A National Framework for Advance Care Directives

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THE CLINICAL, TECHNICAL AND ETHICAL PRINCIPAL COMMITTEE
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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.

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Abbreviations used in this document

ACD Advance Care Directive
CPR Cardiopulmonary resuscitation
SDM Substitute decision-maker

1 Why is a National Framework needed?

Many people fear a loss of autonomy, dignity and the ability 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. ACDs are not only advance medical directions written by a patient; nor are they limited to end-of-life decision-making. They are life-management documents which people may complete in home, community, hospital, institutional and aged care settings. Often when people complete ACDs, they are not seeking to control medical treatment decisions, but hoping to live well and die with dignity in accordance with their personal values.

Although such ACDs are used in all Australian states and territories, they take different forms, have different names and, while 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 elsewhere. 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 should be followed in practice.

Australia's Health Ministers recognise the need for a standardised national format for ACDs and have decided that the challenges posed by divergent laws and the concerns expressed about the use and application of ACDs are best addressed by a national policy framework. This Framework acknowledges the practical and ethical challenges inherent in this undertaking and the diversity of legislation across Australia; however it also recognises 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 for which policy and practice should aim rather than reflecting current law and practice across Australia.

The development of this Framework has been guided by 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 after 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, institutional and aged care settings.
- Clinical care and treatment plans written by health care professionals will be consistent 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 has been developed to explain how common terms are used in this Framework and to encourage its adoption across Australia (see Section 3).
- The Code for Ethical Practice (see Section 4) sets out principles to guide practice where ACDs are applied in health, institutional 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 not written for the general public. It is primarily intended for:

- regulators, including legislators and policy-makers in governments and parliaments; and
- administrators of advance care planning programs in the health and aged care sectors.

It will inform this audience of the key ethical and practical aspects of ACDs, and describe a consistent approach that 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 to harmonise local use with the national terminology to enable nationally 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.

Administrators of advance care planning 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 (in compliance with local laws).

1.4 When does this Framework apply?

This Framework only seeks to address issues of health and aged care decision-making where there is a written ACD in place. It deals with ACDs written by competent people, but not with oral directions or advance care plans written on behalf of others.

The Framework applies to Advance Care Directives that provide for substitute decision-making about health and medical care, residential arrangements and other personal matters, but does not apply to or affect the operation of Enduring Powers that appoint a substitute decision-maker to manage a person's financial and legal affairs.

This Framework places ACDs within a broad context:

- ACDs may be prescribed in legislation or operate under common law.
- ACDs may record personal values and life goals, describe circumstances the person would find unacceptable, identify specific medical interventions, appoint an SDM, or a combination of these.
- ACDs are relevant to adults at all stages of life – they can be completed by competent adults whether they are healthy and active, have recently had a disease diagnosed, are chronically ill, or at the end of their lives.
- ACDs can relate to any future time of impaired decision-making capacity, not just at the end of life – they can be activated during temporary periods of impaired or lost capacity such as an episode of mental illness or transient unconsciousness.
- ACDs may 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, forms and guidelines that cover health, medical, residential and other personal 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 an SDM.

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.

2 What is the context for this Framework?

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 developed 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, along with the possibility of impaired cognitive function due to dementia.

Good care at the end of life that promotes the autonomy and dignity of an 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 is 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 life for a person 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 an unacceptable state increases 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 decisions on behalf of the person dying or in an impaired decision-making state. 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 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 health and personal arrangements resulted in guardianship laws that sought to preserve this right beyond loss of capacity by appointing an SDM. Specific medical ACDs are a more recent phenomenon, which were publicly supported firstly in industrialised nations where personal autonomy is an accepted cultural norm. Some other cultures take a different approach to substitute decision-making which does not necessarily prioritise personal autonomy.

In the 1970s, particularly in the United States of America (USA), concerns about end-of-life care emerged. New technologies were keeping people alive for longer and life-extending medical advances were perceived to be putting some patients in unacceptable circumstances when they were 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,[1] allowing people to record their preferences for medical treatment in advance in case they became unable to communicate. Canada chose not to legislate ACDs but developed advance care planning programs, whereas Britain relied on common law until the passage of the *Mental Capacity Act 2005* which largely reproduces the common law.

[1] *Re Quinlan (1976) 70 NJ 10. 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 became apparent that written medical instructions alone were of limited effectiveness, and recent international legislative, policy and program activity has favoured a combination of substitute decision-making and written directions, supplemented by a statement about values and life-goals.

By the late 1900s, almost all states and territories had passed guardianship legislation generally allowing a person to appoint an 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.

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 Australian Capital Territory and Queensland each combined their ACDs under a single Act to make them more accessible and easily understood. All other states have retained their Enduring Powers of Guardianship. In addition to their Enduring Powers of Guardianship, New South Wales 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, the Northern Territory and Victoria did so in 2009.

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. It was not until August 2009 that an Australian Court[2] delivered a decision that affirmed the legality of instructions in ACDs and provided a summary of principles for practitioners to follow when provided with an ACD in an emergency situation (see Appendix B).

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, 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 his or her life goals, values and personal views and choices about his or her preferred outcomes of care with a trained professional, family and close friends. This approach is particularly appropriate when ACDs are completed by people who already have a chronic or life-limiting physical or mental 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 their own decisions. Their ACDs will apply in circumstances that are as yet unknown and difficult to predict. These people usually complete their ACDs in their homes or with their lawyers (often in conjunction with financial advance directives) without needing advance care planning support from a trained health care professional. They are more likely to appoint a person they trust to make future decisions for them rather than record detailed directions. However it is important that they discuss their personal values, preferences and any advance decisions with family and others close to them.

[2] *Hunter and New England Area Health Service v A [2009] NSWSC 761*

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 in Australia or how many are used for decision-making, although there is evidence that advance care planning programs are increasing the uptake of ACDs in health, institutional 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 indicates the important role of communicating preferences and personal values rather than focusing 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 an 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 an SDM pose fewer problems.

Problems with ACDs have been identified when:

- healthy people write specific medical directions in advance of any diagnosis of disease or injury, either because the ACD form requires them to or because they believe that to be the only way to ensure a dignified death in accordance with their personal values and preferences;
- 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, and lack support in their role;
- people change their stated medical treatment preferences over time but fail to update their ACD, especially as priorities change towards the end of life;
- medical practitioners experience difficulties interpreting directions recorded in ACDs when developing clinical care and treatment plans; and
- health professionals do not follow 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 current standards of informed consent and clinical practice within the health and aged care sectors.

The Framework recognises

- that under common law the terms of an ACD must be respected whether or not the person was medically informed of the consequences when the ACD was written;
- that a person (or the SDM) can consent to treatment options that are offered, and refuse such treatment, but cannot demand treatment that is not medically indicated;
- the need to protect health and aged care professionals from civil and criminal liability if they abide by the terms of an ACD that they believe, in good faith, to be valid;
- that voluntary euthanasia and physician-assisted suicide are currently illegal in Australia.

The Code for Ethical Practice and the Best Practice Standards make it clear that ACDs are not a means of requesting interventions that are not legal, and that health care professionals are not required to abide by unlawful directions in an ACD.

Although disputes may arise and come to the attention of lawyers, governments, courts and the health and aged care sectors, such ACDs represent only a small proportion of those completed and 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.

2.5 The Advance Care Directive journey

There are different stages in life whereby a person might consider completing an ACD. Most people write their ACD when contemplating future illness or gradually diminishing capacity; others focus on accidents or sudden and complete loss of competence.

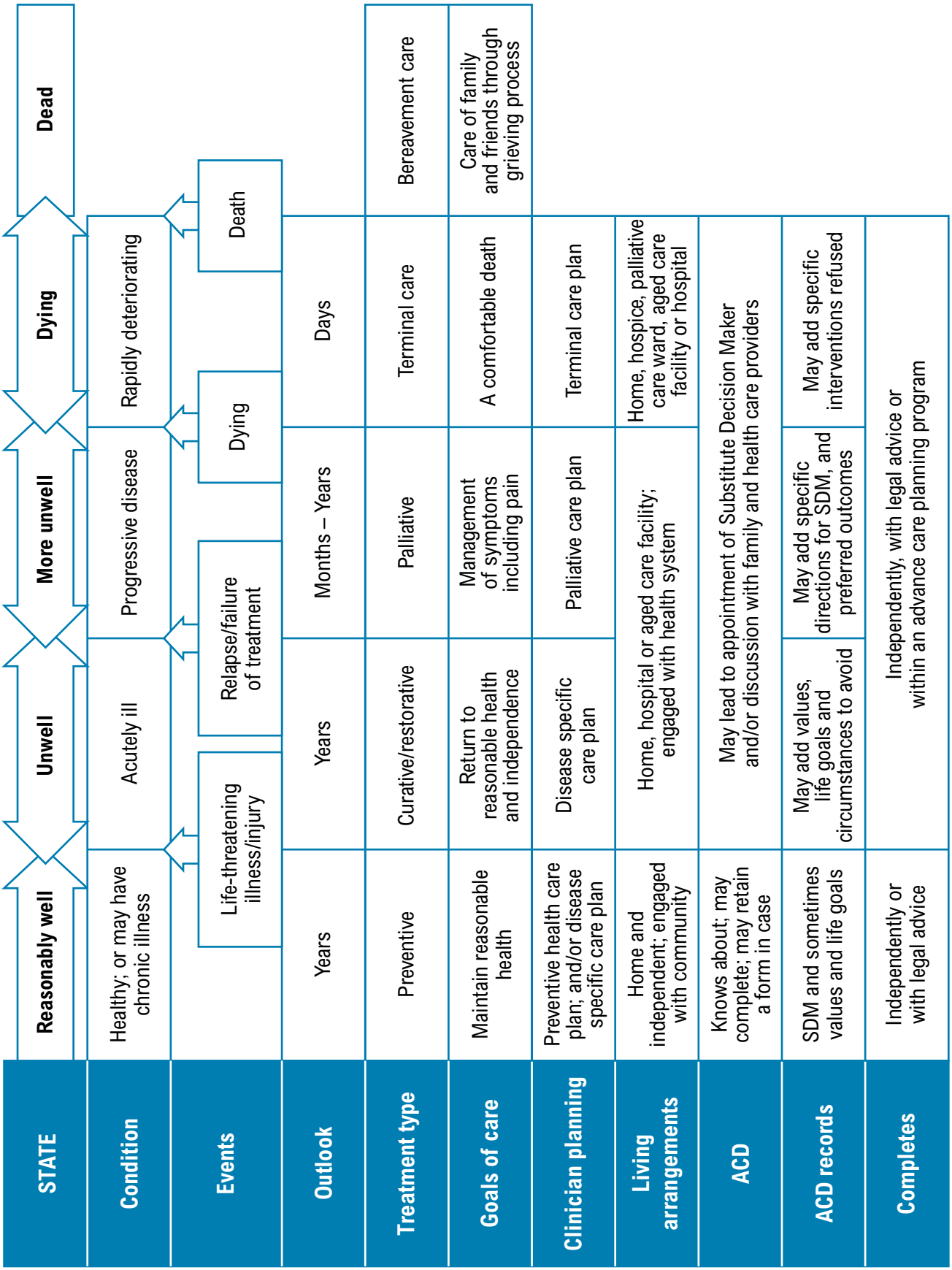
Studies suggest that of people considering an ACD, 10% are near death, 30% are chronically ill and 60% are well. Many people complete their ACD in stages, feeling confident to appoint an SDM while they are healthy but not recording or communicating any directions until they are faced with a life-limiting condition. It is not uncommon for people to keep an uncompleted ACD form in a drawer for many years, until they reach a stage where its value to them becomes greater than the complexities it presents when they attempt to complete it.

A decision to write an ACD can be triggered by a range of situations:

- a family discussion about a television program or news item that features the challenges of making decisions for others at the end of life;
- receiving a form from a financial planner or general practitioner with advice to complete it;
- having a close friend or relative such as an elderly parent who needs decisions made for them;
- a change of lifestyle or retirement;
- the 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. People often move between the categories in the following ‘patient journey’ chart – Figure 1. The chart documents a typical patient journey, but it is recognised that some people will complete an ACD to record specific refusals of interventions from the outset, such as refusing blood transfusions.

Figure 1: Patient journey chart, adapted from Lynn J, Adamson DM. Living well at the end of life; adapting health care to serious chronic illness in old age. Arlington, VA, Rand Health, 2003



3 Nationally consistent terminology

The establishment of a national 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. It is recommended that this lexicon be adopted nationally to align ACDs throughout Australia.

Terms used in this Framework currently have different meanings in different states and territories. For example, Advance Care Directive is a collective term that has different meanings across Australia:

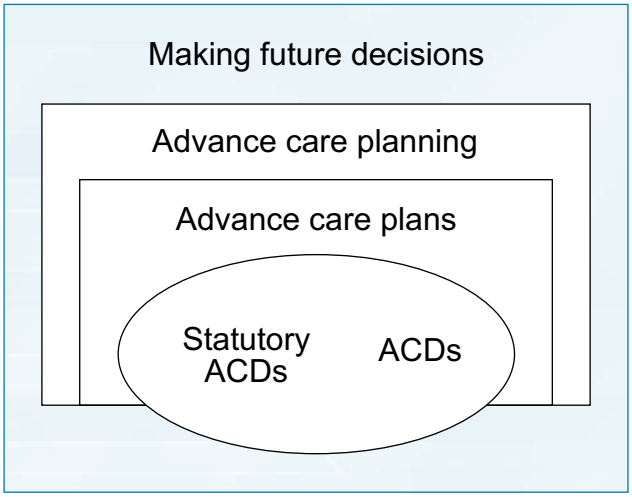
- In New South Wales and Tasmania an Advance Care Directive is a common law document that records a person's future preferences for health care but does not appoint a substitute decision-maker.
- In South Australia an Advance Care Directive is a collective term for legislated instruments that record directions and appoint substitute decision-makers for health and personal decisions, but not financial and legal decisions.
- In Western Australia the term Advance Care Directive is increasingly used as a collective term for Advance Health Directives, Enduring Powers of Guardianship and common law health directives.
- Queensland and Victoria do not use the collective term Advance Care Directives but refer separately to each different instrument by name.

The Framework provides a collective term to describe the range of instruments with which a person can record future preferences and appoint and instruct a substitute decision-maker. 'Advance Care Directives' was chosen because it is already used in this way in at least two states. The term includes both legislated and common law instruments that allow for health, medical, residential and other personal decision-making but is distinct from legislated instruments that allow for decisions about financial and legal matters. The term 'advance directive' is not used in this Framework because it has various meanings across Australia.

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 be adopted and used consistently to ensure greater coherence across Australia.

The terminology follows the schema represented below.



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 that person cannot make or communicate his or her decisions. Formal advance care planning programs usually operate within a health, institutional or aged care setting after a life-limiting condition has been diagnosed, frequently requiring the assistance of trained professionals. However, people can choose to discuss their advance care plans in an informal family setting.

Advance care plan

An advance care planning discussion will often result in an advance care plan. Advance care plans state preferences about health and personal care and preferred health outcomes. They may be made on the person's behalf, and should be prepared from the person's perspective to guide decisions about care.

There are many ways of recording an advance care plan including oral and written versions. They may be made by, with or for the person. A person with diminished competence may complete an advance care plan, or be assisted to complete one. If made on behalf of a person who does not have decision-making capacity by a family member or someone who knows him or her well, they should record the known preferences of the person. A preferred decision-maker named in an advance care plan is not a statutory appointment.

Advance Care Directive

ACDs are one way of formally recording an advance care plan. An ACD is a type of written advance care plan recognised by common law or authorised by legislation that is completed and signed by a competent adult. An ACD can record the person's preferences for future care and appoint an SDM to make decisions about health care and personal life management. ACDs are focused on the future care of a person not on the management of his or her assets.

This Framework deals with ACDs written by competent people, but not with oral directions or advance care plans written on behalf of others.

It is preferable to complete ACDs within an advance care planning program or framework when the person is thinking about future care for known health problems. However, healthy people who simply want to complete an ACD for unanticipated future situations within their family context may not find a formal advance care planning program necessary or useful.

ACDs and advance care plans are not to be confused with clinical care plans, treatment plans or resuscitation plans written by clinicians to guide clinical care. Such clinical plans should be informed by the person's own advance care plan or ACD.

Statutory Advance Care Directive

A statutory ACD is one that is enshrined in legislation (see 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 in legislation. It does not include, for example, the Respecting Patient Choices Program's Statement of Choices form which is not established under legislation but is recognised under common law.[3]

Types of Advance Care Directives

ACDs can record a person's values, life goals and preferred outcomes, or directions about care and treatment refusals, and can formally appoint an SDM – or a combination of these. They may be limited to medical treatment or allow for directions or decision-making about a wider range of health, residential and other personal matters (excluding financial and legal affairs).

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

- ACDs that permit directions to be recorded but do not allow for an SDM to be appointed — these include South Australia's Anticipatory Direction, Victoria's Refusal of Treatment Certificate, Western Australia's Advance Health Directive, and the Australian Capital Territory's and Northern Territory's Directions. Such ACDs are often restricted to medical treatment decisions at the end of life, sometimes limited to medical interventions refused.
- ACDs that only permit an SDM to be appointed but do not allow for directions to be recorded, such as Victoria's Enduring Guardianship and Victoria's Enduring Power of Attorney (Medical Treatment).
- ACDs that allow for both directions to be recorded and an 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. In the Framework, 'the person' refers to the one completing an ACD or the one having appointed a substitute decision-maker.

[3] *The Respecting Patient Choices Program is registered in Australia by Austin Health, Victoria*

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 has both person-based and patient-based ACDs.

Patient-based ACDs are intended to be completed by patients in a health, institutional 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 Statement of Choices and a range of other locally produced or internationally recognised ACDs that are not prescribed by legislation.

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 an 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.

This Framework supports person-based ACDs.

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*. Resuscitation plans, treatment plans and No CPR (cardiopulmonary resuscitation) Orders are clinical care plans.

A clinical care plan sets out treatment directions to be followed by health professionals in a medical or aged care facility. It is appropriate that clinical care plans be put in place whether or not the person has made an ACD, but when there is an existing ACD that records directions about care, the clinical care plan complements, and therefore should be informed by, the person's ACD.

Substitute decisions

A substitute decision is one made on behalf of a person who lacks capacity to make his or her own decision. A substitute decision seeks to replicate the decision it is thought 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 might have made.

A *contemporaneous* substitute decision is one that reflects or takes account of the current or contemporary circumstances, while still seeking to make the decision it is thought the person would have made if he or she had had access to contemporary information and advice.

Substitute decision-maker

SDM 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 document that appoints an SDM to make health, medical, residential and other personal decisions (but not financial or legal decisions) is considered to be an ACD under this Framework.

An 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.

There are three categories of SDMs:

1. SDMs *chosen by* the person (e.g. 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 (e.g. family member, carer or 'person responsible'); and
3. SDMs *appointed for* the person (e.g. a guardian appointed by a guardianship tribunal).

This Framework is intended to apply to category 1, and to category 2 and 3 when an ACD is in place. This Framework does not apply to SDMs who make financial and legal decisions for the person.

Health care, medical treatment and other personal matters

Health care is used to refer to care, treatment (including *medical treatment*) and services or procedures to diagnose, maintain or treat a person's physical or mental condition. Health care may be carried out by a range of health professionals or may be under the direction or supervision of a health professional.

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, which includes dental treatment, can be administered by a range of health professionals. Recent Court judgments have confirmed that artificial hydration and enteral feeding are forms of medical treatment rather than nourishment.[4]

Other personal matters include residential arrangements, employment, holidays, visitors and care of pets. These matters are separate from health care decisions and directions about such matters cannot be binding.

The inclusion of health, medical, residential and other personal matters recognises the World Health Organization's definition of health as not limited to the absence of medical conditions or disease but includes physical, psychological, social and spiritual health and wellbeing.

Health care at the end of life

End of life is used as an umbrella term to denote that part of life where a person is living with, and impaired by, an eventually fatal (or terminal) condition, even if the prognosis is ambiguous or unknown.[5] End of life may refer to varying prognostic time spans where it is acknowledged that the person's condition will no longer respond to curative treatment, and may be used to describe deteriorating illness trajectories for up to 2 years before eventual death.

Life-sustaining measures are medical or surgical interventions 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 (such as mechanical ventilation, dialysis and blood transfusions).

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.[6]

Palliative care uses a team approach to address the needs of patients and their families, to enhance quality of life and to assist those with advanced, progressive, incurable illness to live as actively as possible until they die. Palliative care intends to neither hasten nor postpone death, but affirms life and regards dying as a normal process, provides relief from pain and other distressing symptoms and supports the family to cope. Palliative care can commence well in advance of the terminal stage of an illness, in conjunction with other therapies that are intended to prolong life such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.[7]

Health professionals

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

[4] *Gardner; re BWV [2003] VSC 173 (29 May 2003)in Victoria; Brightwater Care Group (Inc) -Vs-Rossiter [2009] WASC 229 in Western Australia.*

[5] *Palliative Care Australia, Palliative and End of Life Care – Glossary of Terms. PCA, Canberra.*

[6] *Palliative Care Australia, Palliative and End of Life Care – Glossary of Terms. PCA, Canberra.*

[7] *Adapted from the WHO Definition of Palliative Care for Children (1998).*

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:

- A person must have full legal *competence to complete* an ACD. Adults are presumed in law to be competent.
- A person must have sufficient decision-making *capacity to consent to or refuse* medical interventions. If the decision-making capacity is assessed at that time and is found to be insufficient in the context of the nature of that particular decision, the ACD may be activated.

Competence is a legal term used to describe the mental ability required for an adult to perform a specific task. Competence is recognised internationally and in common law as a requirement for completing a legal document that prescribes future actions and decisions, such as a will or an ACD.

A person is deemed to be either competent or not competent to complete an ACD; there are no shades of grey. Competence must be assumed unless there is evidence to suggest otherwise. There must be evidence that the person completing an ACD was incompetent at the time the ACD was written before its terms can be ignored on those grounds.

To complete an ACD, the person should understand:

- the context of the powers he or she is conferring, removing or revoking – for example, that the ACD may be used to appoint an SDM and empower the SDM to make decisions for him or her in the future and that the SDM is required to follow the written directions;
- the choices available to her or him – for example, between different types of ACD, whether to record directions or not, whether to appoint one or more SDMs and who to appoint; and
- the consequences of completing the ACD – for example, that it will apply should he or she be unable to make decisions personally and that it may determine what future health care he or she does or does not receive.

The ACD may be invalid if a person is affected by undue influence or coercion when completing the ACD. Forcing a person to complete an ACD or preventing a person from completing an ACD that express his or her personal values and opinions is considered undue influence or coercion. A person with fluctuating competence due to mental illness can complete an ACD during periods of competence, whereas a person with ongoing diminished competence would only be able to complete a non-statutory (common law) ACD. In some jurisdictions young people less than 18 years of age can consent to medical treatment but they cannot complete a statutory ACD.

Capacity becomes an issue in situations when a decision is needed and the person has completed an ACD. If his or her decision-making capacity is questioned, it is then unclear whether the ACD should be activated.

Having the capacity to make a decision means the person has the ability to understand the information provided about his or her health condition, including options for treatment. It also means that the person has the ability to consider the possible choices in terms of his or her own personal values and preferences, make a decision, and communicate that decision.[8]

Decision-making capacity is assessable, and its assessment depends on the type and complexity of the decision to be made.[9] A person's loss of decision-making capacity may be partial or temporary, and may fluctuate. Decision-making capacity should be assessed at the time a significant decision is required, in order to establish 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 uncertain at the time when a decision is required.

[8] *Molloy, D.W., Let Me Decide, 2nd edition, Vancouver Health Authority, 2004.*

[9] *Kerridge, I. Lowe, M., McPhee, J., Ethics and Law for the Health Professions, 2nd edition, Federation Press, Sydney, 2005, p185.*

4 The Code for Ethical Practice for Advance Care Directives

The Code for Ethical Practice is intended to provide a set of principles to guide practice in health, institutional and aged care settings where Advance Care Directives (ACDs) are used for health, medical, residential and other personal decisions. The Code underpins the Best Practice Standards. It is acknowledged that local laws will override this Code where they differ, but it is intended that over time legislation will align with the Code.

1. **Advance Care Directives are founded on respect for a person's autonomy and are focused on the person**

   An ACD reflects 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 ACD to guide future decision-making; a person's ACD will be valid regardless of whether the person's written directions were informed by, or are consistent with, medical advice.

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

   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 approaches.

4. **Adults are presumed competent**

   An adult should be presumed competent at the time of completing an ACD 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, but may include directions about unacceptable circumstances, and preferred care and residential arrangements.

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

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

7. **The person decides what constitutes quality of life**

   The person determines his or her 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; the person can communicate this information in the ACD or through discussion with a substitute decision-maker.

8. **The substitute decision-maker has the same authority as the person when competent**

   The decision of a substitute decision-maker validly appointed under an ACD 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 to make that particular decision.

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

    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, 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 his or her decision on best interests when there is no evidence of the person's preferences on which to base substituted judgment**

    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 his or her best interests are, they are then defined by the chosen or legally assigned substitute decision-maker.

12. **An Advance Care Directive can be relied upon if it appears valid**

    A health care professional is entitled to assume that an ACD 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 a valid Advance Care Directive must be followed, if intended by the person to apply to the situation**

    A person can indicate in an ACD his or her 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 in an ACD must be respected regardless of whether they may lead to serious deterioration in health or death, even where they differ from the views of a legally recognised substitute decision-maker, family members or health and aged care professionals caring for the person.

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 ACD to demand particular medical interventions or treatment or to request something illegal. 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 ACD. Health care professionals should discuss and explain all appropriate treatment options with legally recognised substitute decision-makers.

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

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

[This Code is designed to be posted on notice boards and incorporated into procedure manuals]

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. The Standards 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. They are not intended to describe model laws, but take a policy rather than legal approach.

When changes to ACDs are contemplated in each jurisdiction, efforts should be made to move regulation and practice towards these Standards to ensure national consistency. It is acknowledged that local law and policy will override these Best Practice Standards where they differ but it is intended that over time legislation will align with the Standards.

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 5.2 relates to ethical principles and best practice for substitute decision-making.
- Subsequent sections relate 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 substitute decision-makers (SDMs) and health and aged care professionals
  - advance care planning programs which use ACDs.

These standards are organised under six subheadings:

- two sets of core standards designed to guide initial development of law and policy and of forms and guidelines (Sections 5.3 and 5.4);
- three sets of specific standards designed to address the detail of law, policy, forms and guidelines that follow the ACDs journey from completing, through activating ACDs to making decisions under ACDs (Sections 5.5, 5.6 and 5.7); and
- a final set of standards specifically related to problem solving (Section 5.8).

The Best Practice Standards apply to Advance Care Directives that provide for substitute decision-making about health and medical care, residential arrangements and other personal matters, but do not apply to or affect the operation of Enduring Powers that appoint a substitute decision-maker to manage a person's financial and legal affairs.

How can these Best Practice Standards be used?

These Best Practice Standards are written as a resource or reference document, and are not intended to be read as a textbook. There is therefore cross-referencing and some repetition where necessary to add clarity to a section.

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. State and territory laws and policies should recognise the variety of circumstances in which ACDs are completed and the range of choices that people want to make, rather than restrict or constrain 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 standards for ACD forms, for information guidelines written for the public, and for advisory guidelines directed at the health and aged care sectors.

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
- non-maleficence or the requirement to do no harm.

These are underpinned by two decision-making standards: substituted judgment and best interests. Substituted judgment 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 judgment standard, others apply the best interests standard; some require both to be applied simultaneously which 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 a competent adult's personal autonomy, which is generally understood as a person's ability to make self-determining choices and direct his or her own life. ACDs are a means to respect a person's autonomy beyond lost or impaired decision-making capacity by respecting the person's will and prior consent. They represent the person's decisions, preferences and directions, recorded when competent and intended to apply when the person's decision-making 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 Australian 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 and what decisions are made.

The decision-making standard of substituted judgment best respects the person's autonomy (however expressed), and is the required standard when a person has completed an ACD that appoints an SDM and has discussed and recorded his or her preferences in advance. This Framework encourages this optimum circumstance; however, it is generally recognised that this is not the situation frequently encountered in health, institutional 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 judgment;
- the ACD appoints an 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 judgment;
- 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 judgment cannot be applied.

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

Substituted judgment

This Framework sets substituted judgment as the primary decision-making standard for SDMs where there is an ACD in place, but extends this to a contemporaneous substituted judgment approach to decision-making on behalf of another.

Contemporaneous substituted judgment seeks to approximate what the person would decide at the time when a decision is needed if his or her capacity had not been impaired and if he or she had access to current information and advice. It recognises that people often change their minds about specific medical interventions when they have accurate information about health care management and likely outcomes. It also ensures the consent of the SDM is informed, and is therefore more aligned to the way competent adults make decisions for themselves. This approach introduces more relevance and reflection to decision-making, and more closely approximates the concept of truly 'authentic' substitute decisions or 'walking in another's shoes'.

The decision-maker should use the following guiding principles when applying the substituted judgment standard in practice:

- First and foremost, SDMs must honour the person's preferences (and, particularly, advance refusals of medical treatments); this requires SDMs to fully take into account the person's views (present and previous, written and oral) and to make the decision they honestly believe the person would have made in the prevailing circumstances.
- SDMs must consider 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 his or her expressed views about quality of life.
- Unless the person's views are clearly known, SDMs must confer with those who may know the person's preferences and values and make a decision based on the most reliable information.
- Where there are alternative options that meet the person's stated preferences, SDMs must choose the option that is the least restrictive of the person's basic rights and freedoms but optimises his or her 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 his or her welfare.

A contemporaneous substituted judgment approach allows for the following:

- SDMs 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 judgment would require the SDM to do likewise.
- SDMs 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. SDMs 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 he or she must refuse the treatment on the person's behalf.

Contemporaneous substituted judgment requires the SDM to consider whether the person intended his or her 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 or an ACD requesting pain relief but refusing antibiotics when the antibiotics would effectively alleviate the pain of an infection;
- be considered in the light of current advice, developments in health care and changed circumstances such as a radically new and successful treatment that was not available or known about at the time the person completed the ACD or lost decision-making capacity.

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 judgment

Nancy had been living in a residential aged care facility for around a year. All residents were encouraged to complete an Advance Care Directive several weeks after they first arrived. Although Nancy had worsening dementia over the last year and was now unable to recognise her family, she had previously recorded her wishes in writing. These included that she wanted treatment of only reversible illness; avoidance of surgery, intensive care and aggressive life-prolonging treatment when she became unable to recognise her family, communicate and was bed bound; and to be kept comfortable and free from pain when she was dying.

Nancy fell and broke her leg. Doctors agreed that transfer to hospital and surgery to stabilise the leg was the best means of controlling her pain and keeping her comfortable. The family were contacted and her Advance Care Directive was reviewed in light of the circumstances. While she had stated that she preferred to avoid surgery and hospital transfer, the family agreed that the proposed course of action would be her choice, given the current circumstances and her stated values.

Nancy had surgery on her broken leg and adequate pain relief was achieved. However, she developed respiratory failure over the next fortnight and a decision was made, consistent with her wishes, to not introduce aggressive life-sustaining measures. She died comfortably, surrounded by her family a day later.

Best interests

Substituted judgment represents the ideal standard for substitute decision-making where an ACD is in place, premised on a person expressing and preferably recording his or her preferences for future care and appointing someone to speak for him or her who understands his or her values and is willing and able to respect them. While this Framework focuses on contemporaneous substituted judgment 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 his or her life goals, values and beliefs, then the SDM will need to make a broader best interests assessment on which to base a decision.

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 an SDM to consider the person holistically, situated within a social environment and to:

- focus only on the person's best interests, excluding consideration of the interests of others, and not base a decision on whether the SDM would wish to have treatment himself or herself 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 while minimising restrictions, and that seeks to optimise his or her proper care and protection.

Despite a commonly shared understanding of substituted judgment, there are many and varied interpretations of what it means to apply a best interests standard of decision-making. This issue continues to be highly contested in both law and ethics, and a consensus definition of a best interests test and the criteria upon which it should be based remain elusive.

The differing, contestable interpretations about what may be legitimately included in a best interests decision-making standard in a health, institutional or aged care setting are illustrated by the following wide range of examples:

- *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 this determination does not require knowledge of the person.*
- *The person's views should only be 'taken into account' rather than be central to decision-making.*
- *Medical treatment interventions that optimise physical health and extend life are always in the person's best interests, regardless of the person's quality of life.*
- *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 his or her personal and social environment are in his or her best interests.*
- *The person's best interests are only served by making the decision that the person would have made had he or she sufficient capacity to make it.*

These wide-ranging interpretations mean that the best interests decision-making standard is a less reliable basis for substitute decision-making. The test for best interests is imprecise, difficult to define both clinically and legally, and remains controversial. Therefore, this Framework sets substituted judgment 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 judgment, rather than resorting to a best interests decision by default.

Case study –
Decision based on best interests

Two brothers, Simon and Gary, were concerned when they were teenagers that their mother, a Jehovah's Witness whose faith prohibited blood transfusions, would insist that blood transfusions be withheld from them as well should they be in an accident. When they were 20 and 18 years old respectively, they appointed each other as Enduring Guardians so their mother could not limit optimal treatment should they need it.

Gary suffered a severe head injury in a car accident the next year. The intensive care doctors asked Simon to consider whether Gary would want to continue life support. The brothers had never discussed what they would do in this kind of scenario and Simon didn't know what his brother's explicit wishes might be. He and the treating doctors had to make a decision based on Gary's best interests.

Doctors outlined the possible outcomes for Simon, including that there was a small but not insignificant chance he might die, even with all intensive care treatments provided. The more likely outcome was that he would survive to leave the intensive care unit, but almost certainly would never be able to care for himself and may not even recover any degree of consciousness.

Gary was young and Simon didn't want his options limited too early. From what he knew of him, he imagined that Gary would be prepared to take a chance at survival, as Gary had lived life with a passion and always extracted the most from every moment. Simon strongly believed, however, that Gary would not want to continue treatment if he could not sense, recognise or communicate with others. Simon agreed with Gary's doctors to continue life support for a number of days and to then re-evaluate the situation.

The decision-making pathway: making decisions for others

This decision-making pathway is recommended for SDMs appointed by the person through an ACD or assigned by law. It should also guide health and aged care professionals who make decisions when the person has not appointed an SDM, no assigned SDM is available and no guardian has been formally appointed by the appropriate authority to make the particular decision. Such decisions should be made in consultation with those who know the person well, including carers and support workers, 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 him or herself, whether the person requires assistance to make a decision and 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 (see Section 5.6 Assessing capacity to make decisions). If the outcome of the assessment is that a substitute decision is required, then the appropriate SDM should be identified and contacted. The SDM should follow the steps below:

1. First, 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 he or she can communicate, and accommodate those preferences as much as possible.
3. For health-related decisions, seek and consider the advice of health care professionals about the likely outcomes of care and treatment options. Consider these options in the light of interventions the person has indicated he or she would find overly burdensome or intrusive and outcomes of care that the person has indicated he or she would seek to avoid.
4. Abide by specific refusals of medical treatments and interventions in an ACD 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 ACD that are relevant to the current decision and that the person intended to cover the current circumstances. Seek to accommodate any written conditions as much as 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 he or she would consider unacceptable or intolerable and what social or relationship factors he or she 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 his or her 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 the SDM believes the person would have made at the time if he or she had access to the same expert advice and was able to make his or her own decision.
8. For health-related decisions, where there are several treatment options that satisfy these 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 the SDM believes best protects the person's personal best interests.

Substitute Decision-Making Pathway

Step 1

Assess capacity to make the decision required

- if substitute decision required, then appointed or assigned substitute decision-maker proceeds to Step 2

Step 2

Establish whether preferences relevant to the situation have been previously expressed in an Advance Care Directive or in previous discussions

Step 3

For health-related decisions, consider the advice of health care professionals about treatment options and likely outcomes in light of the person's wishes:

- interventions considered overly burdensome or intrusive
- outcomes of care to avoid

Step 4

Respect specific refusals of medical treatments and interventions if intended by the person to apply to the current circumstances

Step 5

Give particular weight to other preferences and directions in the ACD relevant to the current decision

Step 6

If no specific relevant preferences and directions, consult with others close to the person to determine any relevant previously expressed views and social or relationship factors he or she would consider in decision-making

Step 7

Consider the person's known values, life goals and cultural, linguistic, spiritual and religious preferences and make the decision that the person would make if he or she had access to current information and advice

Step 8

Where several treatment options satisfy these decision-making criteria, choose the least restrictive option that best ensures the person's proper care and protection

Step 9

For residential decisions, consider the adequacy of existing informal arrangements for the person's care and the desirability of not disturbing those arrangements

Step 10

If there is no evidence of what the person would have decided, make the decision that best protects the person's personal best interests

5.3 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 must apply substituted judgment as the primary decision-making standard, consistent with the Code for Ethical Practice for Advance Care Directives. Legislation prescribing principles to guide substitute decision-making should be cast in terms of contemporaneous substituted judgment.

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, ACD 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 and convey their purpose — to empower others to make directions about future care and to appoint someone they trust to carry them out. Community feedback to the South Australian Advance Directives Review indicates that for many people words such as attorney and guardian are not self-empowering but give the impression 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 contact with the legal system.

Promoting Advance Care Directives

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

Promotion of ACDs should emphasise the importance of conversations between the person and his or her chosen SDMs, family and other close friends. Information about ACDs should explain the authority of an appointed SDM and how this authority differs from the rights of family members and others to make future decisions on his or her behalf. This information should convey that the discussion and planning is critical, and that the completion of an ACD or an advance care plan is simply a means of recording that discussion. Tailored promotional programs and campaigns may be required for Aboriginal and Torres Strait Islander communities, and promotion targeted to people with culturally and linguistically diverse backgrounds may need to be undertaken in collaboration with multicultural agencies and organisations.

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 and more formal validity.

Case study – Different approaches to Advance Care Directives at different times of life

When John was diagnosed with diabetes at 55 years of age, his GP suggested that he should consider advance care planning. He got the forms for making an Advance Care Directive from the Post Office and read them, but never filled them out. After he required hospitalisation for a severe infection that started in his foot, he appointed his wife to be his substitute decision-maker for financial decisions and health matters.

Two years later he required bypass surgery after a heart attack. After he was discharged home, John started to talk to his wife more about the things that were important to him. A few months later he got some more forms from the Post Office so that he and his wife could look at them together. John had hated being on the ventilator after his bypass operation, even though it was for a short time. He was quite clear that he did not want to be kept alive on a ventilator in intensive care ever again. He also knew that his kidneys were starting to fail, and was not sure about dialysis. He did know that if he was going to be dependent on others to get around, he would not want to go onto dialysis. He recorded these wishes on the ACD form.

John was on dialysis for 4 years before he had a small stroke that left him with some left arm weakness. After this event, John reviewed his Advance Care Directive with his wife and sons. He wrote much more explicit instructions about the circumstances in which he would wish to discontinue dialysis. He made sure that his wife and sons and GP and specialists all had a copy of his Advance Care Directive.

John is still on dialysis three times a week, and has a busy life crammed into the times between dialysis. He knows that it is likely that there will be more complications from the diabetes: another heart attack, or stroke, or a severe infection. He feels confident that if this happens and he is in a state where he is unable to communicate, he has done everything he can to ensure that his wishes will be respected.

Preserving common law and mutual recognition

Legislation regulating ACDs should preserve the common law such that it recognises that an ACD must be followed where:

- it was made by a competent adult
- it was made free of undue influence
- it applies to the situation at hand.

Such situations should include where an ACD has been written on a form that is not prescribed by law or on a form prescribed by the law of another state or territory. Each jurisdiction should ensure that systems are in place to enable ACDs to be recognised in different settings and jurisdictions.

ACDs that simply record values, life goals and sometimes directions about unacceptable medical interventions have been recognised under common law for decades. However, it should be made clear that an ACD that appoints an SDM must be supported by legislation to clearly authorise substitute decision-making.

Cultural appropriateness

Autonomy is valued differently by different people depending upon their cultural, spiritual and religious beliefs or background. It should be recognised that as well as inter-cultural diversity there will also be intra-cultural diversity. Laws and policies should allow for autonomy to be exercised in a range of ways, including using an ACD to exercise self-determination, to formally delegate decisions to others, to ensure decisions are made collaboratively with or by the family, and a combination of these approaches.

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. ACDs can provide a means for a person to appoint the culturally-appropriate decision-maker within his or her family or community context. However it must be recognised that ACDs are not appropriate for every person or every community, and that a person may choose not to complete an ACD.

Nevertheless, legislation should not introduce barriers to Indigenous and multicultural families seeking to use ACDs; such families may need specific advice and support to complete ACDs if they choose to use them.

Focus on the person

ACDs are promoted as a means of respecting a person's autonomy beyond loss of decision-making capacity, so ACD policies should be primarily focused on meeting the needs and expectations of people who will complete them. Although it is also important that ACDs work well in health, institutional 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.

Case study – Triggers for making Advance Care Directives

Liz had a car accident and sustained severe brain damage. She was on life support in intensive care for a long time. The doctors asked her family what they thought she might have wanted; but they had never talked about it, so they had to say they didn't know.

Liz spent 9 months in hospital and is in a nursing home now. She needs help with everything; she doesn't recognise her family and cannot communicate. For her sister, it is worse than if she were dead.

When the doctors talked to Liz's family about her wishes, they also encouraged them to think about making their own wishes clear, so that if anything unexpected happened the family could be clear about what outcomes would be acceptable. After this discussion, Joan's sister talked to all of her family about her own wishes, and made it clear that to be like Liz is now would be intolerable for her.

Advance Care Directives and clinical care plans

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 informed by the person's ACD. The clinical care plan may include instructions to staff about resuscitation or transfer to hospital which reflect the terms of the ACD. These instructions may require interpretation from outcome statements in the ACD in consultation with the SDM, family and other carers. The development of clinical care plans can provide greater certainty in the clinical setting for those who have written ACDs, their SDMs and their families, and for junior medical staff, locums and nurses, and are valuable when emergency situations arise especially outside of normal working hours.

Policies should require that health, disability and aged care facilities have in place clear procedures for documenting when ACDs, clinical care plans and resuscitation plans are in place and for ensuring they are readily accessible.

A broad interpretation of health and wellbeing

Law and policy should not restrict ACDs to medical or end-of-life matters. ACDs should apply a wide interpretation of health care and end-of-life stages (see Section 3. Nationally consistent terminology) consistent with community expectations and understanding, rather than a narrow interpretation relating to medical treatment and terminal care. Health and care should be seen as encompassing physical, psychological, social and spiritual aspects of wellbeing. ACDs should allow information to be recorded 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.

Activation triggers

Law and policy should be framed so that ACDs can be written to apply to any period of impaired decision-making capacity, including both partial and temporary impairment, and in a range of circumstances such as renal disease requiring dialysis, episodes of mental illness, chemotherapy for cancer and diabetic coma. Guidelines should advise the person to indicate if he or she intends the ACD to only be activated when decision-making capacity is lost, or for certain directions to apply only to specified circumstances.

Advance Care Directives in mental health settings

It is acknowledged that laws regulating ACDs and mental health treatment and detention operate differently. The rights and role of an SDM appointed under a statutory ACD and Guardianship legislation are not always recognised during episodes of acute mental illness when Mental Health Act provisions are invoked. When a person is involuntary detained for treatment or is placed under a treatment order, Mental Health laws override a person's common law right to consent to treatment. In such cases the standard for substitute decision-making may be based on proper care and protection for the person and the community, rather than respect for autonomy or substituted judgment. This is a very complex interface of law and clinical practice.

While not widely established in Australian mental health care practice, there is however interest, among consumers (and their carers) to be able to use ACDs. They provide an opportunity for people with a mental illness to set out their care and personal preferences to apply when they become unwell, or to appoint an SDM who can make decisions for them at such times. It is acknowledged that the use of ACDs in the management of involuntary mental health patients (those detained under a Mental Health Act) is more limited.

Documents typically called 'Ulysses Agreements' are already used in mental health settings for this purpose. This type of ACD enables a person who experiences episodes of mental illness, while they have decision-making capacity, to stipulate interventions they would prefer or would refuse and the reasons why for future periods when they are mentally unwell. This may include use of specific drugs (either preferred or refused where known to be poorly tolerated), electroconvulsive therapy and physical restraint. Ulysses Agreements typically also list:

- who should be contacted or allowed to visit the person;
- what arrangements should be put in place for their children, other dependents and pets; and
- who should be contacted to maintain continuity of their residential and employment contracts.

These types of ACDs have been shown to reduce the incidence of involuntary detention and treatment, and to help ensure the person receives early interventions which keep them out of hospital.

Jurisdictions should consider the policy implications for ACDs when reviewing and amending mental health laws, and endeavour to formalise:

- the recognition of the role of SDMs to consent to or refuse interventions for a person with mental illness during involuntary treatment or detention as well as other times; and
- respect for prior written directions and preferences, where there is no risk of harm to the person or others.

Governance and quality systems

Governance across the health and aged care sectors, including 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 people are asked whether they have completed an ACD on admission to health or aged care, 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, families and staff.

Information about advance care planning and ACDs should become part of routine contact with the health and aged care sectors. If a person seeks further advice and information about ACDs, it is not essential that such discussion and advice are 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 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.

5.4 Core standards for guidelines and forms

Accessible forms and guidelines

A form for completing an ACD should always be accompanied by guidelines that explain the nature of ACDs and offer advice about completing the form. Guidelines should meet the Best Practice Standards and explain and apply the principles in the Code for Ethical Practice.

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 is 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. Translated guidelines could be provided as downloadable electronic documents rather than in print format as this would allow community groups and legal, health and aged care professionals to provide translated versions to clients, patients and residents 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 (even if the names of the different legal instruments vary). They should provide information about legislated and most frequently used common law ACDs in that jurisdiction, and guidance about completing and using them. Guidelines should emphasise the value of appointing and instructing an SDM, while recognising that some people have no one they know or can depend upon to appoint as an SDM. Guidelines should provide advice on completing an ACD with only values, goals and directions.

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 and also meaningful and useful to health and aged care professionals. These common guidelines would enable the community to understand how their ACDs will be interpreted and applied by health, institutional and aged care professionals and ensure such 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 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. In addition, it is recommended that a printed pamphlet setting out the decision-making pathway be made available for SDMs and staff in health, institutional and aged care settings.

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 an SDM through an ACD. Guidelines should explain the potential liabilities for health and aged care professionals, and the protections available in legislation, to increase the confidence of health and aged care professionals in dealing with ACDs.

Guidelines should be relevant to healthy adults as well as people who have been diagnosed with a chronic or life-limiting illness or injury. Where advance care planning programs are designed to be delivered by trained facilitators, the guidelines should require these programs to comply with the Code for Ethical Practice. Specific guidelines may be required for certain population groups, such as remote Aboriginal people, prisoners and people with a physical disability that prevents them from writing their own ACD.

Preparing guidelines for Advance Care Directives

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 respect the intent of an ACD.

Guidelines should explain:

- the range of ACDs in the jurisdiction, the decision-making for which they allow and whether they appoint an SDM, simply record personal preferences, or both;
- their legal nature, the benefits of completing one, and the role and function of the witness;
- that ACDs 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;
- how and when an SDM is required to make decisions on the person's behalf, what the SDM must consider in making a decision, and under what circumstances the SDM could make a decision different from the written direction of the ACD;
- how decisions would be made on the person's behalf if he or she does not complete an ACD and under what circumstances a guardian would be appointed to make decisions for him or her;
- who could legally make decisions for the person if he or she records preferences and directions but does not appoint an SDM, and how those decisions would be made;
- how an ACD can be reviewed and changed if views, preferences, circumstances (e.g. death of the SDM) or health changes;
- that a healthy person who has completed an ACD should review it and discuss it with a health care professional if his or her health deteriorates while he or she remains competent;
- that directions about matters after death (e.g. funeral arrangements and organ donation) will indicate the person's 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;
- that copies should be provided to relevant people, including any SDMs appointed and family members, and to any health, disability and aged care professionals providing care; and
- when and how SDMs, family and health and aged care professionals will be able to seek advice on dispute resolution if they are concerned by a decision about care made on behalf of a person with impaired capacity.

Designing forms for Advance Care Directives

An ACD can be written in a personal letter and still be recognised under common law. However, where forms for ACDs are provided 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 the Best Practice Standards.

It is recommended that SDMs be appointed through a written statutory ACD, signed by both the person and the SDM. This approach does not preclude designated SDMs (e.g. a 'person responsible' under a Guardianship Act) where no written appointment is made from the legitimate substitute decision-making role. The verbal appointment of an SDM, other than consistent with Guardianship Act provisions, is more problematic as it cannot be easily verified once the person's capacity is impaired.

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

ACD forms should be designed by those with expertise in form development and writing for the public. They should be:

- written in plain English, avoiding legal jargon;
- adaptable to a range of formats including downloadable and online versions;
- readily identifiable and transferable across care settings to enable a person's preferences to be known wherever he or she receives care; and
- separated into sections for health decisions and residential and personal decisions so that copies can be distributed appropriately if different SDMs are allocated to these different roles.

Forms and guidelines should be drafted in consultation with a range of people from different communities and professional sectors to ensure the forms and guidelines meet their needs. They should be tested in focus groups of lay people, including carers, before being finalised to ensure their meaning and intent are widely understood and they are easy to complete and follow. Forms should be shaped by the experiences and perspectives of people who will complete them or be appointed by them, and those who are required to comply with their terms.

5.5 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.

Forms must be designed so that a person can complete a single section, such as only appointing an SDM while not recording directions. The accompanying guidelines should encourage discussion of the person's values and life goals and preferred or unacceptable outcomes of care.

An ACD should be written by the person to whom it relates. When an otherwise competent person cannot write because of a disability, the ACD should be written for him or her by another and then preferably signed by the person as a record of their preferences. A witness is essential in this case.

Interpreters should be engaged where necessary or requested by non-English speaking persons, SDMs, carers or families. Forms should allow for an ACD to be written both in the person's language (so that it is clearly understood by the person, the SDM and the family) and in English (so that it can be understood by those caring for the person).

Although there is no requirement to seek medical advice, when a person consults a medical practitioner or nurse for professional advice about completing an ACD, especially about whether his or her directions will be understood and interpreted as and when intended, it is the responsibility of the health professional to be assured that the person:

- understands what an ACD is for and how it would be used in the future;
- has had adequate opportunity to receive advice on various health care options relevant to any current diagnosis and understands the advice provided; and
- comprehends the likely outcomes of the decisions he or she has made and the preferences he or she has recorded.

Appointing substitute decision-makers

Law and policy should permit a person to choose and appoint a trusted SDM or SDMs, to include written directions, and to stipulate when or under what circumstances their SDM is authorised to make substitute decisions. SDMs should sign the ACD form to confirm that they accept the appointment. Guidelines should make it clear that a person can appoint a trusted SDM who is not a family member or relative, and that this SDM will be able to make decisions on his or her behalf.

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

The importance of discussion

Guidelines should encourage competent adults who are completing ACDs to appoint one or more trusted SDMs and record directions for their SDMs as the most effective means of ensuring their wishes will be known when they have diminished capacity. Guidelines 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 as their SDM a trusted person who shares or understands their values and to discuss their preferences for future care with them to generate a shared understanding.

A person completing an ACD should be encouraged to inform the appointed SDM, and to discuss any written directions with the SDM, the family or close friends and care providers so that everyone concerned has a clear understanding of what the person intended by his or her directions.

Witnessing

Law and policy should require that a statutory ACD be signed by at least one independent witness 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 should not be members of the person's immediate family.

Although not required under common law, it is also preferable for a non-statutory ACD to be signed by the person completing it and an independent witness to avoid questions of validity that cannot be otherwise confirmed after loss of decision-making capacity.

Laws and policies should not require witnesses to formally assess the person's competence to complete a legal document. In signing the form, witnesses should be required to:

- confirm the identity of the person and any appointed SDMs;
- confirm the person is at least 18 years of age;
- check whether the person understands what an ACD is and the implications of completing it; and
- check whether the person is signing the ACD voluntarily, free from coercion and undue influence.

Guidelines should advise witnesses to decline to witness a form if they believe the person's competence is questionable or there is evidence of coercion or undue influence.

Witnesses should be drawn from a broad group of capable community members, and should not be limited to a defined set of professional groups. It should not be a requirement for validity that an ACD be witnessed by the person's medical practitioner, or another medical practitioner.

Requirement for advice and informed decision-making

Common law permits a competent adult to choose to write directions, even medical directions, without expert advice. 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.

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 the ACD to be considered valid. A clearly stated refusal of treatment in a valid ACD cannot be ignored on the grounds that the person was not informed about the consequences to their health when it was written.

Informed consent provisions do apply when decisions about health or medical treatment are required. When treatment is indicated, there is an obligation on the treating health care professional to inform a competent patient, and, if capacity is lost, to inform the SDM. There is no corresponding obligation on patients (or their SDM) to make efforts to be informed for their consent or refusal to be valid.

Writing medical directions

Although people can choose to write directions about future medical interventions, laws and policies must not **require** people to write detailed medical directions, whether in writing or by ticking selected boxes. Such a requirement introduces a significant risk of potentially uninformed or inadequately informed medical directions binding a more informed SDM at a later time. It could be detrimental to the person's health in ways he or she had not envisaged when the ACD was written. Medical directions are best written by medical practitioners in clinical care plans, informed by the person's ACD.

However, guidelines should recommend that, if receiving regular health services or aged care, the person should check with the professional care providers whether the terms used in the ACD convey his or her 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.

Case study – The challenge of completing medical directions

Bill had a severe reaction to his new tablets at work and was rushed unconscious to the emergency department. He already had early symptoms of prostate cancer, and when his heart problems were diagnosed, Bill had written directions in an Advance Care Directive about not wanting to have mechanical ventilation to assist his breathing or cardiopulmonary resuscitation (CPR).

The emergency department doctor phoned Bill's daughter who read his directions over the phone. The doctor explained that the problem wasn't cancer or heart disease, but caused by the tablets and that there was a good chance of complete recovery and return to work, but that Bill would need to be ventilated. Bill's daughter explained that during their discussion about his ACD, Bill had been clear that he didn't want to end up dependent on anyone or in a nursing home, but would like treatment that would maintain his current quality of life.

When Bill's daughter arrived at the hospital, he was on a ventilator, and already starting to improve. She expressed relief that they had had a clear discussion about his wishes before anything had happened.

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 a competent person, or the SDM if the person lacks decision-making capacity, can consent to medical treatment that is offered, or refuse such treatment, but cannot demand treatment. Laws and policies should apply the following standards:

- 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 that are not warranted or not 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;
- such treatment refusals must be respected and followed by health, institutional 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.

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;
- taken into account, such as a preference to die at home.

Although medical directions in an ACD may be binding (provided the requisite conditions are met), directions about personal matters cannot be; for example, a person cannot demand particular accommodation arrangements if these are not available. Forms and guidelines should make it clear that such expressed wishes are only advisory.

"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;
- 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.

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

- 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;
- 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. It would also allow a person to appoint an SDM and require that the SDM make decisions as he or she sees fit.

Case study – Writing clear outcome statements

When Jenny's family first realised that she was dying, it was a shock. At first they wanted her to keep going with the chemotherapy. Luckily, though, she'd written her wishes down in an Advance Care Directive the previous year, when it was clear that she had advanced stage breast cancer which was spreading even with treatment, so everyone knew what was important to her, even when the brain metastases left her unable to communicate.

Jenny hadn't listed treatments like CPR or antibiotics, but she did state 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 years old. She was also very clear in her ACD that she did not want to be in pain.

Because she'd written such clear directions, the treating team found it easy to understand what she wanted and were able to respect her wishes, providing treatment that prioritised comfort during her last days.

Checklist for forms

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

ACD forms should accommodate the following requirements:

- ☐ be expertly designed, focus tested with people from the health and aged care sectors and the general community, and avoid legal language;
- ☐ record the name and date of birth of the person for clear identification, and the date of completion;
- ☐ be easily accessible and free, with readily recognised branding;
- ☐ be available in a variety of formats, including in a kit containing forms and guidelines and online;
- ☐ be accompanied by guidelines that explain how ACDs work, guide completion of the form and also advise what to do when substitute decisions are needed;
- ☐ be easy to complete in a variety of settings without the need for professional advice;
- ☐ apply to any period of impaired decision-making capacity, not just at the end of life;
- ☐ record preferred outcomes and goals of care rather than medical directions;
- ☐ describe what personal circumstances constitute quality of life or reasonable outcomes of care against which treatment decisions can be assessed;
- ☐ record personal values, unacceptable or intolerable levels of functioning, and overly burdensome or intrusive interventions to be avoided;
- ☐ record preferences 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;
- ☐ record specific treatment-related directions, and make it clear whether these directions are intended to apply only to end-of-life circumstances;
- ☐ designate whether specific treatment-related directions are intended to be applied exactly as written or are simply advisory (e.g. to be applied with flexibility according to the SDM's best judgment at the time);
- ☐ allow for separate directions or preferences to be recorded for temporary and permanent periods of lost decision-making capacity and for end of life;
- ☐ require the signatures of the person, the witness and any SDMs appointed, with dates;
- ☐ include a date for review, and make it simple to review and change directions or appointments.

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

- ☐ appointing one or more SDMs, and directing how they act and make decisions (e.g. making decisions together, individually, in a particular order or as available);
- ☐ directing an SDM to act as a substitute for another SDM as a result of a specified circumstance (e.g. 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).

5.6 Activating Advance Care Directives

Ensuring the Advance Care Directive will be available when needed

Jurisdictions should establish a range of different mechanisms to record that an ACD exists so it can be accessed when needed and the contact details of SDMs can be found quickly.

ACD registers are not recommended; they are expensive to establish and run and require a health care professional to check whether an ACD has been registered. Evidence indicates registers 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. 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.

Recording patients' ACDs on their electronic file and including a copy in their medical notes in a coloured sleeve has proved more reliable. This procedure 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 accompany the person between health, institutional and aged care settings.

Case study — Systems for capturing and communicating Advance Care Directives

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 years old and had extensive vascular disease, with several previous hospital admissions for angina and atrial fibrillation. It seemed likely from the initial assessment that he had had a cerebral vascular event, or stroke. He was unable to protect his airway well and the doctors were considering whether to intubate him.

During Bruce's last admission he had been encouraged to think about advance care planning. He said he trusted his daughter to make decisions about his treatment if he could not and so she was assigned the role of 'person responsible' under the state's Guardianship law. He also stated that he wanted to continue to live independently and not to go to a nursing home and did not want treatment that was likely to mean he would be unable to get back to living independently. These wishes were documented in an advance care plan.

The hospital had an electronic alert on the patient admission system for recording advance care plans, as well as a system using coloured sleeves in patients' hard copy files to store Advance Care Directives. Emergency department staff were able to quickly identify that Bruce had an advance care plan so it was much easier to know who he wanted involved in decisions about his immediate care, and to work out what he would want done in the circumstances.

Other means of ensuring the ACD is readily available such as personal wallet cards and magnets that affix a copy of the ACD form to the fridge are also recommended. Such mechanisms are likely to be more effective because they are within the person's control and the person completing the form and the SDM have a personal interest in the ACD being found and applied when needed.

Health, disability and aged care facilities should have systems in place to ensure effective storage of and ready accessibility to a person's ACD, including:

- appropriate record-keeping that keeps track of revisions and revocations;
- keeping the ACD at the front of the person's file and transferring the ACD with the file;
- reminders for competent patients and residents to regularly review their ACD.

Certified copies should not be a requirement for validity; a legible copy with no obvious unauthorised alterations should suffice.

When electronic health records note the existence of ACDs, they should include an alert that there is an ACD and should have the capacity to download a copy. ACDs should not be summarised or extracted, but be accessible in their original form. The development of new electronic health record systems should incorporate ACDs at the design stage and allow for recording of different types of ACDs.

Assessing capacity to make decisions

It is not the responsibility of this Framework to stipulate how decision-making capacity is to be assessed. Decision-making capacity is assessed in many circumstances, not just when an ACD is in place, and is a routine part of professional practice for many health and aged care professionals.

It is not the SDM's role to make a formal assessment of a person's capacity when a decision is needed, as that must be performed by a suitably qualified professional. However, guidelines should recognise that SDMs and family members routinely make ad hoc informal assessments of the person's ability to make decisions on a day-to-day basis, especially when the person is living independently. An SDM may be the first to recognise that a person's decision-making capacity is diminishing or fluctuating.

For people with impaired capacity living at home, SDMs routinely determine capacity to make non-health related decisions about appropriate and affordable residential and holiday arrangements, about the need for support for mobility and meals, and about whether health care should be sought. A competent adult can make a judgment about whether a simple cut or burn requires home first aid or a visit to a GP, but an SDM may need to assess whether the person has the capacity to make such a decision, and may decide to overrule objections and seek medical intervention out of concern for the person. It may only be when the person receives health care that concerns about decision-making may result in a more formal assessment of capacity by a health professional.

Guidelines should include general advice for SDMs about using their knowledge and understanding of the person to assess his or her 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 his or her own decisions for as long as they are able and to the extent that the person can understand the effect of his or her decisions;
- 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, aged care or institutional facility or under a program that provides care in his or her own home, SDMs should be advised to consult with the person's GP or health or aged care professionals if they are concerned about the person's decision-making capacity. If the person insists that he or she can make a decision that the SDM considers he or she is 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 him or her, or contact the Public Advocate or Guardian for advice.

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 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.

Case study — Family demanding treatment requested in an Advance Care Directive but not considered appropriate in the circumstances

Robert was a 77-year-old man with a catastrophic intracerebral haemorrhage who was dying. The intensive care team were asked to see him because his family were demanding that he be taken to the intensive care unit for mechanical ventilation, and insisting that he have cardiopulmonary resuscitation when his heart stopped, even though it was the opinion of the neurology team that these interventions were inappropriate. Robert had written an Advance Care Directive some years before, refusing mechanical ventilation and cardiopulmonary resuscitation on the form. However, his family, unable to accept his impending death, insisted that these treatments be provided.

Robert's case had been reviewed by a senior neurosurgeon, who considered that there was no neurosurgical intervention available that would improve his outcome. A second neurosurgical opinion was obtained which concurred with the first one.

The senior intensive care specialist explained to Robert's family that Robert was dying and that the treatment plan should consider comfort as a priority. It was explained that because the heart and breathing would stop as a result of the injury to Robert's brain, which was rated as unsurvivable, cardiopulmonary resuscitation and mechanical ventilation were not appropriate interventions, with no expectation of any chance of recovery. This discussion was documented in the notes with completion of the hospital resuscitation plan.

Robert continued to deteriorate, and died in the neurology ward with his family around him.

Validity of Advance Care Directives

A health or aged care professional presented with a properly signed and witnessed ACD must feel confident that it is valid and feel protected by local law and policy if he or she abides by its terms in good faith. An ACD containing directions should be considered valid if:

- it was written by a competent adult;
- it was made free of undue influence;
- it was intended by the person to apply to the situation at hand.

Clear directions in an ACD should be respected unless there is evidence that the person was not competent when it was written. There must be no obligation on a medical practitioner to verify the original circumstances under which the ACD was completed to assure him or herself that the person was competent at that time.

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 valid refusal in a statutory ACD given freely by a competent adult may be based upon religious, social or moral grounds, or indeed upon no apparent rational grounds, and is entitled to respect.[10]

Although specific medical treatments cannot be demanded in an ACD, specific directions in a statutory 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 the directions.

Law, policy and guidelines should therefore make it clear that such ACDs are valid:

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

Law, policy and guidelines should encourage outcomes-based ACDs that list values and preferred outcomes or goals of care, but should also recognise a person's right to record his or her advance refusal of specific medical interventions.

Law and policy should offer protection to a health or aged care professional who acts on an ACD presuming in good faith that it is valid, current and not revoked or superseded. An ACD remains valid until it is revoked, replaced or amended, and the appointed SDM remains in place unless there is clear evidence that the person has, or would have, changed his or her preferences (e.g. where the person had since divorced the SDM but had not remade the ACD). If an ACD was completed years before, making decisions under the contemporaneous substituted judgment standard would suffice.

5.7 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 (see Section 5.2. Best Practice Standards for substitute decision-making). SDMs should consult with people who know the person and can advise on preferences he or she may have expressed and personal decisions which may have been made in the past that indicate his or her preferences and values. However they must respect the person's privacy and not share information with people who the person has indicated he or she does 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.

Sometimes a person with diminished decision-making capacity will verbally agree to medical interventions that he or she has refused in an ACD written when fully competent. Alternatively, the person may refuse medical treatment that he or she listed in the ACD as acceptable.

[10] *Hunter and New England Area Health Service v A [2009] NSWSC 761, McDougall J, 6 August 2009*

This situation is recognised as difficult and challenging for the SDM and the health care team, and is one of the reasons why stipulating medical treatments is discouraged. The guiding decision-making standard is to seek to determine what the person would want at the time if he or she had capacity and access to the same advice and information that is provided to the SDM.

Who decides what

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

How decisions are made and by whom

In general, people expect their health care professional to provide advice to their SDM about care and treatment options and their likely effectiveness and outcomes so that their SDM can decide whether to consent or refuse treatment on their behalf. In practice, such decisions are usually made collaboratively by the SDM and the health care team. Health and aged care professionals should respect a person'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. Guidelines should be available to show how decisions would be made on a person's behalf. These may be included with the relevant forms or provided separately in health and aged care facilities, or both. The guidelines should explain how health, medical, residential and other personal decisions, and in particular end-of-life medical decisions, would be made for a person with impaired decision-making capacity in a range of circumstances including when:

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

If the person has not appointed an SDM but has recorded his or her 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.

Decisions by substitute decision-makers

Law and policy should recommend that the SDM follow the decision-making pathway (see Section 5.2. Best Practice Standards for substitute decision-making). Guidelines should include advice for SDMs about:

- determining when an ACD may need to be activated;
- following the decision-making pathway;
- discussing options for care with family members and others who know the person well, and with health or aged care professionals and paid carers who are looking after the person;
- how to seek help with dispute resolution.

Guidelines should explain that contemporaneous substituted judgment is the primary decision-making standard for SDMs; the best interests standard only applies when there are no means to ascertain what the person's values and preferences are and therefore what decision the person might make in the current circumstances.

Law and policy should recognise that health care professionals are obliged to explain available and appropriate treatment options and their likely outcomes to the person or the SDM. When a specific decision is required about health care or medical interventions, it is important that the person making the decision (whether on his or her own behalf or as an SDM) is provided with sufficient information about his or her health status and the proposed treatments to make an informed decision. This information should include the risks associated with treating or not treating. However, just as a competent person can ignore medical advice in deciding about treatment, an SDM can choose to ignore medical advice, or to make a decision that is inconsistent with medical advice, if he or she believes that the person would have made that same decision in the current circumstances.

Within the scope of the ACD, law and policy should permit SDMs to make all decisions that the person could make if he or she were competent, with the following exceptions:

- SDMs should be able to consent to or refuse interventions required for medical reasons. However, decisions about interventions sought for psychosocial reasons (e.g. sterilisation to manage menstruation or termination of pregnancy) must be referred to an appropriate body (e.g. a Guardianship Board or Tribunal);
- SDMs should be able to refuse artificial nutrition and hydration if they have reason to believe that the person would refuse this intervention, but should not be able to refuse natural food and water given by mouth unless the person directly indicates that it is unwelcome.

Guidelines should explain the process to be followed if a substitute decision-maker loses competence and becomes unable to effectively carry out his or her role. Guidelines should make it clear that a competent SDM can resign from the role, but that this act should be recorded in writing and communicated to the person if he or she is competent so that a new SDM can be appointed if necessary. If the person's decision-making capacity has diminished, the resignation should be communicated to:

- other SDMs appointed under the same ACD;
- family members who may subsequently be assigned under legislation as the SDM;
- the health or aged care professional caring for the person so that processes can be initiated to appoint a guardian if that is necessary.

Case study — Unexpected emergency situation

Jim was taken out for dinner by his family for his 80th birthday. However, he choked on a piece of steak and suffered a cardiac arrest. The restaurant called an ambulance and the paramedics performed cardiopulmonary resuscitation (CPR), gave adrenaline and intubated before transporting him to hospital. While the family were insistent at the restaurant that Jim would not want to be resuscitated, the paramedics had insufficient evidence on which to act differently, in particular in this unexpected situation where an immediate decision was required.

On arrival at the emergency department, Jim was intubated requiring mechanical ventilation. His heart and circulation were stable but he had fixed dilated pupils. The period of time where Jim had had no spontaneous heart rhythm or adequate blood to the brain was over 30 minutes – a duration that would usually lead to extremely poor neurological recovery.

On the way to the hospital the family went to Jim's home and found his Advance Care Directive where it had been stuck on the fridge. The Advance Care Directive was clearly signed and witnessed and stated that he did not want any invasive measures like dialysis, mechanical ventilation or CPR. After discussion with the doctors and nurses, the family although still upset, understood that the best that could have been done in this unexpected situation was as the paramedic did, but that a decision about Jim's care was needed at the earliest opportunity based on the information in his Advance Care Directive available to both his doctors and family. The doctors recommended no further life-sustaining treatment and his family agreed that it was what Jim would want in his current circumstances.

Jim was extubated and managed with comfort care measures until he died 2 hours later, with his family present.

[11] *Brightwater Care Group (Inc) v Rossiter [2009] WASC 229*

5.8 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 a Guardianship Tribunal or equivalent to revoke the appointment of an SDM who lacks capacity, is negligent or is unwilling to make decisions.

Protections for SDMs

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

Many health and aged care professionals are concerned about the risk of litigation by a person's family if they abide by the terms of an ACD and withhold or withdraw treatment. They are also concerned about initiating treatment on the insistence of an SDM when there is evidence in an ACD or in previous discussions with the person when they had decision-making capacity that the person would have refused it.

Strategies which emphasise respecting a person's autonomy rather than risk management should be put in place to address concerns about potential litigation. Such strategies would include clearly defined education and policies and may require legislated provisions. 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.

Common law protections from civil and criminal liability have been demonstrated in recent court cases. Where legislative provisions are contemplated, they should reflect common law.[11]

Health care professionals, including nurses and ambulance officers, should be protected from civil or criminal prosecution if they abide by lawful terms in an ACD they reasonably believe to be valid, in good faith and without negligence (see Section 5.6. Validity of Advance Care Directives), and:

- they withhold or withdraw treatment in accordance with the terms of an ACD;
- they abide by a refusal of medical interventions believing that the person intended their refusal to apply to the current circumstances;
- they believe the ACD to be current, if it is subsequently found to have been revoked or replaced;
- the ACD uses a form from another jurisdiction that appears to be a statutory form;
- they provide life-sustaining interventions in life-threatening emergency situations when:
  - there is insufficient time to seek or retrieve an ACD or to contact an SDM without putting the life or health of the person at serious risk;
  - it is unclear from the terms of an ACD whether it was intended to apply to the current circumstances and the SDM cannot be immediately contacted.

Legislation should require that 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 was provided in an emergency where there was no immediate evidence of an ACD or of a refusal of treatment, the decision-making standard of substituted judgment should apply once the person's condition is stabilised and SDMs or family have been contacted.

Health care professionals whose personal views prevent 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.

Case study — Resolving disputes

Eric was diagnosed with motor neurone disease 2 years ago at which time he appointed his partner as his Enduring Guardian and also wrote in an Advance Care Directive that he wanted no heroics if he was dying and would not want to be kept alive like a vegetable.

Eric's condition deteriorated after being admitted to hospital with pneumonia. He was semi-conscious and it was clear that admission to the intensive care unit was needed in the next few hours. The medical team agreed that a trial of intensive treatment was appropriate and necessary.

Eric was ventilated for a week but his condition continued to deteriorate with multiorgan failure setting in. There had been daily family conferences since his arriving in the intensive care unit and doctors now broached the possibility of withdrawing life support. They were keen to know what Eric would have wanted were he able to make a decision himself. His written Advance Care Directive was too vague to really help guide treatment in this situation. His partner was adamant that doctors should continue to do everything, even though the likely success of this treatment was now remote. Eric's adult daughter, on the other hand, was convinced he would want aggressive treatment stopped now.

After extensive and protracted discussion over the following week, agreement about withdrawing life support was unable to be reached. His partner was now demanding that treatment continue on threat of legal action. The treating doctors contacted the Public Guardian for advice and she came to talk with Eric's partner, daughter and the treating doctors to try to find common ground. This approach was unsuccessful and the hospital referred the case to the Guardianship Tribunal to appoint an independent decision-maker. The Tribunal appointed the Public Guardian as Eric's guardian 2 days later. However, his partner was unhappy with this decision and she promptly lodged an appeal with the Supreme Court.

Resolving disputes

Jurisdictions should provide for a clear process of dispute resolution. This process should include advice, mediation and disputation stages and legislation, where it exists, 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 should advise SDMs (and families and others where no SDM is appointed) when and how to seek guidance in the first instance from the treating clinical team or other health and aged care professionals.

The guidelines should advise SDMs, families and health and aged care professionals where to seek guidance or mediation (e.g. 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 measures for dispute resolution and what that entails. Disputes not resolved through advice or mediation should be heard by a tribunal such as the Guardianship Board or a court. The tribunal or court should be required to assess whether the SDM has applied the substituted judgment decision-making standard. Courts remain an option in the small percentage of cases unable to be resolved by these means.

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

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Appendix A: Advance Care Directives in Australian legislation

Legislation	Advance Care Directive	Decision-making standard [substituted judgement or best interests]
ACT		
Powers of Attorney Act 2006	Enduring Power of Attorney	
http://www.legislation.act.gov.au/a/2006-50/default.asp		
Medical Treatment (Health Directions) Act 2006	Health Direction	
http://www.legislation.act.gov.au/a/2006-51/default.asp		
NSW		
Guardianship Act 1987 NSW does not have specific legislation for instructional ACD	Enduring Guardianship Appointment Common law principles apply and give authority to instructional ACDs in NSW (see Justice McDougall's guidance in HNEAHS v A [2009])	Best interests
http://www.austlii.edu.au/au/legis/nsw/consol_act/ga1987136/	Advance Care Directive	
NT		
Natural Death Act 1988	Direction	
http://www.austlii.edu.au/au/legis/nt/consol_act/nda1988134/		
QLD		
Powers of Attorney Act 1998	Enduring Power of Attorney (personal – includes health) Advance Health Directive (includes an attorney for health matters) Note also: S39 – common law ACDs not affected by legislation	S34 recognises EPA equivalent from another State S40 recognises AHD equivalent from another State
Guardianship and Administration Act 2000	None	
http://www.legislation.qld.gov.au/LEGISLTN/CURRENT/P/PowersofAttA98.pdf		

Legislation	Advance Care Directive	Decision-making standard [substituted judgement or best interests]
SA		
Guardianship and Administration Act 1993	Enduring Power of Guardianship	Substituted judgment
www.austlii.edu.au/au/legis/sa/consol_act/gaaa1993304/		
Consent to Medical Treatment and Palliative Care Act 1995	Medical Power of Attorney Anticipatory Direction	Best interests
www.austlii.edu.au/au/legis/sa/consol_act/ctmtapca1995420/		
TAS		
Guardianship and Administration Act 1995	Enduring Guardianship	Best interests
http://www.health.wa.gov.au/mhareview/resources/legislation/TAS_Guardianship_Administration_Act_1995.pdf		
VIC		
Guardianship and Administration Act 1986	Enduring Guardianship Agents (medical)	
http://www.legislation.vic.gov.au/		
Medical Treatment Act 1988	Enduring Power of Attorney (Medical Treatment) Refusal of Treatment Certificate	
http://www.legislation.vic.gov.au/		

Legislation	Advance Care Directive	Decision-making standard [substituted judgement or best interests]
WA		
Guardianship and Administration Act 1990	Advance Health Directive	A legal document that: provides substituted judgement where patient no longer has capacity. Expectation is that the healthcare professional would follow the AHD where a relevant decision has been made by the patient
	Enduring Power of Guardianship	A legal document in which a person appoints a substitute decision maker, known as their enduring guardian. The enduring guardian may be appointed to make treatment decisions, and must make decisions in the best interests of the person, where possible taking into account the persons previous wishes
http://www.slp.wa.gov.au/legislation/statutes.nsf/main_mrtitle_406_homepage.html		

Judgments upholding a person's right to self determination re end-of-life decisions	Judgments upholding the binding nature of instructions in an ACD	Mutual recognition of interstate ACDs
ACT		
None	None	Not stated in law
NSW		
Hunter and New England Area Health Service v A (2009) 74 NSWLR 88 *QAN* [2008] NSWGT 19 (23 September 2008) *BAH* [2007] NSWGT 1 (5 February 2007) *NOTE: Previously this case has been referred to as Re: AG [2007] NSWGT 1 (5 February 2007)* *FI v Public Guardian* [2008] NSWADT 263	*Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88	Section 6O of the Guardianship Act allows for the recognition in NSW of equivalent interstate enduring guardianship appointments
NT		
No specific jurisdictional cases	No specific jurisdictional cases	Not stated in law
QLD		
No specific jurisdictional cases	No specific jurisdictional cases	Yes
SA		
H LTD v J & ANOR *[2010] SASC 176* *Judgement of The Honourable Justice Kourakis* *15 June 2010*	*H LTD v J & ANOR* *[2010] SASC 176* *Judgement of The Honourable Justice Kourakis* *15 June 2010*	Not stated in law
TAS		
None	None	*Guardianship and Administration Act 1995* – section 81 (enduring guardianships)

Judgments upholding a person's right to self determination re end-of-life decisions	Judgments upholding the binding nature of instructions in an ACD	Mutual recognition of interstate ACDs
VIC		
Gardiner; re BWV {2003} VSC 173 (29 May 2003)	1. the provision of nutrition and hydration via a percutaneous endoscopic gastrostomy ("PEG") to BWV constitutes medical treatment within the meaning of the Medical Treatment Act 1988; and 2. the refusal of further nutrition and hydration, administered via a PEG, to BWV constitutes refusal of medical treatment, rather then refusal of palliative care, within the meaning of the Medical Treatment Act 1988	
WA		
Brightwater Care Group (Inc) v Rossiter (2009) WASC 229	No specific case law from WA jurisdiction, however decisions from other jurisdictions maybe relevant	Sections 110O *Guardianship and Administration Act* 1990 allows SAT to make an order recognising an Enduring Power of Guardianship and Advanced Health Care Directive created in another jurisdiction Section 110ZA *Guardianship and Administration Act* 1990 allows SAT to make an order recognising an Advanced Health Care Directive created in another jurisdiction Common law may recognise an interstate AHD

Advance Care Directive	Substitute decision-maker appointed under the ACD	Decisions that can be made under the ACD
ACT		
Enduring Power of Attorney	Attorney	Health care and life-management
Health Direction	None	Medical treatment only
NSW		
Enduring Guardianship Appointment	Enduring Guardian	Medical treatment, health care, other personal decisions as nominated including accommodation, services (excludes any financial decision-making)
NT		
Direction	None	Medical treatment only
QLD		
Enduring Power of Attorney	Attorney	Personal (health care, life-management) and financial (can be separate documents)
Advance Health Directive	May appoint an attorney for health matters	Medical treatment and health care generally
SA		
Medical Power of Attorney	Medical Agent	Medical treatment only
Anticipatory Direction	None	End of life medical treatment at the end of life only
Enduring Power of Guardianship	Enduring Guardian	Health care and life-management
TAS		
Enduring Guardianship	Enduring Guardian	Health care and life-management
VIC		
Enduring Guardianship	Attorney	Health (except if provided to agent (medical) and life management
Agent (medical)	Person responsible	Consent to treatment
Enduring Power of Attorney (medical treatment)	Attorney	Refusal of medical treatment for current condition only – also becomes person responsible under Guardianship Act to consent to medical treatment
Refusal of Treatment Certificate	None	Refusal of medical treatment for current condition only
WA		
Enduring Power of Guardianship	Enduring Guardian	Personal, lifestyle and treatment
Advance Health Directive	None	Treatment only

Advance Care Directive	Witness requirements	Who can witness
ACT		
Enduring Power of Attorney	Requires 2 witnesses	1 of whom can be a relative of either the appointer or SDM and 1 must be a person who can sign statutory directions
Health Direction	For written directions – 2 witnesses For non-written directions – 2 health professionals	Both must witness at the same time 1 of these witnesses must be a medical practitioner
NSW		
Enduring Guardianship Appointment	A witness certifies the appointor and the appointed enduring guardian/s signed the appointment freely and voluntarily and appeared to understand its effect. Signatures of appointor/enduring guardian can be witnessed by different witnesses at different times and places	Australian legal practitioner/ Registrar of the NSW Local Court/Overseas-registered foreign Lawyer/Approved employee of NSW Trustee and Guardian or the Office of the Public/ Guardian who has completed approved course of study
NT		
Direction	A direction will be of no effect unless it is witnessed by two witnesses, who have attained the age of 18 years, neither of whom is the medical practitioner responsible for the treatment of the person	Any two persons, who have attained the age of 18 years, neither of whom is the medical practitioner responsible for the treatment of the person
QLD		
Enduring Power of Attorney	1 witness certifies person appeared to have capacity to make EPA	JP, commissioner for declarations, notary public or lawyer
Advance Health Directive	1 witness certifies person appeared to have capacity necessary to make AHD Also Doctor certifies person appeared to have capacity necessary to make AHD	JP, commissioner for declarations, notary public or lawyer – must be over 21
SA		
Medical Power of Attorney	1 witness certifies both person and SDM appeared to understand the nature and effect of the direction	Justice of the Peace, solicitor, member of the clergy, registered pharmacist or approved police officer
Anticipatory Direction	1 witness certifies both person and Substitute Decision-Maker have appeared to understand the nature and effect of the direction	Justice of the Peace, solicitor, member of the clergy, registered pharmacist or approved police officer

Advance Care Directive	Witness requirements	Who can witness
Enduring Power of Guardianship	1 witness certifies the person and the guardian signed freely and voluntarily and appeared to understand its effect	JP, solicitor or notary public
TAS		
Enduring Guardianship	2 witnesses who are not parties to the Instrument and not related to each other	2 witnesses who are not parties to the Instrument and not related to each other
VIC		
Enduring Power of Attorney (medical treatment)	Two witnesses certify that the person making the enduring power of attorney (medical treatment) is of sound mind and understands the import of this document	At least one of the witnesses to this instrument to be a person authorised in law to take and receive statutory declarations and neither can be the agent who is to be appointed.
Enduring Guardianship	Two witnesses	At least one of the witnesses to this instrument to be a person authorised in law to take and receive statutory declarations and neither can be the guardian who is to be appointed or relative to a party of the instrument
Agent (medical)	Depends on who the responsible person is under the Guardianship Act – a person appointed as Enduring Power of Attorney (medical treatment) takes precedence over Enduring Guardianship	
Refusal of Treatment Certificate	Two witnesses (one registered medical practitioner) to certify	At least one witness must be a registered medical practitioner
WA		
Enduring Power of Guardianship	2 persons to witness signature of person (appointor) and the enduring guardian. The appointor and person accepting role of EG don't need to have the same 2 witnesses	2 witnesses – either both authorised to take declarations; or one who is authorised to take declarations and the other over 18 years or age who is neither the appointer, the person who signed the enduring power of guardianship at the appointor's direction (if applicable) or the enduring guardian
Advance Health Directive	2 persons to witness signature of person making the Advance Care Directive	2 witnesses – either both authorised to take declarations; or one who is authorised to take declarations and the other over 18 years of age. Any person who signed at the direction of the maker cannot be a witness.

Advance Care Directive	Limitations of scope	Limitations of decision-making by SDM
ACT		
Enduring Power of Attorney		
Health Direction		
NSW		
Enduring Guardianship Appointment	Only operative whilst the appointor is, because of a disability, totally or partially incapable of managing his or her person	Enduring guardian must make decisions according to principles and objects of Guardianship Act. Medical consent decisions must be made within the medical consent scheme in Part 5 of the Guardianship Act. An enduring guardian cannot make financial decisions or consent to 'special' medical treatment, such as sterilisation, nor can they consent to treatment if the patient is objecting
NT		
Direction	A direction may only be made in the prescribed form (as outlined in the Natural Death Regulations) by a person of sound mind who has attained the age of 18 years and who desires not to be subjected to extraordinary measures in the event of his or her suffering from a terminal illness	No Substitute Decision Maker
QLD		
Enduring Power of Attorney	Any period of impaired capacity	Attorney cannot make decisions on special personal or special health matters e.g. consenting to marriage, organ donation, sterilisation, pregnancy termination, experimental health care, certain forms of mental health care Attorney must comply with General Principles and Health Care Principle (GAA Schedule 1)

Advance Care Directive	Limitations of scope	Limitations of decision-making by SDM
Advance Health Directive	Any period of impaired capacity S103 POA Act – health provider can override direction if uncertain, inconsistent with good medical practice, or circumstances have changed (making direction inappropriate) S36 POA Act - for direction to withhold/withdraw life-sustaining measures, direction cannot operate unless no chance of regaining capacity and – • Terminal illness/incurable condition and expected to die within 1 year or • Permanent coma/post-coma unresponsiveness or • Illness/injury so severe that no reasonable prospect of recovery without life-sustaining measures • For direction re artificial nutrition/hydration, commencing or continuing ANH would be inconsistent with good medical practice	Direction in AHD takes priority over a power given to an attorney Attorney cannot make decisions on special personal or special health matters e.g. consenting to marriage, organ donation, sterilisation, pregnancy termination, experimental health care, certain forms of mental health care Attorney must comply with General Principles and Health Care Principle (GAA Schedule 1)
SA		
Medical Power of Attorney	Any period of diminished capacity	• Medical decisions only • decision to return person to capacity
Anticipatory Direction	End-of-life medical treatment, only terminal phase of a terminal illness and persistent vegetative state	Terminal phase of terminal illness or persistent vegetative state with no prospect of recovery
Enduring Power of Guardianship	Any period of diminished capacity	Health, medical and life-management decisions • proper care and protection • cannot consent to prescribed treatments eg sterilisation, ECT, termination

Advance Care Directive	Limitations of scope	Limitations of decision-making by SDM
TAS		
Enduring Guardianship	Any period of diminished capacity	Guardian cannot consent to 'special treatments'. Can consent to treatments that involves a substantial risk of death
VIC		
Enduring Power of Attorney (medical treatment)	Does not come into effect until the person becomes incompetent and if alternate agent a statutory declaration provided no more than 7 days before decision that alternate agent believes the agent is dead, incompetent or cannot be contacted/located and details of enquiries made	Refusal of medical treatment for a current condition if treatment would not cause unreasonable distress to patient and there are reasonable grounds for believing patient (if competent) would consider treatment unwarranted
Enduring Guardianship	Appointer becomes unable due to disability to make reasonable judgements in relation to matters contained in instrument or if not specified in relation to matters about him/herself or circumstances	Lifestyle and health care decisions as specified in guardianship instrument. Cannot include consent to particular medical procedures or refusal of medical treatment
Agent (medical treatment)	Applies if patient is over 18 and is incapable of giving consent (incapable of understanding general nature of treatment and incapable of indicating whether he or she consents or not)	Allows for consent to medical treatment (not refusal). In the case of a special procedure or any medical or dental treatment, a decision by the Tribunal is required; in any other case of any medical or dental treatment, the person responsible for the patient can consent
Refusal of Treatment Certificate; Competent Person	Does not cover medical procedures or other procedures that would be considered palliative care. Ceases to operate once the circumstances that gave rise to it are no longer relevant. Applies only to a current condition and not to one that may or may not occure in the future	

Advance Care Directive	Limitations of scope	Limitations of decision-making by SDM
WA		
Enduring Power of Guardianship	An enduring guardian: • Cannot make decisions about finances, property or estate • Cannot consent to sterilisation without the approval of SAT • Cannot vote in an election on behalf of the appointor • Cannot consent to the adoption of a child on behalf of the appointor • Cannot make or change the will of the appointor without an order from the Supreme Court of Western Australia	An enduring guardian: • Only has authority as SDM while the appointor is unable to make reasonable judgements • Must act jointly if there is more than one enduring guardian • Must act in the best interests of the appointor • Must act consistently with the terms of the appointment An AHD takes precedence over an EPG. An enduring guardian cannot override treatment decisions contained in an AHD

Advance Care Directive	Limitations of scope	Limitations of decision-making by SDM
WA		
Advance Health Directive	An AHD cannot record decisions regarding organ and tissue donation An AHD does not apply to treatment decisions where the person is an involuntary patient within the meaning of the *Mental Health Act 1996* An AHD will be invalid if: • It is not made voluntarily • It is made as a result of inducement • It is made as a result of coercion • At the time that the person made it, they did not understand the treatment decision • At the time that the person made it, they did not understand the consequences of making the treatment decision An AHD will be inoperative where: • Circumstances relevant to the treatment decision have changed since the person made the treatment decision • The person could not have reasonably anticipated those changes at the time that they made the treatment decision • A reasonable person with knowledge of the change of circumstances would now change their mind about the treatment decision	No substitute decision maker .

Legislation	Protections for professionals who abide by instructions in an ACD	Professionals who are protected
ACT		
Powers of Attorney Act 2006		
Medical Treatment (Health Directions) Act 2006		
NSW		
Guardianship Act 1987 NSW does not have specific legislation for instructional ACD	No specific provision in this Act provides protection. Health professionals complying with a valid ACD are protected by common law (see Justice McDougall's guidelines from *HNEAHS v A* [2009]	Not applicable Health provider

Legislation	Protections for professionals who abide by instructions in an ACD	Professionals who are protected
NT		
Natural Death Act 1988	A medical practitioner must act in accordance with a direction, unless there are reasonable grounds to believe that the person has revoked, or intended to revoke the direction, or was not, at the time of making the direction, capable of understanding the nature and consequences of the direction. Under subsection 5(3) of the Act, a medical practitioner incurs no liability for a decision made by him or her in good faith and without negligence as to whether a patient: • is or is not suffering from a terminal illness; • revoked or intended to revoke a direction under this Act; or • was, or was not, at the time of making a direction under this Act, capable of understanding the nature and consequences of the direction Furthermore, subsection 6(1) of the Act provides that, for the purposes of the law of the Territory, the non-application of extraordinary measures to, or the withdrawal of extraordinary measures from, a person suffering from a terminal illness does not constitute a cause of death where it was made in accordance with a direction made by the patient However, this section does not relieve a medical practitioner from the consequences of a negligent decision as to whether or not a patient is suffering from a terminal illness	Health provider

Legislation	Protections for professionals who abide by instructions in an ACD	Professionals who are protected
QLD		
Powers of Attorney Act 1998	S99 – for dealing with invalid attorney under EPA or AHD if unaware principal lacked capacity to appoint	Any person (other than attorney)
	S100 – for acting on invalid EPA/AHD if unaware invalid	
	S101 – no less protection that if adult gave consent for health matter	
	Note also:	
	S102 – for not being aware of AHD	Health provider
	S103 – for non-compliance with AHD due to uncertainty, against good medical practice, or changed circumstances	Health provider
Guardianship and Administration Act 2000	S77 – for compliance with purported exercise of power by person who holds themselves out as substitute decision-maker	Health provider
	S80 – no less protection than if adult gave consent for health matter	Health provider
Criminal Code	S282A – for providing palliative care in good faith and with reasonable care and skill, and provision of palliative care is reasonable	Doctor (or person acting under doctor's order)

Legislation	Protections for professionals who abide by instructions in an ACD	Professionals who are protected
SA		
Guardianship and Administration Act 1993	None	
Consent to Medical Treatment and Palliative Care Act 1995 S17	... incurs no civil or criminal liability by administering medical treatment with the intention of relieving pain or distress with consent, in good faith, without negligence and in accordance with proper professional standards of palliative care, even though an incidental effect of the treatment is to hasten death ... under no duty to use, or to continue to use, life sustaining measures if the effect would be merely to prolong life in a moribund state without any real prospect of recovery or in a persistent vegetative state	Medical practitioners and those under a medical practitioner's supervision
TAS		
Guardianship and Administration Act 1995	Valid consent to treatment	Health professionals
VIC		
Guardianship and Administration Act 1986	Protects registered practitioners in relation to particular offences if carrying out/supervising of medical/ dental treatment if practitioner believes on reasonable grounds that consent or purported consent given by person authorised to give consent or practitioner believed was authorised. Also protects practitioners from emergency procedure carried out without consent. Does not effect duty of care owed by practitioner to patient	Registered medical or dental practitioner (other than student)

Legislation	Protections for professionals who abide by instructions in an ACD	Professionals who are protected
VIC		
Medical Treatment Act 1988	Protects all registered medical practitioners or people acting under their direction who, in good faith and in reliance on certificate refuse to perform or continue a procedure or a medical treatment which they believed on reasonable ground has been refused in accordance with the Act. A medical practioner is not guilty of misconduct, any offence or liability in any civil proceeding for failing to perform or continue the relevant treatment Acting in good faith covers practitioners who are not aware certificate has been cancelled	Registered medical practitioners or people acting under their direction

Legislation	Protections for professionals who abide by instructions in an ACD	Professionals who are protected
WA		
Guardianship and Administration Act 1990	Treatment action (commencing, continuing or discontinuing any treatment of a patient, including palliative care) taken by health professionals has the effect as if the treatment decision had been made by the patient and the patient was of full legal capacity ***if*** the health professional has relied in good faith on information and have acted honestly in relying on it	Health professionals as defined in the *Civil Liability Act 2002* to mean: Health professionals registered under the *Health Practitioner* *Regulation National Law (Western Australia)* in any of the following health professions — (i) chiropractic; (ii) dental; (iii) medical; (iv) nursing and midwifery; (v) optometry; (vi) osteopathy; (vii) pharmacy; (viii) physiotherapy; (ix) podiatry (x) psychology Or any other person who practises a discipline or profession in the health area that involves the application of a body of learning

Appendix B: Advance Care Directives and principles for decision-making

Hunter and New England Area Health Service v A [2009] NSWSC 761

Extracted from the decision by Justice McDougall delivered 6 August 2009

Accordingly, to assist those faced with emergency care decisions, I summarise my understanding of the relevant principles (whilst acknowledging that what I say will not apply in every conceivable circumstance):

1. except in the case of an emergency where it is not practicable to obtain consent (see at (5) below), it is at common law a battery to administer medical treatment to a person without the person's consent. There may be a qualification if the treatment is necessary to save the life of a viable unborn child.
2. Consent may be express or, in some cases, implied; and whether a person consents to medical treatment is a question of fact in each case.
3. Consent to medical treatment may be given:
   - by the person concerned, if that person is a capable adult;
   - by the person's guardian (under an instrument of appointment of enduring guardian, if in effect; or by a guardian appointed by the Guardianship Tribunal or a court);
   - by the spouse of the person, if the relationship between the person and the spouse is close and continuing and the spouse is not under guardianship;
   - by a person who has the care of the person; or
   - by a close friend or relative of the person.
4. At common law, next of kin cannot give consent on behalf of the person. However, if they fall into one or other of the categories just listed (and of course they would fall into at least the last) they may do so under the [NSW] Guardianship Act.
5. Emergency medical treatment that is reasonably necessary in the particular case may be administered to a person without the person's consent if the person's condition is such that it is not possible to obtain his or her consent, and it is not practicable to obtain the consent of someone else authorised to give it, and if the person has not signified that he or she does not wish the treatment, or treatment of that kind, to be carried out.
6. A person may make an "advance care directive": a statement that the person does not wish to receive medical treatment, or medical treatment of specified kinds. If an advance care directive is made by a capable adult, and is clear and unambiguous, and extends to the situation at hand, it must be respected. It would be a battery to administer medical treatment to the person of a kind prohibited by the advance care directive. Again, there may be a qualification if the treatment is necessary to save the life of a viable unborn child.
7. There is a presumption that an adult is capable of deciding whether to consent to or to refuse medical treatment. However, the presumption is rebuttable. In considering the question of capacity, it is necessary to take into account both the importance of the decision and the ability of the individual to receive, retain and process information given to him or her that bears on the decision.
8. If there is genuine and reasonable doubt as to the validity of an advance care directive, or as to whether it applies in the situation at hand, a hospital or medical practitioner should apply promptly to the court for its aid. The hospital or medical practitioner is justified in acting in accordance with the court's determination as to the validity and operation of the advance care directive.

9. Where there is genuine and reasonable doubt as to the validity or operation of an advance care directive, and the hospital or medical practitioner applies promptly to the court for relief, the hospital or practitioner is justified, by the emergency principle, in administering the treatment in question until the court gives its decision.
10. It is not necessary, for there to be a valid advance care directive, that the person giving it should have been informed of the consequences of deciding, in advance, to refuse specified kinds of medical treatment. Nor does it matter that the person's decision is based on religious, social or moral grounds rather than upon (for example) some balancing of risk and benefit. Indeed, it does not matter if the decision seems to be unsupported by any discernible reason, as long as it was made voluntarily, and in the absence of any vitiating factor such as misrepresentation, by a capable adult.
11. What appears to be a valid consent given by a capable adult may be ineffective if it does not represent the independent exercise of persons volition: if, by some means, the person's will has been overborne or the decision is the result of undue influence, or of some other vitiating circumstance.

Full judgement available at: http://www.lawlink.nsw.gov.au/scjudgments/2009nswsc.nsf/0000000000000000000000000000000000/48dd2b1db7c8987dca257608000a28da?OpenDocument (accessed 7 January 2011).

Appendix C: Members of the Advance Care Directives Working Group

Name	Expertise	Position
ACT		
Dr I Anne Leditschke	Intensivist	Senior Specialist, Intensive Care Unit, The Canberra Hospital
COMMONWEALTH		
Dr Bronwen Harvey	Public Health Medical Officer	Medical Adviser, Office of Health Protection, Department of Health and Ageing
Ms Melinda Bromley Apr – Sep 2009	Commonwealth Officer	Assistant Secretary, Office for an Ageing Australia, Department of Health and Ageing
Mr 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
NSW		
Ms Jo Montgomery to Feb 2009	Health policy adviser	Principal Project Officer, Advance Care Planning & Healthy at Home programs, NSW Health
Ms Julie Letts from Feb2009	Health policy adviser in clinical ethics	Principal Policy Analyst (Clinical Ethics), Research and Ethics Branch, NSW Health
NT		
Ms Liz Kasteel to Dec 2009	Health policy adviser	A/Principal Policy Advisor, Acute Care Policy and Services Development, Dept of Health and Families, NT Health
Mr John McMahon from Jan 2010	Health policy adviser	Palliative Care Nurse Consultant/Senior Policy Officer, Dept of Health and Families, NT Health
QLD		
Ms Mandy Forster	Health policy adviser	Director – Access Improvement Service, Centre for Healthcare Improvement, Queensland Health
Ms Kim Gasson	Health policy adviser	Manager – Access Improvement Service, Centre for Healthcare Improvement, Queensland Health

Name	Expertise	Position
QLD		
Ms Sue Cawcutt to Sep 2009	Health policy adviser	Principal Policy Officer, Access Improvement Service, Centre for Healthcare Improvement, Queensland Health
SA		
Dr Jean Murray member to May 2009, then principal writer	Health policy ethico-legal adviser	Policy Consultant (previously Principal Consultant, Ethico-Legal Reform, SA Health)
Ms Kathy Williams	Health policy adviser in bioethics	Senior Policy Officer, Bioethics and Reproductive Technology, SA Health
TAS		
Ms Helen Mulcahy to Mar 2009	Health policy adviser	Principal Policy Analyst: Clinical Technical & Ethical Issues, Dept of Health and Human Services
Professor Michael Ashby from Mar 2009	Palliative care physician	Director of Palliative Care, Royal Hobart Hospital, and Clinical Director, Palliative Care, Dept of Health and Human Services
Ms Di Driscoll Mar – Dec 2009	Health policy adviser	Principal Consultant, Palliative Care
Mr Raul Cox from Jan 2010	Health policy adviser	Senior Policy Analyst: Policy, Information and Commissioning Group
VIC		
Ms Gail Roberts to Jun 2009	Health policy adviser	Senior Project Officer, Sub-acute Services, Wellbeing, Integrated Care and Ageing, Victorian Department of Health
Ms Nicole Doran from Jul 2009	Health policy adviser	Manager, Sub-acute Services, Wellbeing, Integrated Care and Ageing, Victorian Department of Health
WA		
Dr Simon Towler (Chair)	Intensivist	Chief Medical Officer, Dept of Health WA
Ms Heather Wilson Sep 2009 – Apr 2010	Health policy adviser	Senior Policy Officer, Dept of Health WA
Ms Jenny O'Callaghan from Apr 2010	Health policy adviser	Senior Policy Officer, Dept of Health WA

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