

**A NATIONAL FRAMEWORK  
FOR ADVANCE CARE DIRECTIVES  
CONSULTATION DRAFT  
2010**

**THE CLINICAL, TECHNICAL AND ETHICAL PRINCIPAL COMMITTEE OF THE  
AUSTRALIAN HEALTH MINISTERS' ADVISORY COUNCIL**



This Advance Care Directives Framework was prepared by a Working Group of the Clinical, Technical and Ethical Principal Committee of the Australian Health Ministers' Advisory Council that advises the Australian Health Ministers' Conference.

The Advance Care Directives Working Group comprised members with backgrounds in: health law; health ethics; health and aged care policy development; and clinical care, including intensive care and palliative care.

Copies of the Advance Care Directive Framework can be downloaded from [www.hwlebsworth.com.au/acdframework](http://www.hwlebsworth.com.au/acdframework)

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## Acronyms used in this document

ACP	advance care plan/planning
ACD	Advance Care Directive
CPR	cardiopulmonary resuscitation
EPA	Enduring Power of Attorney
EPG	Enduring Power of Guardianship
RPCP	Respecting Patient Choices Program
SDM	substitute decision-maker



## 1 Why is a national Framework needed?

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Many people fear a loss of autonomy and dignity and being unable to make their preferences known when crucial health and other personal decisions are required after they have lost decision-making capacity. There is community support for self-determination, particularly in end-of-life matters, and for appointing trusted substitute decision-makers (SDM) to convey preferences when decision-making capacity is impaired.

Advance Care Directives (ACDs) provide a means for people to plan ahead for these situations. They are not simply advance medical directions written by a patient, and are not limited to end-of-life decision-making. They are life-management documents which people complete in home, community, hospital and aged care settings. When completing Advance Care Directives, people are not usually seeking to control medical treatment decisions; they are rather hoping to live well and die with dignity in accord with their personal values.

Although such ACDs are used in all Australian states and territories, they take different forms and names and, although recognised under common law, may be prescribed by legislation. This high level of variability makes it difficult for one jurisdiction to legally recognise an ACD from another. A further difficulty has been the lack of case law in Australia to provide direction on the legality of an ACD and how an ACD may be followed in practice.

In this context, Australia's Health Ministers have recognised the need for a national scheme for ACDs and have decided the challenges posed by divergent laws and the concerns expressed about the use and application of ACDs would be best addressed by a national Framework. This Framework acknowledges the practical and ethical challenges and the diversity of legislation across Australia, but also the potential improvements ACDs may make to care and decision-making during times of impaired capacity, especially towards the end of life.

### 1.1 What is the purpose of this Framework?

This national Framework combines new and existing concepts and is intended to be aspirational; that is, it describes the goals to which policy and practice should aim rather than reflecting current practice across Australia.

This Framework aims to work towards the following objectives.

- Greater use of advance care planning will assist the community to recognise the limits of modern medicine and the role of 'health-promoting' palliative care.
- Mutual recognition of Advance Care Directives across all states and territories will be facilitated through harmonisation of formats and terminology.
- Growing numbers of Australians will contemplate their future potential loss of decision-making capacity, and will appreciate the benefits of planning where and how they will live and be cared for, and of communicating their future life and care choices in advance.
- Advance Care Directives will be well established across Australia as a means of ensuring that a person's preferences can be known and respected beyond the loss of decision-making capacity.
- Decisions by substitute decision-makers chosen and appointed under Advance Care Directives will be respected and will reflect the preferences of the person.
- Advance Care Directives will be readily recognised and acted upon with confidence by health and aged care professionals, and will be part of routine practice in health and aged care settings.
- Clinical care and treatment plans written by health care professionals will accord with the person's expressed values and preferred outcomes of care as recorded in their Advance Care Directive.

### 1.2 What does this Framework comprise?

This Framework includes a Code for Ethical Practice and a set of Best Practice Standards that are designed to work together and are underpinned by nationally agreed terminology.

- This Framework was developed within the context of a high level of variability in approaches to ACDs across Australia and the challenges involved in writing, interpreting, applying and abiding by ACDs (see Section 2).
- The establishment of a Code for Ethical Practice and Best Practice Standards for ACDs requires the development and use of a common language. As the term 'Advance Care Directive' and other related terms have different meanings in different states and territories, a nationally agreed lexicon of common terms has been developed to explain how terms are used in this Framework (see Section 3).
- The Code for Ethical Practice (see Section 4) sets out principles to guide practice where ACDs are applied in health and aged care settings. Most of the principles and standards in this Framework can be applied within current legal and policy systems.
- The Best Practice Standards (see Section 5) seek to enable policy, legislation and practice to become more consistent across Australia over time and allow for the recognition of ACDs across jurisdictional boundaries.

### 1.3 Who is the intended audience?

This Framework is primarily intended to inform policy-makers of the key ethical and practical aspects of ACDs and so is not aimed at the general public. It describes a consistent approach for regulators, policy-makers and advance care planning administrators across governments and the health and aged care sectors and takes account of the needs and expectations of the community.

Policy and legal officers in government departments are encouraged to review their policies and laws that establish ACDs in the light of the Code for Ethical Practice and the Best Practice Standards. Government departments are encouraged to check terms used locally against the agreed terminology and over time seek to harmonise local use with the national terminology to enable a national scheme of consistent ACDs to develop. Guidelines, procedures and protocols should be assessed against this Framework and adapted as necessary to comply to the extent that current legislation permits, and then reassessed when changes to legislation are contemplated.

Advance care planning program administrators should similarly assess their programs against the Code for Ethical Practice, the Best Practice Standards and the agreed terminology and seek to bring their programs into line with this Framework.

### 1.4 When does this Framework apply?

This Framework only seeks to address issues of health and aged care decision-making where there is an ACD in place, whether or not that ACD appoints a SDM. It does not apply to or affect the operation of other statutory directives that allow for only financial and legal decisions.

There are many challenges for families and for health and aged care professionals in making decisions for others, especially at the end of life; not all of these are relevant to ACDs. However it is acknowledged that this Framework may influence decision-making practices where there is no ACD in place.

This Framework places ACDs within a broad context:

- ACDs are relevant to adults at all stages of life — they can be completed by competent adults whether they are healthy and active, recently diagnosed, chronically ill, or at the end of their life.
- ACDs can relate to any future time of reduced capacity, not just at the end of life — they can be activated during temporary periods of impaired or lost decision-making capacity such as an episode of mental illness or transient unconsciousness.
- ACDs cover health and personal care, not just medical treatment — they recognise that health has emotional and spiritual as well as physical dimensions, and can also address residential and other personal matters.

The Best Practice Standards apply to policies, legislation and guidelines that cover health and life-management decision-making by:

- people who have been appointed as SDMs under an ACD; and
- health and aged care professionals and family members who make substitute decisions where a person has recorded directions in an ACD but has not personally appointed a SDM.

## 2 What is the context for this Framework?

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The nature of our lives and deaths has changed progressively over the last century. Due to a combination of medical progress, science and socioeconomic factors, those who live in OECD countries can now expect to live longer on average than at any time in human history.

In the past, serious illness, infections or injuries usually led to a fairly rapid death. Unless death is sudden, most of us can now expect to face an extended period of progressive disease burden, increasing dependence, pain and unpleasant symptoms as the end of life approaches, coupled with alarming predictions of impaired brain function.

Good care at the end of life that promotes the autonomy and dignity of the individual can reduce suffering both for the individual and the family. There are wider benefits for the community if those close to the dying person feel that the care was appropriate. It is common to hear people say that they do not wish to be kept alive if they are ‘a vegetable’ and are unable to respond to or communicate with their loved ones. There is concern about the quality of a life maintained by ventilator-dependent life-support, or in a permanent coma or a ‘vegetative’ state, and there is almost universal fear of advanced cancer and dementia. People often indicate that they fear the process of dying more than death itself. Although expectations that modern medicine can prolong life and postpone death often exceed reality, concerns about being kept alive in unacceptable states increase as people age.

People fear being unable to make their preferences known when crucial health and other personal decisions are required after they have lost decision-making capacity. Community opinion overwhelmingly supports self-determination, particularly in end-of-life matters, and appointing a trusted person to make substitute decisions. A renewed focus on advance decision-making that recognises the need for planning and communication is therefore consistent with contemporary community interest. This Framework has been initiated in this context.

### 2.1 A short history of Advance Care Directives

Nearly three decades of evolving international experience now informs policy and regulation addressing impaired decision-making capacity and its impact in health and care settings. In the mid-1900s, rising community expectations that individuals should be able to make their own decisions about their health and personal arrangements resulted in guardianship laws that sought to preserve this right beyond loss of capacity by appointing a SDM. Specific medical ACDs are a more recent phenomenon, which were publicly supported firstly in Western nations, and subsequently in other countries where personal autonomy is an accepted cultural norm.

In the 1970s, particularly in the USA, concerns about end-of-life care emerged. New technologies kept people alive longer and life-extending medical advances were perceived to leave some patients in unacceptable circumstances but unable to communicate. Some states of the USA were quick to legislate ‘living wills’ in response to public concern about the plight of Karen Quinlan,<sup>1</sup> allowing people to record their preferences for medical treatment in advance in case they became unable to communicate them. Canada chose not to legislate ACDs but developed advance care planning programs, whereas Britain (until recently) relied upon medical codes.

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<sup>1</sup> *Re Quinlan* (1976) 70 NJ 10, NJSC. In 1976 Karen Quinlan was in a coma for a year. The New Jersey Supreme Court ruled that her parents could decide that she could be removed from the respirator.

## 2.2 Advance Care Directives in Australia

In the 1980s, South Australia and the Northern Territory enacted Natural Death Acts, which allowed end-of-life medical preferences to be recorded in a 'living will'. These were eventually recognised as too limited, and subsequently several Australian jurisdictions passed legislation providing for ACDs that addressed a broader range of health and personal matters, as well as values and lifestyle preferences. It soon became apparent that written instructions alone are of limited effectiveness, and recent international legislative activity has favoured a combination of substitute decision-making and written directions.

By the end of last century, almost all states and territories had passed guardianship legislation generally allowing a person to appoint a SDM to make health and other personal decisions. Some states have legislated ACDs that specifically record health care or medical treatment preferences while others rely on common law. South Australia and Victoria each legislated four different ACDs under three different Acts that contain both internal and external legal inconsistencies. This high level of variability makes it difficult for one jurisdiction to legally recognise an ACD from another jurisdiction.

One of the difficulties faced by the States has been the lack of case law in Australia to provide direction on the legality of an ACD and how an ACD may be followed in practice. It was not until August 2009 that an Australian Court<sup>2</sup> delivered a decision that affirmed the legality of ACDs and provided a summary of principles for practitioners to follow when provided with an ACD in an emergency situation.

Over the past decade, the inadequacies and divergence of Australia's ACDs have been the subject of several state and national reviews. As a result, the ACT and Queensland each combined their ACDs under a single Act to make them more accessible and easily understood. NSW formally relies on common law ACDs and issued guidelines for their use in 2005. Since 2005, most states and territories have reviewed their legislation and some have made extensive changes to respond more appropriately to public needs and expectations. Western Australia and South Australia conducted reviews in 2008, and Queensland, Northern Territory and Victoria did so in 2009.

## 2.3 Advance Care Directives and advance care planning

ACDs are founded on respect for personal autonomy and are intended to ensure a person's preferences can be honoured during any period of temporary or permanent impaired decision-making capacity, and not only at the end of life.

A worldwide trend to advance care planning offers a more holistic approach, whereby the person is supported to discuss with a trained professional, family and close friends their life goals, values and personal views and choices about their preferred outcomes of care. This is particularly appropriate when ACDs are completed by people already diagnosed with a chronic or life-limiting illness or injury who know the nature and understand the course of their diagnosed condition and want to record directions about preferred care or appoint a chosen SDM, or both.

However, a high proportion of ACDs are completed by healthy Australians anticipating a future time when they might be unwell and unable to make decisions. Their ACDs will apply in circumstances that are as yet unknown and difficult to predict. These people usually complete their ACD in their home or with their lawyer (often in conjunction with financial advance directives) without needing advance care planning support from a trained health care professional. They are more likely to simply

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<sup>2</sup> *Hunter and New England Area Health Service v A* ([2009] NSWCS 761), NSW Supreme Court

appoint a person they trust to make future decisions for them rather than record detailed directions. However it remains critically important that they discuss their personal values, preferences and any advance decisions with family and others close to them.

## 2.4 Addressing the challenges

Australian and international research indicates the uptake of ACDs has generally been low and that they are neither well-known nor widely understood outside of specific advance care planning programs. There are no data available on how many ACDs are completed around Australia or how many end up being used for decision-making, although there is evidence that advance care planning programs are increasing the uptake of ACDs in health and aged care settings for people with a known condition.

Although outcome and utility data are limited, recent studies indicate ACDs can lead to treatment decisions that respect patient preferences and reduce hospitalisation rates at the end of life, especially for nursing home residents. Research increasingly indicates the important role of communicating preferences and personal values rather than focussing exclusively on completing legal forms.

It is thought that ACDs probably work well most of the time for most of the people who complete them, especially those that simply appoint a SDM. However, ACDs cannot solve all the challenges of substitute decision-making; they cannot resolve all conflicts in families, nor can they guarantee a smooth decision-making pathway for the health and aged care sectors.

This Framework recognises that the public promise of ACDs is not always realised, and that there are challenges for those writing, interpreting, applying and abiding by ACDs. Most difficulties have arisen when the ACD form specifically requires medical instructions to be written, whereas ACDs appointing a SDM pose fewer problems.

Common problems have been identified when:

- healthy people struggle to write medical directions in advance of any diagnosis of disease or injury;
- decision-makers try to interpret written medical directions that are uninformed, too specific to account for new treatments or too non-specific to guide medical decisions;
- SDMs are confused by differing legal requirements and do not understand the principles that should guide their decisions;
- people change their stated medical treatment preferences over time but fail to update their ACD, especially as priorities change towards the end of life; and
- medical practitioners do not respect written directions in an ACD or do not understand the rights of SDMs to make decisions.

Developing this national Framework for ACDs has entailed serious consideration of these barriers to their completion and use. This Framework seeks to address these challenges with concepts and mechanisms that respect the rights of people to have a say about care that will be provided when their capacity to make decisions is impaired or lost, but that also fit with norms of informed consent and clinical practice within the health and aged care sectors.

This Framework recognises that voluntary euthanasia and physician-assisted suicide are currently illegal across Australia. The Code for Ethical Practice and the Best Practice Standards make clear that ACDs are not a means of requesting euthanasia or medically assisted suicide, and that health care professionals are not required to abide by unlawful directions in an ACD.

Although at times disputes arise about ACDs and come to the attention of lawyers, governments, courts and the health and aged care sectors, these may represent only a small proportion of those completed and also reflect the current lack of understanding of the role of ACDs. In seeking to improve ACDs and community and sector understanding of them, it is important that processes that are working well are not disrupted and that, in aiming to resolve existing difficulties, revised laws and policies do not generate new and unanticipated challenges.

### 3 Nationally consistent terminology

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Terms used in this Framework (such as ACD) have different meanings in different states and territories. The establishment of a Code for Ethical Practice and Best Practice Standards for ACDs requires the development and use of a common language. A nationally agreed lexicon of common terms has been developed to explain how terms such as ACDs, advance care plans, clinical care plans, competence and capacity are used in this Framework.

The term 'advance directives' is not used in this Framework as it has various meanings across Australia. The term ACD is used to differentiate both legislated and common law instruments that allow for health, medical, residential and other life-management decision-making from legislated instruments that allow for decisions about financial and legal matters.

#### 3.1 Specific terms used in this Framework

Specific terms and how they are used in the Code for Ethical Practice and the Best Practice Standards are explained here. It is recommended that the following terminology for ACDs is adopted and used consistently to ensure greater coherence across Australia.

##### **Advance care planning**

Advance care planning is 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 the person cannot make or communicate their decisions. Advance care planning is usually undertaken within a health or aged care setting and with the assistance of trained professionals after a person has been diagnosed with life-limiting condition. It requires respect for the person and their autonomy.

##### **Advance care plan (ACP)**

An advance care plan is the outcome of advance care planning and may be established by discussion or in writing. Advance care plans state preferences about health and personal care and preferred health outcomes, and are prepared from the person's perspective to guide decisions about care made on the person's behalf. They may be made by, with or for the person; if made on behalf of a person by a family member or someone who knows them well, they should record the known preferences of the person. Advance care plans can name preferred decision-makers.

Advance care plans are not to be confused with clinical care or treatment plans written by clinicians to guide clinical care, and which should be consistent with the person's ACP.

##### **Advance Care Directive (ACD)**

An Advance Care Directive is a type of written advance care plan made by a competent person that is recognised by common law or authorised by legislation. An ACD can record binding directions about care, formally appoint a SDM, or both.

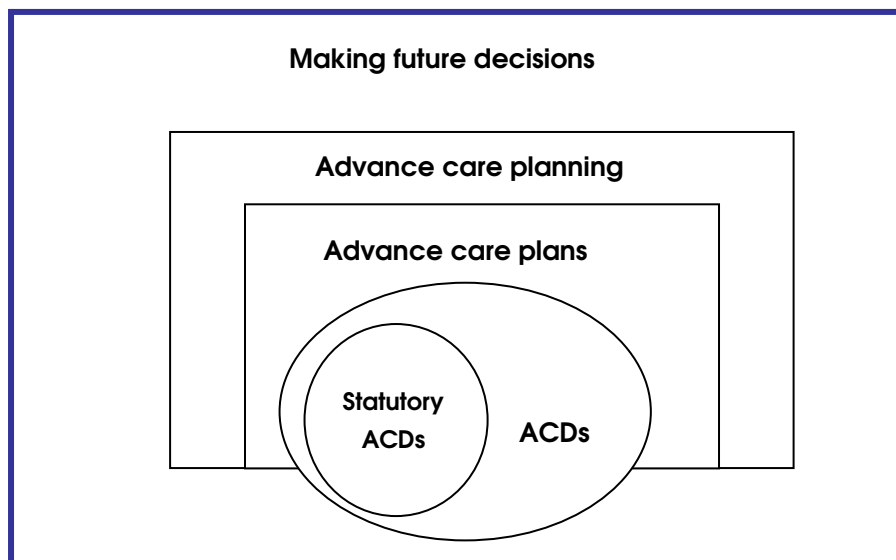
##### **Statutory Advance Care Directive**

A statutory ACD is one that is enshrined in legislation (refer Appendix A).

This term is intended to include, for example, an Enduring Power of Guardianship, an Enduring Power of Attorney for health or personal decisions, an Advance Health Directive, a Medical Power of Attorney, a Refusal of Treatment Certificate, a Health Direction and any other similar ACD enshrined

in legislation, but does not include, for example, the Respecting Patient Choices Program's Statement of Choices.

This schema is represented below as subsets of advance care plans within an advance care planning framework.



Note: ACDs are best completed within an advance care planning framework when the person is planning for future care for known health problems. However, an advance care planning approach may not be appropriate for or useful to healthy people who want to complete an ACD for unanticipated future situations.

#### **Types of Advance Care Directives**

ACDs may appoint a SDM, may record a person's preferences and directions, or may allow for both. They may be limited to medical treatment or allow for directions or decision-making about a wider range of health, residential and other life-management matters.

There are examples of each of these in Australian states and territories:

- ACDs that permit directions to be recorded but do not allow for a SDM to be appointed — these include South Australia's Anticipatory Direction, Victoria's Refusal of Treatment Certificate, and the ACT and Northern Territory's Directions; such ACDs are often restricted to medical treatment decisions at the end of life;
- ACDs that only permit a SDM to be appointed but do not allow directions to be written on the form — these include the Victoria's Enduring Power of Guardianship and Enduring Power of Attorney (Medical Treatment), and NSW Enduring Power of Guardianship; and
- ACDs that allow for both directions to be recorded and a SDM to be appointed — these include Queensland's Advance Health Directive and South Australia's and Tasmania's Enduring Powers of Guardianship.

#### **A focus on the person**

This Framework uses the term person, not patient, because it cannot be assumed that ACDs will be completed in a health, aged care or medical setting. Enduring Powers of Guardianship and Enduring Powers of Attorney that include health decision-making are the most commonly used ACDs, and

these are often completed by people in their homes and communities. Currently, Australia's ACDs may be person-based or patient-based.

*Person-based* ACDs are intended to be completed by people in their own home or community and enable them to record their own values, preferences and life goals or to appoint and instruct a SDM of their choosing (or both); they are designed to be completed outside of a care setting by the average person who has no medical knowledge, without the need for expert clinical advice.

Examples of person-based ACDs include the Enduring Powers of Guardianship legislated in South Australia, Tasmania and Victoria.

*Patient-based* ACDs are intended to be completed by patients in a health care or aged care setting; they are often medically initiated and are designed for patients who have a life-limiting or chronic condition for which they are receiving care. They frequently list medical interventions and seek instructions about future treatment options, require expert clinical advice to complete, and contain medical treatment instructions that would normally be found in a patient's clinical care or treatment plan.

Examples of patient-based ACDs include Queensland's Advance Health Directive, South Australia's Anticipatory Direction, Victoria's Refusal of Treatment Certificate, the RPCP Statement of Choices and a range of other locally produced or internationally recognised ACDs that are not prescribed by legislation.

### **Clinical care plans and Advance Care Directives**

ACDs written by a person are distinct from clinical care or treatment plans written by health care professionals for a patient. A clinical care plan sets out treatment directions to be followed by health professionals in a medical or aged care facility so it complements, and therefore should be congruent with, the person's ACD. Resuscitation plans and No CPR Orders are clinical care plans.

### **Substitute decisions**

A substitute decision is one made on behalf of a person who lacks capacity to make their own decision. A substitute decision seeks to replicate the decision the person would have made, whereas a surrogate decision reflects the view of the decision-maker and may not necessarily accord with the decision the person would have made.

### **Substitute decision maker (SDM)**

Substitute decision maker is used in this Framework as a collective term for SDMs appointed or identified by law to make substitute decisions on behalf of a person whose decision-making capacity is impaired. A SDM may be appointed by the person, appointed for (on behalf of) the person, or identified as the default decision-maker by Guardianship Acts around Australia. More than one SDM can be appointed under an ACD.

The three categories of substitute decision-makers are:

1. SDMs chosen by the person (eg one or more Enduring Guardians appointed under a statutory ACD or a nominated SDM in a common law ACD);
2. SDMs assigned to the person by the law in the absence of an appointed SDM (eg family member, carer or 'person responsible'); and
3. SDMs appointed for the person eg a Guardian appointed by a guardianship tribunal.

This Framework is intended to apply to category 1, and to category 2 when an ACD is in place but no SDM is appointed. It may also be useful in category 3 situations.

### End-of-life and terminal states

*End-of-life* is used as an umbrella term to denote a stage of life where a person is living with, and impaired by, an eventually fatal condition, even if the prognosis is ambiguous or unknown, and it is acknowledged that the person's condition will no longer respond to curative treatment. End-of-life may refer to varying prognostic time spans and is not, therefore, limited to the final or 'terminal' stages of a 'terminal' illness (usually hours or days) but may be used to describe deteriorating illness trajectories for up to two years before eventual death.

A *life-limiting condition* is a terminal disease, condition or injury that is likely to lead to or contribute to death, but is not restricted to the terminal stage when death is imminent. The terminal phase of a terminal illness means the phase of the illness reached when there is no real prospect of recovery or remission of symptoms (on either a permanent or temporary basis).

*Post-coma unresponsiveness* is a state or condition in which a person has emerged from coma to the extent that he or she has sleep/wake cycles but with no observable, purposeful responses to stimuli. Persistent vegetative state (PVS) was redefined by the National Health and Medical Research Council as post-coma unresponsiveness (PCU) to differentiate it from minimally responsive state (NHMRC 2008).

### Health care, medical treatment and life-management

This Framework uses the term *health care* to refer to care, treatment (including medical treatment) and services or procedures to diagnose, maintain or treat a person's physical or mental condition, which may be carried out by a range of health professionals or under the direction or supervision of a health professional. *Life-management* decisions concern personal matters such as residential arrangements, employment, holidays, visitors and care of pets; these are separate from health care decisions. In combination, these two elements recognise the World Health Organisation description of health as not limited to the absence of medical conditions or disease but including physical, psychological, social and spiritual health and well-being.

*Medical treatment* refers to administration of therapy by either physical, surgical or psychological means, or administration of medications to prevent disease, to restore or replace body function in the face of disease or injury, or to improve the comfort and quality of life; medical treatment can be administered by a range of health professionals and includes dental treatment. Recent Court judgments have confirmed that artificial hydration and enteral feeding are forms of medical treatment rather than nourishment.<sup>3</sup>

*Life-sustaining measures* are medical or surgical measures that prolong life, or are intended to prolong life, by supplanting or maintaining the operation of bodily functions that are temporarily or permanently incapable of independent operation.

*Palliative care* is specialist care provided for people living with, and dying from, an eventually fatal condition and for whom the primary goal is quality of life (Palliative Care Association); palliative care intends neither to hasten nor postpone death, but provides relief from pain and other distressing

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<sup>3</sup> *Gardner; re BWV [2003] VSC 173 (29 May 2003) in Victoria; Brightwater Care Group (Inc) -V- Rossiter [2009] WASC 229 in Western Australia.*

symptoms, affirms life and regards dying as a normal process (Palliative Care Council SA). Palliative care can commence well in advance of the terminal stage of an illness.

The focus of end-of-life care is to assist all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met through the last phases of life and into bereavement. It includes management of pain and other symptoms and provision of coordinated psychological, social, cultural and spiritual support and education.

### Health professionals

In this Framework, *health professionals* include registered professionals such as medical, dental and nursing practitioners and also other professionals who provide care including social workers, ambulance paramedics, Aboriginal health workers and allied health staff. These people are often collectively referred to as clinicians.

### Competence and capacity

While it is recognised that competence and capacity are often used interchangeably, for the purpose of this Framework they will be used and be distinguished as follows:

*Competence* is a legal term used to describe the mental ability required for an adult to complete and sign a legal document. Competence is recognised internationally and in common law as a requirement for completing a legal document such as a will or ACD that prescribes future actions and decisions. Such decisions must not be affected by such undue influence or coercion as prevents the person reaching a decision that expresses their values and opinions.

The person must demonstrate that they understand:

- the context of the powers they are conferring, removing or revoking – for example, that it empowers a SDM to make decisions for them in the future and that their SDM is required to follow their written directions;
- the choices they have available to them – for example, between different types of ACD, whether to record directions or not and whether to appoint one or more SDMs; and
- the consequences of completing the form – for example, that it will apply should they be unable to make decisions personally and that it may determine what health care they do or do not receive.

A person is deemed to be either competent or not competent to write an ACD; there are no shades of grey. Although in some jurisdictions young people under 18 years can consent to medical treatment, they cannot complete an ACD. Since in law an adult is presumed to be competent, there must be evidence that they were incompetent when they wrote their ACD before its terms can be ignored on those grounds.

To have *capacity* to make a particular decision means to have the ability to:

- comprehend and retain the information provided;
- believe the information;
- weigh the information in reaching a decision; and
- communicate the decision in some way.

Decision-making capacity is assessable; it may be partial or temporary, and may fluctuate. A person's level of decision-making capacity is assessed at the time a significant decision is required, to ascertain

the person's level of cognitive ability to make decisions (or to make a particular decision) about personal or health care matters.

Capacity assessment does not assess whether the decision is considered 'good' or 'bad' by others such as clinicians or family, but considers the person's ability to make a decision and comprehend its implications. A formal assessment of capacity by a qualified professional may be indicated if decision-making capacity is unclear or uncertain and there is an event for which a decision is required.

### **Informed consent**

It is acknowledged that there is contention about what constitutes informed consent or refusal. The National Health and Medical Research Council (NHMRC) National Statement describes consent in terms of it being voluntary and based on sufficient information and adequate understanding.<sup>4</sup> In summary, the NHMRC advises that informed consent:

- requires information to be presented in ways suitable to the person making the decision to facilitate an understanding of both the proposed procedure or treatment and the implications of undergoing it;
- may be expressed orally, in writing or by some other means, depending on the nature, complexity and level of risk of the procedure or treatment and the person's personal and cultural context; and
- requires there be no coercion or pressure, recognising that coercion may not be overt, but might reflect deference to the health professional's perceived position of power, or to someone else's preferences.

While the National Statement is specifically designed for consent to research, it embodies the common law principles of consent and refusal of medical interventions and is therefore adopted in this Framework in the context of ACDs.

This Framework recognises that there is no requirement for informed consent or refusal when an ACD is completed, and that competent adults can write medical directions refusing future treatment with no requirement to be informed themselves about the potential consequences of their ACD being applied. A clearly stated refusal of treatment in a valid ACD cannot be ignored on the grounds that the person was not informed about the medical consequences when they wrote it.

Informed consent provisions do apply when decisions are made by a SDM at the time that health or medical treatment is required, in the same way as they apply when a competent adult decides whether or not to undergo treatment. The treating health care professional is obligated to provide the SDM with sufficient information to make that decision in an informed manner.

When treatment is indicated, the obligation is on the treating health care professional to inform patients or their SDMs, not on patients and SDMs to ensure they are informed in order for their consent to be valid or their refusal to be binding.

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<sup>4</sup> This description of consent is adapted from Chapters 2.2 and 2.3 of the NHMRC's *National Statement on Ethical Conduct in Human Research 2007*

## 4 The Code for Ethical Practice for Advance Care Directives

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The Code for Ethical Practice is intended to provide a set of principles to guide practice in health and aged care settings where Advance Care Directives are used. The following principles underpin the Best Practice Standards.

**1 Advance Care Directives are founded on respect for autonomy and are focused on the person**

An Advance Care Directive records personal views and is intended to ensure that a person's preferences and directions are known so they can be respected and honoured beyond loss of decision-making capacity.

**2 Competent adults are autonomous individuals and are entitled to make their own decisions about personal and health matters**

A competent adult can complete an Advance Care Directive to guide future decision-making and is not required to be informed or to seek or follow medical advice in order for their Advance Care Directive to be valid.

**3 Autonomy can be exercised in different ways according to the person's culture, background or history**

Autonomy can be exercised by self-determined decisions, delegating decisions to others, making collaborative decisions within a family or community context, or a combination of these.

**4 Adults are presumed competent**

An adult should be presumed competent at the time of completing an Advance Care Directive unless there is good reason to question his or her competence at that time.

**5 Directions in Advance Care Directives may reflect a broad concept of health**

Directions are not limited to medical treatment decisions.

**6 Directions in Advance Care Directives can relate to any future time**

Directions can apply to any period of impaired decision-making capacity, and are not limited to decisions at the end of life.

**7 The person decides what constitutes quality of life for them**

The person determines their own preferred outcomes of care and desired levels of personal functional ability, and decides what circumstances are intolerable or unacceptable, and what interventions are overly burdensome or intrusive.

**8 The substitute decision-maker carries the same authority as that of the person when competent**

The decision of a substitute decision-maker validly appointed under an Advance Care Directive expresses the wishes and directions of the person; health care professionals provide advice to the substitute decision-maker about appropriate, beneficial and available treatment options.

**9 The substitute decision-maker must honour residual decision-making capacity**

The substitute decision-maker must consider each decision as the need arises and only make a substitute decision if the person is unable or unwilling to make that particular decision.

**10 The primary decision-making standard for substitute decision-makers is substituted judgement**

The substitute decision-maker has an obligation to make the decision the person would have made in the current circumstances had decision-making capacity not been impaired; substitute decision-makers should base their decision on what they know or can surmise about the person's life-goals, views, values and beliefs, however and whenever expressed, taking into account information, including medical advice, that the decision-maker believes the person would have considered relevant.

**11 A substitute decision-maker should only base their decision on best interests when there is no evidence of the person's preferences on which to base substituted judgement**

The best interests of a person are personal in nature and not limited to medical interests or biological factors; if a person is unable to indicate what their best interests are, they are defined by their chosen substitute decision-maker or those close to them.

**12 An Advance Care Directive can be relied upon if it appears valid on its face**

A health care professional is entitled to assume that a properly witnessed Advance Care Directive was completed by a competent adult without undue influence or coercion and is therefore valid, unless there are reasons to question that assumption.

**13 A refusal of a health-related intervention in an Advance Care Directive is binding**

A person can indicate in an Advance Care Directive their advance refusal of health care, medical treatment, life-sustaining measures or hospital transfer through either written directions or appointing a substitute decision-maker; if intended to apply to the situation, such refusals are binding regardless of whether they may lead to serious deterioration in health, or death, where they differ from the views of a legally recognised substitute decision-maker, family members or treating health and aged care professionals.

**14 A person, or their legally recognised substitute decision-maker, can consent to treatment offered, refuse treatment offered, but cannot demand treatment**

A person cannot use an Advance Care Directive to demand particular medical interventions or treatment or to request something illegal, such as euthanasia or assisted suicide. Health care professionals are not required to offer treatment options that they consider neither medically beneficial nor clinically appropriate, nor to accede to demands for such treatment written in an Advance Care Directive but should discuss and explain all treatment options with legally recognised substitute decision-makers.

**15 A valid Advance Care Directive that expresses choices or preferences relevant and specific to the situation at hand must be followed**

When the terms of an Advance Care Directive do not apply directly in the circumstances, the person's expressed values and preferred outcomes of care should guide decisions by health and aged care professionals and substitute decision-makers.

## 5 The Best Practice Standards for Advance Care Directives

### 5.1 Application of the Standards

#### The role and intent of the Best Practice Standards

The Best Practice Standards for Advance Care Directives describe best practice in the development and use of ACDs, are underpinned by the Code for Ethical Practice and are founded on best available evidence. They are intended to be aspirational and to set Standards to which the law and policy in all Australian states and territories should aim, in order to meet the needs and expectations of Australian communities and families. When changes to ACDs are contemplated in each jurisdiction, efforts should be made to move regulation and practice towards these Standards to ensure greater national consistency. It is recognised that local law and policy will override these Best Practice Standards where they differ.

These Best Practice Standards guide the development of law and policy, but are equally applicable to community and project groups who are developing or reviewing advance care planning programs that use ACDs. They also set standards for those developing ACD forms and guidelines, information for the public, advice for professionals, and procedures and protocols for working with and abiding by ACDs.

- Section 1 relates to ethical principles and best practice for substitute decision-making.
- Section 2 relates to best practice in the development of:
  - law and policy;
  - forms;
  - guidelines for the community;
  - information for the health and aged care sectors;
  - protocols to guide decision-making by SDMs and health and aged care professionals; and
  - advance care planning programs which use ACDs.

#### How can these Best Practice Standards be used?

The Best Practice Standards take a permissive but protective approach, and are designed to be facilitative rather than regulatory. It is equally important that State and Territory laws and policies are crafted to support the choices people make in their ACDs and to protect those who in good faith honour and abide by those choices. They should recognise the variety of circumstances in which ACDs are completed and the range of choices that people want to make, rather than restricting or constraining those choices.

The Best Practice Standards are intended to guide the development of policy and legislation that regulate ACDs. The Best Practice Standards provide a means to measure practice against a national standard and determine whether law or policy needs to be changed to meet that standard. They set benchmark standards for ACD forms, for information guidelines written for the public, and for advisory guidelines directed at the health and aged care sectors.

#### The Advance Care Directive journey

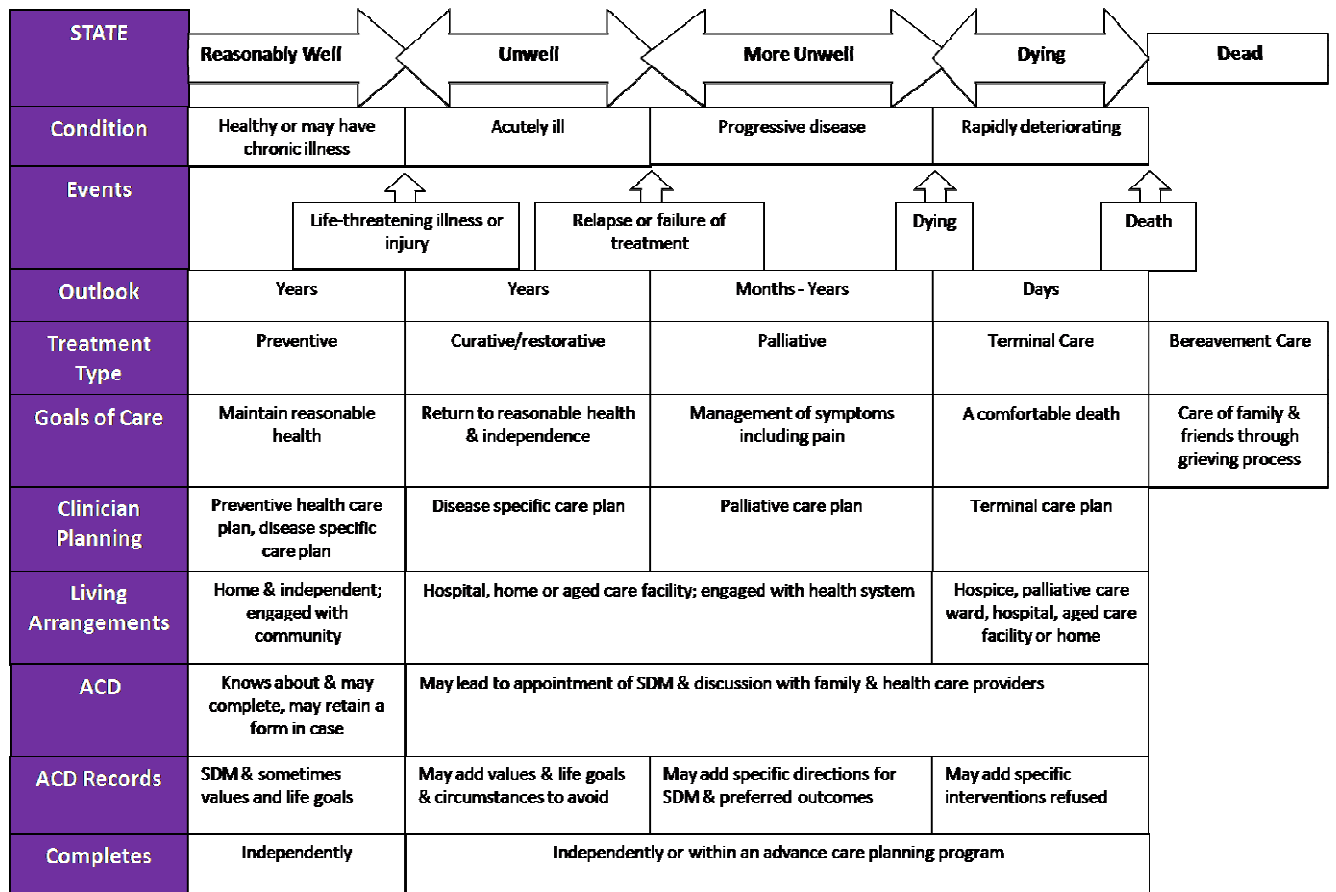
There are different stages in life whereby a person might consider completing an ACD. Some people complete their ACD in stages, feeling confident to appoint a SDM while they are healthy but not recording or communicating any directions until they are faced with a life-limiting condition. It is not uncommon for a person to keep an uncompleted ACD form in a drawer for many years, and then

eventually reach a stage where its value to them becomes greater than the complexities it presents when they attempt to complete it.

Different triggers influence a decision to complete an ACD:

- a family discussion about a television program or news item that features the challenges making decisions for others at the end of life;
- being handed a form by their financial planner or GP with advice to complete it;
- someone close to them such as an elderly parent who needs decisions made for them;
- a change of lifestyle or retirement;
- a diagnosis of a chronic illness, a life-limiting condition or a serious injury; or
- a poor prognosis of a current condition.

Different disease trajectories mean these triggers can occur in quick succession or over many decades. Studies suggest that of people considering an ACD, 10% are near death, 30% are chronically ill and 60% are well. It is not simply a one-way journey — people often move between the following categories.



## 5.2 Best practice standards for substitute decision-making

### Ethical principles and decision-making standards

There are three key ethical principles that provide a framework for substituted decision-making on behalf of adults unable to make their own decisions:

- respect for autonomy or the requirement to respect a person's right to self-determination;
- beneficence or the requirement to do good; and
- non-maleficence or the requirement to do no harm.

These are underpinned by two decision-making standards: substituted judgement and best interests. Substituted judgement decisions are based upon respect for a person's autonomy whereas the best interests decision-making standard applies the ethical principles of beneficence and non-maleficence. Some laws around Australia regulating ACDs apply the substituted judgement standard, others apply the best interests standard, and some require both to be applied simultaneously. This can present significant challenges because the two decision-making standards can result in different decisions.

#### Respect for autonomy

ACDs in Australia are based primarily upon the ethical principle of respect for an adult's personal autonomy, which is generally understood as a person's ability to make self-determining choices and direct their own lives. ACDs respect a person's autonomy beyond lost or impaired decision-making capacity by respecting the person's will and prior consent. They represent the decisions, preferences and directions of the person, recorded when competent and intended to apply when capacity is impaired. ACDs should therefore be recognised by SDMs and health and aged care professionals as the will and consent of the person.

The focus on respect for autonomy reflects the centrality of the individual in contemporary Western society. However, this focus on individualism is not universally shared, and other cultures recognise the value of delegating decisions to others and making collaborative decisions within a family context. A wider concept of 'relational autonomy' sees the person as part of a network of relationships that influence how they make decisions and what decisions they make.

The decision-making standard of substituted judgement best respects the person's autonomy, and is the required standard when a person has completed an ACD that appoints a SDM and has discussed and recorded their preferences in advance. This is the optimum circumstance that this Framework encourages; however, it is generally recognised that this is not the situation encountered in health and aged care settings. Currently, it is more common to find the following circumstances:

- an ACD is completed and records personal preferences but there is no SDM appointed, in which case decisions made collectively by the family and care professionals seek to honour those preferences by applying substituted judgement; or
- the ACD appoints a SDM but there has been no discussion of personal preferences and none recorded, in which case the SDM should make enquiries to best determine what the person is likely to have decided and then seek to apply substituted judgement; or
- most commonly, there is no ACD in place or the SDM has been given no directions and is unable to determine what the person is likely to have decided in the circumstances, so substituted judgement cannot be applied.

Sometimes discussions between the SDM, family members and care professionals reach a consensus decision balanced between substituted judgement and best interests; however, in cases where the person had never expressed any preferences relevant to the circumstances, the default decision-making standard of best interests usually applies.

### **Substituted judgement**

This Framework applies substituted judgement as the primary decision-making standard for SDMs where there is an ACD in place, but extends this to a contemporaneous substituted judgement approach to decision-making on behalf of another. Contemporaneous substituted judgement seeks to approximate what the person would have decided at the time a decision is needed if their capacity to make their own decision had not been impaired and if they had access to the same information and advice. It ensures the consent of the SDM is informed, and is therefore more aligned to the way competent adults make decisions for themselves. This introduces more relevance and reflection to decision-making, and more closely approximates the concept of truly 'authentic' substitute decisions or "walking in that person's shoes".

Applying the substituted judgement standard in practice requires the decision-maker to apply the following:

- First and foremost, to honour the person's preferences; this requires the SDM to take full account of the person's views (present and previous, written and oral) and to make the decision the SDM honestly believes the person would have made in the prevailing circumstances.
- Unless the person's views are clearly known, confer with those who may know the person's preferences and values and make a decision based on the most reliable information.
- Weigh up whether the likely outcomes of care or interventions as explained to them by the health care professional accords with the person's preferred outcomes of care and their expressed views about their quality of life.
- Where there are alternative options that meet the person's stated preferences, to choose the option that is the least restrictive of the person's basic rights and freedoms but optimises their proper care and protection, and seek to preserve existing informal care arrangements that are functioning adequately. On balance, the substitute decision must be the one that most respects the person's autonomy while not unduly compromising their welfare.

#### **Case study — Contemporaneous substituted judgement**

*My brother, Kevin had a stroke, which meant he couldn't walk or speak, and the medication he was on meant he wasn't able to think clearly. He wasn't dying, but he did need medical treatment to get him to the stage when he could go home again.*

*He had appointed his sister, Margaret, as his Enduring Guardian and written his directions on the form. When we read the form, he'd written that he didn't want any treatment at all. Margaret thought that he must have been thinking of a time when he might be dying and didn't want to be kept alive artificially, but this wasn't helpful when he could get well enough to go home, even if he'd be in a wheelchair for quite a while. The doctors helped us work through the form and we decided that he hadn't meant the directions that he'd written to apply to just having a stroke. He's much better now and learning to talk again, and is very relieved that he was given treatment.*

A contemporaneous substituted judgement approach allows for the following:

- A SDM should take into account any particular factors that they believe the person would have considered important; if the person would have factored in family interests in making a decision in the circumstances, then contemporaneous substituted judgement would require the SDM to do likewise.
- A SDM may consider a prior refusal of a particular treatment in the light of new information and advice that they believe the person would have taken into account, and determine that the person would have consented to or refused the treatment in the current circumstance. The SDM may therefore, under some conditions, make a different decision to that written on the ACD form (which may, in some circumstances, require clarification by the Courts or other legal bodies). However if the SDM knew the person would have refused that treatment under any circumstances, then they must refuse the treatment on the person's behalf.

Contemporaneous substituted judgement requires the SDM to consider whether the person intended their written or oral directions to:

- apply in every circumstance, such as a Jehovah's Witness refusing a blood transfusion;
- apply in the prevailing circumstance, such as refusal of life-sustaining measures near the end of life; and
- be considered in the light of current advice or changed circumstances, such as an ACD requesting pain relief but refusing antibiotics when the antibiotics would effectively alleviate the pain of an infection.

Making substitute decisions for others can be a practically difficult and very challenging exercise. SDMs need support, advice and information to help them make such decisions.

#### **Case study — Contemporaneous substituted judgement**

*Nancy had dementia and had been a resident of the aged care home I work in for about a year. All our residents complete what we call a 'facility form' when they are admitted, and Nancy was competent enough to tell us her wishes then, although she hasn't recognised her family for a long time now.*

*Last month Nancy had a urinary tract infection, a very painful condition that is often easily relieved by giving antibiotics. I called the family and we looked at her form, which said that she wanted to be kept free of pain but didn't want antibiotics if she got sick. This was a problem because antibiotics would fix the pain so we had to decide what she would think was more important. She was distressed by the pain and becoming very hot and confused which upset her children. Her family and I talked it through with her doctor when he came to see her that afternoon, and we decided that Nancy was much more distressed by the pain of the infection than she would be by having the antibiotic. We thought that if she could communicate she'd be asking for treatment.*

*We gave her a course of antibiotics and that fixed the pain and her temperature, and she settled down again. I'm glad we didn't follow her written directions and leave her in pain, but considered instead what she would want now.*

### Best interests

Substituted judgement presents an ideal for substitute decision-making where an ACD is in place, premised on a person expressing and preferably recording their preferences for future care and appointing someone to speak for them who understands their values and is willing and able to respect them. While this Framework focuses on contemporaneous substituted judgement as the primary decision-making standard for SDMs, it is acknowledged that this standard alone will not always be possible in practice. When the person's preferences are unknown and cannot be surmised by SDMs from their knowledge of the person and their life goals, values and beliefs, then the SDM will need to make a broader best interests assessment and base their decision on this.

Decision-making in a person's best interests is not a concept reserved only for ACDs; it is applied in a wide range of circumstances beyond health and aged care. Broadly speaking, it entails weighing the relative harms and benefits of different courses of action. A best-interests standard of decision-making generally requires a SDM to consider the person holistically, situated within their social environment and to

- focus only on the person's best interests, excluding consideration of the interests of others, and not base their decision on whether they would wish to have treatment themselves in that situation
- for health-related decisions, assess and take into account objective criteria such as the invasiveness of the proposed treatment and its potential to provide therapeutic benefit, relieve pain or discomfort, avoid disability and preserve life, and the consequences to the person if the treatment is not carried out
- make the decision that provides the maximum anticipated benefit to the person whilst minimising restrictions, and seeks to optimise their proper care and protection.

Despite a commonly shared understanding of substituted judgement, there are many and varied interpretations of what it means to apply a best interests standard of decision-making. This continues to be a highly contested issue in both law and ethics, and a consensus definition of a best interests test and the criteria upon which it should be based remains elusive. The following demonstrate the range of differing, contestable interpretations about what may be legitimately included in a best interests decision-making standard in a health or aged care setting.

- Care and protection should override personal views that might put health and life at risk.
- The best interests of a person can be determined objectively and that this determination does not require knowledge of the person.
- The person's views should only be 'taken into account' rather than being central to decision-making.
- Medical treatment interventions that optimise physical health and extend life are always in the person's best interests.
- Personal best interests and medical best interests are different and separate.
- Interests beyond 'medical' best interests should be taken into account.
- Family interests should be accommodated as part of personal best interests.
- Only decisions made in the light of the person's own perception of quality of life and their personal and social environment are in their best interests.
- The person's interests are only served by making the decision that the person would have made had they sufficient capacity to make it.

This wide range of interpretations of the best interests decision-making standard means that it is a less reliable basis for substitute decision-making. It is for this reason that this Framework sets substituted judgement as the primary decision-making standard and requires a broad interpretation of best interests beyond medical best interests.

This Framework seeks to improve the promotion and use of ACDs so that it becomes more common for SDMs to have sufficient knowledge of the person's preferences to apply substituted judgement, rather than defaulting to a best interests decision.

**Case study — A best interests decision**

*My brother and I were very concerned when we were teenagers that my Mum was a Jehovah's Witness who didn't believe in transfusions. She always said if we were in an accident she would refuse blood for us. When I was 20 and Simon turned 18, we appointed each other as our Enduring Guardian so Mum couldn't refuse blood for us.*

*When Simon suffered really bad head injuries in a car accident the next year, he didn't need blood but I had to make a decision about continuing life support. We had only talked about blood transfusions, and I had no idea what he would want me to decide about this situation. We hadn't anticipated anything like this happening to us. In the end, I had to just decide for myself what was best for him. I didn't know what he would have chosen for himself.*

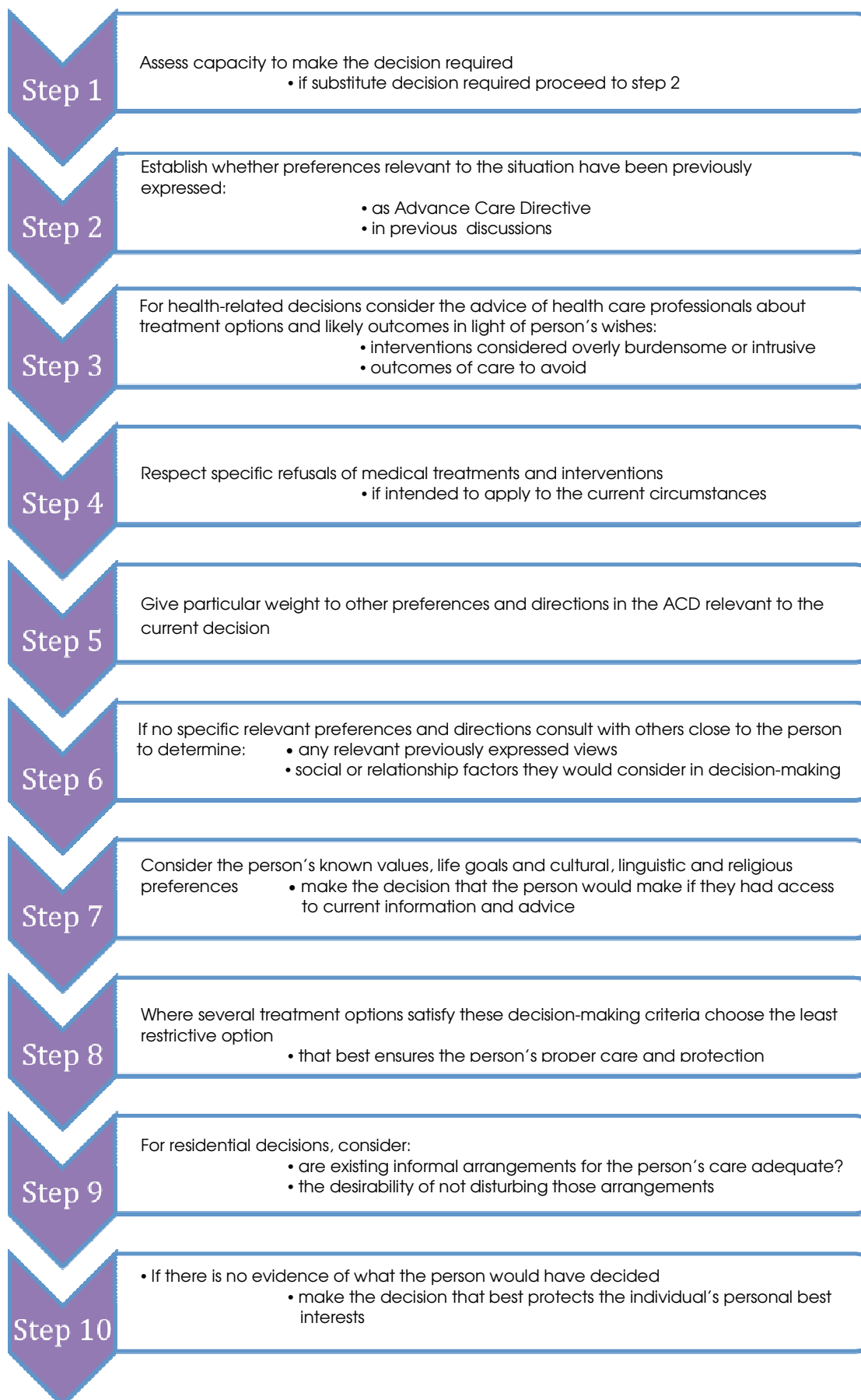
### The decision-making pathway

This decision-making pathway should be followed by SDMs appointed by the person through an ACD. It should also guide health and aged care professionals to make decisions where the person has not appointed a SDM and no Guardian has been formally appointed by the appropriate authority to make the particular decision. Such decisions should be made in consultation with family members and others assigned substitute decision-making rights by law.

The first step is to assess, considering the nature of the decision to be made, whether the person can decide for themselves, requires assistance and support to make a decision or whether a substitute decision is required. If the capacity of the person to make the decision required is questionable, a formal assessment of decision-making capacity should be organised.

If the outcome of that assessment is that a substitute decision is required, then SDMs should follow the steps below.

1. In the first instance, establish whether the person has expressed preferences previously in an ACD, or in a discussion, that are relevant to the situation
2. Seek the person's current preferences if they can communicate, and accommodate them to the extent possible.
3. For health-related decisions, seek and consider the advice of health care professionals about the likely outcomes of care and treatment options, and consider these in the light of interventions the person has indicated they would find overly burdensome or intrusive and outcomes of care that the person has indicated they would seek to avoid.
4. Abide by specific refusals of medical treatments and interventions if it is clear (or the SDM considers) that the person intended them to apply to the current circumstances.
5. Give particular weight to other preferences and directions written in the directive that are relevant to the current decision and that the person intended to cover the current circumstances and seek to accommodate any written conditions to the extent possible.
6. In the absence of specific relevant preferences and directions written in the ACD, consult with others close to the person to determine if the person had previously expressed any views about what circumstances they would consider unacceptable or intolerable and what social or relationship factors they would have taken into account in making a decision. Information might include: a previously completed advance care plan; any preferences previously expressed by the person, whether written or oral, that offer insights; and decisions and actions previously taken that indicate their beliefs and values.
7. Weigh up all this information in the light of the person's known values, life goals and cultural, linguistic and religious preferences, and make the decision they believe the person would have made at the time if they had access to the same expert advice and were able to make their own decision.
8. For health-related decisions, where there are several treatment options that satisfy these decision-making criteria, choose the least restrictive option that best ensures the person's proper care and protection.
9. For residential decisions, consider the adequacy of existing arrangements for the person's care and the desirability of not disturbing those arrangements.
10. If, having followed this process, there is no evidence to surmise what the person would have decided in the specific instance, then make the decision that they believe best protects the individual's personal best interests.



### 5.3 Best practice standards for policy, law, forms and guidelines

These standards are organised under seven subheadings:

- two sets of core standards: designed to guide initial development of law and policy and of forms and guidelines;
- four sets of specific standards designed to address the detail of law, policy, forms and guidelines that follow the ACDs journey from completing, through activating to making decisions under ACDs; and
- a final set of standards specifically related to problem solving.

#### Core Standards for law and policy

##### Applying the Code for Ethical Practice

Laws and policies regulating ACDs must be premised on respect for a person's autonomy and apply substituted judgement as the primary decision-making standard, consistent with the Code for Ethical Practice for Advance Care Directives. Where legislation prescribes principles to guide substitute decision-making, these should be cast in terms of contemporaneous substituted judgement.

##### Simplifying Advance Care Directives

Statutory ACDs should be simple and straightforward, avoiding legal language as much as possible. Legislation should specify the matters that an ACD ought to minimally address. Instead of being prescribed in legislation or as schedules, forms should be consistent with the legislation but expertly designed and laid out for ease of use and public understanding with official approved versions recognised in law. ACDs should be provided in a single kit containing information, guidelines for completion and activation that are easy to navigate, and a minimum number of separate forms to cover all types of decision-making.

ACDs should have names that are meaningful to ordinary Australians that convey their purpose — to empower persons to make directions about future care and appoint someone they trust to carry them out. Community feedback to the South Australian Advance Directives Review indicates that to many people words such as Attorney and Guardian do not portray an instrument of self-empowerment but rather one of handing over power to others. Such names may mean ACDs are not embraced by some communities such as Aboriginal and Torres Strait Islander families with a history of removal of children, people who have had negative experiences with governments in other countries, and those who seek to avoid any engagement with the legal system.

##### Promoting Advance Care Directives

The use and benefits of ACDs should be promoted to the public but also to healthcare providers and aged care facilities so that they are increasingly accepted as part of normal admission and care protocols.

Promotion of ACDs should emphasise the importance of conversations between the person and their chosen SDMs, family and others close to them. Information about ACDs should explain the authority of an appointed SDM and how this differs from the rights of family members and others to make future decisions on their behalf. The information should convey a message that it is the discussion and planning that is critical, and that the completion of an ACD or an advance care plan is simply a means of recording that discussion. The public should be advised that, although a verbal or written advance care plan may be recognised under common law and its terms should always be taken into

account when substitute decisions are made, a written and signed ACD has greater clarity, formal validity and will be respected in health and aged care settings if decisions are needed in the future.

**Case study — Encouraging ACDs**

*When Joan had the car accident she had severe brain damage. She was in intensive care on life support for a long time. The doctors asked us about what she might have wanted; but we had never talked about it, so we had to say we didn't know.*

*Joan spent 9 months in hospital and is in a nursing home now, needing help with everything. She doesn't recognise us or communicate. I think it is worse than if she was dead.*

*When the doctors talked to us about Joan, they encouraged us to think about making our wishes clear, so that if anything unexpected happened to us the ones left could be clear about what we would want. I have talked to all my family about it, I never want to be in a home in a state like Joan, it would be intolerable for me.*

**Preserving common law and mutual recognition**

Legislation regulating ACDs should preserve the common law, such that it recognises an ACD written on a form that is not prescribed by law or on a form prescribed by the law of another state or territory, and accepts that the terms of such an ACD will be respected if they are relevant to the circumstances. Each jurisdiction should ensure that systems are in place to ensure ACDs are recognised in different settings and jurisdictions.

**Personal autonomy and cultural appropriateness**

Autonomy is a term that means different things to different people depending upon their cultural beliefs or background. Laws and policies should allow for autonomy to be exercised in a range of ways, including by self-determination, delegating decisions to others, making collaborative decisions with their family and a combination of these.

Given Australia's indigenous heritage and increasingly multicultural population, it cannot be assumed that individual autonomy is the prevalent ethic in all communities or that normative Western values and decision-making norms will apply to all families. It must be recognised that ACDs are not appropriate for every person or every community, and that a person can choose not to complete an ACD.

**Focus on the person**

This Framework supports personal-based ACDs. ACDs are promoted as a means of respecting a person's autonomy beyond loss of decision-making capacity, so ACD policies should be primarily focussed on meeting the needs and expectations of people who will complete them. Although it is also important that ACDs work well in health and aged care settings, this primary focus on the person completing the ACD should not be compromised in order to meet the needs and expectations of hospitals, hospices and aged care facilities and their staff.

Policies should make it clear that ACDs are different to and separate from clinical care or treatment plans written by medical practitioners, and that clinical care plans should be consistent with the person's ACD.

**A broad interpretation of health and well-being**

ACDs should apply a wider interpretation of health care and end-of-life stages consistent with community expectations and understanding, rather than a narrow medical interpretation of medical treatment and terminal care. Health and care should be seen as encompassing physical, psychological, social and spiritual aspects of wellbeing. ACDs should be able to record information about preferred residential and holiday arrangements, what relationships the person wants to continue and who the person does not want to see, and other personal matters. Some Enduring Powers of Guardianship already accommodate such matters; law and policy should not restrict ACDs to only medical or end-of-life matters.

**Activation triggers**

Law and policy should be framed so that ACDs can be written to apply to any period of impaired decision-making capacity. Decision-making capacity can be impaired partially or temporarily in a range of circumstances such as renal disease requiring dialysis, episodes of mental illness, chemotherapy for cancer and diabetic coma. Guidelines should advise that a person should specifically indicate in their ACD if they intend that it be activated when decision-making capacity is lost in such circumstances.

**Governance systems**

Governance across the health and aged care sectors and accreditation systems should accommodate ACDs and seek consistency with the national Code for Ethical Practice, Best Practice Standards and the agreed terminology. Accreditation standards should require that residents in aged care facilities who are competent are offered information about ACDs and that health care facilities make information about ACDs readily available to patients.

A discussion about advance care planning and ACDs should become part of routine contact with the health and aged care sectors. It is not essential that such discussion and advice is facilitated by a medical practitioner; in many settings nurses and other health professionals have relevant knowledge and skills to conduct discussions with and advise people about advance care planning and ACDs. Such discussions may also answer questions about potential for organ and tissue donation and other end-of-life issues.

Health and aged care practitioners should be encouraged to inquire whether their patients and residents have completed an ACD and to propose a review of their ACD when health circumstances change.

## Core Standards for forms and guidelines

### Accessible forms and guidelines

Where a form is provided, it should always be accompanied by guidelines that explain the nature of ACDs and offer advice about completing the form. Guidelines should explain and apply the principles in the Code for Ethical Practice and meet the Best Practice Standards.

It is recommended that the guidelines use scenarios and stories to illustrate and clarify how ACDs can be used and applied, including the circumstances in which an ACD would be useful, or would have been useful, and how SDMs should make decisions.

ACD forms and accompanying guidelines should be readily available and free. They should be widely disseminated and made available by electronic means through a dedicated web page, but also in hard copy for communities and people who are unlikely to access them electronically.

Translation of guidelines into local commonly spoken languages is essential, but translated guidelines could be provided as downloadable electronic documents rather than in print format; this would allow community groups and legal, health and aged care professionals to provide a translated version to clients, residents and patients as needed.

### Comprehensive guidelines

Guidelines should reiterate and reflect the principles in the Code for Ethical Practice and be consistent with the Best Practice Standards, but be tailored to local legislation and policy in each State and Territory so that national practice is established even if the names of the different instruments varies. They should provide information about legislated and most frequently used common law ACDs in that jurisdiction, and guidance about completing and using them.

Separate guidelines for the public and for the health and aged care sectors are not recommended. Instead, there should be a single set of guidelines that are broadly targeted to the population but also meaningful and useful to health and aged care professionals. This would enable the community to understand how their ACDs will be interpreted and applied by health and aged care professionals and ensure health and aged care professionals are aware of community expectations. Ensuring the public and the professional sector have a common understanding and share equal expectations may help to eliminate some of the misunderstandings that arise when ACDs are used.

Guidelines should be relevant to healthy adults as well as people who have been diagnosed with a chronic or life-limiting illness or injury. They must be written in simple, easily understood English, using the nationally agreed terminology and avoiding legal and medical jargon. Definitions and an explanation of terms likely to be unfamiliar in the general community should be included. It is recommended that laws, policies, guidelines and forms refer to impaired decision-making capacity or ability rather than to incapacity or incompetence.

Guidelines should be logically ordered so that they begin by explaining how relatives and others close to the person can ordinarily make some health and other personal decisions on behalf of a person with impaired decision-making capacity. They should then describe the means by which a competent adult can override those arrangements by appointing a SDM through an ACD.

In addition, it is recommended that a printed pamphlet setting out the decision-making pathway be made available for SDMs and staff in health and aged care settings.

### **Preparing Advance Care Directive guidelines**

Guidelines should provide adequate and accurate information and offer practical advice about the roles and responsibilities of:

- people completing ACDs and SDMs being appointed through ACDs;
- witnesses who are asked to sign ACDs;
- lawyers and other professionals who may be asked to advise about completing ACDs; and
- professionals who may be required to recognise and abide by ACDs.

Guidelines should explain:

- the range of ACDs in the jurisdiction and what decision-making they allow for and whether they appoint a SDM, simply record personal preferences, or both;
- their legal nature, the benefits of completing one, and the role and function of the witness;
- that they do not require medical, legal or other expert advice in order to be valid;
- whether and under what conditions ACDs from other jurisdictions are recognised locally;
- who could legally make decisions for them if they record preferences and directions but do not appoint a SDM, and how those decisions would be made;
- how decisions would be made on their behalf if they do not complete an ACD and under what circumstances a Guardian would be appointed to make decisions for them;
- that a healthy person who has completed an ACD should review it and discuss it with their health care professional if their health deteriorates while they remain competent;
- that directions about matters after death (eg funeral arrangements and organ donation) will act as a guide to their wishes but may be better recorded in other documents or through other means;
- that ACDs are personal rather than private documents, which must be readily available when needed if they are to guide decision-making beyond the loss of capacity; and
- that copies should be provided to relevant people, including any SDMs appointed and family members, and to any professionals providing care.

### **Designing Advance Care Directive forms**

Although ACDs can be written in a personal letter and be recognised under common law, where forms are set out in legislation or designed for use in advance care planning programs they should meet the standards described here and be able to accommodate the full scope of ACDs as described in these Standards.

Statutory ACD forms must be designed to be easily completed without assistance or professional legal or medical advice in a variety of settings including a person's home, residential care facility or the office of their professional adviser.

When designing ACD forms, it is recommended that expertise in form development and writing for the public be engaged, and that forms:

- be written in plain English, avoiding legal jargon;
- be adaptable to a range of formats including downloadable and online versions;

- be readily identifiable and able to travel across care settings to enable a person's preferences to be known wherever they receive care; and
- have separate sections for health decisions and residential/personal decisions so that copies can be distributed appropriately if different SDMs are allocated these roles.

Forms and guidelines should be drafted in consultation with a range of people from different communities and professional sectors to ensure they meet their needs. They should be tested through focus groups of lay people and professional experts before being finalised to ensure their meaning and intent is widely understood and they are easy to complete and follow.

**Case study — The challenge of completing medical directions**

*When John was diagnosed with diabetes at 55, his GP gave him some forms and said both of us should fill them out. The one about appointing someone to make financial decisions and pay the bills for you was hard enough. Then we looked at the one about deciding what treatments you would want if you were dying, and whether you'd want CPR or ventilation or something.*

*Well John's diabetes was not stopping us from working and travelling, and we keep fit enough to enjoy our little grandchildren. There's no way we could write those sort of directions at that stage, so we put the forms away. We got them out again when I had my knee done, and we decided which of the children we would appoint to make health decisions for us. We tried to discuss all this end-of-life stuff but that wasn't the problem for us – we were worried about being unconscious from an accident or John being in a diabetic coma – temporary things like that.*

*When we reread the section that asked us about our values and life goals and what circumstances we would want to avoid, we felt we could do that. I wrote that I didn't want to not be able to recognise and communicate with my children like my mother was when she had dementia – that would be intolerable for me. John said he wouldn't care if he had dementia, but he'd hate to be bedridden and have to rely on someone changing him and feeding him like his uncle was last year. It's funny how we're all different.*

*It was a good conversation with the boys, though, and we filled in the forms and got them signed and witnessed. We've all got copies, even our GP, and it's good to have all that in place. Later on if we get really sick, we may be able to fill in that part about what treatment we'd want if we were dying, but by then we probably would have lost our marbles and not be able to do it anyway.*

### **Completing Advance Care Directives**

Policies must emphasise that completing an ACD is always optional and that people are free to make a choice. A person must not feel coerced to write an ACD or be lead to believe (intentionally or unintentionally) that it is mandatory to complete one.

An ACD should be written by the person to whom it relates. When an otherwise competent person cannot write it personally because of a disability, it should be written for them by another and signed by the person as a record of their preferences. It is recommended that SDMs are appointed through a written document, preferably an ACD, signed by the person; a verbal appointment of a SDM cannot be easily verified once the person's capacity is impaired.

#### **Appointing substitute decision-makers**

Law and policy should permit a person to choose and appoint a trusted SDM or SDMs and to include written directions and to stipulate when or under what circumstances their SDM is authorised to make substitute decisions.

Legislation should also permit and policy should encourage a person to appoint someone they know and trust as a monitor to oversee the actions and decisions (or types of decisions) made by their SDM and set conditions under which the monitor operates. Monitors are encouraged in some overseas jurisdictions such as Canadian provinces to reduce the imposition on public officials to oversee decision-making for vulnerable adults. People often choose as a monitor someone they know personally who has greater professional understanding than their SDM but who may not have the time to perform a daily decision-making role. Guidelines should advise that reporting arrangements between the SDM and the monitor should be documented in the ACD.

Legislation should not create conflicts of duty and should not permit a person's paid carer or a witness to an ACD to be appointed as a SDM. While competent a person must be able to revoke the appointment of an appointed SDM at any time, but guidelines should recommend that they advise the SDM and relevant others of the revocation.

#### **The importance of discussion**

Guidelines should encourage competent adults who are completing ACDs to appoint a SDM and record directions for their SDM. They should advise that, to optimise the chance that future care will accord with the person's values and life goals and avoid unwanted circumstances, the best option is to choose a trusted person who shares or understands their values as their SDM and discuss their preferences for future care with them to generate a shared understanding.

A person completing an ACD should be encouraged to inform others whom they have appointed as their SDM, and to discuss any written directions with their family or close friends and care providers, and in particular with any SDMs and monitors they appoint, so that everyone concerned has a clear understanding of what the person intended their directions to convey.

**Case study — Advance Care Directives in aged care**

*Maureen asked me to be her Enduring Guardian a few years ago. We were neighbours and we spent a lot of time together. Her son was overseas and she rarely saw her sister or her niece. When she got dementia, I had to decide whether she could manage to live independently and whether I could keep looking after her. When I had my hip done she went into respite care while I got myself mobile again, and I spoke to the aged care team about finding her an aged care place.*

*They found her a place with a tree outside the window – she liked to watch the birds so I knew she’d appreciate that. I visit her and they ask me to sign consent forms when she needs any treatment or has to go to hospital. She’s getting frail and forgetting things, and I know I’ll be telling them soon that she wouldn’t want any treatment that just keeps her alive. We talked about that. We had lots of discussions during all those hospital dramas we used to watch together and I know what she wants.*

**Witnessing**

Law and policy should require that an ACD be signed by an independent witness or witnesses so that its validity can be more readily confirmed when it is required to be activated after the person’s capacity has become impaired. To be independent, witnesses must not be appointed as SDMs and must not be providing care to the person as a health care professional or professional paid carer.

It should be the role of the witness to assess the person’s understanding of what an ACD does and whether their decision to complete the form is freely taken, based on a ‘reasonable person’ assessment. It is not sufficient for this purpose that the witness simply verifies the identity of the person and any SDMs. Neither is it appropriate to require the witness to be qualified to formally assess competence or to conduct a formal psychometric assessment of the person’s competence to complete a legal document. Training should be made available for witnesses to ensure they can undertake their role competently and with understanding.

Law and policy should require that a person completing or revoking an ACD, and any SDMs appointed, must demonstrate to the satisfaction of the witness that they understand (refer to the terminology section, page 16):

- the context of the powers they are conferring, removing or revoking;
- the choices they have available to them; and
- the consequences of completing the form.

Witnesses should be required to complete a certificate incorporated into the form confirming they were satisfied that the person appeared to understand the nature of the form and the consequences of completing it, and there was no evidence of coercion or undue influence. Witnesses should be advised to decline to witness a form if they believe the person’s competence is questionable.

**Requirement for advice and informed decision-making**

Law and policy must not require that a competent adult completing an ACD be medically informed or seek or follow medical advice in order for their ACD to be considered valid. A competent adult can choose to write directions, even medical directions, without expert advice.

However, guidelines should recommend that, if the person is receiving regular health services or aged care, they should check with their professional care providers whether the terms they have used in their ACD convey their preferences and goals of future care. In particular, people who choose to write specific medical directions should be encouraged to discuss them with someone informed, and with their health care professional if their directions are medically complex, to ensure their directions are clear, unambiguous and more likely to achieve the outcomes they are seeking.

### Writing medical directions

Laws and policies must not require people to write detailed medical directions, whether in writing or by ticking selected boxes, because this introduces a significant risk of potentially uninformed or inadequately informed directions binding more informed decision-makers at a later time. This could be detrimental to the person's health in ways they had not envisaged when they wrote their ACD. Medical directions are best written by medical practitioners in clinical care plans, consistent with the person's ACD.

However, where people choose to write specific medical directions ACDs should enable their directions to stipulate both advance refusal and advance consent (indicating to SDMs that the person does not object to receiving certain treatments).

Where medical directions are written in an ACD, legislation and policy should make it clear that:

- an ACD cannot be used to demand unlawful medical interventions such as voluntary euthanasia or physician-assisted suicide;
- an ACD cannot be used to demand specified treatment interventions if they are not warranted or medically indicated;
- treatments refused in a validly completed ACD must be withheld if the person clearly intended their refusal to apply to the current medical circumstances and the current period of impaired capacity; and
- such treatment refusals are to be regarded as binding on health and aged care professionals and SDMs, including in emergency situations, if they are relevant and were intended by the person to apply to the circumstances.

#### Case study — A life-threatening emergency

*Dad had a bad reaction to his new tablets at work and was rushed unconscious to the emergency department. He already had early signs of prostate cancer, so when he was first diagnosed with his heart problems he wrote directions in an ACD about not wanting CPR.*

*They rang me from the hospital so I read them his directions over the phone and then drove there. When I arrived they had given him CPR because his heart had stopped. The doctor explained she had interpreted his directions as intended to be followed if he had a serious heart attack from which he was not likely to recover completely.*

*When she explained that it wasn't the cancer or the heart disease but the tablets that were the problem and they could fix that, and that he would recover and be able to continue working, I agreed they had made the right decision and that's what Dad would have wanted.*

It is not always easy to determine whether a refusal of treatment in an ACD is a strongly held view or an expression of a preference, or whether it is intended that such directions be:

- followed exactly, such as a refusal of blood transfusion by a Jehovah's Witness;
- assessed by the SDM, such as a refusal of ventilation which may only be required for a temporary post-operative period; or
- simply taken into account, such as a preference to die at home.

Although medical directions may be binding, directions about personal matters cannot be; for example, a person cannot demand particular accommodation arrangements if these are not available.

**“What do you fear most?”**

Law and policy should support ACDs that record values, life goals and preferred outcomes of care and should discourage listing of medical interventions consented to or refused. These outcomes-based ACDs reduce problems such as:

- healthy adults writing medical directions for an unknown future;
- unanticipated new treatments, and
- medical directions being too specific, too non-specific or ill-informed.

Studies suggest that medical treatment preferences change over time, whereas values and life goals generally remain consistent.

**Case study — Writing clear outcome statements**

*It was sad when Jenny was dying of breast cancer, we all wanted to make her last days as good as we could. Luckily, she'd written her wishes down in an ACD last year, after she was first diagnosed, so the doctors and nurses knew what was important to her.*

*She hadn't listed treatments, like saying that she didn't want CPR or antibiotics. She just wrote that being bedridden and unable to have a conversation would make her life unbearable, and that she never wanted to have to depend on someone else to feed her and keep her clean. Dignity was very important to Jenny. She was still a young woman, only 45 this year. She had written, "I only want to be kept free of pain and be able to communicate with my family and close friends, but I don't want treatment just to keep me going if I am bedridden and unable to communicate or recognise people I care about."*

*The nurses explained that, because she'd written such clear directions, the treatment they were giving her respected her wishes, kept the pain away and let her die with dignity.*

Guidelines should encourage people to consider what personal circumstances they would seek to avoid, and forms should allow people to write:

- life goals, values and beliefs and what quality of life means to them;
- personal circumstances or levels of functioning considered unacceptable or intolerable;
- types of interventions considered overly intrusive or burdensome;
- conditions to be met, preferences to be accommodated and wishes to be respected; and
- social or relationship factors they would like taken into account in decision-making.

This format would not prevent a person from directing that specific medical interventions be withheld, however it enables such directions to be assessed in conjunction with the person's personal values and views about unacceptable levels of functioning when decisions are made.

### Checklist for forms

Forms should not require people to tick boxes but rather provide open leading statements that people may complete in their own words. Accompanying guidelines should include example outcome statements that the person can adapt to their needs.

ACD forms should accommodate the following requirements:

- expertly designed, focus tested with people from the health and aged care sectors and the general community, and avoiding legal language;
- easily accessible and free, with readily recognised branding;
- available in a variety of formats, including in a kit containing forms and guidelines and online;
- accompanied by guidelines that explain how ACDs work, guide completion of the form and also advise what to do when substitute decisions are needed;
- easy to complete in a variety of settings without the need for professional advice;
- a witness certificate or check list;
- applying to any period of impaired decision-making capacity, not just at the end of life;
- recording preferred outcomes and goals of care rather than medical directions;
- describing what personal circumstances constitutes quality of life or reasonable outcomes of care for them against which treatment decisions can be assessed;
- recording personal values, unacceptable or intolerable levels of functioning, and overly burdensome or intrusive interventions to be avoided;
- recording directions about personal matters, such as indicating preferred holiday arrangements, relationships the person wants to continue and who they do not want to see, as well as health matters;
- designating whether specific treatment-related directions are intended to be binding (eg applied exactly as written) or simply advisory (eg with flexibility according to the SDM's best judgement at the time);
- making it clear whether specific directions are intended to apply only to end-of-life circumstances;
- allowing separate directions for temporary and permanent periods of lost decision-making capacity and for end-of-life; and
- making it simple to review and change directions or appointments.

Where a SDM is being appointed, forms should allow for:

- appointing one or more SDMs, and directing how they act and make decisions including making decisions together, individually, in a particular order or as available;
- directing that a SDM can act as a substitute for another SDM as a result of a specified circumstance (eg the original SDM losing capacity, dying or being unwilling to act);
- appointing different SDMs for different types of decisions (health, residential or other personal decisions); and
- appointing a monitor to oversee the decisions of the SDM and describing reporting arrangements between the SDM and the monitor.

## Activating Advance Care Directives

### Ensuring the Advance Care Directive will be found when needed

Jurisdictions should establish a range of different mechanisms to record that an ACD exists so they can be accessed when needed and contact details of SDMs can be found quickly. Innovative means that are close to and within the control of the person, such as personal wallet cards and magnets that affix a copy of the ACD form to the fridge, are recommended. Such mechanisms are likely to be more effective because the person completing the form and their SDM have a personal interest in their ACD being found and applied.

#### Case study — Emergency care and treatment withdrawal

*Jim was taken out for dinner by his family for his 92<sup>nd</sup> birthday. However, he choked on a piece of steak and had a cardiac arrest. The restaurant called the ambulance, and the paramedics did CPR, gave adrenaline and intubated him before retrieving him to hospital. The paramedics were upset because the family had tried to stop them from intubating, and kept telling them that Jim had strongly stated he didn't want anything like that. On arrival to the ED Jim was intubated requiring mechanical ventilation, haemodynamically stable but had fixed dilated pupils.*

*There was a little delay before the family arrived. They had been to Jim's home and got his ACD off the fridge where he kept it. The ACD was clearly signed and witnessed and said that he did not want any invasive measures like dialysis or mechanical ventilation or CPR, and that he only wanted treatment that would allow him to be able to live independently. The down time was over 30 minutes so we thought it very unlikely that Jim would recover to be independent, so with the family present we extubated him and managed him with comfort care.*

ACD registers are not recommended; they are expensive to establish and run and rely upon a busy health care professional checking whether an ACD has been registered. Evidence indicates they are not an effective means of ensuring that an ACD is found when needed; while ACDs remain uncommon, time-consuming register searches will rarely yield results. Recording patients' ACDs on their electronic file and including a copy in their medical notes in a coloured sleeve has proved more reliable. This also permits data to be collected about the use of ACDs and whether treatment provided is consistent with their terms. Mechanisms such as designated ACD sleeves in the front of patients' notes that are readily identifiable help to alert staff to ACDs and also to ensure they travel with the person between health and aged care settings.

Overseas experience indicates registration needs to be both free and compulsory to be effective. There is little evidence that registers have reduced abuse or inappropriate decision-making by SDMs. Where registers are established, formal registration of ACDs must not be a condition of validity. A completed and witnessed but unregistered ACD would be considered valid under common law. In the future, ACDs may become more accessible through national electronic health record systems and local registration systems may not be warranted.

### Assessing capacity to make decisions

It is not the SDM's role to make a formal assessment of capacity when a decision is needed, as that must be performed by a suitably qualified professional. However, guidelines should recognise that SDMs routinely make ad hoc informal assessments of the person's ability to make the decision in question on a day-to-day basis, especially when the person is living independently.

Guidelines should include general advice for SDMs about using their knowledge and understanding of the person to assess capacity to make the decision in question, including in situations where capacity is fluctuating or gradually diminishing, and about when and how to seek a capacity assessment.

Guidelines should inform SDMs that

- decision-making capacity relates to the decision or task in question, and they must not presume that impaired capacity in one area indicates a total loss of decision-making capacity
- the person should be supported to make their own decisions for as long as they can and to the extent that they are able to understand their effect
- where a person's decision-making capacity fluctuates, decisions should be made when the person's capacity is optimum.

If the person is being cared for in a health or aged care facility or under a program that provides care in their own home, the SDM should be advised to consult with person's GP or health or aged care professionals if they are concerned about the person's decision-making capacity. If the person is insisting that they can make a decision that the SDM considers they are not capable of making, then the guidelines should recommend that the SDM seek advice from the person's GP or another health care professional who knows them, or to contact the Public Advocate or Guardian for advice.

#### **Case study — Assessing decision-making capacity**

*Grace struggles some afternoons. The nursing home is very nice and she likes her room. I'm her Enduring Guardian so they call me if she needs any significant health care. As her Enduring Guardian, I have to ask her what she wants before I decide.*

*She needed to see the dentist last week and we know that she's good in the mornings but gets very confused in the afternoons, so the nurse and I made sure we talked to her in the morning about it. She understood, so I gave consent and we made an appointment for her for another morning so she'd be clear in her head about what was going on.*

*Her doctor has assessed her and thinks she can make simple decisions herself, such as having a hot pack for her knee or where she wants to go for Christmas lunch. But she needs to leave the complex decisions to me now.*

#### **Contacting substitute decision-makers**

Policies and guidelines should make it clear that, where multiple SDMs are appointed to make decisions together or separately, health and aged care professionals should only be obliged to contact and consult with the first available SDM. If a joint decision is required, it should be the role of the first SDM contacted to get in touch with and confer with other SDMs, and the first SDM contacted can be considered the spokesperson for the group. However, where multiple SDMs are appointed to make decisions alone, a decision made by the first SDM contacted should be regarded as valid.

#### **Validity of Advance Care Directives**

An ACD containing directions written by a competent person who was not coerced nor unduly influenced should be considered valid. Clear directions in an ACD should be respected unless there is evidence that the person was not competent when it was made. If the validity of an ACD is not under question, then written directions must be accepted as a true record of the person's preferences even if they appear to be contrary to accepted norms of medical practice.

A health or aged care professional presented with a properly signed and witnessed ACD must be able to feel confident that it is valid and feel protected by local law and policy if they abide by its terms in good faith. There must be no obligation on a medical practitioner to verify the original circumstances under which the ACD was completed to assure him/herself that the person was competent at that time. It should be sufficient that the ACD includes a signed witness statement verifying that the person appeared to understand:

- the context of the powers they were conferring, removing or revoking;
- the choices they had available to them; and
- the consequences of completing the form.

Law, policy and guidelines should encourage outcomes-based ACDs that list values and preferred outcomes of care, but also recognise a person's right to record specific medical directions. They should make it clear that such ACDs are valid and that:

- health and aged care professionals cannot override any medical directions in a valid ACD on the basis that they believe them to be inadequately informed; and
- a SDM's decision should not be considered either uninformed or invalid on the basis that it is contrary to medical advice.

Although specific medical treatments cannot be demanded in an ACD, specific directions in an ACD refusing medical interventions must be respected by both SDMs and health care professionals even if the person who wrote the directions had not sought information or advice from a medical practitioner at the time of writing it.

## Making decisions under Advance Care Directives

### Honouring values and preferences

SDMs and health and aged care professionals making decisions for a person who lacks capacity should follow the decision-making pathway. SDMs should consult with people who know the person and can advise on preferences they may have expressed and personal decisions they may have made in the past that indicate their preferences and values, however they must respect the person's privacy and not share information with people whom the person has indicated they do not want included in discussions.

Even if an ACD was not validly completed or witnessed or fails to comply with legal or other conditions, the person's expressed values and preferences should be honoured and should guide decision-making.

#### Case study — Emergency with ACD on file

*When the paramedics brought Bruce in, he was unconscious. He had been found at home on the floor, after his daughter couldn't contact him by phone. Bruce was 77 and had extensive vascular disease, with several previous admissions with angina and atrial fibrillation. It seemed likely from our initial assessment that he had had a cerebral vascular event. He was unable to protect his airway well and we were considering intubation.*

*However, during Bruce's last admission he had been encouraged to think about an advance care plan and he had made one while still in hospital. Because there is an electronic alert on our patient admission system, we knew that an ACD existed in his file, so we looked for it as soon as the file arrived. In his ACD Bruce had made it clear that he wanted to continue to live independently and not to go to a nursing home and he had nominated his daughter as substitute decision maker.*

*Because it appeared that Bruce had had a major stroke and was unlikely to be able to live at home independently again, we deferred intubation until his daughter arrived, who was very upset, but confirmed that Bruce's wishes in this situation would be for comfort care.*

### Who decides what

Whether an intervention is overly intrusive or burdensome is something only the person, or someone who knows them well, could decide. Some people would find a breathing mask overly intrusive because it stifles conversation; others would tolerate that but not a feeding tube. Some people would find being bedridden overly burdensome, while others would tolerate that but would refuse an amputation. These are personal rather than medical assessments, linked closely with personal dignity and quality of life. Assessing what treatment is medically inappropriate and not likely to improve the health of the patient in any way, is a medical assessment.

### How decisions are made and by whom

In general, people expect their SDM to make decisions about their care, but expect their health care professional to provide advice about care and treatment options and their likely effectiveness and outcomes. Health and aged care professionals should respect their patient's concerns about living and dying with dignity and without pain, and advise the SDM about medical interventions and health care more likely to achieve the person's preferred outcomes of care.

The guidelines should explain how health and life-management decisions, and in particular end-of-life decisions, would be made for a person with impaired decision-making capacity in a range of circumstances including where:

- the person has recorded their values and preferred goals of care, with and without appointing a SDM; or
- the person has chosen and appointed a SDM, with and without discussing their values and preferences, and with and without written directions.

If the person has not appointed a SDM but has recorded their preferred outcomes of care, then the health and aged care professionals should consult with family members or carers who are assigned by legislation to make decisions.

#### **Case study — Palliative care in hospital, going home to die**

*I was asked to see Tanya, a 48-year-old woman in the oncology ward with metastatic breast cancer. She had extensive bony, brain and lung metastases and was extremely emaciated. She had progressive disease despite multiple rounds of chemotherapy and a peripheral blood stem cell transplant.*

*The main problem now was vomiting, and the family were concerned that she was not eating anything. The issue of whether to insert a feeding tube was being discussed.*

*When I saw Tanya, she was semiconscious and she had poor respiratory function. It was my view that she was only a few days from death. Her family was distraught. I asked about advance care planning, and the family stated that Tanya had made an ACD, expressing her wish to die at home.*

*I arranged for home terminal care resources to support the family in caring for Tanya. We got her home and she died the next day. Afterwards, the family thanked me for respecting Tanya's wish to die at home.*

#### **Decisions by substitute decision-makers**

Principles for decision-making by SDMs in law and policy should require the SDM to follow the decision-making pathway described in these standards. Guidelines should include guidance for SDMs about:

- determining when an ACD may need to be activated;
- following the decision-making pathway;
- any obligations to report to or consult with others; and
- how to seek help with dispute resolution.

Guidelines should explain that contemporaneous substituted judgement is the primary decision-making standard for SDMs, and the best interests standard only applies when there is no means to ascertain what the person's values and preferences would be and therefore what decision the person would have made in the current circumstances.

Law and policy should recognise that health care professionals are obliged to explain available treatment options and their likely outcomes to the person or their SDM. When a specific decision is required about health care or medical interventions, it is important that the person making the decision (whether on their own behalf or as a SDM) is provided with sufficient information about their health status and the proposed treatments, including risks associated with treating or not treating, to make an informed decision. However, just as a competent person can ignore medical

advice in deciding about treatment, a SDM can choose to ignore medical advice, or to make a decision that is inconsistent with medical advice, if they believe that the person would have made that same decision in the circumstances.

Law and policy should permit SDMs to make all decisions that the person could have made if they were competent, within the scope of the ACD, with the following exceptions:

- SDMs should be able to consent to or refuse interventions required for medical reasons; decisions about interventions sought for psycho-social reasons must be referred to an appropriate body (eg a Guardianship Board or Tribunal); and
- SDMs should be able to refuse artificial nutrition and hydration if they have reason to believe that the person would have refused this, but must not be able to refuse natural food and water given by mouth unless the person directly indicates that it is unwelcome.

## Problem solving

### Protections against abuse by SDMs

Legal protections against inappropriate decision-making by SDMs should include:

- requiring SDMs to act in good faith and to follow the decision-making pathway;
- permitting and encouraging a person to appoint a trusted adult as a monitor to oversee the actions and decisions of their SDM at regular intervals, and set conditions under which the monitor and SDM operate; and
- permitting a Guardianship Tribunal or equivalent to revoke the appointment of a SDM who lacks capacity, is negligent or is unwilling to make decisions.

SDMs who act in good faith believing an ACD to be valid, or who are unaware that an ACD has been revoked, should be protected from civil and criminal liability.

### Protections for health care professionals

Strategies should be put in place which address health professionals' concerns about potential litigation. These strategies may include clearly defined education and policies and may require legislated provisions. The emphasis should be on respecting a person's autonomy rather than risk management. Policies should support health and aged care professionals and facilities to accommodate and abide by ACDs rather than seeking reasons to overrule or ignore them.

Health care professionals should be protected from civil or criminal prosecution if:

- they abide by lawful terms in an ACD they reasonably believe to be valid; or
- they provide life-sustaining interventions in life-threatening emergency situations when there is insufficient time to seek or retrieve an ACD or to contact a SDM without putting the life or health of the person at serious risk.

However, treatment interventions must not be provided even in a life-threatening emergency if there is a known refusal that is relevant to the situation and was intended by the person to apply to the circumstances. If medical treatment has been provided in an emergency where there was no immediate evidence of an ACD, once the person's condition is stabilised and SDMs or family have been contacted, the decision-making standard of substituted judgement should apply.

Health care professionals whose personal views preclude them from complying with lawful directions in a valid ACD must be required to refer the patient (or their SDM) to another health care professional.

### Resolving disputes

Jurisdictions should provide for a clear process for dispute resolution. This should include advice, mediation and disputation stages and where legislation exists it should set out a clear process for dispute resolution that includes these stages. When disagreements arise about the application and interpretation of ACDs, the guidelines should encourage discussion and advise SDMs (and families and others where no SDM is appointed) when and how to seek advice from the treating clinical team or other health and aged care professionals.

The guidelines should advise SDMs, families and health and aged care professionals when and how to seek advice or mediation (eg through the office of the Public Guardian or Advocate) if they are concerned by decisions about care made on behalf of a person who lacks capacity. If mediation proves unsuccessful or the matter is clearly one that requires external review, the guidelines should provide advice about further dispute resolution measures and what that entails. Disputes not

resolved through advice or mediation should be heard by a tribunal (eg Guardianship Board), with court as a last option. The tribunal or court should be required to assess whether the SDM has applied the substituted judgement decision-making standard.

Whistle-blower protections should permit anyone with a concern about a SDM's decisions or a health or aged care professional's actions to report their concerns to a designated official (eg a Public Advocate or Public Guardian) and seek advice on what to do next.

**Case study — Resolving disputes**

*Our son, Eric, was in a terrible motor bike accident and when they got him to the hospital it looked like he wouldn't make it. They had him plugged into all these machines and the doctors said that he couldn't breathe on his own and thought he might be 'brain dead'. Eric had written an advance directive when he had the melanoma – that was before we separated. There was nothing in the form about pulling the plug in these circumstances, but his father told the doctors he thought Eric wouldn't want to be kept alive on machines. Eric had never said anything to me or his sister about that.*

*The doctors couldn't tell us if he would ever wake up and if he did wake up, how bad the brain damage would be. The doctor and I wanted to wait to see what would happen before any decision was made to withdraw his life support, but his dad wanted his wishes respected and for the doctors to let him go.*

*We tried sitting down to discuss it but we couldn't agree on anything – it was tearing the family apart. The doctor contacted the Public Advocate who came and talked to us all about it to find some common ground. We still could not agree so we had to go to the Guardianship Board. In the end it was decided there was no certainty about Eric's wishes so we should wait while they did more tests to see if his condition was permanent. If only Eric had discussed his wishes with us then we would at least have known what he would have wanted.*

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## APPENDIX A: Advance Care Directives in Australian legislation

	<b>Legislation</b>	<b>Advance Care Directive</b>
ACT	<i>Powers of Attorney Act 2006</i>	Enduring Power of Attorney
	<i>Medical Treatment (Health Directions) Act 2006</i>	Direction
NSW	<i>Guardianship Act 1987</i>	Enduring Power of Guardianship
NT	<i>Natural Death Act 1988</i>	Direction
QLD	<i>Powers of Attorney Act 1998</i>	EPA (health) and EPA (personal)
	<i>Guardianship and Administration Act 2000</i>	Advance Health Directive (includes a personal attorney)
SA	<i>Guardianship and Administration Act 1993</i>	Enduring Power of Guardianship
	<i>Consent to Medical Treatment and Palliative Care Act 1995</i>	Medical Power of Attorney and Anticipatory Direction
TAS	<i>Guardianship and Administration Act 1995</i>	Enduring Power of Guardianship
VIC	<i>Guardianship and Administration Act 1986</i>	Enduring Power of Guardianship
	<i>Medical Treatment Act 1988</i>	Enduring Power of Attorney (Medical Treatment) and Refusal of Treatment Certificate
WA	<i>Guardianship and Administration Act 1990</i>	Enduring Power of Guardianship and Advance Health Directive

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	<b>Advance Care Directive</b>	<b>Substitute decision-maker</b>	<b>Decisions that can be made</b>
ACT	Enduring Power of Attorney	Attorney	health care and life-management
	Health Direction	none	medical treatment only
NSW	Enduring Power of Guardianship	Enduring Guardian	health care and life-management
NT	Direction	none	medical treatment only
QLD	Enduring Power of Attorney	Attorney	health care, life-management and financial (separate)
	Advance Health Directive	may appoint a personal attorney	medical treatment and health care generally
SA	Medical Power of Attorney	Medical Agent	medical treatment only
	Anticipatory Direction	none	medical treatment only
	Enduring Power of Guardianship	Enduring Guardian	health care and life-management
TAS	Enduring Power of Guardianship	Enduring Guardian	health care and life-management
VIC	Enduring Power of Attorney (medical treatment)	Attorney	medical treatment only
	Enduring Power of Guardianship	Enduring Guardian	health and life-management
	Refusal of Treatment Certificate	none	medical treatment only
WA	Enduring Power of Attorney	Attorney	life-management
	Enduring Power of Guardianship	Enduring Guardian	medical treatment only
	Advance Health Directive	none	medical treatment only

**Appendix B: Members of the Advance Care Directives Working Group**

	<b>Name</b>	<b>Expertise</b>	<b>Position</b>
WA	Dr Simon Towler (Chair)	Intensivist	Chief Medical Officer, Dept of Health WA
	Heather Wilson Sep2009 – Apr2010	Health policy adviser	Senior Policy Officer, Dept of Health WA
	Jenny O’Callaghan from Apr2010	Health policy adviser	Senior Policy Officer, Dept of Health WA
SA	Dr Jean Murray member to May2009, then principal writer	Health policy ethico- legal adviser	Policy Consultant (previously Principal Consultant, Ethico-Legal Reform, SA Health)
	Kathy Williams	Health policy adviser in bioethics	Senior Policy Officer, Bioethics and Reproductive Technology, SA Health
ACT	Dr I. Anne Leditschke	Intensivist	Senior Specialist, Intensive Care Unit, The Canberra Hospital
NT	Liz Kasteel to Dec2009	Health policy adviser	A/Principal Policy Advisor, Acute Care Policy and Services Development, Dept of Health and Families, NT Health
	John McMahon from Jan2010	Health policy adviser	Palliative Care Nurse Consultant/Senior Policy Officer, Dept of Health and Families, NT Health
QLD	Mandy Forster	Health policy adviser	Director – Access Improvement Service, Centre for Healthcare Improvement, Queensland Health
	Kim Gasson	Health policy adviser	Manager – Access Improvement Service, Centre for Healthcare Improvement, Queensland Health
	Sue Cawcutt to Sep2009	Health policy adviser	Principal Policy Officer, Access Improvement Service, Centre for Healthcare Improvement, Queensland Health
NSW	Jo Montgomery to Feb2009	Health policy adviser	Principal Project Officer, Advance Care Planning & Healthy at Home programs, NSW Health
	Julie Letts from Feb2009	Health policy adviser in clinical ethics	Principal Policy Analyst (Clinical Ethics), Research and Ethics Branch, NSW Health
TAS	Helen Mulcahy to Mar2009	Health policy adviser	Principal Policy Analyst: Clinical Technical & Ethical Issues, Dept of Health and Human Services

	<b>Name</b>	<b>Expertise</b>	<b>Position</b>
	Prof Michael Ashby from Mar2009	Palliative care physician	Director of Palliative Care, Royal Hobart Hospital, and Clinical Director, Palliative Care, Dept of Health and Human Services
	Di Driscoll Mar – Dec2009	Health policy adviser	Principal Consultant, Palliative Care
	Raul Cox from Jan2010	Health policy adviser	Senior Policy Analyst: Policy, Information and Commissioning Group
VIC	Gail Roberts to Jun2009	Health policy adviser	Senior Project Officer, Sub-acute Services, Wellbeing, Integrated Care and Ageing, Victorian Department of Health
	Nicole Doran from Jul2009	Health policy adviser	Manager, Sub-acute Services, Wellbeing, Integrated Care and Ageing, Victorian Department of Health
CWLTH	Dr Bronwen Harvey	Public Health Medical Officer	Medical Adviser, Office of Health Protection, Department of Health and Ageing
	Melinda Bromley Apr – Sep2009	Commonwealth Officer	Assistant Secretary, Office for an Ageing Australia, Department of Health and Ageing
	Chris Reid	Barrister and solicitor	General Counsel, Dept of Health and Ageing
	Dr Tim Dyke	Senior government executive	Executive Director, Quality and Regulation Branch, National Health and Medical Research Council

Secretariat support was initially provided by Judy Mills, Coordinator of the AHMAC Clinical Technical & Ethical Principal Committee, Department of Health and Families, NT; and from November 2009 by Kim Southgate, Office of the Chief Medical Officer, WA Health.

Advice was also sought during the drafting stage from:

- Margaret Brown, Adjunct Research Fellow at the University of South Australia
- Bernadette Richards, Lecturer at the University of Adelaide Law School
- Associate Professor Cameron Stewart, Centre for Values, Ethics and the Law in Medicine at the University of Sydney
- Professor Colin Thomson, Faculty of Law at the University of Wollongong