation, terminology and documentation to support patients in advance care planning is critical. A failure to achieve this leads to systemic problems where some patients have inappropriate and unwanted health care.
- 7.4 Advance care planning respects the patient's right to take an active role in their health care. It can be undertaken with patients of all ages within the primary care environment or hospital setting and should be part of routine clinical practice.
- 7.5 Advance care planning is a wider process of ongoing reflection, discussion and communication of health care preferences that may result in oral and/or written documents such as an ACD or ACP.
- 7.6 Patients are strongly encouraged to discuss advance care planning with their doctor. They may also wish to involve others in planning such as family members and religious advisers. Patients are encouraged to inform their doctor, the MTDM, family members and carers, and, where relevant, residential aged (or other) care facility (RACF) that they have an advance care planning document, keep them informed of any updates to their plan and provide them with copies of their current plans. Patients are encouraged to

excessively burdensome or insufficiently beneficial interventions for patients at the end of life. At some point in the course of life limiting illness, a shift in the focus of care away from aggressive intervention and towards a palliative approach is often the agreed outcome. NSW Health. *Use of Resuscitation Plans in Decisions at the End of Life. Evidence Check.* September 2021.

¹⁵ As outlined in the Australian Department of Health's *National Framework for Advance Care Planning Documents*. May 2021, medical goals of care may include attempted cure of a reversible condition, a trial of treatment to assess reversibility of a condition, treatment of deteriorating symptoms, or the primary aim of ensuring comfort for a dying patient. Non-medical goals of care may include returning home or reaching a particular milestone, such as participating in a family event.

¹⁶ A medical treatment decision-maker is sometimes referred to as a substitute decision-maker. For more information on medical treatment decision-makers refer to the Office of the Public Advocate Victoria. <https://www.publicadvocate.vic.gov.au/medical-treatment/medical-treatment-decision-makers>

upload any health directives into their My Health Record which will provide easy access to doctors and other health practitioners involved in the patient's care.

7.7 The role of the doctor in advance care planning

7.7.1 When discussing advance care planning with patients, doctors need to be aware of their own values, biases and external influences and their potential to impact on clinical decisions.

7.7.2 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
- are acting voluntarily (as best as the doctor can determine this)
- understand the purpose of an ACD or ACP and when it is utilised.

7.7.3 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 My Health Record.

7.7.4 Advance care planning documents should be reviewed as the patient's condition progresses and treatment options or goals of care change. The most senior doctor available with an understanding of the patient's clinical situation should be involved in advance care planning where practicable. Additional guidance (and support by senior doctors) should be provided to junior doctors where required.

7.7.5 There must be comprehensive transfer of a person's ACP or ACD and other related information between all relevant health care settings; for example, when transferring to hospital via ambulance both the hospital and ambulance staff should be made aware of the information. In particular, clear, concise instructions (preferably accompanied by medical history) should be made available to responders in emergency situations who may not know the patient, especially with respect to matters such as resuscitation.

7.7.6 The AMA believes that RACF residents must have a current ACD which can include their wishes and preferences for hospital transfer at times of acute care need, recognising

that older people have a right to receive palliative care and to die in the RACF they are residing in, if that is the place of their choosing.^{17, xv}

7.7.7 Advance care planning documents should be created, stored, accessed and transferred consistent with privacy legislation.

7.8 Issues specific to children

7.8.1 Advance care planning can help children and young people talk with their family, carers and doctors about their values and wishes regarding future health care preferences; however, end-of-life care for children requires a cautious and sensitive approach to advance care planning, which may or may not be appropriate depending on the circumstances, age of the patient and family support.

7.8.2 Parents should be offered the opportunity to consider advance care planning, if circumstances are appropriate; however, parents and children will vary in how and when they choose to participate in decision-making for the future and their views should be respected.^{xvi}

7.9 Instructional directives

7.9.1 MTDMs and health practitioners should act in good faith to reflect an individual's values and preferences outlined in their advance care planning document into treatment decisions.

7.9.2 Some patients may include instructional directives in their ACD regarding refusal of treatment and/or specific health care procedures (for example, blood transfusions or cardio-pulmonary resuscitation) and the specific circumstances in which they intend for them to apply. Patients should be supported to fully understand and appreciate the potential applications and unintended consequences of instructional directives.^{xiii}

7.9.3 A relevant and medically indicated instructional directive should be followed and not overruled by an MTDM or doctor, even where the instruction involves refusal of treatment.^{xiii}

7.9.4 Doctors are not obliged to provide care that is not clinically appropriate and instructional directives cannot be used to compel treatments that are illegal or of no medical benefit.

¹⁷ Refer to the AMA *Position Statement. Palliative Approach in the Aged Care Setting 2020* for further information on related AMA policy.

7.10 Protection for doctors, other health practitioners and MTDMs acting on advance care planning documents

7.10.1 MTDMs, doctors and other health practitioners who are acting in good faith on an advance care planning document should be legally protected from civil and criminal liability.

7.10.2 MTDMs, family members and health practitioners may seek dispute resolution if they are concerned a health care decision made on a person's behalf does not reflect their ACP or ACD. The process should focus on timely resolution, involvement of relevant parties and be carried out in line with the jurisdictions' legislative and common law requirements.

7.11 Nationally consistent approach to advance care planning legislation

7.11.1 Australian States and Territories have different advance care planning legislation which can result in confusion for doctors as well as patients, their MTDMs and family.

7.11.2 A nationally consistent approach to advance care planning will reduce confusion and medico-legal risk for doctors and increase the uptake of advance care planning by patients.

7.12 Resourcing for advance care planning

7.12.1 There must be ongoing and appropriate funding, rebates and other support for all aspects of the advance care planning process across relevant health settings and during transitions of care. This includes resourcing for developing, and updating, ACP documents and for staff in the acute care and related hospital settings to undertake relevant communication, record transfer and information transfer aspects.

8. Palliative Care

8.1 The *National Palliative Care Strategy 2018*^{xvii} defines palliative care as an approach that improves the quality of life of patients and their families facing the problems associated with life-limiting illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms

- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death offers a support system to help the family cope during the patient's illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

8.2 Palliative care focuses on addressing patients' physical needs such as alleviating pain and suffering and reducing unwanted treatments and those of no medical benefit while supporting their cultural, psychological, social, emotional and spiritual needs, all of which may vary as the person's health fluctuates with periods of deterioration, stabilisation and sometimes improvement.ⁱⁱ It is critical that a patient's care needs, goals of care and care plan are regularly reviewed and updated to reflect their changing needs throughout the disease trajectory.

8.3 All doctors should endeavour to provide, or support their patients to access, quality palliative care across a range of clinical settings including the hospital, community-based settings and RACFs as well as the home setting, where appropriate. A range of clinical treatments and interventions can be used in palliative care including the administration of palliative medications along with interventions such as surgery for symptom relief and improvement of quality of life.^{xviii} Palliative care can be given early to manage symptoms throughout the disease trajectory including alongside treatments directed at the disease itself.

8.4 Patients at the end of life have the right to receive relief from pain and suffering even where this may shorten their life. There should be nationally consistent legislation that protects a doctor responsible for the treatment or care of a patient at the end of life, or a person participating in the treatment or care of the patient under a doctor's supervision, from incurring civil or criminal liability by administering or prescribing medical treatment with the intention of relieving pain or distress:

- with the consent of the patient or the patient's representative, and
- in good faith and without negligence, and
- in accordance with the proper professional standards, even though an incidental effect of the treatment may be to hasten the death of the patient.

8.5 For some patients, their ability to take in food or fluid by mouth reduces or becomes compromised as their condition progresses. As with other life-sustaining medical

treatments, medically administered nutrition and hydration may be withheld or withdrawn as a part of appropriate palliative care and in accordance with good medical practice.

- 8.6 Doctors should understand the limits of medicine and recognise when efforts to prolong life provide little or no medical benefit (or cause actual harm) to the patient.
- 8.7 Unless required by law, doctors are generally not obliged to provide non-beneficial treatment; however, where possible a doctor should discuss their reasoning with the patient, MTDM and family members (as appropriate) before deciding not to offer the treatment. In some cases, a treatment that is non-beneficial in the long term may enable the patient to fulfil a personal wish or desire in the short term. For example, briefly extending the life of the patient to allow time for long-distance relatives to visit before the person dies.

8.8 Issues specific to children

- 8.8.1 Palliative care for children is family-centred, focused on improving the quality of life for the child as well as support for the whole family and carers.^{iii,vii} Early consultation with the palliative care team is particularly beneficial for children, their families and carers to discuss and plan for the management of future palliative care needs.ⁱⁱ
- 8.8.2 In addition, the provision of early, community-based services is particularly important in the context of paediatric palliative care.^{iii,vii}
- 8.8.3 Integrated grief and bereavement support is particularly important for the child, their family and their community as well and includes support in preparing for the death of the child, understanding the process of dying and bereavement support after death.^{iii,vii}
- 8.8.4 Parents and guardians should be offered guidance on how best to talk to their child, along with their other children, regarding the child's condition, treatment and related issues.

8.9 Funding for palliative care

- 8.9.1 Palliative care must be affordable for patients and their families and services providing care must be appropriately remunerated, including the provision of care in rural and remote areas and for those with specific needs.^{xix}
- 8.9.2 Palliative care services can take pressure off the health system through reduced health service utilisation (such as fewer hospital transfers and admissions, shorter hospital

stays and reduced use of Intensive Care Units and Emergency Departments), improved coordination of the health care system, improved productivity and well-being for carers and reduced bereavement costs.^{xx,xxi}

8.9.3 As such, there must be appropriate, ongoing investment in palliative care delivery including in specialised services, general practice and RACFs, workforce development, research and data collection in order to keep up with demand for services, which itself is likely to increase due to Australia's ageing population.^{xxii} There should be accountability and transparency of funded systems including their performance in areas such as access, care transition and coordination and patient and family satisfaction.

9. Obligations in relation to death of a patient

9.1 Doctors should be aware of their legal obligations when their patient dies in relation to issues such as certification of death, referral to the coroner, cremation permits and storage, retention and access to the deceased person's medical records.^{xxiii, xxiv}

9.2 The rules regarding certification of death differ in each State and are often covered by a range of legislation and regulations. Doctors should seek advice from their medical defence organisation or other appropriate entity if unsure of their legal obligations.

10. Grief and Bereavement

10.1 Resources on managing grief and bereavement and where possible referral to support groups should be made available to patients' family and carers.¹⁸

10.2 The death of a child is a particularly traumatic event for their family and surrounding community which can result in prolonged, or even lifelong grieving.

11. Carers

11.1 Carers play an important and integral role in working with the health care team to support the patient's health care needs; however, caregiving itself can result in physical, emotional and financial strain that compromises the carer's own health and well-being.

¹⁸ Grief is the response to loss that can affect thoughts, behaviours, beliefs, feelings, physical health and relationships with others while bereavement is the process of grieving and the period of mourning that is entered after someone has died. Defined in the Palliative Care Australia (PCA) and the Australian Centre for Grief and Bereavement (ACGB) *Joint Statement on Grief and Bereavement*. August 2018.

- 11.2 Carers should be supported within the community to provide appropriate care to the patient through services such as:^{xxv}
- improved access to timely in-home support (including services, personal care, equipment, information, education, training and resources)
 - expanded access to planned and emergency respite care services (in-home or centre-based)
 - early identification of carers' financial, emotional and physical health needs, including during bereavement.

12. Health Workforce and System Development

- 12.1 A well distributed, accessible and appropriately trained and skilled health workforce is required to meet the needs of people at the end of life throughout Australia.
- 12.2 The end-of-life and palliative care workforce is made up of a broad range of professional groups such as general practitioners, specialist palliative medicine physicians, other medical specialists, palliative care nurses and pharmacists as well as other allied health professionals and support staff. Each of these groups, along with volunteers, family members and carers, as well as religious and other community groups, play a unique and vital role in supporting people with a life limiting illness to receive comprehensive, patient-centred care.^{xxvi}
- 12.3 Investment in workforce development and training is essential for improving access to palliative care throughout Australia.^{xvii} This requires greater access to specialist palliative care providers, greater delivery of palliative care by non-specialist palliative care providers and increasing understanding and awareness of palliative care among health and social care providers not directly involved in its provision.^{xviii}
- 12.4 Appropriate investment in workforce development and training is also required to ensure there are a sufficient number of specialist paediatric palliative care clinicians accessible throughout Australia along with a greater capacity of health professionals providing support to children receiving palliative care, their families and carers.ⁱⁱⁱ
- 12.5 In rural and remote Australia, where services are limited, there should be flexible delivery of end-of-life care established through services such as outreach (including 'pop-up visits') or telehealth services. Doctors working in rural and remote regions should be supported to develop knowledge and skills in end-of-life care and to access relevant specialists as required.

12.6 Workforce development approaches must be supported by relevant organisational structures and systems including policies, protocols and funding arrangements in order for them to be effective.^{xvii}

12.7 Education and training

12.7.1 In order to obtain the knowledge and skills to provide safe, competent and effective care to support patients and their families at the end of life, relevant medical education and training should begin early in training programs (eg, undergraduate courses) and extend throughout continuing professional development.^{xvii}

12.7.2 Education and training including continuing professional development should include (but not be limited to):^{xxv}

- the relevant aspects of clinical care including the ability to recognise when a patient is nearing the end of life including babies, children and young people
- skills in effective and sensitive communication with patients (including those with limited decision-making capacity), their families, carers and MTDMs
- knowledge on basic anticipatory prescribing and medications used in palliative care
- the ethical, legal and practical aspects of end-of-life care such as advance care planning, guardianship, privacy, VAD and withholding and withdrawing life-sustaining treatment
- understanding grief and bereavement and identifying prolonged grief disorder
- self-care including the ability to identify one's own mental health needs (such as moral distress or burnout) as well as when colleagues may need mental health support¹⁹
- providing culturally safe and culturally responsive care.

12.7.3 Medical students and doctors-in-training should receive appropriate supervision and support from senior doctors when providing end-of-life care to patients.²⁰

12.7.4 Palliative care is largely provided by General Practitioners and the patient's regular carers. GPs should have access to both education and support in palliative care provision and regular care staff including those working in RACFs should be upskilled to be able to provide the bulk of routine palliative care in house.^{xv}

¹⁹ One good resource is <https://palliativecare.org.au/resource/re3sources-self-care-matters/>

²⁰ Refer to *AMA Position Statement on Building Capacity for Clinical Supervision of Non-Fellowed Doctors 2023* for further information on clinical supervision of medical practice and training.

12.8 Collaboration and teamwork

- 12.8.1 A wide range of integrated and multidisciplinary services work together to provide quality end-of-life care. This includes a variety of health care professionals such as doctors nurses, allied health professionals (such as occupational therapists, physiotherapists, dieticians, hospital and community pharmacists, social workers, psychologists and speech pathologists), Aboriginal and Torres Strait Islander health workers, paramedics, professional carers, grief counsellors and language services along with aged care providers.^{xxv} Pastoral carers and spiritual advisors can be important members of the interdisciplinary team along with others such as music and art therapists.
- 12.8.2 With the doctor at the centre of the health care team, the roles and responsibilities of different team members should be clearly defined and understood by all those involved in a patient's care including the patient themselves and their family members, carers and MTDM.^{xxv}
- 12.8.3 Patients may be treated by a variety of clinical staff in more than one clinical setting including inpatient hospital care, RACFs, palliative care facilities, intensive care (including neonatal intensive care) as well as at home. Effective communication, collaboration and teamwork is required to ensure continuity and coordination between health care teams, within and in the transition between care settings, and across multiple episodes of care.^{xxvii}
- 12.8.4 Adequate resources for support should be available to enable GPs, primary care and specialist and interdisciplinary teams to work together. All health practitioners involved in a patient's care should have reasonable access to relevant end-of-life care specialists for clinical and ethical advice. 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 RACF.^{xxv}
- 12.8.5 The older person's usual GP should be central to provision and coordination of palliative care in the RACF setting. RACFs must be appropriately equipped to support doctors' access to patients and their files, allow a palliative approach to be provided effectively and at the earliest opportunity. RACFs need to be adequately staffed with the right skill mix available to provide quality care at all hours for patients needing palliative care, including staff qualified to administer pain and palliative care medications.^{xv}

12.9 Managing conflict

- 12.9.1 All team members should be supported to engage with the broader team and encouraged to voice any concerns they may have in relation to the patient's care.^{xxv}
- 12.9.2 Where conflict or lack of clarity exists between the health care team and the patient and/or family members/carers, clinicians should be made aware of, and provide education on, the processes and resources available to reach an acceptable resolution.
- 12.9.3 The health care team may involve a person who is skilled in mediation, medical ethics and the law when trying to manage conflict, complex family dynamics or ethical dilemmas.^{xxv}

12.10 Support for doctors working in end-of-life care

- 12.10.1 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 and training on developing coping strategies to minimise the personal impact of working in end-of-life care, access to peer support, mentoring and appropriate clinical supervision, counselling, debriefing and doctors' health services. This support is particularly important for doctors working in isolated or poorly supported settings.

13. Palliative and End-of-Life Care Research

- 13.1 Increased and ongoing investment in quality improvement and research in palliative care is needed to meet the increased demand for palliative care services, and improve the care provided for people throughout Australia, particularly those from underserved population.^{xvii,xx} Reliable, accurate and comprehensive palliative care data can improve quality of care and health outcomes by assisting policymakers, palliative care providers, researchers and the general public to better understand the nature of and demand for palliative care including population trends and the quality of service delivery responses.^{xvii,xxiv}
- 13.2 Investment should include greater funding for paediatric palliative care research in order to address the unique illness trajectories, experiences and needs of children and their families.ⁱⁱⁱ

13.3 In order to maintain and continuously improve the standard of palliative care and broader end-of-life care delivery in Australia, it is important that health care providers engage in quality improvement activities and participate in relevant research.^{xxv}

ⁱ Australian Medical Association. *Position Statement on Cultural Safety 2021*

ⁱⁱ Australian Commission on Safety and Quality in Health Care. *National Consensus Statement: Essential Elements for Safe and High-Quality Paediatric End-of-Life Care*. Sydney: ACSQHC, 2016

ⁱⁱⁱ Palliative Care Australia. *Paediatric Addendum. Palliative Care Service Development Guidelines*. December 2018

^{iv} Australian Government. Department of Health. *Exploratory Analysis of Barriers to Palliative Care. Issue Report on People from Culturally and Linguistically Diverse Backgrounds*. September 2019

^v Australian Government Department of Health. *Exploratory Analysis of Barriers to Palliative Care Issues Report on People Who Identify as Lesbian, Gay, Bisexual, Transgender or Intersex*. September 2019

^{vi} Australian Government. Department of Health. *Exploratory Analysis of Barriers to Palliative Care. Issue Report on Aboriginal and Torres Strait Islander Peoples*. September 2019

^{vii} Palliative Care Australia and Paediatric Palliative Care Australia and New Zealand. *Policy Statement. Paediatric Palliative Care*. February 2019.

^{viii} Queensland University of Technology. *End of Life Law in Australia. Withholding and Withdrawing Life-Sustaining Treatments for Adults, and Guardianship Law*. Accessed 27 October 2022. <https://end-of-life.qut.edu.au/treatment-decisions/adults>

^{ix} Queensland University of Technology. *End of Life Law in Australia. Capacity and Consent to Medical Treatment*. <https://end-of-life.qut.edu.au/capacity>. Accessed 15 March 2023.

^x Avant. Fact Sheet. *Consent. The Essentials*. <https://www.avant.org.au/Resources/Public/Consent-essentials/>. Accessed 15 March 2023

^{xi} Avant. Fact Sheet. *Children and Consent*. 2019. <https://www.avant.org.au/Resources/Public/Children-and-consent/>. Accessed 1 June 2022

^{xii} MIGA. *Consent for minors*. <https://www.miga.com.au/education/resources/Consent/Consent-for-Minors>. Accessed 1 June 2022

^{xiii} Australian Government. Department of Health. *National Framework for Advance Care Planning Documents*. May 2021.

^{xiv} Advance Care Planning Australia. <https://www.advancecareplanning.org.au/understand-advance-care-planning/advance-care-planning-explained>. Accessed 28 April 2022.

^{xv} Australian Medical Association. *Position Statement. Palliative Approach in the Aged Care Setting 2020*.

^{xvi} Palliative Care Australia. *Paediatric Palliative Care. Advance Care Planning*.

^{xvii} Australian Government. *Department of Health. National Palliative Care Strategy 2018*.

^{xviii} Royal Australasian College of Surgeons, Australian College of Rural and Remote Medicine, Australian College for Emergency Medicine, The Royal Australasian College of Physicians, the Australian & New Zealand College of Anaesthetists. *PG67(G) Guideline for the care of patients at the end-of-life who are considered for surgery or interventional procedures*. 2022

^{xix} Australian Government Department of Health *Exploratory Analysis of Barriers to Palliative Care Summary Policy Paper* September 2019

^{xx} Palliative Care Australia and KPMG. *Investing to Save. The economics of increased investment in palliative care in Australia*. May 2020

^{xxi} Palliative Care Australia. *Economic Research Note 1, July 2017. The Economic Value of Palliative Care and End-of-Life Care*

^{xxii} Palliative Care Australia. *Roadmap 2022-2027*. 2022

^{xxiii} Avant. *When a former patient dies: Completing the death certificate*. 16 November 2022

^{xxiv} Avant. *Medical records of deceased patients*. 13 August 2019

^{xxv} Palliative Care Australia. Consumers Health Forum of Australia. Carers Australia. *Consensus Statement. Carer and Consumer Engagement in Palliative Care and End-of-Life Care*. 2018

^{xxvi} Australian Institute of Health and Welfare. *Palliative Care Services in Australia. Summary*. 2022.

^{xxvii} Australian Commission on Safety and Quality in Health Care. *National Consensus Statement: essential elements for safe and high-quality end-of-life care*. Sydney: ACSQHC, 2015

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