

# Advance care planning: have the conversation

## Module 1: The facts



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# Advance care planning: have the conversation

## Module 1: The facts

**Healthcare settings:** GP practice, hospital, aged care

**Target skills:** confidence, knowing your role

**Time:** 15-20 mins

## 1.1 The aim of these resources

The aim of these resources is to support Victorian doctors to ‘have the conversation’ with patients about end of life decision making, engage patients in decisions about their care, and help them to undertake advance care planning.

Currently the process of advance care planning frequently occurs in the context of serious medical illness. The aim of these resources is to encourage doctors to engage in advance care planning conversations with patients well before any diagnosis, when the patient is medically stable and thinking clearly.

This emphasises a focus on patient-centered care and living well within the Victorian healthcare system.

## 1.2 The important role of doctors in advance care planning

In today's society, "the concept of a good death appears to have been superseded by the concept of a managed death, one that requires professional support and knowledge... resulting in the modern death becoming 'cellular, private, curtained, individualised and obscured'" (Buchan et al. 2011).

Death is a part of life and living, but the 'management of death and dying' has had a direct impact on the way in which society communicates, or avoids communicating about, end of life care. There is a profound taboo surrounding talking about death and dying, that it can be perpetuated by the way it is discussed by some doctors.

It is common for many doctors to view death as a failure in medical care. This is reflected in the language used to describe death, for example, 'he lost his battle with cancer'. If death is viewed as a failure in medical care, rather than an important part of life, patients are diverted from preparing for it (Smith 2000). This oversight eliminates the opportunity for patients to engage in discussions about the dying process and plan for a 'good death' based on their own preferences.

Doctors are best placed to be at the forefront of a cultural shift in healthcare services and the broader community to promote the importance of talking about and planning for a 'good' death. Reinstating a personal approach to dying in health services will counteract the current medicalised, professionalised and sanitised deaths (Smith 2000) that so few patients want (Swerrisen et al. 2014).



## 1.3 A good death

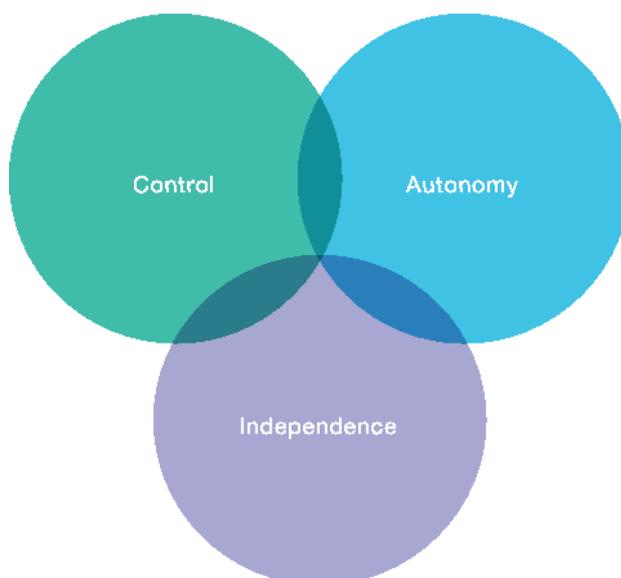
It is common practice for doctors to assist patients to plan, as much as possible, for a good birth. It is likely that the treating doctors will discuss elements such as the location and timing of the birth, and the values of expectant parents who may have particular preferences relating to how their child is brought into the world. Similarly, patients require assistance to plan, as much as possible, for a good death.

But what is a good death?

Richard Smith, doctor and former editor of the *British Medical Journal*, outlines the 12 principles of a good death:

- To know when death is coming, and to understand what can be expected
- To be able to retain control of what happens
- To be afforded dignity and privacy
- To have control over pain relief and other symptom control
- To have choice and control over where death occurs - at home or elsewhere
- To have access to information and expertise of whatever kind is necessary
- To have access to any spiritual or emotional support required
- To have access to hospice care in any location - including at home, not only in hospital
- To have control over who is present and who shares the end
- To be able to issue advance directives that ensure wishes are respected
- To have time to say goodbye, and control over other aspects of timing
- To be able to leave when it is time to go, and not to have life prolonged pointlessly

Smith also highlights 3 key themes of a good death for patients, beyond simply being free of pain:



# 1.4 What is advance care planning?

Advance care planning is the process of planning for future health and personal care whereby a patient's values, beliefs and preferences are made known to their family members, medical treatment decision makers and treating doctors.

This process can involve writing an advance care directive that contains the patient's clearly expressed values and preferences. An advance care directive can be used by doctors to inform clinical decision making when the patient becomes too unwell to participate directly.

Advance care planning places the patient at the centre of care, involving them, their medical treatment decision maker, their family (if appropriate), carers and their doctors in medical and personal care decisions.

The advance care planning process can result in:

- expression of personal values and preferences for treatment and care
- completion of an advance care directive
- appointment of a medical treatment decision maker
- appointment of a support person

The advance care planning process can take place at any stage of an adult patient's life. For people who are marginalised and disempowered in the face of medical decision making, advance care planning can be an empowering tool. Some suggested times to talk to patients about advance care planning are:

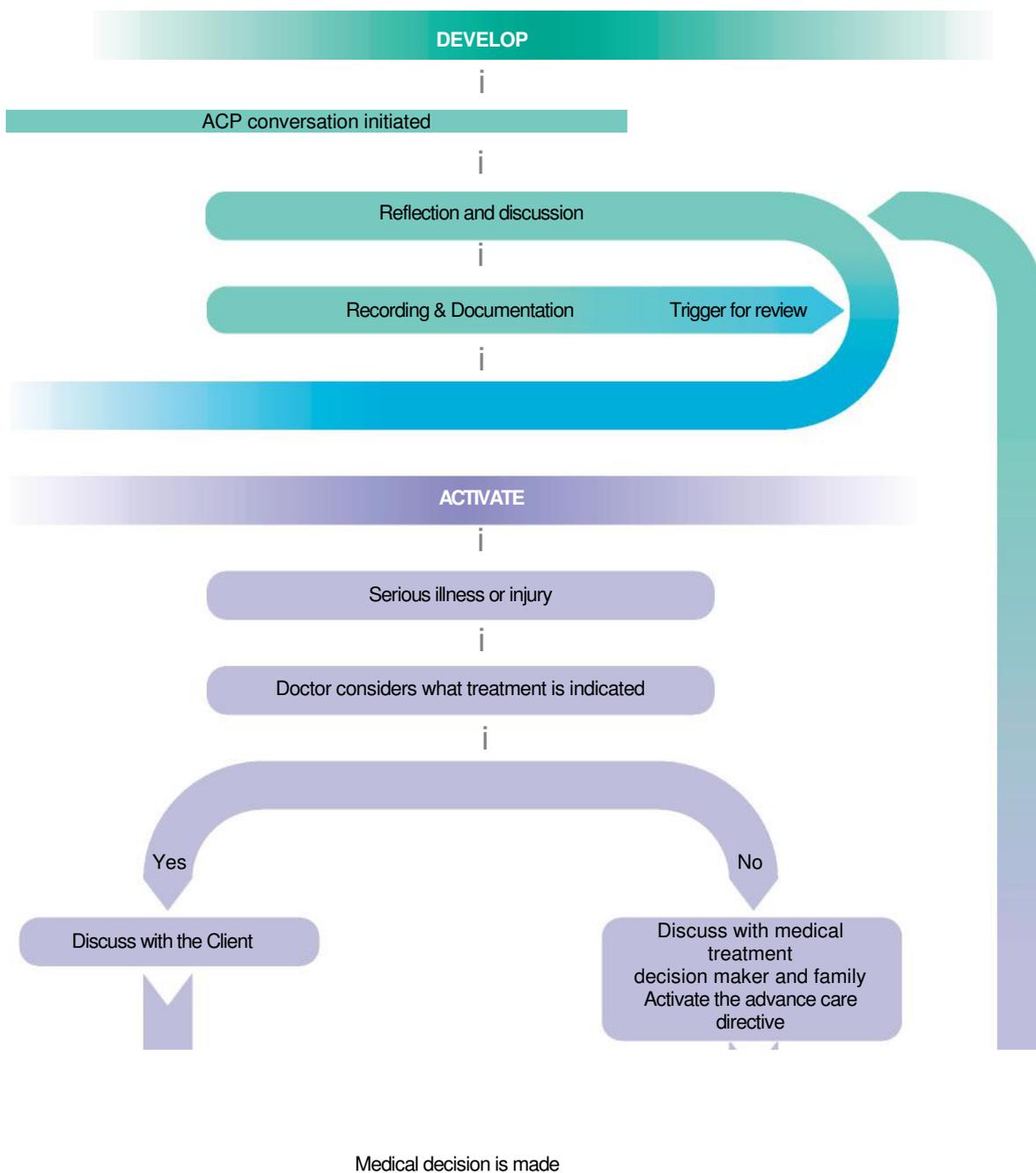
- When a patient is making a will
- When a patient is considering organ donation
- When a patient has had a new baby
- When a patient has been diagnosed with a disease
- When a patient is isolated and vulnerable
- When a patient is curious about advance care planning and how it works
- When a patient has differing opinions, values or beliefs to their family members

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

The process of advance care planning in this resource has 4 steps



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



### 1.4.1 What is an advance care directive?

In these modules, an advance care directive refers to a statement of the patient's values or preferences for their treatment and care. An advance care directive is a legal document that must be signed and witnessed. A patient may go through a process of advance care planning and decide they do not want to create an advance care directive. The process and conversation will still be helpful in informing future medical treatment decisions.

An advance care directive may include:

- an instructional directive (which must be explicitly described as an instructional directive and will constitute consent to or refusal of treatment when the patient does not have decision-making capacity)
- a values directive (which contains more general statements about what is important to the patient and will inform treatment decisions when the person does not have decision-making capacity).

### 1.4.2 Shared decision making

A patient-doctor partnership and shared decision making offers patients 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.

The following is an edited excerpt from 'ACP in 3 Steps' *Northern Health*, 2009. There are 3 experts in the shared decision making process.



The patient is an expert on the patient. The patient discusses what is important or matters to them in terms of lifestyle and health outcomes in advance care planning discussions.

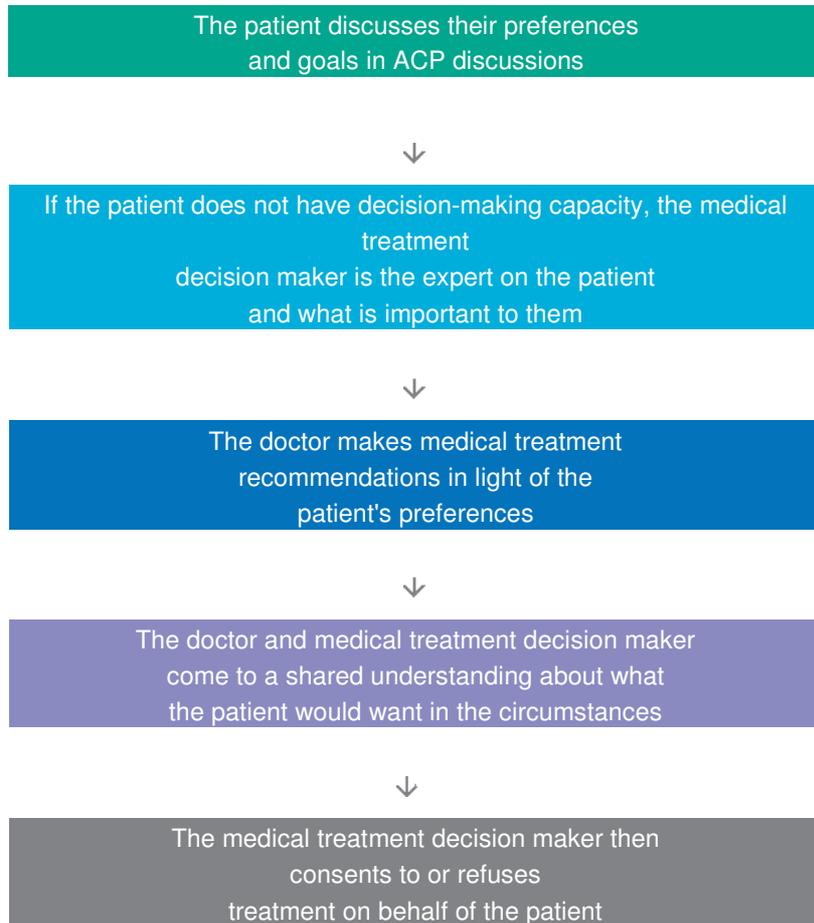


The doctor and treating team are the experts on the medicine. They interpret the medicine within the context of the patient's preferences.



The medical treatment decision maker (see Section 2.1.4 for a definition of medical treatment decision makers) is an expert on the patient. They represent the preferences of a patient who does not have decision-making capacity.

## An overview of shared decision making in the advance care planning process



### 1.4.3 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 preferences may help clarify decisions about these)
- a tool for applying fair and equitable distribution of healthcare resources across the wider community, or “cutting costs” or limiting what is spent on the care of older patients
- a replacement for clinical face-to-face communication and engagement with people and their families
- voluntary assisted dying
- a direction that doctors must provide futile or non-beneficial treatment



## 1.5 Why is advance care planning important?

### 1.5.1 Deliver patient-centered care

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).

Patient-centered care supports patients to participate in decisions about their healthcare through patient-doctor collaboration. Effective patient-centered care creates ownership through decision making, which in turn increases self-determination and participation, and supports patient self-management.

Patient-centered care is associated with improved patient health outcomes including less discomfort, less concern and better mental health. Effective patient-centered communication may also result in an increased efficiency of care resulting in fewer diagnostic tests and referrals conducted by doctors (Stewart et al. 2000).

Doctors can support patient-centered care at three levels:

- The client-provider level: provide tailored therapy and medical treatment that reflects the patient's values and wishes.
- The multidisciplinary level: communicate and liaise effectively with other health service providers, to ensure that the patient's wishes are implemented across the Victorian health system and in residential aged care.
- The organisational level: coordinate and actively participate in team conferencing, mentoring and mutual skill-building, participate in quality audits including mortality and morbidity review committees, provide feedback to staff when an advance care plan is activated, contribute to governance arrangements such as steering committees and participate in accreditation activities to improve care for the deteriorating patient.

If a patient's preferences are not known by doctors or family members, it can result in provision of unnecessary or unwanted treatment, and increased anxiety and uncertainty for families and treating staff. Failure to engage patients 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).

When providing a patient-centered approach to advance care planning a doctor would:

- See the patient as a person, an experiencing individual (Mead et al. 2000)
- Look beyond the patient's medical problems towards the patient's social context and range of non-medical problems (Stewart et al. 1995)
- Share power and responsibility with the patient so both doctor and patient are active mutual participants in care, and discuss all aspects of problems and decisions together (Stewart et al. 1995)
- Develop a personal bond with the patient based on empathy and trust
- Understand their own personal views, to enable 'two-person medicine' where the patient and doctor establish common ground for effective communication (Mead et al. 2000)
- View the medical treatment decision maker as the expert on the patient where the patient lacks capacity, and work together with the medical treatment decision maker to ensure the patient remains at the centre of medical decision making.

## 1.5.2 Care for an ageing population

“Australians are living longer than they ever have before. The number of people who die each year in Australia will almost double in the next twenty-five years” (Swerissen et al. 2014).

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 specialised care and decision making from a variety of doctors.

There is an increasing prevalence of chronic life-limiting diseases that need ongoing management. These diseases include, cancers, chronic respiratory and cardiovascular disease, neurological conditions, stroke, 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 diseases are likely to experience one of three trajectories:

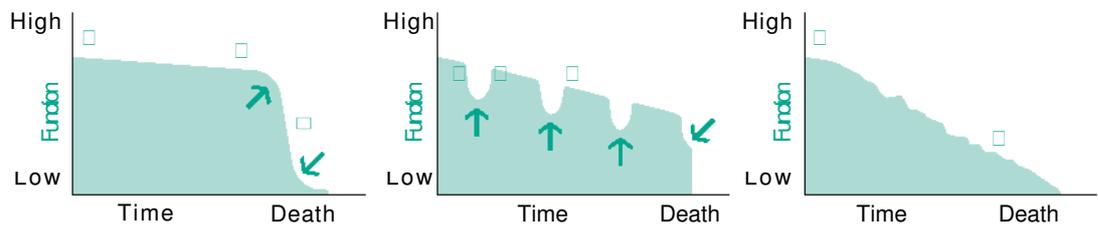
- Care delivered over a short period of decline (such as some cancers)
- Long-term limitations with intermittent serious episodes of decline (such as heart and lung failure)
- Prolonged decline (such as neurodegenerative conditions)

These trajectories are illustrated below. The arrows indicate changes to a patient’s health status and should trigger an advance care planning discussion.

### Chronic disease trajectories

<p><b>Trajectory A</b> Short period of evident decline</p> <p>Mostly cancer</p>	<p><b>Trajectory B</b> Long-term limitations with intermittent serious episodes</p> <p>Mostly heart and lung failure</p>	<p><b>Trajectory C</b> Prolonged decline</p> <p>Mostly frailty and dementia</p>
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Most older people will have limited decision-making capacity for a period of time before they die (Kaspers et al. 2013). Many frail, aged people and those with advanced chronic disease or terminal conditions indicate that they do not want life-prolonging treatment 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).



### 1.5.3 Reduce distress for healthcare workers

“At the end of life, people given treatment that is inappropriate or futile in the circumstances may well have chosen to forego those treatments had they been given the opportunity to discuss their care preferences well ahead of their death” (Scott et al. 2013)

Healthcare workers report psychological, moral and emotional distress and conflict (Mobley et al. 2007) in acute hospital settings and where decisions must be made in crises. The process of assisting patients to design an advance care plan may reduce the level of distress experienced by doctors who are left to make difficult last-minute end of life decisions in acute settings.

Advance care planning has also been demonstrated to improve patient and family satisfaction with medical care, and reduce the risk of stress, anxiety and depression in the surviving relatives of deceased patients (Detering et al. 2010). Open discussions about end of life care also significantly help carers manage their bereavement (Addicott 2010).

## 1.6 Lead by example

“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” (Gunther-Murphy 2013)

To assist you to develop your communication skills and discuss advance care planning with your patients, have a go at completing an advance care directive for yourself before you read the remaining modules.

Think about your quality of life priorities and goals of care that matter most to you, and who you would appoint to be your medical treatment decision maker if you could not speak for yourself.

Undertaking this process yourself may enable you to understand the social, emotional and practical issues that surround end of life decision making from the patient’s perspective.



## 1.7 How to overcome common barriers identified by doctors

### “I find talking about death with patients emotionally demanding”

- A discussion about advance care planning does not have to focus solely around the theme of death. Although it is expected that the process will be emotional for the patient, their family and the doctors, the outcome of the discussion and development of an advance care directive may ultimately be a positive experience.
- Try to steer the focus of end of life discussions towards patient-centered care principles: the patient’s power to have a say in their own care, increased self-determination and participation. Patients may feel that a weight has been lifted off their shoulders after discussing end of life care choices.
- Families may appreciate the opportunity to alleviate the stress and potential conflict that may have eventuated if the patient’s wishes had not been discussed. Remind the patient that advance care planning may provide peace of mind and reduce the panic and anxiety their family members may feel when faced with making challenging decisions in emergencies.

### “I don’t have time to have the conversation about advance care planning with patients”

- GPs could advise their patients to make a double appointment in advance to discuss advance care planning with the patient, family members, and a medical treatment decision maker (if relevant). This will ensure that you are not rushed and that there is designated time set aside to talk.
- Every conversation counts. Time spent having the conversation over a number of consultations with the patient may save time later by reducing unnecessary trips to the hospital and unwanted emergency procedures.
- Take a coordinated approach and employ the skills of other members of your medical team to help have the conversation with patients, such as practice nurses.

### “I don’t have the communication skills and knowledge about advance care planning to confidently have the conversation with patients”

- This learning program will assist you to develop your communication skills and knowledge about advance care planning and equip you with the tools and confidence to have the conversation with your patients.
- Have a go at drafting your own advance care directive, and think about who you would elect to be your medical treatment decision maker.
- Practice advance care planning conversation with your peers. Get a group together in your healthcare setting and take turns using the phrases in these modules

## 1.8 Mythbusters

### 1. Myth: These days patients are well informed about end of life treatments and services

**The Facts:** While health literacy is gradually improving in Australia (Australian Bureau of Statistics, 2006) the public is overly optimistic and uninformed about the effectiveness of end of life care treatments (Swerissen et al. 2014). This is particularly the case for Australians aged over 65 whose health literacy is generally lower than that of younger generations (Australian Bureau of Statistics, 2006).

Films and the media present misinformation to the public about the rate of success of treatments like CPR when actors quickly recover on screen (Diem et al. 1996). In reality, most people only get detailed information about end of life treatments and services when they experience the death of a family member or friend. Given the extended life expectancy of people today, some adults may not encounter the death of a friend or family member until later in life.

There is also a wider problem: that the acknowledgement of the inevitability of death, and preparation for it, have largely lost their place in our culture (Ashby et al. 2005). Historically, end of life care would have been provided by family members and the patient's immediate community. In contrast, patients today are increasingly reliant on healthcare and medical systems to provide end of life care (Horsfall 2012).

### 2. Myth: Advance care planning only covers medical treatments that the patient does or doesn't want

**The Facts:** An advance care planning process may cover all elements and decisions related to end of life care or ongoing management of a condition. This may include:

- Appointment of a medical treatment decision maker
- Acceptable health outcomes and preferred levels of treatment
- Values and beliefs
- Medical treatments
- Palliative care (including care in the terminal phase)
- Spiritual care
- Location of death (e.g. hospital, aged care home, patient's home etc.)
- Family members and friends present at death

For example, research consistently shows that between 60-70% of Australians would prefer to die at home (Swerissen et al. 2014). Instead, approximately 14% of people die at home, 54% die in hospitals and 32% die in residential care (Broad et al. 2013).

Where the patient records their preference to die at home in an advance care directive, clinical staff can consider accommodating this preference in practice by making medical treatment decisions that will safely enable this outcome. For example, clinical staff may explore and acquaint themselves with their local services to enable the patient to spend the end of their life at home.

A patient's preferences in their advance care directive, such as a preference to die at home, should be acknowledged by clinical staff, as it may influence the medical care decisions made by treating doctors.

### 3. Myth: The doctor's role in end of life care is always to prolong life

**The Facts:** The Medical Board of Australia states that good medical practice involves understanding that doctors do not have a duty to try to prolong life at all cost. However, doctors do have a duty to know when not to initiate and when to cease attempts at prolonging life, while ensuring that their patients receive appropriate relief from distress (MBA Code of Conduct, 3.12.4).

To quote Hippocrates, the purpose of medicine is "To cure sometimes, treat often, comfort always". Patients need doctors to apply a holistic focus to end of life treatment. This means reviving patient-centered care, and implementing the wishes of the patient, which may be to prolong life, or refuse, or withdraw treatment, and provide effective palliative care (Keon-Cohen 2013).

### 4. Myth: Advance care planning conversations should only be initiated by a doctor when the patient begins to deteriorate medically

**The Facts:** Ideally, advance care planning discussions will take place when the patient is medically stable, thinking clearly, comfortable and, if applicable, has had time to adjust to changes in their condition or prognosis.

While the process of advance care planning may be conducted commonly in the context of serious medical illness, the process should also be initiated with a healthy patient by encouraging a focus on living and staying well. Doctors are encouraged to engage in conversations with patients well before any diagnosis, and where relevant, explore earlier patient triggers such as having a baby, writing a will, and attending a 45-49 year old health assessment.

→ **View Modules 3.2, 3.3 and 3.4 for a list of 'triggers' for discussing advance care planning with patients in the GP practice, hospital and aged care facility settings**

### 5. Myth: Advance care planning has to be completed all in one go

**The Facts:** The process of advance care planning is an ongoing one. It can be initiated at certain 'trigger' points in the patient's treatment and care. It is most likely that the patient will require a number of meetings with the treating doctor, medical treatment decision maker, family members and other relevant people before a plan is completed.

The best way to help with the development of an advance care directive is to start the conversation with the patient and follow up on progress at future routine consultations.

*Remember: every conversation counts.*

## 6. Myth: The advance care planning process is a conversation and does not need to be written down

**The Facts:** Advance care planning can be verbal or written. For some patients, having a verbal conversation about their future medical care and personal care with doctors, medical treatment decision maker, family members and friends may be sufficient, however, these conversations should be documented for future reference.

A lack of a written document could give rise to genuine and reasonable doubts about applicability. This may cause uncertainty about its use in clinical decision making. Therefore it is always preferable for the patient and the healthcare staff to document all discussions about advance care planning in writing. If the person chooses, this may be in an advance care directive, which may contain binding instructional directives.

Creating an advance care directive also helps to clarify the patient's intentions and ensures that any ambiguities are addressed early on.

→ **View Module 5 for more information about how to record an advance care plan.**

## 7. Myth: Once an advance care directive is completed, it cannot be changed

**The Facts:** Review of advance care planning can be undertaken at any time while the patient retains decision-making capacity. Review is encouraged and important because patients may refine their goals for treatment and care during the course of their lives and their illnesses (Michael et al. 2013). Conversely, the advance care directive may also demonstrate a patient's consistent position over time. Ensure that information contained in an advance care directive is up to date, as this will make it easier for treating doctors to assess

→ **View Module 6 for more information about how and when to review an advance care plan**

## 8. Myth: Doctors are not protected if they implement an advance care directive to withhold or withdraw treatment

**The Facts:** Good medical practice involves understanding the limits of medicine in prolonging life and recognising when efforts to prolong life may not benefit the patient (MBA Code of Conduct 3.12.3). While doctors do not have a duty as a doctor to try to prolong life at all cost, they do have a duty to know when not to initiate and when to cease attempts at prolonging life, while ensuring that their patients receive appropriate relief from distress (MBA Code of Conduct 3.12.4).

If a patient has lost decision making capacity to communicate their instructions regarding treatment, and has a current **advance care directive** containing a relevant instructional directive to withhold or withdraw treatment, doctors must withdraw treatment in accordance with the person's refusal of treatment.

The *Medical Treatment Planning and Decisions Act 2016* provides an express protection for a health practitioner who, in good faith, does not (or does) administer treatment in accordance with a valid advance care directive.

→ **View Module 2.5 for information about good medical practice**

→ **View Module 2.4 for information about health practitioner liability**

*Remember: "there is no obligation to provide non-beneficial treatment and such treatment cannot be demanded by the patient or their family" (Skene 2004).*

## 9. Myth: Only doctors who work in palliative care settings need to worry about advance care planning

**The Facts:** The Medical Board of Australia Code of Conduct (3.12.8) states that all doctors have a vital role in assisting the community to deal with the reality of death and its consequences.

It is vital that advance care planning conversations are introduced earlier in the patient's health trajectory by doctors across Victorian health services. This is because by the time the patient enters the palliative care setting they may no longer have the capacity to have conversations about their preferences. All doctors have a legal obligation to implement an advance care directive previously created by the patient when they had capacity, who has subsequently lost decision-making capacity.

## 10. Myth: Implementation of an advance care directive replaces the need for communication with the patient and their family or carers

**The Facts:** Communication with the patient, medical treatment decision maker (if the patient does not have decision making capacity), family members and carers is key to every stage of the advance care planning process. It is important to communicate effectively and meaningfully during implementation of an advance care directive, including providing reasons behind decisions not to provide, or to cease treatment.

Good medical practice involves effective communication about treatment or poor prognosis at key decision-making points in the patient care pathway. This may establish a solid foundation for effective communication during the patient's end of life, and reduce complaints relating to end of life care (Australian Commission on Safety and Quality in Health Care, 2013).

The Medical Board of Australia Code of Conduct (3.12.6-7, 3.12.9-11) requires doctors to:

- strive to communicate effectively with patients and their families so they are able to understand the outcomes that can and cannot be achieved;
- take reasonable steps to ensure that support is provided to patients and their families when it is not possible to deliver the outcome they desire;
- communicate bad news to patients and their families in the most appropriate way and provide support for them while they deal with this information;
- respect different cultural practices related to death and dying; and
- when your patient dies, be willing to explain, to the best of your knowledge, the circumstances of the death to appropriate members of the patient's family and carers, unless you know the patient would have objected.