

Advance care planning: have the conversation

A strategy for Victorian health
services 2014–2018



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Ministerial foreword

Having the conversation about what treatment and care loved ones want during a serious illness or at the end of their lives can be difficult and emotional for families. These conversations often occur in a hospital after an admission for an acute illness or due to the deterioration of a chronic disease.

Due to a combination of medical progress, science, public health improvements and socioeconomic factors, we can now expect to live longer than ever before, and both the way we live in old age and the way we die have changed. Nevertheless, as we move closer to dying, many of us will have a period of increasing dependence, a loss of cognitive ability and limited decision-making capacity.

Advance care planning is the process of planning for future health and personal care whereby a person's values, beliefs and preferences are made known so they can guide clinical decision making at a future time when that person cannot make or communicate their decisions due to lack of capacity.

Clinicians – doctors, nurses, and allied health staff – can also find these conversations difficult and it is human nature to avoid challenging situations. However, it is important for all Victorians to have confidence that our health services are providing the treatment and care that a person wants.

For these reasons embedding advance care planning into usual clinical practice is vital.

For over a decade, Victoria has led developments in advance care planning. In 2002, Austin Health introduced advance care planning to ensure there was a formal process for these conversations to occur. With Austin Health's support, a number of other health services followed.

The *Victorian Health Priorities Framework 2012–2022* identifies the expansion of advance care planning as an important action to improve every Victorian's health experience.

Advance care planning: have the conversation – a strategy for Victorian health services 2014–2018 aims to increase opportunities for people to develop advance care plans and for these to be activated by health services. It provides practical information to guide the implementation of advance care planning.

This strategy sets key measures in four priority action areas:

1. establishing robust systems so that your organisation can *have the conversation*
2. ensuring you have an evidence-based and quality approach to *have the conversation*
3. increasing your workforce capability to *have the conversation*
4. enabling the person you are caring for to *have the conversation*.

This strategy is a positive step towards understanding and discussing the limitations of modern healthcare and to help people express their preferences for treatment and care.

The development of this document has been informed by the practice wisdom of an expert advisory group, consultations with key stakeholders and the lessons learned from implementing advance care planning in our health services to date. Victoria's existing legal framework supports the implementation of advance care planning.

Advance care planning should not just occur in our health services. We need everyone involved in providing care for people with chronic diseases and life-limiting conditions to work cooperatively and play their part in having the conversation.

I am committed to ensuring the outcomes in this strategy are achieved. They will enhance the care and experience of people needing Victoria's health services. I urge chief executive officers and senior staff to support and drive advance care planning implementation throughout their organisation. I commend this strategy to you and encourage you to *have the conversation*.

A handwritten signature in black ink, appearing to read 'David Davis', with a stylized flourish at the end.

Hon David Davis MP
Minister for Health

Why advance care planning is important – a clinician’s heartfelt explanation

Most of us enjoy life and want to live as long as we can – so we are reassured to know that medical care is there for us when we need it. We instinctively want to prolong our lives.

Given advances in medical treatment, most of us will live to old age, but we will live with long periods of decline. During this time there are likely to be a number of medical crises, often getting more frequent as the condition progresses.

Doctors and families feel a tremendous responsibility to extend life if there is a chance of survival, however small. Because of this it is not uncommon for a great deal of technology to be used in the weeks and months before death. Unfortunately by the time everyone agrees that treatment is not working (or is too much), life has become very miserable for the person concerned.

When we move beyond our instinct to prolong our lives, most of us can imagine situations where it is important to consider quality of life rather than just quantity of life. Worries about severe impairment, burdensome treatment and simply prolonging the dying process are almost universal.

From a rational perspective, very few of us actually want our lives extended at ‘any cost’. However when faced with such a decision, even family members who know us intimately would struggle to know our wishes, and having to make a decision about end-of-life care can lead to prolonged guilt whichever way the decision goes.

People have very different degrees of tolerance for prolonged and burdensome treatment (and enthusiasm generally decreases as people get older and frailer). It is impossible for doctors and family members to make good treatment decisions for others unless these concerns and wishes are clearly understood.

Many people put off talking about these decisions but this is not wise. It is difficult to think rationally in a crisis. Serious disease may impair clear thinking, and quite often people who are very sick are unconscious, so cannot say anything at all.

It is vital that we all plan before a medical crisis, when there is no pressure and plenty of time.

As medical treatment gets more complex, we need, more than ever, to put the person at the centre of care and *have the conversation*.



Associate Professor Charlie Corke

Intensive Care Specialist, Barwon Health

Advance care planning advocate and member of the Advance Care Planning Strategy Development Advisory Group

Acknowledgements

This advance care planning strategy for Victorian health services 2014–2018 has been developed with extensive consultation across the health sector, including primary, secondary and tertiary healthcare providers, representatives from professional colleges and organisations, peak bodies, aged care and private health providers.

Feedback from the 250 people who attended the workshops in August 2013 was overwhelmingly positive and constructive. The structure of this document has been influenced by this feedback. Participants wanted a document that would provide some context and background about why advance care planning is important, practical implementation steps at the clinical as well as the organisational level and clear information about the law as it relates to advance care planning.

Thank you to all the consumers who contributed to this strategy either through their stories and experiences or for allowing us to use their images in this document.

The Victorian Department of Health (the department) would like to acknowledge the stakeholders who participated in the consultations and who contributed to the development of this strategy.

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Ms Julianne Davies, Austin Health

Dr Karen Detering, respiratory medicine physician, Austin Health

Dr Barbara Hayes, palliative care physician, Northern Health

Associate Professor William Silvester, intensive care physician, Austin Health

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The advance care planning managers group has contributed to case studies and provided feedback on drafts of this document. This strategy has been informed by their experiences of introducing advance care planning into their health services.

This document was developed by the Department of Health. The team was:

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Introduction

Case study: Having the conversation with my brother

We all sat down with my brother, while we still had the opportunity to understand what he would want. The main thing he said was that he wouldn't want heroic measures. We talked about what 'heroic measures' meant and all felt we had an idea of what he would want.

When it came time to make a decision, my sister-in-law who was his substitute decision maker almost agreed to intubate. We gently reminded her of the discussion we had together and my brother's wishes. Despite it being difficult, his wishes were respected.

He died peacefully in hospital with his family by his bedside.

Despite it being one of the saddest moments in my life, my brother had a 'good death' – without pain and surrounded by the people he loved.

This strategy aims to ensure all Victorians accessing health services will have opportunities to express their preferences for future treatment and care through advance care planning. To do this, people need to be supported to develop an advance care plan that will guide medical treatment and care if they become unable to communicate or participate in decision making. Advance care planning is a tool for supporting client–clinician communication. It is a process for planning for future health and personal care whereby the person's values, beliefs and preferences are made known so they can guide future decision making. It enables them to continue to influence decisions even when they cannot directly do so.

Successful advance care planning depends on services having an organisational commitment to delivering person-centred care. Person-centred care supports people to participate in decisions about their healthcare through client–clinician collaboration.

Advance care planning is relevant to everyone, but this strategy has a particular focus on people who are most likely to benefit from support to articulate their wishes for care at the end of their lives. These include:

- people with chronic progressive disease
- people approaching end of life
- people who are managing multiple comorbidities, including frailty.

A word about terminology

The term **advance care plan** is used in this strategy to encompass a range of documents that people may use to express their values and preferences for care and treatment. The department expects health services to give due consideration to whatever form a person's advance care planning documentation takes.

The term **clinician** includes doctors, nurses and allied health professionals.

The term **substitute decision maker** refers to a person appointed as an enduring power of attorney (medical treatment), enduring guardian or a person responsible within s. 37 of the *Guardianship and Administration Act 1986*.

Have the conversation is a phrase adopted by the Victorian Department of Health, used within this strategy and more broadly to promote advance care planning. *Have the conversation* encompasses all the phases of advance care planning: develop, review and activate.

The terminology section at the end of this document provides further clarification.

Expected outcomes

The purpose of this strategy is to enhance opportunities for people to develop advance care plans and for these to be activated in health services. It is a positive step towards understanding and discussing the limitations of modern healthcare and to help people to express their preferences for end-of-life care. Expected outcomes of the strategy include the following:

- Victorians are supported to use advance care planning to communicate their future healthcare choices.
- Health services approach advance care planning in a systematic way.
- There is mutual recognition of advance care plans across services and sectors along the person's care pathway.
- Advance care planning is integrated into routine healthcare.
- People participate in decisions about their treatment and care.
- A person's preferences are known and respected after they lose decision-making capacity.
- Decisions by substitute decision makers clearly reflect the person's preferences, and the decisions are respected by clinicians.
- Clinical treatment plans written by clinicians are consistent with the person's expressed values and preferred outcomes of care as recorded in their advance care plan.
- Standardised documents that support and strengthen advance care planning at the local health service level are developed.
- Key performance indicators are used to measure the outcomes and progress of implementation.

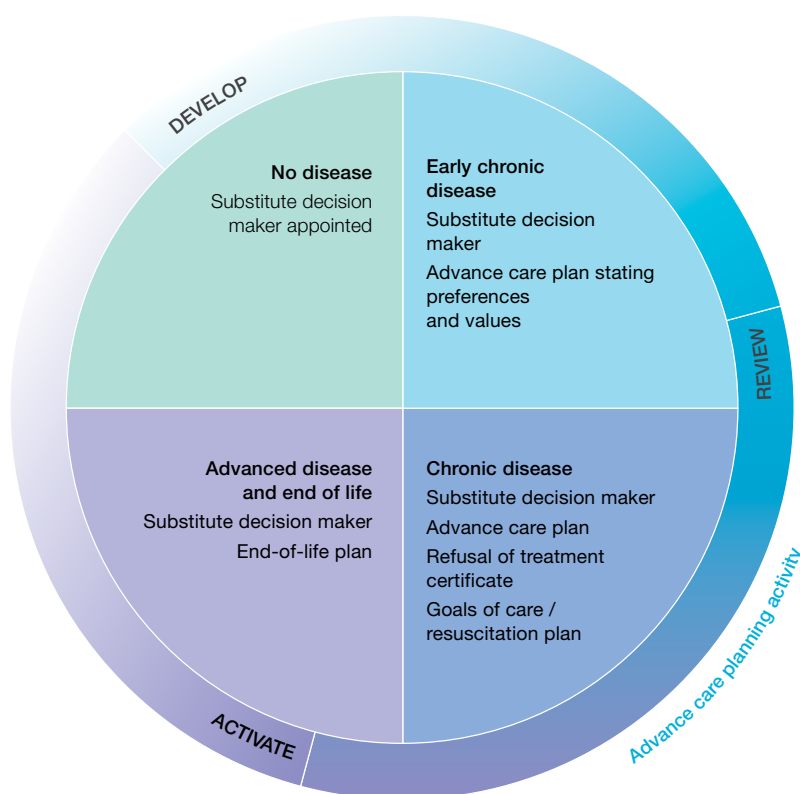
Audience

The primary audience for this strategy is health services in Victoria. These services include:

- publicly funded health services
- private hospitals and services
- primary care providers, particularly general practitioners
- community providers including primary care organisations
- aged care providers
- ambulance services.

As health services operate within the broader health and social service systems, the directions and actions outlined in this document are relevant to a range of other service providers.

Table 1: Facilitating advance care planning across the health and disease spectrum



No disease	Early chronic disease	Chronic disease	Advanced disease and end-of life
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Advance care planning facilitated by:

Internet-based resources (www.health.vic.gov.au/acp) Office of the Public Advocate's Take control kit Resources that enable an advance care plan to be completed independently	GP introducing the topic Admission to an admitted or non-admitted service prompting consideration of preferences for future care Admission, discharge and transfer processes incorporate advance care plans	Care coordinators, patient advocates and clinicians at health service programs who target chronic and progressive conditions supporting advance care planning	Specialist teams consider advance care planning at admission, discharge and transfer, and when a person's condition changes
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Triggers for advance care planning

Completion of will Public campaign, media coverage Experience of death of a loved one Admission to a health service Admission to a residential aged care facility	Admission to a health service for: <ul style="list-style-type: none"> a diagnostic procedure an acute illness related to an emerging chronic condition GP visit 	Relapse of a chronic and progressive condition Failure of treatment	Failure of treatment and/or rapid deterioration
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Advance care planning goals

Identify someone to advocate on person's behalf Begin thinking and discussing values and life goals	Identify values, beliefs and preferences	Identify treatment and care preferences and preferred outcomes	Identification of specific interventions refused
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Possible outcomes of advance care planning

Substitute decision maker appointed	Written advance care plan records preferences and values that can inform clinical decision making	Advance care plan that clearly informs clinical decision making Refusal of Treatment Certificate Disease-specific care plan supports the advance care planning process Resuscitation/goals of care plan	End-of-life plan including identification of specific interventions refused
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Aims

This document aims to provide clear and useful information to guide the implementation of advance care planning across Victorian health services. It will promote consistent practice and inform the development of processes, policies, guidelines, training, governance and quality structures that support advance care planning.

This strategy is divided into four parts:

- Part 1: Why we need to have advance care planning conversations
- Part 2: How to have an advance care planning conversation
- Part 3: How the law supports you to have the conversation
- Part 4: Getting your organisation ready for advance care planning conversations.

Context

National Framework for Advance Care Directives

The National Framework for Advance Care Directives (the national framework) was endorsed by the Australian Health Ministers' Advisory Council (AHMAC) in September 2011.

The national framework combines new and existing concepts about advance care planning and is intended to be aspirational. It describes the objectives for which policy and practice should aim, rather than attempting to give a comprehensive overview of current law and practices across Australia. Specifically, the national framework provides nationally consistent language to describe the components of advance care planning as well as best practice standards and a code for ethical practice.

Victoria is committed to aligning with the national framework as far as possible within its existing legal framework to promote harmonisation and best practice in advance care planning.

The Victorian context

Victoria has been leading the way in supporting the development and implementation of advance care planning for over a decade. The *Victorian Health Priorities Framework 2012–2022* guides health reform by outlining seven priority areas to address key issues in the health system. It identifies the expansion of advance care planning as an important action to improve every Victorian's health status and health experience, improving health knowledge and supporting choices.

This strategy outlines in more detail the four priority actions aimed at supporting advance care planning.

Table 2: Victorian Health Priorities Framework 2012–2022 guiding advance care planning priority actions

Developing a system that is responsive to people's needs	Priority action: Establishing robust systems so that your organisation can <i>have the conversation</i>	Priority action: Enabling the person you are caring for to <i>have the conversation</i>
Improving every Victorian's health status and health experience		
Increasing the system's financial sustainability and productivity		
Increasing accountability and transparency		
Utilising eHealth and communications technology		
Expanding service, workforce and system capacity	Priority action: Increasing your workforce capability to <i>have the conversation</i>	
Implementing continuous improvements and innovation	Priority action: Ensuring you have an evidence-based and quality approach to <i>have the conversation</i>	

This strategy will provide guidance for health services in Victoria to develop and implement advance care planning. It supports key policy directions for the Victorian health system including:

- reform and planning policies
- client rights and responsibilities
- client healthcare participation.

Medical Treatment Act 1988

The *Medical Treatment Act 1988* preamble recognises that:

‘... it is desirable to:

- a) give protection to the person's right to refuse unwanted medical treatment;
- b) give protection to medical practitioners who act in good faith in accordance with a person's express wishes;
- c) recognise the difficult circumstances that face medical practitioners in advising clients and providing guidance in relation to treatment options;
- d) state clearly the way in which a person can signify his or her wishes in regard to medical care;
- e) encourage community and professional understanding of the changing focus of treatment from cure to pain relief for terminally ill people;
- f) ensure that people who are dying receive maximum relief from pain and suffering.’

The purpose of the *Medical Treatment Act 1988* is to:

- clarify the law relating to the right of a person to refuse medical treatment
- establish a procedure for clearly indicating a decision to refuse medical treatment
- enable a substitute decision maker to make decisions about medical treatment on behalf of an incompetent person.

Guardianship and Administration Act 1986

Guardianship and Administration Act 1986 allows a person to appoint an enduring guardian to make healthcare decisions on their behalf. The Act also allows VCAT to make a guardianship order for a person who is unable, by reason of a disability, to make reasonable judgments in respect of all or any of the matters relating to their person or circumstances, including healthcare and medical matters. The Act also sets out who can consent to medical treatment on behalf of a person who is unable to consent to the treatment themselves (the person responsible hierarchy).

Charter of Human Rights and Responsibilities Act 2006

The Charter requires that public authorities, including public health services, act compatibly with and give proper consideration to human rights.

Strengthening palliative care: policy and strategic directions 2011–2015

This policy aims to ensure that Victorians with a life-threatening illness and their families and carers have access to a high-quality palliative care service system that fosters innovation, promotes evidence-based practice and provides coordinated care and support that is responsive to their needs.

Doing it with us not for us

This document guides health services to promote and embed client participation in their organisation through strategies including community advisory committees and patient advocacy.

Health Services (Conciliation and Review) Act 1987

This Act establishes the Office of the Health Services Commissioner (OHSC), an independent statutory authority established to receive and resolve complaints about health services and providers.

Communication issues made up ten per cent of the primary issues raised in complaints in 2013, and experience shows that communication is a feature of the majority of complaints.

The guiding principles of the OHSC are:

- quality healthcare, given as promptly as circumstances permit
- considerate healthcare
- respect for the privacy and dignity of persons being given healthcare
- the provision of adequate information on services provided or treatment available, in terms which are understandable
- participation in decision making affecting individual healthcare
- an environment of informed choice in accepting or refusing treatment or participation in education or research programs.

Part 1: Why we need to have the conversation

WHY





Part 1: Why we need to have the conversation

Vision

The vision is that all Victorians who access health services will be given opportunities to express their preferences for future treatment and care through advance care planning.

They will be supported to develop an advance care plan that guides medical treatment and care needs if they become unable to communicate or participate in decision making.

I want everyone to do one, so that people who are unwell can feel what I feel. ... Mine has brought me relief.

Lisa Leskie, consumer and advance care planning advocate

What is advance care planning?

Advance care planning is the process of planning for future health and personal care whereby a person's values, beliefs and preferences are made known so they can guide clinical decision making at a future time when that person cannot make or communicate their decisions due to lack of capacity.

Advance care planning can be verbal or written. Ideally, advance care plans are written in order to strengthen their influence on clinical decision making. Both verbal and written advance care plans can result in:

- expression of personal values, preferences for treatment and care
- appointment of a substitute decision maker.

Advance care planning is an approach to communication that allows a person to discuss goals, values and choices about their preferred outcomes of care. It is most successful when their level of health literacy is taken into account. This allows information to be provided in a way that best supports a person's understanding of their health condition and future treatment implications. It puts the person at the centre of care, involving them, their family (if appropriate) and the clinicians responsible for their care.

Routine care should provide opportunities to discuss and review people's wishes and preferences at clearly identified points along their care journey.

A client–clinician partnership offers people the opportunity to express their preferences for care as well as develop an understanding of their current and anticipated future health status and treatment options.

Advance care planning allows people to clearly express their values and preferences to inform clinical decision making when they are too unwell to directly participate. The advance care planning discussion is important; people can also simply choose to discuss their preferences for future care with family members, clinicians or significant others. Putting it in writing strengthens this process.

An advance care plan can have several names including advance care directive, advance care plan, living will, advance directive and statement of choices. In Victoria due consideration needs to be given to an advance care plan, whatever form this documentation takes.

Who is advance care planning for?

Advance care planning is relevant to everyone but is particularly important for key groups.

This strategy focuses on priority groups of people who would benefit from support to articulate their wishes for future treatment and care.

These include:

- aged or older people who are frail
- people of any age with chronic progressive and life-limiting conditions
- people approaching end of life
- people with multiple comorbidities and/or at risk of conditions such as stroke or heart failure
- people with early cognitive impairment.

People undergoing medical or surgical treatment should also have the opportunity to discuss advance care planning. Pharmaceutical interventions and the impact of treatments, both anticipated and unanticipated, may result in transient and temporary loss of capacity.

Case study: Having the conversation with Sue

Sue was 77 years old with multiple chronic conditions when she presented at hospital with fever, tiredness and increasing shortness of breath. This left her unable to discuss her care with staff.

During a previous admission she'd had a conversation with staff about her wishes for future care and developed an advance care plan. Sue had previously appointed her daughter as her substitute decision maker. She explained that she had enjoyed her independence and was increasingly frustrated about how her illnesses were limiting this.

In particular she had identified that in view of her current health she would not want cardiopulmonary resuscitation, invasive life-prolonging treatments or a transfer to intensive care. She would however accept intravenous antibiotics. This was documented on the health service's advance care plan form and an alert was placed on her file.

Doctors spoke with family members, particularly her daughter, and they agreed on a course of intravenous antibiotics, but not a bronchoscopy as she had refused such treatment in the past. Her condition deteriorated further. In consultation with the family and in accordance with her advance care plan, the decision was made to provide her with palliative care.

Sue spent her final days with her family, being kept comfortable and free from pain.

Message

This advance care planning conversation meant that Sue received the care she wanted at a time when she was unable to communicate her wishes directly.

The importance of advance care planning for health services

The introduction of advance care planning as part of usual clinical practice is important because health services are responding to a range of changing needs and demands including:

- delivering person-centred care
- caring for an ageing population.

Delivering person-centred care

Person or patient-centred care focuses on collaboration between health workers, the person and their family or carer, and is centred on respecting the person's wishes and needs (Department of Human Services 2006). Person-centred care supports people to participate in decisions about their healthcare through client–clinician collaboration.

One of the priority action areas for the *Victorian Health Priorities Framework* is to improve every Victorian's health status and health experiences through improving people's health knowledge and supporting their choices. Expanding advance care planning and improving end-of-life care are identified as key enablers of person-centred care.

Health services need to support person-centred care at three levels:

- the organisational level, through policies that support the involvement of people in their care
- the multidisciplinary service delivery level, through care planning based on client goals
- the client-provider level, through tailored therapy and medical treatment that reflects people's values and wishes.

Person-centred approaches can reduce anxiety, improve quality of life and improve chronic disease management (Stewart et al. 2000; Bauman et al. 2003; Stewart 2001) by ensuring the person's concerns and needs are met.

Research shows that people who access health services want information related to their medical condition and prognosis, and want to participate in discussions about their future medical treatment preferences (Curtis et al. 2004; Davison 2010; Laakkonen et al. 2008; Patel et al. 2012; Schell et al. 2012).

People who feel they are engaged in shared decision making are more satisfied with their care, however people are frequently involved in decision making less than they would like (Alston et al. 2012).

If a person's preferences are not known by the clinicians or family members, it can result in unnecessary or unwanted treatment being provided and increased anxiety and uncertainty for families and providers.

Failure to engage people in decision making can result in 'preference misdiagnosis'. This refers to the gap between what people want and what doctors think they want (Mulley et al. 2012). Preference misdiagnosis can result in people not receiving the treatment they would choose if they were fully informed about treatment options.

Understanding and documenting values is important

People have concerns besides simply prolonging their lives. Surveys of patients with terminal illness find that their top priorities include, in addition to avoiding suffering, being with family, having the touch of others, being mentally aware, and not becoming a burden to others. Our system of technological medical care has utterly failed to meet these needs, and the cost of this failure is measured in far more than dollars.

Atul Gawande 2010

When assisting someone to develop an advance care plan it is important to understand and document the person's values. Medical intervention statements alone do not provide clinicians and substitute decision makers with the context for understanding the person's decision-making process.

It is unreasonable to expect people to understand the full applications and implications of a medical decision under all potential scenarios. Clearly articulated values that avoid ambiguity will help clinicians and substitute decision makers *to stand in the person's shoes*. This provides context when they consider the current treatment and care options, and it will allow them to be as sure as they can that they are giving effect to the wishes of the person and acting in the person's best interest.

Values are inherent to an individual whereas medical preferences depend on many variables including the type of condition, its severity, how disabling it is for the individual and the emergence of new treatments. To make decisions about treatment involves a thorough understanding of the condition. Using a values-based discussion is a helpful way for people to describe what is important to them. This can then lead to a discussion about preferred outcomes. For some people talking about their values may be all they want to discuss. For others they may then have a conversation with their doctor about medical treatment options.

I want to start the conversation with things that are easy for people to talk about. Usually, the technical component of medical decision making is complex. However people's values are pretty consistent throughout life and this should inform a discussion between a person and their treating team about the outcomes that the person wants and what this means in terms of treatment decisions.

Associate Professor Charlie Corke, Intensive Care specialist, 2013

Caring for an ageing population

Due to a combination of medical progress, science and socioeconomic factors, people can now expect to live longer than ever before. This longer life may be in a state of compromised health with an extended period of chronic progressive disease, discomfort and increasing dependence and loss of cognitive ability.

People aged over 70 are admitted to hospital more often and stay longer than younger age groups. It is likely that this group will have more multi-morbidity, including dementia, and more complex needs requiring more specialised care and decision making from a wider variety of specialists.

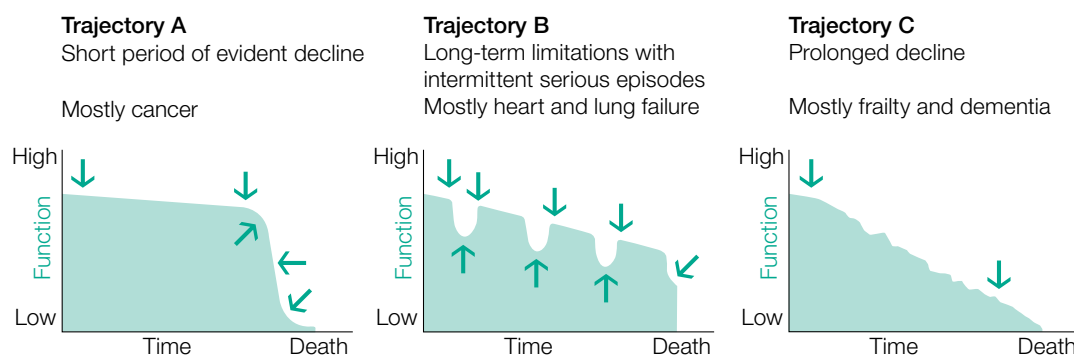
There is an increasing prevalence of chronic life-limiting diseases needing ongoing management. These diseases include frailty, cancers, chronic respiratory and cardiovascular disease, neurological conditions, stroke, organ failure and dementia. Prior to death the trajectory of many of these diseases results in increased disability, often with recurrent hospital admissions and progressive decline over time.

People with life-threatening disease are likely to experience one of three trajectories:

- care delivered over a short period of decline (such as some cancers)
- long-term limitations with intermittent serious episodes of decline (such as heart and lung failure)
- prolonged decline (such as frailty and dementia).

These trajectories are illustrated in Figure 1 below. The arrows in this figure indicate changes to a person's health status and should trigger an advance care planning discussion.

Figure 1: Chronic disease trajectories



Most older people will have limited decision-making capacity for a period of time before they die (Kaspers et al. 2013). Currently many people accessing health services are at risk of not being able to communicate their wishes and are receiving treatment that they may not have chosen.

Many frail aged people and those with advanced chronic disease or terminal conditions indicate they do not want life-prolonging treatments if they develop further illness, particularly if there is no realistic expectation of recovery (Wright et al. 2008; Hickman et al. 2011; Monturo et al. 2007 in Silvester et al. 2012).



The client group I am involved with has very specific needs. Their disease is chronic, they experience loss weekly, for some daily, and grief is part of their every day. A very important part of my role is to support a patient through every aspect of their disease, before it happens, and when it is happening. To give a patient the permission and a safe environment to talk about death and dying, and to plan it to the best of our ability, is the only way to succeed in a good death, honouring a person's wishes.

Health Independence Program clinician 2013

Research has identified five key desires that people report as important at the end of their life (Singer et al. 1998; Steinhauser et al. 2000):

- having their symptoms managed
- avoiding prolongation of dying
- achieving a sense of control
- relieving burdens placed on their family
- strengthening relationships.

What advance care planning is not

Advance care planning illuminates a number of separate, but related treatment issues.

As a result, the role and purpose of advance care planning can become blurred with other decision-making, legal and communication concerns.

Advance care planning is not:

- a substitute for good informed consent about current treatment options (although discussions about values and wishes may help clarify decisions about these)
- a tool for applying fair and equitable distribution of healthcare resources across the wider community
- a replacement for clinical face-to-face communication and engagement with people and their families
- euthanasia.

Distinguishing advance care planning from euthanasia

Euthanasia is the act of knowingly and intentionally directly causing the death of a person at the request of the person to relieve difficult suffering (adapted from International Taskforce of Euthanasia in ANZSPM 2013).

In Victoria euthanasia is unlawful and it is unlawful to aid or abet the suicide or attempted suicide of another person.

There are misunderstandings about some legal aspects of end-of-life care decision making and advance care planning. End-of-life decision making can be complicated by confusion and concerns by people and clinicians about what is, or what is not, euthanasia.

Victoria's *Medical Treatment Act 1988* allows for:

- providing palliative care, including the provision of reasonable medical procedures for the relief of pain, suffering and discomfort
- complying with a person's Refusal of Treatment Certificate.

Part 3 of this document sets out how Victorian law supports advance care planning, including how withholding or withdrawing a treatment or procedure may be lawful where:

- a competent and properly advised adult has refused treatment, either at the time or in advance
- another person (an agent, parent or guardian) has refused on the person's behalf
- the treatment is non-beneficial
- the treatment imposes a burden not justified by the potential advantages.

Advance care planning can be delivered within Victoria's existing legal framework.

Benefits of advance care planning

Advance care planning has been shown to improve quality of care at the end of life and increase the likelihood of a person's wishes being known and respected. It improves the end-of-life care experience. Clients and families report being more satisfied with the end-of-life care provided. Symptoms of anxiety, depression and post-traumatic stress in the surviving family members are reduced (Detering et al. 2010).

Advance care planning has benefits for the person and their family, the health practitioner and the broader health service system. These include:

- supporting better client outcomes
- assisting clinicians to provide person-centred care
- optimising the use of health resources.

Table 3: Benefits of advance care planning

	Person and family	Health practitioner	Health services and system
Person-centred care	Open conversation is promoted. Values and preferences are discussed and documented.	People's values and preferences are understood and they guide clinical decision making.	Expectations of the person and family are met.
Care provision	Wanted or unwanted interventions are identified.	Clarity about a person's preferences informs decisions about treatments if the person loses capacity.	Unwanted treatment is not provided. The likelihood of non-beneficial treatment being offered or continued is reduced.
Experience	Care and treatment instructions are documented and substitute decision makers are appointed. The substitute decision maker makes decisions that the person would want. Carer and family stress and anxiety are reduced.	Focus on goals of care. Communication is streamlined through clear identification of the substitute decision maker. More confident that treatment decisions reflect what the person wanted.	The experience with the health service for the person, their carer and family is improved. Staff satisfaction is improved and staff stress is reduced.
Quality	Identified values and preferences influence care and treatment decisions when the person cannot directly participate in decision making.	Clinical care and decision making is consistent with the existing legal framework.	National Safety and Quality Health Service Standards specific to advance care planning are met which support accreditation efforts.

Best practice standards for advance care planning

Advance care planning is underpinned by ethical and legal frameworks encompassed in the best practice standards below (which are based on principles developed by the National Framework for Advance Care Directives, adapted to reflect Victorian law). The following best practice standards can guide a clinician's approach to developing or activating an advance care plan.

Best practice standards

Decisions are person-centred. Care decisions reflect personal views and choices and those preferences should be honoured at all times.

Respect for autonomy. Competent adults are entitled to make their own decisions about personal matters, including health. Autonomy can be exercised in different ways according to the person's culture, background, history or spiritual and religious beliefs.

Adults are presumed competent. Adults should be presumed to be competent at the time of completing an advance care plan or at the time that medical treatment is offered, unless there is reason to believe this is not the case.

Health decisions may be broad. Decisions outlined in an advance care plan may be broader than just medical treatment and might include preferences in relation to residential arrangements and unacceptable circumstances.

Decisions can relate to any time in the future. Advance care plans can relate to any future period of medical care, not just end-of-life care, where a person is unable to participate in decision-making.

Quality of life is defined by the individual. The person defines what level of functional ability defines quality of life and communicates it to their substitute decision maker through advance care planning.

The substitute decision maker who has been validly appointed has the authority to express the preferences of the person and be involved in medical decision making on behalf of the person who has lost capacity. Their authority and limits of their authority are defined by relevant Victorian legislation.

The substitute decision maker must only make a decision on the person's behalf as the need arises and only if the person is considered unable to make that particular decision at that particular time. Victorian law helps to guide a substitute decision maker about how they must take into account what the person would have wanted and the best interests of the person.*

* Section 38 of the *Guardianship and Administration Act 1986* helps to explain that in relation to consenting to medical treatment on behalf of a person who cannot consent to such treatment him or herself, the best interests of the person includes taking into account the person's wishes. Additionally, substitute decision makers who sign certificates under the Medical Treatment Act 1988 should also refer to s. 5B(2) of that Act, which explains that treatment under that Act can be refused if it would cause the person unreasonable distress or if it is reasonable to believe that the person, after giving serious consideration, would consider the treatment unwarranted. See Part 3 for more detail.

Part 2: Having the advance care planning conversation





Part 2: Having the advance care planning conversation

This section focuses on the fundamentals that need to be considered when implementing advance care planning at the clinical level. It highlights:

- the advance care planning cycle
- when to introduce advance care planning
- how to have an advance care planning conversation
- recording an advance care planning conversation
- the role of different clinical groups
- having a conversation about not offering or ceasing treatment
- talking about palliative care and end-of-life care
- having the conversation with people who have different needs.

Case study: What was important to Violetta was to *have the conversation*

Violetta, a 73-year-old woman, said she wanted to appoint one of her daughters as enduring power of attorney (medical treatment) and the other as the alternate. She said her daughters were ‘just like me’, and that she would later appoint her son as enduring power of attorney (financial) as he was ‘very good with numbers’.

We talked about the role of the enduring power of attorney (medical treatment) and the importance of talking to that person and important others about her preferences for future healthcare, and her values and beliefs that shape those preferences. Violetta also wrote down her preferences to help her family and others remember those preferences.

Violetta and I met again a few weeks later. Violetta told me she had talked to her three children and was surprised by their reaction to being asked to be enduring power of attorney (medical treatment). Her eldest daughter was happy to accept this role, but her other daughter said she did not feel capable of undertaking this role and she would find it too upsetting. Her son surprised her most. He agreed to be the alternate enduring power of attorney (medical treatment), and said that while he hoped not to have to make a hard decision on her behalf, that he would be honoured to do this for her.

Violetta and her three children spent the afternoon talking about how she had slowed down lately and what was important to her for her health. They shed a few tears that afternoon, but that the process of having this chat had been very worthwhile. She told me she didn’t think she needed to write an advance care plan as she had chosen the best people for the role of enduring power of attorney (medical treatment) and she and her family had ‘everything out in the open’ now.

Message

This advance care planning conversation meant that Violetta’s children were better able to understand her perspective, and felt prepared to make decisions that would reflect her wishes.

While Violetta’s family found the experience very emotional, having the conversation in a timely way can reduce the stress of making decisions during a crisis. It is important to acknowledge that discussions about people’s wishes for future care can be emotional.

Documenting Violetta’s wishes would support the son to act in his mother’s best interests.

The advance care planning cycle: develop, review, activate

Advance care planning can be straight forward – involving an ongoing conversation with the person and their family.

Health Independence Program clinician 2013

Developing an advance care plan is simple.

It involves:

- having a conversation about what health decisions are important
- identifying who would make decisions if the person was unable to participate
- determining what those decisions would be.

Advance care planning is a personal experience that is often undertaken at a time when the person feels vulnerable. This may be because they are dealing with a progression of their chronic illness or becoming aware of their prognosis or end-of-life issues.

Effective discussions require a skilled and empathetic approach to communication. Taking the time to prepare for the discussion, and having it in a suitable physical environment, will enable a positive experience for everyone involved.

Embedding advance care planning as part of routine care gives people opportunities to talk about and review their preferences at clearly identified points along their care journey. Advance care planning is a dynamic process. Clinicians need to revisit discussions with their clients over time in order to consider and review their advance care plans. Some people may not wish to participate in advance care planning. This should be acknowledged and respected.

When is it a good time to introduce advance care planning?

Advance care planning can be initiated at a number of points during a person's treatment and care including:

- when a person indicates they would like to talk about their future care and treatment
- by clinicians at key points in the person's illness trajectory (such as after hospitalisation)
- a change in the condition or the person experiences an unstable phase of an illness
- as a routine part of the care for key groups, such as those with chronic progressive disease, people approaching end of life, and people who are managing multiple comorbidities.

Advance care planning does not need to be completed all in one go.

The best way to develop an advance care plan is to start the conversation and follow up the development of the advance care plan at future routine consultations.

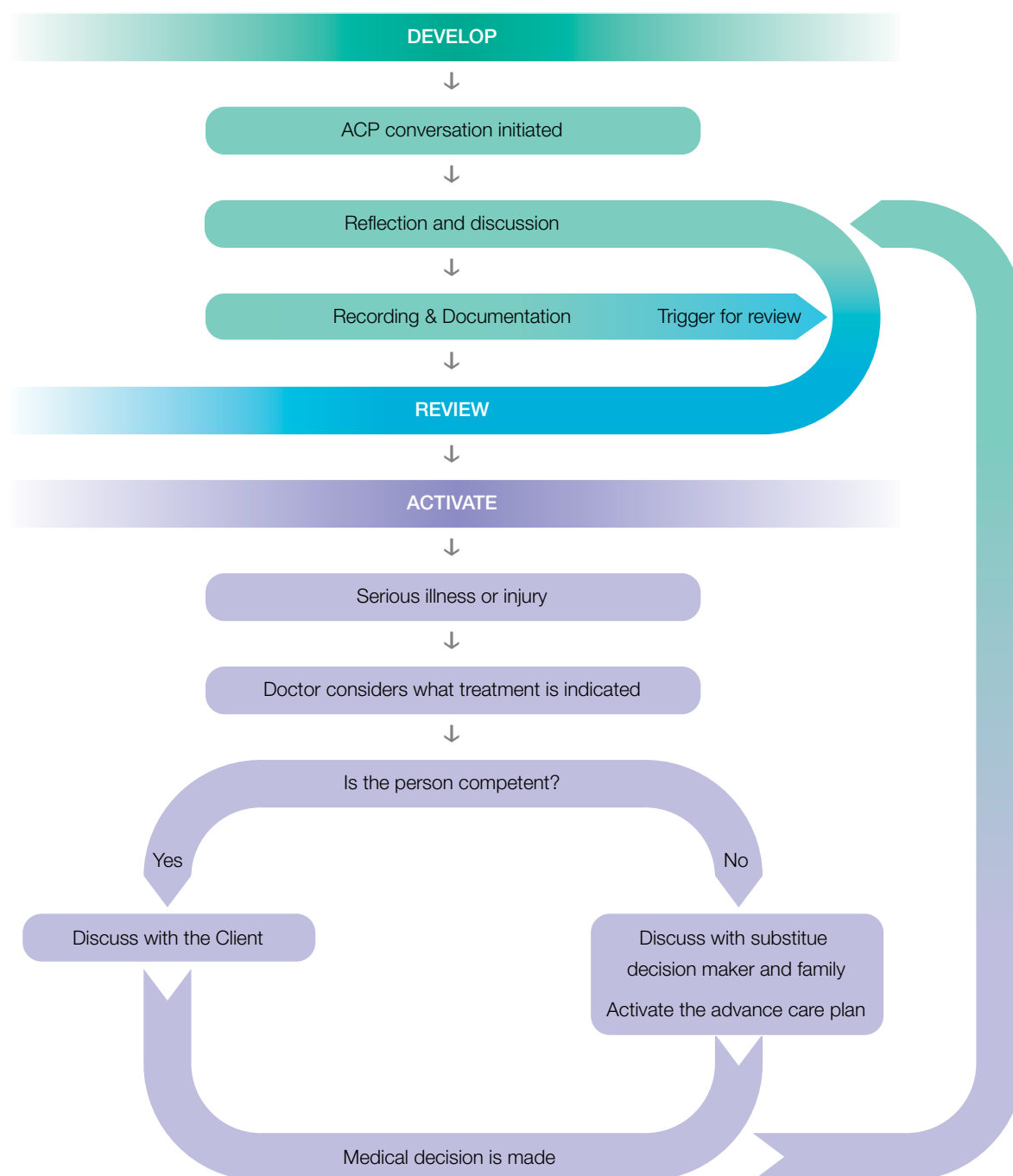
Physicians seem to wait until the patient begins deteriorating medically. Instead physicians should consider moving conversations closer to diagnosis and initiating conversations while the patient is doing comparatively well, so the patient has time to plan for more difficult times in the future.

Mack 2012

The following flow chart and guide illustrate the dynamic nature of the advance care planning cycle and steps through the phases of developing, reviewing and activating a person's advance care plan.

Figure 2: Advance care planning and decision-making process

Note: SDM refers to substitute decision maker.



DEVELOP**Develop – having an advance care planning conversation****When**

Ideally advance care planning discussions will take place when the person is medically stable, thinking clearly, comfortable and has had time to adjust to changes in their condition or prognosis. However, these discussions frequently need to take place in the context of serious medical illness. Advance care planning can be developed, built upon and reviewed over time.

Who

The plan should be discussed between the person, their substitute decision maker, their family and relevant clinicians involved in the person's care.

How

1. There's no better time than now to *have the conversation*.
2. Prepare to give the discussion your full attention. Where possible choose a private, quiet space, and allow time. Turn your phone off or on silent if this is possible.
3. Find out about the person's past experience of illness and what they understand about their current condition. Identify any gaps in their understanding of their condition and ensure relevant information is provided.
4. Clarify the person's concerns and expectations.
5. Introduce the purpose of advance care planning and provide written information and documentation on advance care planning that the person can take away.
6. Describe possible outcomes of the advance care planning conversation such as:
 - the appointment of a substitute decision maker
 - documentation of values and preferences.
7. Check back with the person about their understanding of advance care planning and the possible outcomes.
8. Aim to involve the substitute decision maker in all discussions. This could be by telephone if they are not able to be present at the time of the discussion. If this is not possible encourage the person to inform others about their advance care plan so that all clinicians and family members involved in the person's care and medical decision making are aware of their preferences.
9. The advance care plan belongs to the person. They will keep the original documentation. Tell them that the record of the conversation and/or advance care plan will be kept in the medical record and how it will be used. Encourage them to provide a copy of the advance care plan to their substitute decision maker, family members, general practitioner, other treating clinicians and their local hospital.
10. Ensure the person is aware that they can change their advance care plan and build upon it at any time.

DEVELOP

Record the conversation

How

1. Document advance care planning discussions in the person's clinical record in the designated location (such as the legal section or the advance care planning discussion record).
2. Document the advance care plan using clear and unambiguous language that is easily understood. This should ideally be done with the person, in their own words, making sure that it will be clear to a clinician who reads the document in the future.
3. Document the person's values, preferred outcomes and medical treatment preferences using for example
 - a template developed by health services or peak bodies (see www.health.vic.gov.au/acp for relevant links)
 - a free-form letter (see Part 3, strengthening the validity of advance care plans).
4. Identify the substitute decision maker.
5. If the person chooses, use the legislated forms to:
 - appoint an enduring power of attorney (medical treatment)
 - complete a Refusal of Treatment Certificate.
6. Give the original advance care planning documents to the person.
7. Place an advance care plan alert in their physical and/or electronic medical record.
8. Place a copy of the advance care plan in their medical record in the designated location.
9. Ask the person to make sure the substitute decision maker has copies of the advance care plan.
10. With the person's consent ensure that other treating clinicians, including their GP or residential aged care facility and other relevant family members, are provided with copies of the advance care plan.



REVIEW

Review an advance care plan

When

Review of advance care planning can be undertaken at any time. This is important because people refine their goals for treatment and care during the course of their illness (Michael et al. 2013).

An up to date advance care plan also makes it easier for clinicians to assess its validity.

A review may be initiated by the person or could be prompted at key times in the person's illness trajectory, including the following situations:

- The person has been hospitalised for a severe progressive illness.
- There has been a change in the person's condition, or the person experiences an unstable phase of an illness.
- The person says they want to refuse life-sustaining treatment.
- The person or family enquire about palliative care.
- There has been a medical decision not to provide certain interventions.

Who

The plan should be reviewed with the person, their substitute decision maker, their family and relevant clinicians involved in the person's care.

How

1. Clarify what has prompted the review.
2. Use the pre-existing advance care plan to guide discussions.
3. Ask the person about any changes to their current condition, treatment plan or quality of life and whether this changes anything in their advance care plan.
4. Identify any emerging gaps in the person's understanding of their condition and ensure relevant information is provided.
5. If they wish, help the person revise their plan, and confirm any changes to goals and treatment preferences. Make sure the revised advance care plan is clearly dated.
6. Give the person their updated plan and ask them or help them to provide copies to the nominated substitute decision maker, the family, treating team and other services promptly.
7. Update advance care planning alerts and documents in the medical record promptly.

ACTIVATE

Activate the advance care plan

When

When the person cannot be directly involved in decision making because of lack of capacity or inability to communicate.

Who

This will involve all clinicians linked to the person's care, both internal and external to the health service, in collaboration with the nominated substitute decision maker and/or family.

How

1. Access the person's medical record and locate their advance care plan.
2. Enquire about whether an advance care plan exists elsewhere (such as with their GP, nursing home or family).
3. Locate the advance care plan. It could be a standard form, a letter, a Refusal of Treatment Certificate or in another format. It could be located in the medical records, with the GP, with the substitute decision maker or the custodian could be identified on the person's eHealth record.
4. Contact the appointed substitute decision maker such as enduring power of attorney (medical treatment).
5. Involve the person as much as possible in the decision-making process, even if they do not have legal capacity to make a specific decision.
6. Discuss the advance care plan with the appointed substitute decision maker and treating team and use it to guide decision making.
7. Interpret and include the person's expressed values and preferences in their clinical care and medical treatment plan.
8. The medical practitioner should make decisions about what medical treatment is offered. The substitute decision maker consents or does not consent to treatment based on what is in the person's best interest and supported by the person's advance care plan.
9. In the case that a person does not have a substitute decision maker and the advance care plan is clear and unambiguous, the medical practitioner would document a decision consistent with the advance care plan in the medical record. Contact OPA for information about obtaining consent for treatment.
10. Communicate with the GP, nursing home and other people involved in the person's care (such as through a treatment or discharge plan).

Having the conversation: some words you can use

Here are some phrases that might be helpful in conversations about advance care planning (based on Oncotalk 2013).

Conversations starters

‘I try to talk to all my clients about what they would want if they become more unwell. Have you ever thought about this?’

‘We are working hard to help you get better. While I hope for the best, some of my clients want to also prepare if treatment does not go as well as expected. I wonder if you have ever thought about this?’

‘As you think about the illness, what is the best and the worst that might happen?’

Introduce the topic of care and treatment preferences

‘If something should happen and you could not talk to me at the time ...’

‘Have you thought about if things don’t go well?’

Open the discussion for individual quality of life priorities and goals of care

‘What is important for you to live well?’

‘If life proves to be shorter than expected or we would like, what are the things that are important to you and what would you like to achieve in this time?’

Appointing a substitute decision maker

‘If something should happen to you and I could not talk to you about it in more detail, who would you want to help me make these decisions?’

‘Who would you like to make decisions for you if you become very unwell and cannot make them for yourself?’

‘Would this person know what you would want?’

To close

‘I want to thank you for helping me understand your values and goals. Have you talked to anyone else about these issues?’

‘I want to thank you for helping me understand your position if you should get more unwell. It has been very helpful to me. I know that in the past, you have not given this very much thought. Would you be willing to think a bit more about what we spoke about today so we can talk some more at your next visit?’



Case study: Zoe calls the shots

As part of Zoe's care, her Transition Care Program case manager helped her to develop an advance care plan. They had already had some preliminary discussions and were delving deeper into Zoe's preferences. Zoe's daughter, Lynne had made sure she was available so that she could understand what her mother would want.

Zoe was delighted to list all the things she didn't want: no antibiotics, no transfusions, no IV hydration, no mechanical ventilation and no tube/stomach feeding.

Her case manager asked about whether she would want comfort care?

'You mean pain meds to make me feel good? Yep, I'm for that!'

The discussion was progressing easily. 'We both know everything about what I want,' said Zoe and Lynne nodded in agreement.

However when asked what she would like when death is imminent, Zoe responded, 'I want to die alone.'

This came as quite a shock to Lynne who had always imagined being at her mother's side, holding her hand and listening to sounds of the ocean. When Lynne shared this, Zoe was very surprised. Zoe's assumption, and fear, was that would be a burden for Lynne. This was something she wanted to avoid for her daughter.

Lynne explained to her mum that she felt being with her would be supportive and add closure.

Zoe tearfully held her daughter's hand and said, 'I had no idea you felt like that.'

For the case manager this reaffirmed the importance of having the conversation with the person and those close to them.

Zoe then added that she wanted music, sounds of the ocean, and people who could support Lynne. Both Lynne and Zoe expressed gratitude that Zoe's explicit wishes were well-documented.

Zoe was so excited to take her document with her. She relished that it belonged to her and that – to use her words she had 'called the shots'.

Message

For Zoe and Lynne the dialogue with each other was important. Having the conversation clarified and created deeper and a more accurate understanding of what was important to them. Creating an advance care plan was very empowering for Lynne. The Transition Care case manager facilitated the discussion as part of her role.

Working as a team

The delivery of advance care planning at the clinical level works best when it is seen as a team responsibility, with each team member having a clear and shared understanding of their role.

Senior clinicians (medical, nursing and allied health) and health service executives play an important role in establishing clear expectations, processes and practices for advance care planning and support for communicating decisions about treatment.

The role of the multidisciplinary team in advance care planning

Clinicians at the frontline of care balance the timeliness of interventions, client involvement and consent, and decisions about ceasing or not initiating treatment.

All clinicians (medical, nursing and allied health) can contribute to advance care planning. There are considerable benefits to using the skills of a multidisciplinary team in the communication, development and review of advance care plans. A multidisciplinary team approach can:

- allow staff to contribute information about treatments and interventions based on their area of expertise
- break the task into manageable components
- provide a 'sounding board' for problem solving complex issues and checking appropriate communication approaches
- ensure staff are working within their areas of competency in translating wishes and values expressed in an advance care plan into a clinical treatment plan.

Senior medical practitioners have a clear leadership role within the multidisciplinary team to provide advice and evaluate the overall impact of treatment on prognosis and wellbeing.

This is important to ensure that values and wishes expressed by the person are reflected in medical treatment plans and communicated to the treating team. It is also particularly important when deciding to cease treatment. This is guided by the bioethical principles that follow.

Bioethical principles provide the foundation for medical practice

The role of doctors in promoting partnerships with people, their families and clinical treating teams to improve and maintain health is supported by the bioethical principles used in medicine for centuries (*AMA code of ethics 2006*). These are:

- **autonomy** – respect the right of an individual to make their own decisions with regard to their own health and future. Respect for autonomy is a component of respect for human dignity
- **beneficence** – the duty to do the best for the individual or to act in the best interests of the person, for example to undertake actions that are intended to benefit the person (to do good)
- **non-maleficence** – the duty to do no harm to patients or others
- **justice** – incorporates the notions of equity and fair distribution. This ethical principle emphasises that clinicians have responsibility to the wider community as well as to individual patients.

These fundamental bioethical principles of medicine along with the general ethical virtues of trustworthiness, respectfulness, integrity and compassion will guide a clinician's relationship with their client and support a clear decision-making process.

Having the conversation: some specific situations

Care that is not in the person's best interest

Medical intervention that causes suffering may be acceptable to the person if there is ultimately some benefit to their prognosis or health status, or if it permits them to achieve some other valued goal.

However, treatments or investigations that cause suffering to the person should be avoided when there is clearly no benefit to be gained.

Non-beneficial treatment is the continued provision of medical treatment where there is no real benefit or potential for cure. Deciding whether a treatment or intervention is non-beneficial is complex and multi-factorial.

Decisions need to take into account the person's condition and circumstances. Non-beneficial medical interventions can cause considerable suffering and have little or no benefit in improving a person's prognosis or health status.

To do everything possible just because it is possible, without regard to the patient's goals, values and wishes, is ethically unsound and not good medical practice. There is a growing call ... to realign medical treatment with people's well-informed and realistic expectations.

Silvester and Detering 2011

There is no obligation to provide non-beneficial treatment and such treatment cannot be demanded by the person or their family (Skene 2004 in Murphy 2008; Skene 2008). It is important, however, to clearly communicate to the person, or the nominated substitute decision maker and family of the non-competent person, the reasons behind decisions not to provide, or to cease treatment.

Communication about treatment or poor prognosis at key decision-making points in the care pathway is particularly important.

Honest and open discussions about poor outcomes should be held with the person and their family without using the term 'futile'. This should be avoided because:

- it is a highly subjective term which can be used powerfully by doctors and it is hard to refute by the person or family
- it can be influenced by the clinician's own values
- has negative connotations including the unintended implication that the person, rather than the condition, is not worth treating and is therefore 'worthless'
- its meaning is ambiguous and open to misinterpretation.

Using language that describes the treatment as 'not being beneficial', 'overly-burdensome' or 'not in the person's best interests' enables clinicians to provide a clear message that the decision is about the effectiveness of the treatment, not the person's worth. This approach is also consistent with doctors' common law duty to act in the person's best interests.

When medical decisions are made to cease treatment that is no longer providing benefit to the person, there should be full consultation with the person and their family. People may require additional time to come to terms with the limitations of treatment, reduced quality of life and prognosis.

The question is never whether the patient's life is worthwhile but whether the treatment is worthwhile.

Duggan 2003

Case study: Demanding treatment

Louise was riding her bike on the way to the shopping centre when a car door was opened in front of her. This caused her to fall off her bike and subsequently into the path of a passing car. She was taken to hospital with severe injuries and was placed on life support.

After some time the treating team determined that she was brain dead and proposed to turn off the life-support system as she would not recover.

Louise's husband Damien could not believe that she was dead and demanded that the life-support system be left on until she had a chance to make a proper recovery.

The hospital adhered to the relevant protocols and guidelines and allowed an independent second opinion to verify that Louise was brain dead. Damien was grief-stricken and continued to demand treatment.

The treating team took the time to sit with Damien and discuss his concerns. They gently explained that the medical treatment was not beneficial. While devastated about the loss of his wife, Damien came to understand that the treatment was only giving the illusion of life.

Damien and Louise's parents were by her bedside when the life-support system was turned off. While devastated at losing Louise, they understood and were comfortable with the medical decision that had been made.

Message

Communication with Louise's family is critical to managing the situation; but a person, or anyone on their behalf, cannot demand treatment that a doctor considers to be of no benefit.

Palliative interventions and end-of-life care

A decision to not offer, or to cease, treatment is **not a do-nothing option**. It is a trigger to initiate palliative care discussions with the person and their family about providing symptom management, comfort measures with a focus on quality of life, and support through the continued provision of skilled medical, nursing and allied healthcare.

Palliative care interventions may also be compatible with some life-prolonging treatments. Receiving palliative care does not necessarily require ceasing all treatment aimed at prolonging life.

Six questions a doctor should think about and sensitively explore with a person who has a progressive life-limiting illness

1. Do they know their prognosis?
2. What are their fears about what is to come?
3. What are their goals?
4. What would they like to do as time runs short?
5. What trade-offs are they willing to make?
6. How important is it to them to have more time?

Atul Gawande 2010

While decisions to cease treatments need to be clearly considered and communicated, so does the message that compassionate and expert care is going to continue for the person.

Care at the end of life is not just about making decisions to cease specific treatments. The provision of effective end-of-life care requires the delivery of specific care interventions delivered by skilled clinicians.

End-of-life care includes:

- ensuring the person is involved in decisions about their care as far as they are able
- end-of-life discussions with the client and the family to provide support and education about end-of-life and bereavement support
- spiritual care
- initiating observations for common end-of-life symptoms such as restlessness, pain, nausea and breathlessness in order to provide timely symptom management
- reviewing and ceasing all non-essential medications and interventions
- impeccable assessment and treatment of symptoms.

Doctors often tell me that they don't have the time to engage in discussions with their patients about advance care planning, but I'm concerned that they use this as a reason to cover underlying discomfort in having these discussions, and not knowing how to bring these matters up with their patients.

Palliative care consultant, Melbourne Health

Examples of alternative advance care plans

Notes in advance care plan discussion record

03.09.13 Advance care plan information

Introduced advance care planning and provided David with brochure. David said he will think about advance care planning over the next few weeks. In particular he mentioned that he would **not** like to die as his partner had died – in ICU and with lots of machines and tubes.

Ward Social Worker

01.10.13 Advance care plan information

Asked David who he would want to speak on his behalf if he becomes too unwell to speak for himself. He mentioned that he had previously had some discussions with his family, but is worried that when the time comes his mum will want him to continue all treatments.

David **chose to appoint his sister, Brenda, as his enduring power of attorney (medical treatment)** as he felt that she would respect his wishes and be strong enough to refuse treatment on his behalf. Documentation completed (see copy of documentation in legal section). David has original and certified copy to give to sister. Copy sent to David's GP.

HIP care coordinator

24.10.13 Advance care plan information

David expressed that he was feeling reassured to have appointed his sister as his enduring power of attorney (medical treatment). Questioned David about whether his sister would know what he would want if she needed to make a decision on his behalf. David hasn't discussed this with his sister. David **expressed that he would not like to die in ICU with extensive use of machines. He was concerned about how pain will be managed and said this was a priority. He would like to stay at home for as long as possible.** He said that he will discuss this with his family, especially his sister. David reported that being able to talk about his fears has enabled him to see that he can still have some control in the later stages of his illness. Will discuss completing advance care planning documentation at next visit on 08.11.13.

HIP care coordinator

Message

An advance care plan can be developed over a period of time.

Everyone can contribute at different points to this process.

Information about the person's preferences needs to be captured in an agreed, readily accessible place.

Elements of an advance care plan in a medical record should be noted by an advance care planning alert.

A letter as an advance care plan

28 March 2013

Dear family

As you are aware, the doctors have told me that I probably have only three months to live. I have lived a wonderful and fulfilling life, my family being my greatest treasure. To know I will only be with you for a few more months fills me with sadness.

However being a nurse I have seen many people die in drawn-out circumstances with significant pain, discomfort and enduring countless medical procedures. I want you to know that this is not the death I want for myself.

It is important for me to stay at home for as long as possible, however if it becomes too hard to care for me I understand that I may need to go to a hospice or hospital. If I do go to a hospice can you please make the room as homely as possible for me? Decorate it with some of my books, photos of my family and friends and items from my dressing table.

I would only like medical treatment that relieves symptoms or reduces my pain. I do not want medical treatment just to prolong my life. I have discussed this with both my oncologist and GP.

I would like you all to be involved in discussion about how to care for me. However I have asked Jenny to make medical decisions on my behalf. This is because Jenny has had a lot of experience negotiating and advocating through her job. I understand that this is a very hard time for you too. I hope you can understand my wishes and do what you can to support them.

I am also providing a copy of this letter to my GP, oncologist and local hospital so that they also know what these wishes and preferences.

My love always,

Carmen

CC GP, Oncologist, local hospital.

Message

Carmen has clearly indicated her wishes for future care and these need to be considered by clinicians.

While the letter can stand alone as a form of advance care plan, discussing it with the treating team and the doctor providing a supporting letter (such as the one that follows), provides further depth and context for understanding Carmen's wishes.

A doctor's letter as an advance care plan

2 April 2013

Re: Anh

Dear Dr Black,

I am writing this letter to document a discussion that I have had today with Anh and her daughter Hien. Hien is Anh's substitute decision maker (enduring power of attorney (medical treatment)).

Our discussion addressed Anh's deteriorating lung function, which is now quite limiting. She is unable to do much around the house and is breathless at the least exertion. The oxygen has not helped much.

Given the precarious situation we discussed what to do in a crisis, which I fear is imminent.

Anh is clear that she does not want to be 'saved' to continue to deteriorate but is very concerned about being frightened and unable to breath.

We discussed a plan to aggressively treat any breathlessness with morphine and she was much relieved by this. If it is possible she would like to stay in her own home when her lungs fail but if this is impractical she is happy to go to the local hospital where most of her family will be close. She does not want to be transferred to a larger hospital.

Hien participated in today's conversation and was understanding of her mother's medical situation and her wishes.

I think this is a very reasonable plan given her advanced and relentlessly progressive lung disease that has responded poorly to treatment.

I would be pleased if you can implement this plan for Anh when appropriate.

With all best wishes,

Respiratory physician

Cc Anh, Hien

Message

An advance care plan may take a variety of formats.

Documentation of a discussion between the doctor, the client and the substitute decision maker (the three key participants) can be a very effective way of developing an advance care plan as it conveys the messages of discussion, consensus formed and confirms that the medical prognosis has been considered.

Having the conversation with people with different needs

Health services have a responsibility to develop appropriate communication and information strategies that meet the needs of key groups in our community. Working with people with diverse needs may require a modified approach to advance care planning.

Health services with a philosophy of person-centred care will understand the importance of listening to the person and their carers in order to understand and respect their wishes and needs. Clinicians must be aware of their own personal attitudes, assumptions and stereotypes and ensure these do not influence the discussion. This will assist in genuinely understanding the values and wishes of the person as they develop their advance care plan.

This section only briefly touches on the importance and complexity of understanding and responding appropriately to people with different needs.

People from culturally and linguistically diverse communities

More than a quarter of Victorians were born overseas and come from over 200 different countries. Clinicians need to be open to learning about and understanding different attitudes and cultural practices towards healthcare, communicating with doctors and discussions about end-of-life care. Many people, including those from non-Western cultures, consider the broader social network as the basis for treatment decisions, rather than focusing on the needs of the individual.

The communication of 'bad news', decision-making roles, attitudes towards advance care plans and end-of-life care vary culturally (Hickman et al. 2005; Winzelberg et al. 2005; Searight and Gafford 2005). This will impact on the process of advance care planning.

People delegate medical treatment decisions for a variety of reasons (Hickman et al. 2005; Winzelberg et al. 2005), and for many the preference is that these decisions are made by people they trust such as family and doctors.

It is most important not to make assumptions about a person's cultural differences regarding how decisions are made or whether to include the person, or their family, in discussions or providing information. There is as much variation in values, beliefs and practices within cultural groups as there is between groups. The safest, most respectful and most person-centred approach is to ask the person, either directly or through an independent, accredited interpreter.

Health services need to work in partnership with culturally and linguistically diverse services to develop appropriate culturally sensitive information and ensure access to qualified and trained healthcare interpreters for advance care planning conversations.

The Ethnic Communities' Council of Victoria has produced a policy paper with recommendations for enhancing health literacy in culturally and linguistically diverse communities published in *An investment not an expense: enhancing health literacy in culturally and linguistically diverse community* (2012).

Case study: *Avere la conversazione with Angelo*

Angelo, an 80-year-old Italian man with Parkinson's disease was referred for advance care planning. Angelo was a single man, never married, with no children, and no other family. When I met with Angelo, he gave me three handwritten pages outlining all the treatments that he wanted the doctors to give him, should he be unable to communicate with them in the future.

On speaking with Angelo, it was clear that he was very concerned at being 'written off' as a sick elderly man with no family and nothing to live for. His 'list of priorities' was his effort to protect himself from a fear of medical neglect, especially as he had no family to advocate for him.

Further discussion revealed a strong faith and firm belief in the sanctity of life. Angelo felt it was his duty to accept and have all treatment and that anything less would be contrary to the expectations of his beliefs. For Angelo, life, even with significant disability, was still a valuable life. We chatted about how some treatments may not be offered to some people as they would not bring any benefits to that person.

I suggested he speak to his local doctor, whom he had known for many years, about the sorts of treatments that may be suitable for his condition. He also visited his parish priest to talk further about the expectations of the church and their faith.

Over the next few weeks, Angelo modified his list of demands. He appointed his parish priest as enduring power of attorney (medical treatment). He wrote an advance care plan in the form of a letter to his priest which described how they shared the same belief system and that he trusted his priest to make the decisions he would have made for himself. The local doctor was a witness to the advance care plan, and Angelo felt confident that he would be treated as he would have chosen for himself, and more significantly, he would be fulfilling the requirements his religion required of him.

Message

Advance care planning was important for Angelo because he did not have a family member to act as a substitute decision maker if he could no longer fully participate in decisions. By planning ahead he was able to appoint his parish priest to be his decision maker. Because the priest understood Angelo's values, Angelo felt that the priest would make the decision that he would have. He, therefore, did not need to make an extensive list of treatments that he did or did not want.

Aboriginal and Torres Strait Islander Community

Communicating about advance care planning can be a sensitive issue for Aboriginal and Torres Strait Islander people. Discussions about end-of-life care can be challenging given the spiritual, cultural and community sensitivities about dying. Gaining trust and acknowledging these issues is important before beginning discussions about advance care planning with Aboriginal and Torres Strait Islander people.

Providing a culturally safe environment in which to have a conversation about advance care planning is an important consideration when working with Aboriginal and Torres Strait Islander people. This may include the involvement of family (not necessarily genetically related), carers, friends and community members as well as the use of culturally appropriate resources such as the use of art work, music and storytelling.

Use of formal cultural awareness programs is recommended to train staff working with Aboriginal and Torres Strait Islander people. Aboriginal hospital liaison officers may be available to provide support and advice about how to work with Aboriginal and Torres Strait Islander people in a culturally safe and responsible manner. Generally speaking Aboriginal and Torres Strait Islander community members are the most appropriate people to begin and, hopefully, complete advance care planning discussions and documentation. Aboriginal community members employed in health and support programs may be well placed to do this. Consultation from clinicians with expertise in advance care planning is likely to be of benefit in addition to the provision of good clinical support and good information on clinical processes and expected outcomes.

Other resources include:

- *Advance care yarning* (SA Health 2006)
- *Taking control of your health journey* (Austin Health for the Victorian Aboriginal Palliative Care Program auspiced by the Victorian Aboriginal Community Controlled Health Organisation 2013)
- *Providing culturally appropriate palliative care to Indigenous Australians* (National Palliative Care Program for the Commonwealth Department of Health and Ageing 2004)
- *Palliative care: it's the beginning of your health care dreaming* (jointly developed by Palliative Care Victoria and VACCHO).

Case study: Dhumba-djerring (talk about it – Wurundjeri)

Aunty Sue is a 55-year-old Aboriginal woman living in an inner-Melbourne suburb. She is widowed with four children, and a number of grandchildren. Recently, Aunty Sue was advised that her diabetes had progressed to chronic kidney disease and she would therefore need to be dialysed at least once per week, possibly more.

The Aboriginal hospital liaison officer (AHLO), who usually assisted Aunty Sue with her appointments, introduced the concept of advance care planning. Initially Aunty Sue was uncomfortable with the topic, so the liaison officer suggested she take some time to think it over and have a 'yarn' with her family. He gave her the Taking control of your health journey booklet to take home.

The following week, accompanied by her daughter, Aunty Sue returned to the hospital for an appointment. The AHLO broached the subject of advance care planning again. Aunty Sue replied, 'My daughter is going to be my medical power of attorney'. The AHLO helped Aunty to fill in an enduring power of attorney (medical treatment) and the early foundations of her advance care plan were recorded. These included her definitions of quality of life and outcomes that would be acceptable to her.

Her daughter was given a copy of the documents. Her family now feel more involved and have greater confidence that in the future their mum will receive the healthcare she would like.

Message

Aboriginal hospital liaison officers have an important role in facilitating advance care planning conversations within the Aboriginal population. Specific information about advance care planning for Aboriginal people is available.

People with mild cognitive impairment

My end of life wishes should be discussed while I can still make decisions. I should have a say about how I spend my final days, so my end of life care wishes should be discussed with me while I can still make decisions.

I should have a say in the care and support that I am given.

I have a voice and should have a say in the care that I am given, for as long as I can.

Global Dementia Charter

Alzheimer's Disease International and BUPA

Advance care planning is best done when a person has sufficient cognitive function to understand the decisions they face. Clinicians need to offer clients with mild cognitive impairment the opportunity to discuss their wishes as early as possible, before further decline limits their ability to participate.

A person with dementia should not be assumed to lack decision-making capacity, however their capacity will fluctuate and decline over time. Clinicians need to tailor their approach to align with the person's cognitive abilities, including concentration.

Advance care planning when undertaken in the early stages of dementia, provides a means of clarifying values, beliefs and preferences so that they can be respected and supported in decision making at a later time. It also enables the person with dementia to appoint a substitute decision maker while they still have capacity to do so.

Case study: Signs of memory loss triggered Peter to have the conversation

Peter attended a memory clinic with his wife, Josie, after they had noticed him experiencing some memory loss problems. This confirmed a diagnosis of a fairly rapid form of dementia. As part of their discussions, the memory clinic clinician asked if he had appointed a substitute decision maker. He had previously appointed his wife to be power of attorney (medical treatment). However when asked if Josie would know what would be important to him in making future decisions they both acknowledged that they had never really talked about this.

The clinician helped Peter to identify his values and preferences for future treatment. He explained that what mattered to him was living with his wife, going for regular walks and being active in the garden. He reflected on his own father's long deterioration which included behavioural issues. He said he would welcome an exit instead, if it was appropriate. He was assisted to document an advance care plan.

Over the next year, Peter was hospitalised following a fall and had the chance to review and update his advance care plan.

Eighteen months after he had created his advance care plan, Peter died. He had a peaceful death at home with his wife beside him. As per his advance care plan, Peter received palliative care, and was not transferred to hospital for life-prolonging treatment.

A few months after his death, Josie contacted the memory clinic to express her gratitude. She was grateful that Peter had been given the opportunity to voice his wishes and have ongoing discussions as his condition deteriorated. This provided peace of mind for his family knowing he died as he wanted to.

Message

It is important that people with memory loss are offered help and assisted to partake in advance care planning early, even before a definitive diagnosis.

Substitute decision makers can have more confidence in the decisions they make if they have had discussions about values, preferred outcomes and wishes for future care with the person they are representing.

People with an intellectual disability

Advance care planning discussions need to involve the person to the best of their ability and take into account their capacity to make their own care and treatment decisions. The appointed substitute decision maker or guardian and other support people should be included in these discussions (Bigby, Bowers and Webber 2012). All explanations should use plain language and provide sufficient time for communication to be effective.

Advance care planning discussions will be most beneficial if undertaken well before there is an acute medical crisis or end-of-life planning. Depending on the situation, the person's disability support provider may be in the best position to lead these discussions with input from health services and other clinicians so that decisions are fully informed.

National Disability Services hosts a website <<http://fl3150.sky.flip.net.au/>> which has resources to support people with intellectual disability who are ageing. This provides information on end-of-life care and advocating for individual involvement in decision making.

Case study: Matthew chose to have the conversation

Matthew, a 27-year-old man with cerebral palsy and mild intellectual disability, had been in hospital for many months following orthopaedic surgery. Matthew had spent a total of many years in hospital for various medical conditions, and was now awaiting supported accommodation as his family circumstances meant he could not return home. Having spent so long in hospital this time, he had developed a close rapport with some staff members, but remained suspicious and distrustful of others.

Matthew had overheard a doctor talking to an elderly person about 'not doing resuscitation if his heart stopped beating' and he became worried he might not be resuscitated because of his disability.

I met with Matthew over a number of weeks, for an hour at a time. We talked about his family, who he was not close to, and his friends who enjoyed art and music as he did. Matthew talked about how music makes him feel calm when he is sick and that art makes him feel inspired and happy.

He was worried that when he left hospital and went to supported accommodation that no one would know him well, and if he got sick again, they would not actively treat him. Although Matthew was not able to appoint a substitute decision maker, he wrote an advance care plan. He wrote about his love of art and music. He wrote, 'I am an adult and I am making decisions for myself'. He stated he would like resuscitation if it was needed.

Message

People with intellectual disabilities have opinions about the extent and nature of the care and treatment they receive should they become unwell and need to be supported to partake in decision making as much as possible. Advance care planning can be used by anyone to advocate for maximum, not just minimum treatment. Documenting what is important to a person, provides the clinician activating the advance care plan with a context for the preferences they have indicated.

People with mental health conditions

People with long-term mental health conditions are at higher risk of developing physical health conditions (Lawrence et al. 2013). Likewise people with chronic medical conditions are more at risk of developing mental health conditions (Clarke 2009).

Advance care planning in general health gives all people, including people with a comorbid mental illness, the opportunity to appoint a substitute decision maker and express their values and preferences for future care related to their physical health conditions. This would be activated when the person does not have capacity to make decisions about their treatment and care, but is not requiring compulsory mental health treatment.

For information relating to how a person with a mental illness can record their treatment preferences if they become unwell and require compulsory mental health treatment, refer to <www.health.vic.gov.au/mentalhealth/mhactreform>.

Children with life-threatening conditions

The department's Strengthening care for children with a life-threatening condition: a policy for health, palliative care, disability, children's services and community care providers 2008–2015 outlines the principles that underpin care for neonates, infants, children and adolescents with a life-threatening condition, and their families and the relationships that are critical to providing care in an appropriate and timely way.

Principle one is particularly relevant to advance care planning.

It states:

- 'Children with a life-threatening condition and their families have information about options for their future care and are actively and appropriately involved in those decisions.'

The expected outcomes are:

- 'Children and their families are consulted about who is informed about their care and who makes decisions about their care.'
- Children are informed about, and involved in, making decisions about their care as appropriate to their age and developmental stage.
- Families of children with a life-threatening condition are informed about and involved in decision making about their child's care.
- The unique needs of the child with a life-threatening condition and their families are addressed through developing and implementing an agreed plan.'

A Child and Young Person's Advance Care Plan is designed to communicate the healthcare wishes of children or young people who have chronic and life-limiting conditions. It sets out an agreed plan of care to be followed when a child or young person's condition deteriorates. It provides a framework for both discussing and documenting the agreed wishes of a child or young person and his or her parents, when the child or young person develops potentially life-threatening complications of his or her condition. It is designed for use in all environments that the child encounters: home, hospital, school, hospice, respite care and for use by the ambulance service.

West Midlands Paediatric Palliative Care Network, NHS 2011

This strategy recognises the importance of advance care planning discussions for children with life-threatening conditions and their families but it does not specifically address this very complex area. A companion document will be developed in 2014–15 to support approaches to advance care planning to guide clinicians working with children and their families.

Part 3: How the law supports you to have the conversation





Part 3: How the law supports you to have the conversation

Advance care planning is implemented within Victoria's current legal framework.

- The *Medical Treatment Act 1988* enables a person to refuse all or some medical treatment for a current condition. It is also possible to appoint a person as a substitute decision maker who has the powers of enduring power of attorney (medical treatment).
- The *Guardianship and Administration Act 1986* allows a person to appoint an enduring guardian to make healthcare decisions on their behalf. The Act also allows VCAT to make a guardianship order for a person who is unable, by reason of a disability, to make reasonable judgments in respect of all or any of the matters relating to their person or circumstances, including healthcare and medical matters. The Act also sets out who can consent to medical treatment on behalf of a person who is unable to consent to the treatment themselves (the person responsible hierarchy).

Collectively this legislation enables substitute decision makers to be appointed to consent, not consent or refuse treatment if the person loses capacity. Advance care planning, which captures people's preferences for care and treatment, supports substitute decision makers to make decisions that are as close as possible to the one that the person themselves would have made.

The *Charter of Human Rights and Responsibilities Act 2006* requires that public authorities, including public health services, to act compatibly with and give proper consideration to human rights.

The following section provides a broad overview of some of the legal issues that may be relevant to advance care planning in Victoria. These include the principles of consent and capacity and how legislation might support treating teams to activate a person's preferences for care when they no longer have capacity to fully participate in decision making.

Please note that this section only touches briefly on what is a very complex area. While various scenarios relating to advance care planning are described throughout this section, each case has its own unique circumstances and must be considered in context. Health services are encouraged to seek their own independent legal advice in relation to advance care planning.

The Victorian Office of the Public Advocate <www.publicadvocate.vic.gov.au> can provide assistance to health services and resources related to advance care planning.

For example:

- an advice line is available (phone: 1300 309 337)
- an interactive program, *You decide who decides*, assists people to choose a substitute decision maker
- a support kit, *Take control*, helps with appointing powers of attorney.

Important considerations for clinicians

- A person has the right to refuse medical treatment in most circumstances.
- An advance care plan provides people with the opportunity to continue to express their wishes and preferences for future healthcare if they should lose capacity.
- The medical practitioner must usually seek the person's consent prior to carrying out medical treatment.
- A person's capacity to consent is assumed unless there are indications otherwise.
- The hierarchy of persons responsible can help you establish who the substitute decision maker is. The *Guardianship and Administration Act 1986* defines who a person responsible is. The substitute decision maker can consent to medical treatment when the person is not capable of doing so themselves.
- The Victorian Civil and Administrative Tribunal (VCAT) can appoint a guardian with the powers to make decisions concerning medical treatment, including the power to refuse treatment under the *Medical Treatment Act 1988*.
- An enduring power of attorney (medical treatment) also has the power to refuse treatment under the *Medical Treatment Act 1988*.
- A competent person can refuse treatment in relation to a current condition under the *Medical Treatment Act 1988* by completing a Refusal of Treatment Certificate. Likewise the person's enduring power of attorney (medical treatment) or VCAT appointed guardian can complete a Refusal of Treatment Certificate on their behalf if they no longer have capacity to do so themselves.
- An advance care plan will carry increased weight if it is documented using appropriate and clear language, is consistent, witnessed appropriately, dated, reviewed regularly and clearly relates to the current condition.

Capacity

As a general principle, a person with capacity can make decisions regarding medical treatment. Capacity is a legal concept and is recognised as a requirement for completing legal documents that prescribe future actions or decisions (AHMAC 2011). A person is assumed to have decision-making capacity unless there is evidence to indicate otherwise. Assessment of capacity should take place as close as possible to the time at which the decision is required.

A person with capacity should:

- know the decision facing them
- know the possible options
- know the reasonably foreseeable outcomes of the options available
- be able to understand the information, retain the information to the extent necessary, use or weigh the information and communicate the decision.

Competence or lack of competence can fluctuate over time. Competence relates to the specific issues, actions or decisions at hand. Despite reduced competence a person may still have sufficient decision-making capacity for the specific decision. Alternatively they may be able to contribute to making the decision. People should always be involved in decisions that concern them to the maximum extent possible. It is the responsibility of the clinician to actively ensure that the person is involved in medical treatment decision making as much possible. Even though a person may not have legal capacity to make a specific decision, they may still be able to express a view about what they want (Hope et al. 2003, p. 78).

People who are competent frequently refuse treatment, or fail to follow medical advice without their capacity being challenged. A person should not be regarded as lacking capacity merely because they are making a decision that is unwise or against their best interests. An unwise decision made by a person might alert a health professional to the need for a formal assessment of capacity. The assessment needs to focus on the way the decision is made, not a judgement about the decision itself.

Capacity assessment frameworks have been developed. The six-step capacity assessment model by Darzins and colleagues (2012) emphasises the need to work from a presumption of capacity.

Capacity assessment should primarily seek evidence of incapacity, and if this evidence cannot be found, the presumption of capacity should prevail. Under s. 36(2) of the *Guardianship and Administration Act 1986*, the legislative test for assessing incapacity to consent is as follows:

- ‘(a) the person is incapable of understanding the general nature and effect of the proposed procedure or treatment; or
- (b) the person is incapable of indicating whether or not he or she consents or does not consent to the proposed procedure or treatment.’

Capacity is relevant to advance care planning in its development and implementation.

People who have capacity can refuse treatment now or in advance and they can document this in an advance care plan.

Loss of capacity is the trigger to activate an advance care plan, including giving effect to a substitute decision maker, if appointed. If the person has capacity they will participate in decision making directly.

Identifying the substitute decision maker

Substitute decision maker is the general term for a person who is either appointed or identified to have authority to make medical treatment decisions on behalf of a person whose decision-making capability is impaired.

Depending on the situation a substitute decision maker may be either:

- formally appointed by the person under the *Medical Treatment Act 1988* in which case they would be referred to as **agent** under enduring power of attorney (medical treatment) (sometimes referred to as medical enduring power of attorney). Appointing an enduring power of attorney (medical treatment) is a highly recommended option in the process of developing an advance care plan.
- appointed for the person under the *Guardianship and Administration Act 1986*, in which case they are a **guardian**
- appointed by the competent person under the *Guardianship and Administration Act 1986*, in which case they will be referred to as an **enduring guardian**
- nominated as the person responsible according to the hierarchy identified in the *Guardianship and Administration Act 1986* (see below).

Person responsible hierarchy

The *Guardianship and Administration Act 1986* sets out who can consent to medical treatment on behalf of a person who is unable to consent to the treatment themselves (the person responsible hierarchy). The hierarchy is as follows:

- an agent appointed by the person under enduring power of attorney (medical treatment)
- a person appointed by the Victorian Civil and Administrative Tribunal (VCAT) to make decisions about the proposed treatment
- a guardian appointed by VCAT to make decisions about medical/dental treatment
- an enduring guardian appointed by the person to make decisions about medical/dental treatment
- a person appointed in writing by the person to make decisions about medical/dental treatment including the proposed treatment
- the person's spouse or domestic partner
- the person's primary carer, including carers in receipt of a Centrelink carer's payment but excluding paid carers or service providers
- the person's nearest relative over the age of 18 years, in the following order listed:
 - son or daughter
 - father or mother
 - brother or sister (including adopted and half siblings)
 - grandfather or grandmother
 - grandson or granddaughter
 - uncle or aunt
 - nephew or niece.

The first person who is available, willing and able to act in any given circumstances will be the person responsible. The person responsible can consent to or not consent to a medical procedure.



Case study: Person responsible consents to treatment

Helen is involved in an accident. She recovers consciousness but is very confused and disoriented. She has broken her hip and requires urgent surgery.

Helen is assessed as having a delirium and is not capable of making decisions about the proposed procedure. Therefore, it is necessary to seek consent from the substitute decision maker.

The substitute decision maker should make a decision in the best interests of the person – this includes taking into account the views of other family members and as far as possible giving effect to the person's wishes.

Helen's daughter Rebecca attends the hospital. She explains that she is Helen's only child and that Helen is widowed and as far as she knows has never appointed anyone to be her enduring power of attorney (medical treatment) or enduring guardian.

Rebecca is identified as person responsible as per the person responsible hierarchy. She consents to the hip surgery in her role as substitute decision maker as she believes it to be in Helen's best interests to do so.

Message

The person responsible hierarchy identifies the substitute decision maker who can consent to treatment.

The role of the substitute decision maker

The substitute decision maker's role is to 'stand in the shoes' of the person who lacks decision-making capacity, and to discuss medical treatment options as the person's representative.

The substitute decision maker represents the person to the medical practitioner. Their role is one of advocating for the person when planning medical treatment, based on what they know about the person – what is important to the person and what the person might have said or written about this decision or about medical care more generally.

The aim is for a shared understanding between the substitute decision maker and the medical practitioner about the person's best interests and the medical decisions that are consistent with this.

When making a decision the substitute decision maker must act in the best interests of the person for whom they are making decisions. This means they must take into account:

- the wishes of the person, so far as they can be ascertained
- the wishes of any nearest relative or any other family members
- the consequences to the person if the treatment is not carried out
- any alternative treatment available
- the nature and degree of any significant risks associated with the treatment or any alternative treatment
- whether the treatment to be carried out is only to promote and maintain the health and wellbeing of the person.

There will be times when medical treatment is offered but the person responsible considers it is not in the best interests of the person to consent to such treatment. It is only if the medical practitioner considers the decision not to have been made in the best interests of the person that it would be necessary to seek advice about whether and how to challenge the decision of the person responsible. If differences of opinion exist, resolution can often be achieved through sensitive and clear communication. This sometimes requires the involvement of more experienced colleagues. As a last resort the Office of the Public Advocate and VCAT can assist.

Consent

Informed consent is generally required prior to carrying out medical treatment. Medical treatment is defined by the *Medical Treatment Act 1988* as the carrying out of an operation, the administration of a drug or other substance, or any other medical procedure.

Informed consent is generally understood to mean the voluntary agreement by a person to a proposed health management approach after proper and adequate information in an appropriate format is conveyed about the proposed management, including potential risks and benefits and alternative management options.

The law supports the rights of adults with capacity to make decisions about what happens to them. For consent to be valid it must:

- be voluntarily given and not coerced
- cover the procedure undertaken
- be given by a person who has decision-making capacity (although presumption of capacity is assumed unless evidence of otherwise).

Case study: Emergency treatment

Amy is aged 77. She falls over on a slippery supermarket floor and is apparently unconscious. She is transported to hospital by ambulance.

Upon presentation to the accident and emergency department, she receives emergency treatment – insertion of cannula for administration of medication, diagnostic scans and so on.

Amy is not capable of providing consent as she is unconscious.

Message

It is possible to provide treatment without consent in an emergency.

When treatment is unwanted

A person's wish not to receive treatment can be respected in a number of ways. Whatever path is taken, clear sensitive communication will facilitate the person's preferred outcome and provide support for family and important others. *Having the conversation* is critical here.

People who are competent can refuse clinically appropriate treatment without their medical practitioner expecting them to complete a Refusal of Treatment Certificate. Likewise a person who does not have capacity may have treatment withheld because the substitute decision maker does not consent to this or their advance care plan clearly indicates that they would not have wanted the treatment being offered.

Additionally, the right to refuse treatment is reflected in the provisions of the *Medical Treatment Act 1988* which permits a competent person to make a Refusal of Treatment Certificate in relation to a current condition. The Act creates an offence of medical trespass if a medical practitioner provides treatment knowing this certificate is in place.

An enduring power of attorney (medical treatment) can also refuse treatment on a person's behalf if they lose capacity, subject to very specific criteria by completing a Refusal of Treatment Certificate. This would most commonly be undertaken to pre-empt a medical treatment that may be provided in a crisis for a known medical condition. Under the *Medical Treatment Act 1988*, a substitute decision maker may only refuse medical treatment on behalf of a person if:

- 'the medical treatment would cause unreasonable distress to the person; or
- there are reasonable grounds for believing that the person, if competent, and after giving serious consideration to his or her health and well-being, would consider that the medical treatment is unwarranted.'

A Refusal of Treatment Certificate cannot be used to refuse palliative care. The *Medical Treatment Act 1988* defines palliative care as including the provision of reasonable medical procedures for the relief of pain, suffering and discomfort or the reasonable provision of food and water.

Case study: Person does not consent to treatment

George is 46-years-old. He has motor neurone disease. As he was socially isolated he thought it was crucial to clearly express his wishes for future care. He has written a detailed advance care plan about the sort of treatment he is currently prepared to have and the treatment he does not want at a future point as his disease progresses. He has discussed this with his GP and specialists and provided them with copies of his advance care plan.

It is very clear that George does not want to be intubated or fed via PEG when he loses the independent capacity to swallow food and water.

In due course this does occur. As a consequence of not receiving nourishment, George loses consciousness and is no longer capable of making and communicating his wishes about medical treatment.

George's advance care plan about not being intubated and fed via PEG is clear and unambiguous. Therefore, the medical treating team are confident that they do not need to offer such treatment knowing that George, if competent, would have refused this.

Message

George's discussions with his treating team and his clear and unambiguous advance care plan assisted clinical decision making.

A Refusal of Treatment Certificate would have further protected George's right to refuse treatment.

It is not possible to refuse palliative care. Palliative care includes the reasonable provision of food and water. However, artificial nutrition and hydration are considered to be medical treatment – and it is possible to refuse such treatment.

Case study: Substitute decision maker does not consent to treatment

Jim is aged 87. He is admitted to hospital following a stroke. He also has a urinary tract infection and a range of other medical needs requiring attention. He is not capable of providing consent to any proposed treatment.

His wife, Anna, is asked to consent to him receiving intravenous antibiotics to manage the urinary tract infection and to intubation.

Anna says she will not consent to any treatment and explains that Jim would not want to continue to live in these circumstances and it would be kindest to him to let him pass away. She asks that he be treated palliatively.

The treating team do not consider that Anna is making a decision in Jim's best interests.

The social worker suggests that while seeking assistance from the health service's legal team, Office of the Public Advocate and VCAT is an option, inviting a senior consultant to review the situation may be useful. A senior consultant reviews the files notes, speaks with the treating team and talks with Anna about what she feels Jim would have wanted. The discussion better allows Anna to better understand what is being proposed and she consents to antibiotics to treat his urinary tract infection and prevent pain but not to intubate as that would be contrary to his wishes.

Message

It is the treating team's role to offer clinically appropriate treatment and it is up to the substitute decision maker to consent or not consent to treatment.

If Jim had developed an advance care plan, this would have provided additional clarity regarding his wishes.

Case study: Person refuses treatment

Geoff is a Jehovah's Witness. He is admitted to hospital to have a surgical procedure – a knee reconstruction.

It is not anticipated that it will be necessary for him to have a blood transfusion. However, in any surgical procedure it is possible that an emergency might arise, and this treatment might be necessary.

Geoff is adamant if there are complications during his surgery and it becomes necessary to have a blood transfusion that he will not consent to this. He completes a Refusal of Treatment Certificate Competent Person.

Fortunately, the surgery goes well and the issue of blood transfusions does not arise.

Given that the condition which led to Geoff completing the certificate has been resolved, the certificate no longer has effect. In order to ensure his wishes are respected in the future if any other medical crisis arises unexpectedly, Geoff should consider engaging in the same sort of advance care planning as George in the above scenario.

Message

The *Medical Treatment Act 1988* creates an offence of medical trespass if a doctor provides treatment knowing a Refusal of Treatment Certificate is in place.

Strengthening the validity of advance care plans

An advance care plan will be strengthened if it demonstrates that:

- it is consistent with the person's wishes
- the person has repeated these wishes regularly
- the person appoints a substitute decision maker who has a clear understanding of their wishes and is willing to be a strong advocate for them.

While there is no requirement for an advance care plan regarding future medical treatment to be documented, signed and witnessed, the lack of a written document will most likely give rise to genuine and reasonable doubts about validity and current applicability. This will cause uncertainty about its use in clinical decision making.

Accordingly, an advance care plan can also be strengthened by the following:

- It is a written document. It is important that clinicians give proper consideration to any written advance care planning document. When documented, an advance care plan may be recorded on an advance care planning template, a Refusal of Treatment Certificate, a letter or a medical record file note.
- There is evidence that when signed, the person was competent and not unduly influenced. Using witnesses may provide further support, as may the qualifications of a witness, for example, a doctor. When a doctor witnesses an advance care plan, it facilitates implementation of the person's instructions by health providers.
- It is reviewed regularly. A more recent advance care plan may be stronger because it provides more certainty about its currency.
- It relates to a current condition. An advance care plan that clearly contemplates the current clinical circumstances will reduce doubt about its applicability.
- It is appropriately worded. An advance care plan will be stronger if it avoids vague or imprecise language. For example, to say, 'I refuse life-sustaining treatment unless I can be sure of a reasonable quality of life' is very difficult to apply because the question of what is 'reasonable' will vary from person to person.

Adapted from <www.health.vic.gov.au/acp>

Victorian Civil and Administrative Tribunal (VCAT)

Lodging an application for guardianship with the Victorian Civil and Administrative Tribunal should only be made if matters cannot be resolved less restrictively. It is a last resort for families and friends who cannot agree on the best interests of the person. The Office of the Public Advocate telephone advice service can assist with exploring this.

If a medical practitioner thinks that the substitute decision maker is not acting in the best interests of the person they can consider contacting Office of the Public Advocate's advice service to discuss options, including making applications to VCAT.

VCAT also has jurisdiction under the *Medical Treatment Act 1988* to suspend or revoke an enduring power of attorney (medical treatment) or to revoke a guardianship order, which would have the effect of revoking a Refusal of Treatment Certificate completed by such agent or guardian

If a substitute decision maker cannot be identified Office of the Public Advocate can provide advice.

VCAT can be contacted on 03 9628 9900, or toll free on 1300 079 413 (country callers only).

If people have concerns about how health services respond to their advance care plan they should be encouraged to discuss this with their senior medical practitioners.

If the issue is not resolved they should contact the Health Services Commissioner by telephone on 1300 582 113 or by email to hsc@health.vic.gov.au.



Part 4: Getting your organisation ready to have the advance care planning conversation





Part 4: Getting your organisation ready to have the advance care planning conversation

This section identifies four priority action areas and associated measures to guide health services in the implementation of advance care planning. The measures listed in the following tables identify the steps that should be implemented over the life of the strategy.

Figure 3: Action areas



Being ready to have the conversation requires a paradigm shift centred around asking about and understanding what matters most to people. Organisational culture can both support and impede the implementation of advance care planning. Leadership at all levels of the organisation will be the key factor in ensuring the successful implementation of advance care planning.

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Priority action 1: Establishing robust systems so that your organisation can have the conversation

Organisations need to elicit and capture information about what matters to patients and their families about end-of-life wishes. This information should be treated with the same reverence – and recorded with equal reliability – as patients' medication allergies, for example, so that it can be reliably and easily accessed by all healthcare providers.

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Health service priorities	Action	Impact	Measure	Estab. Timeline	National standard
Create a shift in organisational culture and coordinate and monitor advance care planning within the health service setting through: <ul style="list-style-type: none"> • policies • governance • alerts • documentation • quality improvement. 	Institute an organisation-wide advance care planning policy that is endorsed by executive and clinical leaders.	People accessing Victorian health services will be offered the opportunity to undertake the advance care planning process.	Health service has an advance care planning policy.	Year 1	1.18.4
			Number of service policies reviewed for consistency with health service advance care planning policy.	Year 1	
	Health services work towards creating alert systems for advance care plans and provide access-related documentation.	People receive care consistent with their wishes and values as their advance care plans are readily accessed and/or reviewed when needed.	Advance care planning resources (for example storage sleeves and discussion record cards) are available in key clinical areas.	Year 1	9.8.1, 9.8.2
			Health service has an advance care plan alert process and a system to record and store advance care plans.	Year 2	
	Health services use quality audits to inform and improve advance care planning systems.	People have confidence that the health service has processes that support quality advance care planning.	Executive and clinical leaders receive and respond to results of advance care planning quality audits.	Year 1	9.8.1, 9.8.2
Promote advance care planning with key external stakeholders.	Establish mechanisms that support the mutual recognition of advance care plans developed in other settings or services.	A person's advance care plan is accessible at any point of care across the continuum and is recognised and activated in services involved in the person's care.	Advance care plans included in communication templates between health services and other care providers, including identification of the substitute decision maker.	Year 2 and 3	9.8.1

- ✓ Ensure suitable governance is in place.
- ✓ Involve senior management.
- ✓ Identify partners within the health service.
- ✓ Introduce strategies to promote advance care planning across the health service.
- ✓ Develop and adapt general policies and procedures.
- ✓ Link to existing safety and quality processes.
- ✓ Promote advance care planning across the broader health service system.

Actions

Supportive culture

- Address issues identified by staff that are seen as creating barriers to advance care planning.
- Identify advance care planning champions working in targeted units who can support and build capacity within their team.

Governance

- Provide information to health service boards on the key action areas relating to advance care planning.
- Identify executives to lead the implementation of advance care planning across the health service.
- Develop an overarching plan for the health service that will guide implementation of this strategy.
- Develop a communication strategy about advance care planning and how staff can make it part of their role.
- Provide clear instructions to the workforce on their role in assisting people to undertake advance care planning.
- Position advance care planning within the existing quality systems and framework.
- Utilise existing corporate and clinical governance structures and processes to monitor and ensure that an effective advance care planning system is in place.

Policies and procedures

- Ensure all relevant policies reflect advance care planning as part of usual clinical practice.
- Create a service-wide advance care planning policy.
- Identify how advance care planning documentation is recorded at admission, discharge and transfer.
- Incorporate regular review of advance care plans into care pathways and key points (such as at intake or follow up).

Documentation and alerts

- Introduce an alert system for advance care plans that is consistent across the health service.
- Identify systems for storage of advance care planning documentation.
- Encourage changes to documentation to reflect advance care planning conversations and documents.

Working across the broader health service system

- Identify local providers with shared clients and establish common practices for advance care planning including how advance care planning information is transferred between health services. For example with
 - primary healthcare organisations
 - community and aged care providers
 - residential aged care facilities
 - ambulance services and
 - private hospitals.
- Consider how personal eHealth records, an initiative of the Commonwealth Government, can support communication of advance care plans.

(See ASQCH 2012b which outlines several strategies)

Case study: Barwon Health

Barwon Health provides a coordinated and systematic approach to advance care planning. Advance care planning is offered across all sectors of the health service, with a particular focus on the Health Independence Program and Community Palliative Care.

Barwon Health has been working collaboratively with the wider Barwon community including general practices to increase the uptake of advance care planning.

A small team of advance care planning experts have facilitated the establishment of processes and systems throughout and beyond the health service. This includes education, training, mentoring, public awareness and expert consultation.

The team can receive and allocate electronic referrals, audit incoming documents, distribute advance care plans and facilitate regular review of advance care plans.

Barwon Health has developed systems for activating electronic alerts in medical files, ensuring documentation is correctly scanned into electronic medical records, incorporating advance care planning into clinicians' core competencies and establishing key performance indicators for staff. As part of understanding the client experience staff routinely review whether client preferences were activated.

Collaboration with both internal and external stakeholders has aided the general awareness and uptake of advance care planning throughout the region. As a result, Barwon Health is experiencing a significant increase in the number of people presenting to their service with an advance care plan.

Case study: St Vincent's Hospital, Melbourne – best CARE

St Vincent's has developed an approach to advance care planning consistent with the ethics of the Catholic teaching, through the establishment of their best CARE model.

The best CARE model of advance care planning promotes best care for each person at every stage of their illness. The acronym stands for consider, act, record, effect.

The development of best CARE engaged stakeholders with authority to shape and endorse a model consistent with the hospital mission and based on the guiding principles of excellence, compassion, integrity and justice. The stakeholders included key representatives across the Catholic community including the Caroline Chisholm Centre for Health Ethics and the Mary Aikenhead Ministries. Following ethics consideration, senior church figures, the Archbishop of Melbourne and the Vicar for Health and Aged Care endorsed the model.

St Vincent's aims to incorporate best CARE into usual practice by establishing systems to flag and record advance care planning documentation and staff education and orientation programs.

The best CARE model will support St Vincent's accreditation efforts by meeting the requirements of Standard 1 and Standard 9 criteria relating to advance care planning.

Case study: Austin Health

Austin Health has been implementing advance care planning in a systematic way since 2002. Austin Health employs a small number of experienced nurses to specifically have advance care planning conversations with clients and their family and to provide education and support to other hospital staff to *have the conversation*.

In 2013, six part-time nurses (working two days per week) conducted approximately 2,500 advance care planning discussions with over 1,000 clients. They assisted 80 per cent of these clients to document their wishes.

The need for strong executive support and clinical leadership, a standardised way to incorporate advance care plans into the medical record and the need for regular medical and nursing staff education has been recognised and provided. Austin Health has implemented the following:

- All junior doctors have access to medical advance care planning education sessions.
- Nursing education sessions including formal study programs and ward in-services incorporate advance care planning.
- Advance care planning documentation has been refined and is incorporated into medical records and electronic alert systems ensuring wishes can be activated.
- Audits reviewing documentation, use of alerts and consistency with medical treatment orders are conducted.
- Mortality audits are used to investigate whether advance care planning has improved the person's experience.

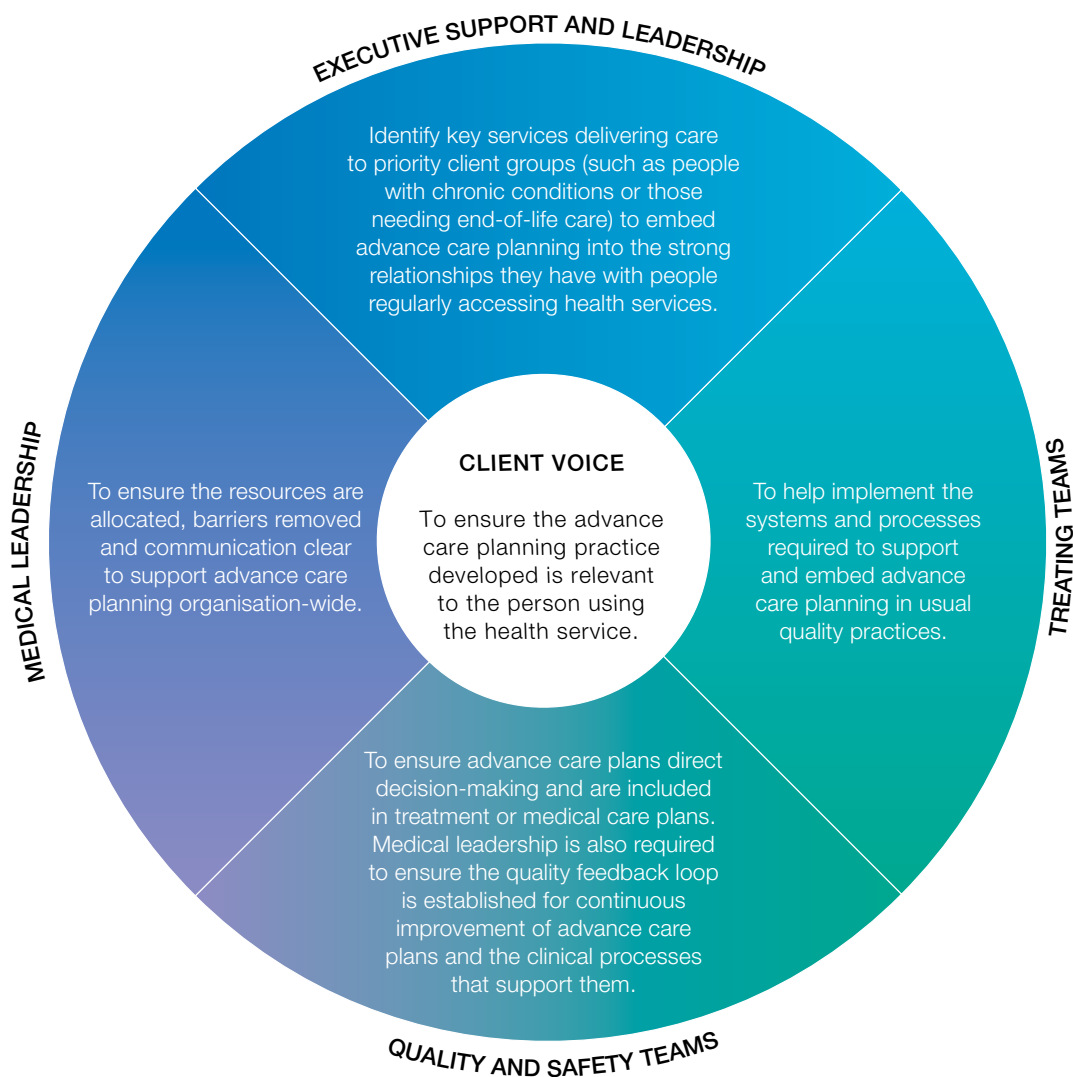
These advance care planning activities have led to further refinement of the clinician model, processes, and procedures for document storage and electronic alerts so that advance care planning can become part of routine care at Austin Health. When people who have undertaken advance care planning at Austin Health die, their wishes are known and respected.

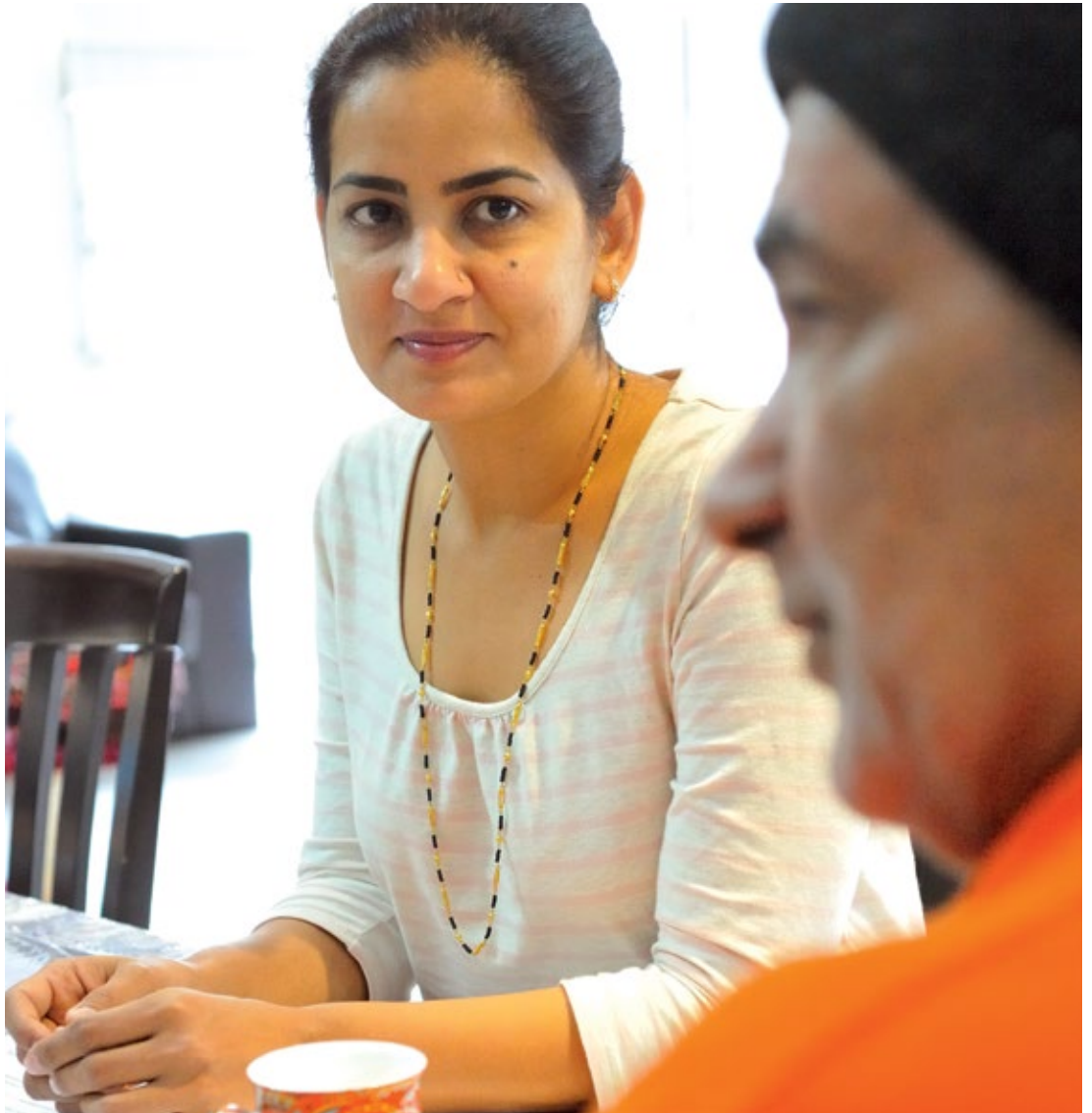


One way to think about how health services can support advance care planning

The overarching plan for the health service will need to strengthen the structures and processes that support staff to provide advance care planning. This can be achieved by identifying a suitable governance structure to drive advance care planning across the health service. The key internal partners to achieve a well-designed advance care planning system are represented in the diagram below.

Figure 4: Advance care planning partners for implementation





Case study: Ballarat Health Services CEO, Andrew Rowe demonstrates executive leadership to have the conversation

Ballarat Courier, 21 December 2013

‘Ballarat Health Services is asking families to give each other a special Christmas gift by discussing future healthcare wishes. BHS chief executive officer Andrew Rowe said festive gatherings were the perfect time to start talking about what health decisions were important. “If you were too unwell to speak for yourself about your treatment options, who would you want to speak on your behalf?”’

Priority action 2: Ensuring you have an evidence-based and quality approach to have the conversation

One thing that is clear is that improving safety and quality is now seen as part of the normal business of health care. More and more systems are in place to standardise routines and processes, making it easier for doctors, nurses and others to deliver the care they would like to deliver to the standard they would like to deliver it. The National Safety and Quality Health Service (NSQHS) Standards and the associated mandatory accreditation scheme are an important step in this direction.

Australian Commission on Safety and Quality in Health Care 2013



Health service priorities	Action	Impact	Measure	Estab. Timeline	National standard
Health services review and improve advance care planning to suit their local needs.	Inform advance care planning practice through review of activity, quality and patient experience data.	People engage in an advance care planning process that they have had the opportunity to influence and improve.	Advance care planning included as a parameter in an assessment of outcomes including <ul style="list-style-type: none"> • mortality and morbidity review reports • patient experience • routine data collection. 	Year 2 and 3	9.8.2
Health services base advance care planning practice on the best available evidence.	Shape advance care planning practice with available evidence.	People are offered advance care planning as part of usual care.	Health services establish implementation plans for advance care planning that is based on evidence.	Year 2	

- ✓ Policies, procedures and practices are based on current evidence.
- ✓ Promote advance care planning research and evaluation.
- ✓ Disseminate findings from research and evaluation.
- ✓ Provide professional development opportunities.
- ✓ Embed advance care planning in quality and redesign practices.

Actions

Base practice on evidence

- Establish policies, procedures and practice based on best available evidence.
- Provide professional development opportunities.
- Use information from health service audits and reviews to improve clinical practice.
- Review health service data and utilisation patterns to target the introduction of advance care planning in the organisation.

Undertake targeted research

- Support quality improvement activities that further the understanding and application of advance care planning within the organisation.
- Widely disseminate findings of research undertaken.

Monitor and evaluate

- Monitor the impact of advance care planning by developing indicators that are important to clients, staff and the organisation.
- Incorporate advance care planning into the health service's existing quality activities.
- Incorporate advance care planning into the health service's approach to managing and responding to deteriorating patients.
- Use mortality and morbidity review committees to monitor the presence and the impact of advance care planning on preferred patient outcomes.
- Audit the documentation of advance care plans through medical record reviews.
- Support advance care planning system audits that identify the effectiveness of developing, reviewing and activating advance care plans throughout the organisation.

National Safety and Quality Health Service Standards

The national standards aim to protect the public from harm and to improve the quality of healthcare provision. The standards determine how an organisation's performance will be assessed. The standards articulate the requirements of health services in establishing advance care planning mechanisms. Specific requirements of the national standards in relation to advance care planning are outlined below.

Standard 1 – Governance for safety and quality in health service organisations

Criteria 1.18

Implementing processes to enable partnership with patients in decisions about their care, including informed consent to treatment.

Actions required

1.18.4 – Patients and carers are supported to document clear advance care directives and/or treatment-limiting orders.

Standard 9 – Recognising and responding to clinical deterioration in acute healthcare

Criteria 9.8

Ensuring that information about advance care plans and treatment-limiting orders is in the patient clinical record, where appropriate.

Actions required

9.8.1 – A system is in place for preparing and/or receiving advance care plans in partnership with patients, families and carers.

9.8.2 – Advance care plans and other treatment-limiting orders are documented in the patient clinical record.

Priority action 3: Increasing your workforce capability to have the conversation

Healthcare leaders and providers must lead by example by making a commitment to have conversations about their own ... wishes with their loved ones. By doing so, they will better understand the process, emotions and fears that can arise.

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Health service priorities	Action	Impact	Measure	Estab. Timeline	National standard
Enable workforce to deliver advance care planning through targeted education, training and mentoring.	Staff are informed and educated about their role through	People know they can talk to clinical staff about advance care planning who are skilled and confident to assist them.	Position descriptions described role in advance care planning.	Year 1 and 2	9.8.1
	<ul style="list-style-type: none"> • position descriptions • induction programs • access to training programs • mentoring and support. 		Induction programs include advance care planning.	Year 1	
			Number of training sessions and attendance.	Year 1	
			Mentoring is identified in health service implementation plan.	Year 1	

- ✓ **Provide training and professional development opportunities.**
- ✓ **Offer mentoring and supervision.**
- ✓ **Identify clinical champions.**
- ✓ **Talk about advance care planning in team meetings.**
- ✓ **Include advance care planning in:**
 - position descriptions
 - induction programs
 - grand round topics.

Actions

Education and training

- Provide an induction program for new staff that covers the essential aspects of advance care planning and identifies related policies and procedures.
- Deliver ongoing training for staff through access to in-house and external education and training programs, including self-guided training programs.
- Offer programs that increase staff understanding of the legal framework that supports advance care planning.
- Provide opportunities for all staff to enhance their communication skills using a person-centred approach.

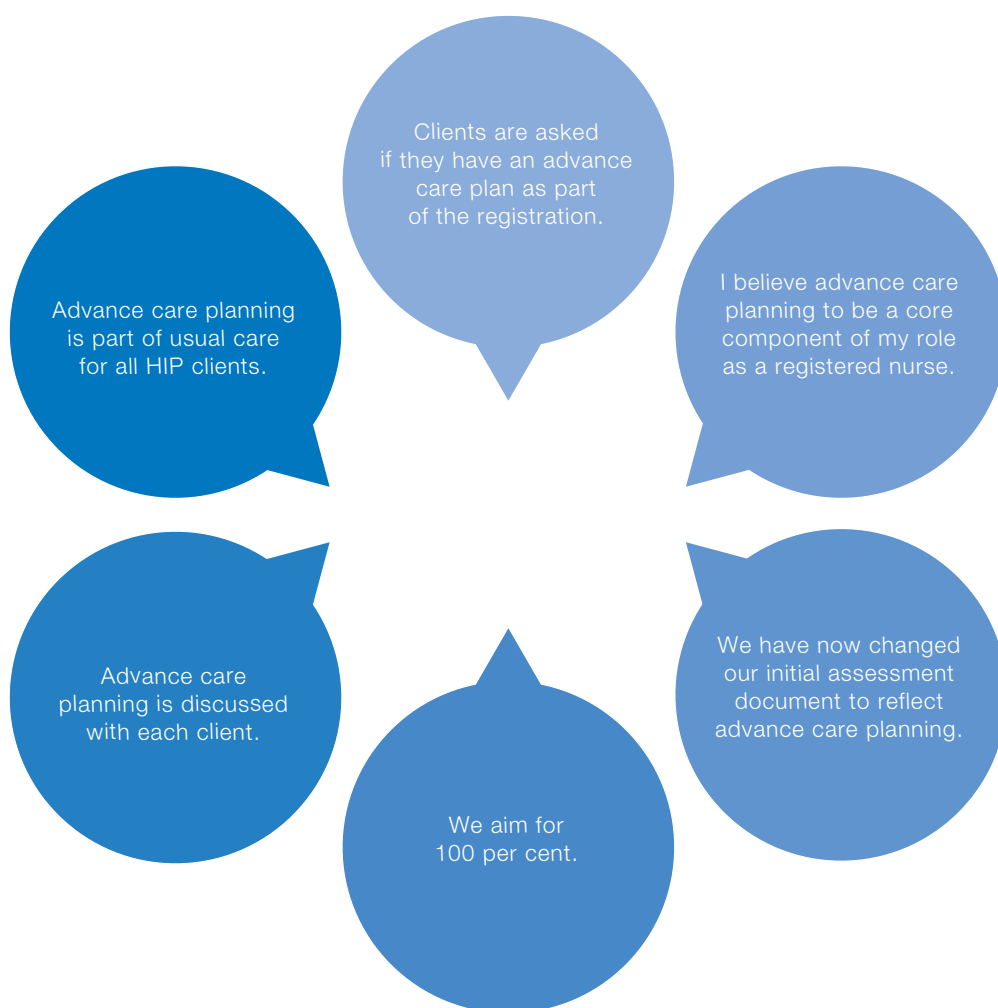
Mentoring, supervision and clinical leadership

- Actively support supervision and mentoring to build skills in advance care planning across your health service.
- Provide opportunities to promote and build staff capacity in advance care planning. This could include using team meetings, grand rounds and case conferences.
- Supporting junior clinical staff to observe family conferences and discussions as part of their training and mentoring.
- Identify advance care planning champions who model good practices in advance care planning
- Support junior staff to review and reflect on client care.

Embedding into usual care

- Integrate advance care planning in documentation that describes the expectations of various staff groups and their role in supporting advance care planning.
- Incorporate advance care planning into position descriptions for clinical staff.
- Include advance care planning as part of staff performance reviews.

Clinicians having the conversation: feedback from consultation



Priority action 4: Enabling the person you are caring for to have the conversation

Healthcare providers need to partner with patients and their families to translate an individual's ... wishes into a healthcare plan consistent with those needs. For example, a person might articulate that what matters most to her is reading aloud to her grandchildren; a healthcare provider needs to understand how to prioritize treatments and interventions to help meet this goal.

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Health service priorities	Action	Impact	Measure	Estab. Timeline	National standard
Deliver advance care planning in the context of person-centred practice.	Provide clients with opportunities to discuss and record their wishes and preferences at clearly identified points in their care.	People with chronic and progressive conditions are supported to participate in advance care planning.	Number and percentage of people with an advance care plan.	Year 2	1.18.4
Provide an individualised approach that considers and is responsive to the illness trajectory.		A person's substitute decision maker is easily identified by the treating team.	Client information collected includes identification of the substitute decision maker.	Year 2	

- ✓ Promote multiple opportunities for advance care planning.
- ✓ Embed advance care planning into usual care.
- ✓ Identify triggers along key client care pathways for review of advance care planning.
- ✓ Activate advance care plan if the person loses capacity.

Actions

Engage people who use the health service to inform the implementation of advance care planning.

- Consult with the people who use your health service in developing strategies to inform and monitor how advance care planning is implemented. This includes the involvement of the health service's Community Advisory Committee.
- Incorporate client experience of advance care planning into existing feedback systems.

Information from people about their experiences of care can help health services to improve the way that they provide care, and help ensure that people get the best outcomes from their care

Australian Commission on Safety and Quality in Health Care 2013

Offer people regular opportunities to develop and review their advance care plan.

- Pro-actively identify substitute decision makers and existing advance care plans, particularly on admission.
- Document a person's existing advance care plan (substitute decision maker and/or advance care planning documents) on
 - admission documents
 - care planning documents
 - medical alerts
 - discharge documents.
- Identify and target key groups in the health services that would benefit from opportunities to have advance care planning discussions.
- Develop systems that provide clients and staff with confidence that advance care plans are known and accessible.
- Use evidence-based communication principles, for example, the guidelines for end-of-life care developed by Clayton et al. (2007), to support good communication practices.
- Ensure clients are routinely offered opportunities to develop or review advance care plans at key points during their illness.
- Provide user-friendly information on advance care planning.
- Include the substitute decision maker in discussions with the person when a person's capacity to participate fully in decision making becomes compromised.



Case study: Northern Health

Northern Health conducted research and undertook community consultations to ensure that their approach to advance care planning was sensitive to their large culturally and linguistically diverse population.

In doing this, an approach to advance care planning was developed that can be easily introduced to their clients. This is called advance care planning in three steps:

- A Appoint an agent (substitute decision maker).
- C Chat and communicate.
- P Put it on paper.

At Northern Health, advance care planning is part of usual care. A program manager and medical lead are employed to assist with the system-wide changes, workforce development, community education, and to support staff with more complex cases.

The role of the department

The delivery of advance care planning as part of routine care is embedded in health service funding, and the Victorian Department of Health (the department) will provide support for and monitor the implementation of this strategy. The department's expectations are included in the Statement of priorities and the departmental *Policy and funding guidelines*. The department will undertake the following next steps:

- Establish a steering committee comprised of leaders in advance care planning and senior representatives of health services to provide expert advice on advance care planning together with practical and operational advice on the implementation of the key actions of the strategy.
- Continue to work in partnership with leaders in advance care planning to identify, develop and make available resources that promote community understanding and provide practical support to health services.
- Promote the development and implementation of evidence-based advance care planning in the local context.
- Provide opportunities to disseminate the lessons learnt.
- Monitor, review and evaluate implementation of advance care planning.
- Develop opportunities to promote advance care planning across the broader health service system, including facilitating access to available advance care planning education and resources by primary healthcare providers including GPs and the private health sector.
- Promote advance care planning through a comprehensive communication strategy.
- Communicate updates and new resources relevant to advance care planning on the department website (www.health.vic.gov.au/acp).

We need to ensure that advance care planning becomes part of the culture of care across all sectors – hospital, community and non-government services.

Feedback from peak body during final consultation

Resources

Resources are constantly evolving and being updated. For a comprehensive list of resources visit the Victorian Department of Health website (see below). When referring to interstate and international resources some laws, processes and terminology are not consistent with Victoria, but offer very useful perspectives for understanding advance care planning.

Victorian Department of Health

The Victorian Department of Health website provides useful advance care planning information, particularly for health services.

Website: www.health.vic.gov.au/acp

Provides:

- FAQ providing overview of Victorian legal framework
- link to *A national framework for advance care directives*
- links to resources, including the Next Steps training resource.

Office of the Public Advocate

The Office of the Public Advocate provides a useful resource for people considering advance care planning and for clinicians wishing to clarify legal issues.

Website: www.publicadvocate.vic.gov.au

Provides:

- information line – 1300 309 337
- *Take control: a kit for making powers of attorney* which provides information about the roles of powers of attorney and guardianship, step by step instructions, and a complete set of all the forms
- *You decide who decides*, an interactive program to assist people considering making powers of attorney and are unsure who to appoint
- forms and fact sheets on powers of attorney, medical consent and guardianship, and administration.

Office of the Health Services Commissioner

In Victoria individuals have a right of access to their health information and to make complaints about health service providers. The Office of the Health Services Commissioner (HSC) is an independent statutory authority established to receive and resolve complaints about health services. The HSC also handles complaints about disclosure of health information and access to health information.

Website: www.health.vic.gov.au/hsc/

Advance care planning terminology

This document has adopted the following definitions related to advance care planning.

Advance care directive

An advance care directive is one way of formally recording an advance care plan. An advance care directive 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 advance care directive can record the person's preferences for future care and appoint a substitute decision maker to make decisions about health care and personal life management.

AHMAC 2011

The term advance care plan is used in this strategy to encompass both advance care plans and advance care directives. The department expects health services to give due consideration to whatever form a person's advance care planning documentation takes.

Advance care plan

An advance care plan is made by a competent person and supported by legislation or common law. It records directions about medical treatment, appoints a substitute decision maker, states preferences about health and personal care, and preferred health outcomes.

Advance care plans are prepared from the person's perspective to guide decisions about care that may need to be made on the person's behalf. They are established through discussion and are preferably documented.

Any statement of the person's preferences for future care and treatment needs to be considered when the person can no longer participate in decision making. Advance care plans should not be confused with clinical care or treatment plans written by clinicians to guide clinical care; however, clinical care plans would be expected to be consistent with the person's advance care plan.

Advance care planning

Advance care planning is the 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.

AHMAC 2011

The process can take place in a number of ways including in an informal family setting or more formally in a community or inpatient health setting with a health professional, general practitioner or care provider.

Best interest decision making

AHMAC (2011) states that decision making according to best interests should:

- focus on the person's best interests not on what the substitute decision maker would or would not do
- take into account risks versus benefits and the consequences if not carried out
- seeks to optimise benefit while minimising restriction.

In Victoria, a best interest decision making framework is used under the *Guardianship and Administration Act 1986* and this includes a number of factors, including taking into account the wishes of the person. The Act covers persons such as:

- enduring guardian
- guardian appointed under VCAT
- person responsible identified under person responsible hierarchy.

Common law

'Common law', also referred to as case law or precedent, is based on the idea that like cases should be decided alike. Common law develops through judgements of courts on matters brought before them.

End-of-life care

This term describes care that is planned and delivered to a person at the end of their life. There is no set timeline that defines this phase but, due to illness or old age, many people will require responsive care as they approach death. Death is a normal part of the life cycle and all clinicians should be able to understand and contribute to the care of a dying person.

Goals of care

Goals of care identify the aims for a person's medical treatment as agreed between the person, their family, carers and health care team. Goals of care may also include non-medical goals such as returning home or reaching a particular milestone.

Medical goals of care may include cure of a reversible condition, a trial of treatment to assess reversibility of a condition, treatment of deteriorating symptoms, or the primary aim of ensuring comfort for a dying person.

Non-beneficial treatment

Non-beneficial treatment refers to medical interventions that will not be effective in treating a person's medical condition or improving their quality of life. Non-beneficial treatment may include interventions such as diagnostic tests, medications, the provision of intensive care, and medical or surgical procedures.

Palliative care

The *Medical Treatment Act 1988* identifies that palliative care includes:

- the provision of reasonable medical procedures for the relief of pain suffering and discomfort; or
- the reasonable provision of food and water.

The World Health Organization (2010) has a more extensive definition of palliative care as:

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.

In Victoria, a designated palliative care service system is funded to provide specialist palliative care including bed-based, community and consultancy palliative care services. These services can support people with a life-threatening illness by providing:

- direct care for people requiring specialist palliative care interventions
- shared care with other clinicians
- consultation and advice to other services and treating teams providing end-of-life care.

Victoria's Strengthening Palliative Care Policy (2011) states:

Specialist palliative care services are not required to provide care for everyone at the end of life and, in many instances, the most valuable role specialist palliative care can play is to support other healthcare teams and professionals to provide end-of-life care to their patients.

Person-centred care

The Department of Human Services (2009) defines person-centred care as follows:

Person-centred care focuses on collaboration between health workers, the person and their carers. Person-centred care is centred on the person and respects their wishes and needs. It is demonstrated by consultation with the person about their healthcare and their active participation in decision making.

Statutory law

Statutory law – statute law, also referred to as legislation or Acts of Parliament – is the law which has been passed by Parliament, for example the *Guardianship and Administration Act 1986*, the *Medical Treatment Act 1988*, and the Charter of Human Rights and Responsibilities Act. In Australia both federal and state/territory parliaments can pass Acts.

Substitute decision maker

Substitute decision maker is a general term for a person that is either appointed or identified to make care decisions on behalf of a person whose decision-making capability is impaired. Refer to Part 3 for further details.

Values

Values refer to a person's principles or standards of behaviour and their judgement of what is important in life.

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