Advance care planning: have the conversation

Module 4: Develop – How to have the conversation
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**Healthcare settings:** GP practice, hospital, aged care

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

**Time:** 20-25 mins
4.1 Be a good communicator

- Advance care planning conversations need to take place on more than one occasion (over days, weeks, even months) and should not be completed on a single visit in most circumstances.
- Do not think of the conversation as a simple checklist exercise, take time and effort to engage with the patient. Give the discussion your full attention.
- Conversations should not include medical jargon.
- Language should be positive to determine values, goals and preferences.
- Consider the literacy and health literacy of the patient, and adapt your communication style to suit the patient’s level of understanding.
- Build trust by using empathic listening skills, actively hear what the patient is saying about their preferences.
- Patients should be given realistic information on prognosis and treatment and personal care options with emphasis on how their illness is expected to impact on their daily function.
- Identify whether patients have specific desires for how information is shared among family members.
- If an interpreter is present, do not ignore the patient and speak only to the interpreter. Remember to communicate with the patient through eye contact and appropriate body language.

(Scott et al. 2013)
4.2 A 10-step guide to having the conversation

1. Be prepared
2. Introduce the purpose of advance care planning
3. Introduce the potential outcomes of advance care planning
4. Clarify the patient’s current health status
5. Discuss the patient’s fears and expectations
6. Discuss the patient’s quality of life priorities and goals of care
7. Encourage the patient to appoint a medical treatment decision maker
8. Encourage the patient to write it down
9. Confirm the patient’s understanding
10. Provide materials and emphasise the importance of future review and ongoing conversations

4.2.1 Be prepared

• Where possible choose a private, quiet space, and allow time. Try not to have the conversation in emergency situations.
• Turn your phone off, or on silent if this is possible.
• Inform yourself: have the patient’s medical file in front of you so that you can address any existing or future medical concerns the patient may have during discussions.
• Download or have ready written resources for the patient about advance care planning that they can take away to read.
• Ask the patient whether they would like to involve family members in the discussions. Only invite family members to participate in conversations about advance care planning where this has been approved by the patient.
• For patients, medical treatment decision makers or family members present who are not fluent in English, arrange an independent, accredited interpreter well before the appointment. Be sure to let the interpreter know prior to the discussion that the conversation will be about advance care planning and end of life decision making.
• Aim to involve any existing appointed medical treatment decision makers in all discussions. The medical treatment decision maker can be involved by telephone if they are not able to be present at the time of the discussion. If this is not possible, encourage the patient to inform others about their advance care preferences or any existing plan so that all clinicians and family members involved in the patient’s care and medical decision making are aware of their preferences.
4.2.2 Introduce the purpose of advance care planning

The following recommended phrases are excerpts from Clayton et al 2007; Department of Health 2014; ANZICS 2014; Gawande 2010.

Introduce the purpose of advance care planning and describe simply and clearly what it is to the patient and to any other relevant people that the patient decides should be part of the conversation.

Relevant to patients at the following stages:

✓ no disease
✓ early chronic disease
✓ chronic disease
✓ advanced disease
✓ end of life

“I try to talk to all my patients about what they would want if they become (more) unwell, or too sick to speak for themselves. Have you ever thought about this?”

“Sometimes having a plan that prepares you for the worst makes it easier to focus on what you hope for most.”

“When people get sick, sometimes they are unable to speak or communicate to their doctors or family members. You can choose to write down your wishes in an advance care plan, a letter, or talk to your family members or carers about your preferences. I can help and support you to create your own plan.”

“Advance care planning is a process you can use to plan for your future health and personal care. This is a list of your personal values, beliefs and preferences about the types of care that you would like to receive, if one day you can’t communicate these decisions.”

“An advance care directive doesn’t just cover the medical treatment that you would prefer, but also documents your own values and beliefs, spiritual care, and personal care. This might include for example the location where you would prefer to die (e.g. at home, in hospital, aged care facility etc.), and who and what you would like to be present (important people, pets, music, belongings).”
4.2.3 Introduce the potential outcomes of advance care planning

Describe the possible outcomes of the advance care planning conversation:

- The appointment of a medical treatment decision maker;
- Discussion and documentation of values and preferences; and/or
- Creation of an advance care directive.

**Relevant to patients at the following stages:**

✓ no disease  
✓ early chronic disease  
✓ chronic disease  
✓ advanced disease  
✓ end of life

“An advance care planning conversation may result in two outcomes: selecting a medical treatment decision maker to make decisions for you when you can’t communicate due to illness or injury, and writing down your values and preferences in an advance care directive.”

“A medical treatment decision maker is legally appointed by you to ‘stand in your shoes’ and make decisions they believe you would make in the circumstances. So if you become too unwell to speak to doctors and medical staff due to an illness or injury, we can speak to the medical treatment decision maker and they can tell us what you would have wanted.”

4.2.4 Clarify the patient’s current health status

**Relevant to patients at the following stages:**

✓ early chronic disease  
✓ chronic disease  
✓ advanced disease  
✓ end of life

“I would like to know more about your past experience of your illness.”

“I would like to know more about what you understand about your current condition.”

(If there are gaps in patient’s understanding)

“There are a few more things I would like to talk about relating to your condition that you may not be aware of...”

“Here is some more information about your condition to read in your own time.”
4.2.5 Discuss the patient’s fears and expectations

Relevant to patients at the following stages:
- early chronic disease
- chronic disease
- advanced disease

Surgeon and author, Atul Gawande, recommends using the following 4 questions to open discussions with the patient about their fears and expectations in relation to their condition:

“Do you know your prognosis?”

“What are your goals and fears about what is to come?”

“It’s often easier to talk through tough decisions when there isn’t a crisis. Have you thought about if things don’t go well?”

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

4.2.6 Discuss the patient’s quality of life priorities and goals of care

Relevant to patients at the following stages:
- chronic disease
- advanced disease

“I would like you to tell me what things in your life are most important to you, so that if you become unable to speak for yourself due to illness or an injury, I, or other healthcare workers will be able to use those goals and values as a guide to the medical treatment and personal care decisions we make on your behalf.”

“While we are hoping that things will go well with treatment...or be possible for....to occur, if by some chance you didn’t get better, what would be the most important things that you would want or need to do while you are still able to?”

“What shorter-term things would you like to achieve?”

“What is important for you to live well?”

Relevant to patients at the following stages:
- advanced disease
- end of life

“People who have an illness such as yours sometimes experience worries or concerns about how they will manage as their disease progresses. Is this something on your mind?”

“It is very difficult for any of us to contemplate our own death. Are there particular fears or issues concerning you about dying?”

“Have you had any thoughts about where you would like to be when you get sicker with this illness – Some want to die at home, others in a hospice, and others in hospital, where would you like to be cared for when you die?”
“When talking about dying, some people are very clear where they would want this to happen, who they would want there with them, including pets and personal belongings. Do you have any particular wishes?”

“If you choose not to receive certain treatments, this does not mean we will give up on you. On the contrary, we will continue to be extremely active and supportive in our care for you. It simply means that when death does eventually come, our focus will be on keeping you comfortable and supported rather than prolonging the dying period.”

4.2.7 Encourage the patient to appoint a medical treatment decision maker

Relevant to patients at the following stages:
✓ no disease
✓ early chronic disease
✓ chronic disease
✓ advanced disease
✓ end of life

“People are surprised to learn that there is a ‘medical treatment decision maker hierarchy’ that would inform doctors who could consent to treatment on your behalf if you were too unwell to speak for yourself. Would you like to see if you’re happy with the person who’s likely to be contacted according to the hierarchy?”

“The Office of the Public Advocate has information on appointing medical treatment decision makers to take care of medical and health decisions should you become unable to speak for yourself.”

They recommend to appoint:
- someone you can trust,
- who can act according to your interests and not their own,
- who is likely to be able to take on the role when it is needed,
- who is happy to take on the role, and
- who will listen to what you want and respect your preferences even after you have lost decision-making capacity.

“I encourage you to identify a person who would be able to speak on your behalf if you cannot speak for yourself. I also encourage you to then discuss your health and personal care preferences with that person to see if they would be willing to take on the role, and make sure they know what you would want.”

“If you would like me to facilitate a discussion between you and the person you want to appoint as your medical treatment decision maker, I would be glad to do that.”

“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?”

“Would this person know what you would want?”

“Have you spoken to the person who you want to make decisions for you?”

“Would you like to include them in these discussions, so they know what is happening and what might happen in the future?”
4.2.8 Encourage the patient to write it down

Relevant to patients at the following stages:

✓ no disease
✓ early chronic disease
✓ chronic disease
✓ advanced disease
✓ end of life

“Without a written advance care directive document stating your values and preferences, doctors and healthcare staff may be uncertain about what you want.”

“Ideally, advance care plans are written down to make sure that doctors and healthcare staff understand your preferences and preferred outcomes of care. This means that your values are clear and we can be sure that we are making the decisions that you would have wanted.”

“If you would like to, writing down your preferences yourself may assist you to define what things are most important to you. Here is an advance care plan template which you can have a go at filling out following on from our discussion today.”

“An advance care plan belongs to you, and you are responsible for making sure that all the relevant people have a copy of it. If you create an advance plan I encourage you to provide a copy of it to your substitute decision maker, family members (if appropriate), general practitioner, other treating clinicians and your local hospital. I can help you with this, if you would like.”

4.2.9 Confirm the patient’s understanding

Check back with the patient, and medical treatment decision maker if they are present, about their understanding of the advance care planning conversation and potential outcomes.

Relevant to patients at the following stages:

✓ no disease
✓ early chronic disease
✓ chronic disease
✓ advanced disease
✓ end of life

“I want to thank you for helping me understand your values and goals.”

“I would like to be sure that we agree on what we have discussed. Could you please describe for me in your own words what we have discussed?”

“Is there anything else you are concerned about in terms of your treatment, or would like more information about?”
4.2.10 Provide materials, emphasise the importance of future review and ongoing conversations

Relevant to patients at the following stages:
- no disease
- early chronic disease
- chronic disease
- advanced disease
- end of life

“I want to thank you for helping me understand your position if you should become (more) unwell. It has been very helpful to me.”

“I know that in the past, you may not have 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/another time?”

“I will save my notes of this discussion so that we have a record here.”

“These are discussions that we can revisit and build upon at any time if there are changes in the course of your health, and if you change your mind in the future.”
4.3 Manage conflict

There may be times when conflict arises as a result of advance care planning conversations, particularly towards the end of the patient’s life. This conflict may occur between the doctor and the patient, the patient’s family, carers and medical treatment decision maker(s). Below are some useful tips to assist you to prevent and manage conflict both during advance care planning conversations and when implementing the advance care plan.

Relevant to patients at the following stages:
✓ early chronic disease
✓ chronic disease
✓ advanced disease
✓ end of life

• Identify and recognise family discord as early as possible and make other members of the health care team aware if it is likely to affect the patient’s care.
• Suggest that the patient write down their preferences in their own words when they have a moment alone to help make it clear what they want for themselves.
• Offer meetings (on repeated occasions if needed) with the patient and/or key family members or caregivers to explore concerns and to try to increase understanding about the patient’s condition.
• Explore and acknowledge the emotional issues and concerns of the patient or caregiver that are not always expressed and that may result in frustrating communication barriers.
• If possible, negotiate a family spokesperson, preferably one nominated by the patient if feasible, who can communicate with the rest of the family.
• Preferably have someone with you (another health care professional or patient liaison officer) and document all discussions clearly in the notes.
• Openly negotiate with patients and family members to try to reach a mutually acceptable solution.
• Recognise limitations (i.e. you are unlikely to resolve longstanding family dysfunction).

Relevant to patients at the following stages:
✓ advanced disease
✓ end of life

• Allow the patient and family time to come to terms with the impending death of the patient.
• Continually focus on what is known about the patient’s values and preferences – “If [he/she] were able to talk to us, what do you think [he/she] would want?”
4.3.1 Avoid the term ‘futile’

Honest and open discussions about poor outcomes should be held with the patient 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 patient or family
- It can be influenced by the clinician’s own values
- It 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.

Instead, use language that describes the treatment as “not beneficial”, “overly-burdensome”, “likely to cause harm” or “not in the person’s best interests”. This enables clinicians to provide a clear message that the decision is about the effectiveness of the treatment, not the patient’s worth. This approach is also consistent with doctors’ common law duty to act in the patient’s best interests.

Where the patient’s family or carers believe that non-beneficial treatment is in the best interests of the patient, use language that describes the process as “allowing for a natural death to occur”. This phrase conveys that any non-beneficial treatment desired by those other than the patient may be denying the patient a peaceful death.

Relevant to patients at the following stages:

✓ advanced disease
✓ end of life

“I understand that you want us to do everything we can, but this treatment will not be beneficial or in [patient’s] best interests, as [patient] is now too sick to fully recover. Instead we would like to do everything we can to allow [patient] to die naturally and peacefully surrounded by the people who matter to [him/her] most.”

“We are becoming concerned that the burden of continuing this sort of treatment outweighs the benefit. I am afraid the treatment is not working.”

“We will do everything we can to ensure [patient’s] last days are as comfortable and dignified as possible.”

“We are recommending making comfort a priority and to stop doing things that are not helping.”

“We are recommending continuing good care while stopping treatments that are distressing and not helpful.”

Where these efforts are not successful and the conflict is affecting the patient’s care, consider arranging:

- a second opinion for the family, or
- a skilled communicator to facilitate a patient care conference, or
- a patient advocate if there are unresolved issues between health care professionals and the family or patient.
4.4 Explain the dying process and end of life treatments in plain language

The process of advance care planning facilitates open discussions about end of life care between doctors and patients.

Doctors are encouraged at first instance to engage in values-based discussions with the patient about their wishes and goals for their future.

A values-based discussion encourages the patient to identify their own goals and values in their own words, rather than specific information about medical treatments e.g. “I would like to attend my granddaughter’s wedding in March this year”, or “I need to walk my dog each day”, or “pain management is very important to me.”

Some patients may naturally be interested to know about their medical treatment options and the pros and cons of each type of treatment.

This guide is intended to inform patients who are interested to know more about end of life treatments and procedures, and should not be used at first instance by doctors to engage the patient in advance care planning conversations.

The following phrases are excerpts from Department of Health 2012; and Clayton et al. 2007.

Relevant to patients at the following stages:

✓ no disease
✓ early chronic disease
✓ chronic disease
✓ advanced disease
✓ end of life

4.4.1 Explain the dying process

• Explore fears and expel myths
• Consider explaining the likelihood of decreasing consciousness levels as death approaches
• Explain that they will gradually become weaker, needing longer rest periods and eventually become less conscious
• Promote understanding of the decreased need for fluid and foods, non-essential medications, routine observations, tests and investigations in the final days
• Consider reassuring patients and caregivers that dying will neither be inappropriately prolonged nor hastened by any treatments or medications given in the patient's final days

“In your final days, you may gradually go into a coma, which is like a deep sleep. However, it is not the same as sleep and going to sleep at night won’t make this happen any sooner.”

“Often what happens is that people become more and more drowsy, and less and less aware of what is going on around them. As far as we can tell, this is not distressing or frightening at all. If you do become distressed, however, we will do our best to ease this as quickly as possible. We will also be there for your family at this time to help support them if necessary.”

“We will not be measuring your blood pressure and pulse on a regular basis any more, but will be concentrating on relieving your symptoms.”
“Some tablets may not be of any help at this stage, and may be difficult to swallow.”
“ Intravenous fluids may be unlikely to alter the course of the disease and at this time they may pool in the lungs and make breathing more difficult.”
“ As the body slows and starts to shut down, you will naturally need less food, drink and medication.”
“ We will continue all the medications that are essential, but give them in a form that you can manage.”

4.4.2 Cardiopulmonary resuscitation (CPR)

Explanation of CPR
“This is a treatment that may be used if your heart and/or breathing suddenly stops. If the heart stops it is called a ‘cardiac arrest’. During CPR, pushing forcibly on the chest compresses the heart, circulating some blood, and air is pushed into the lungs by blowing into the mouth, allowing oxygen to be provided to the lungs.”

“In a hospital setting (or if an ambulance is called), in addition to CPR, emergency resuscitation will also involve a needle in a vein to deliver drugs to try and improve the heart function and often a tube down the throat to assist with getting oxygen into the lungs.”

“Electric stimulation of the heart, better known as defibrillation, may be used in hospital or by ambulance to try to return the heart rhythm back to normal. It does not start the heart as appears often on TV, but stops the irregular or erratic electrical activity of the heart that is preventing it from pumping blood.”

Likelihood of successful recovery
“If effective CPR is not provided within approximately five minutes of the heart stopping, it is likely that permanent brain damage will occur. If the heart and breathing cannot be restored, death will occur. If your heart stops and CPR is not provided you would remain unconscious and then you would die naturally.”

“Even if effective CPR is provided early, it is often not successful. Unlike what is seen on television programs, in real life less than 15% of people who receive CPR survive and return to their previous ‘normal’ life and ‘normal’ level of function. For many people with advancing age serious illness, such as cancer, chronic heart or lung problems and advanced dementia, the likelihood of success is much less, and may be close to zero. Unless the underlying cause of the problem can be corrected, further cardiac arrest will occur.”

Potential benefits
“The potential benefit of CPR is that it can stop the person from dying. This is more likely to be the case in generally reasonably healthy people who may have been involved in an accident, or drowning, or may have had a heart attack. If CPR is provided early and effectively, and if the person receives care to reverse the underlying cause of the problem, there may be a complete recovery.”
Potential negative outcomes

“The possible negative impacts of CPR in people who survive the resuscitation include broken ribs, they will usually need for a breathing machine and intensive care for a period of time afterwards, and CPR may result in permanent brain damage. Most people who survive will need a period of hospitalisation, which may be long, and they may never make a full recovery, or may die during this time. For most people who have serious medical illnesses and who are successfully resuscitated, it is usually temporary, and often the heart stops again. In many circumstances, CPR may only prolong the dying process.”

“In some cases, CPR has almost no chance of being effective. It might also mean that a patient can’t be with their family when they are close to death. In some cases, it can be better to allow death to come naturally and continue all treatments that are potentially effective for the person’s comfort instead.”

4.4.3 Artificial ventilation (breathing machines)

Explanation of artificial ventilation

“If you stop breathing, it may be possible to artificially support your breathing using a ventilator (breathing machine) and a tube which is either inserted via the mouth into the lungs, or into the windpipe (called a tracheostomy).”

“Ventilation would only be initiated in a hospital if it was expected that you had a reversible illness and would be able to breathe independently after this treatment.”

Likelihood of successful recovery

“This process is often required when there is a major illness or injury, and it may allow a person to be kept alive while the underlying problem is treated and recovery is occurring. This may be the case if someone has had a serious accident, or has developed pneumonia. In such situations, it would normally be short-term treatment, and many people make a good recovery.”

“There are other circumstances where the breathing may need to be supported long term. This may be the case in someone who has permanent severe lung disease, or may have a muscle disease such as motor neurone disease, or who may have had a permanent brain injury. Often in these circumstances, the person would have a tracheostomy and be connected to a ventilator. The ventilator may be connected 24-hours a day, or it may be possible to come off the machine for short periods of time.”

Potential negative outcomes

“For many people in this circumstance they may not be able to live at home, and they may not be able to swallow and eat normally, and may have difficulty speaking. The breathing machine does not treat the underlying cause of the breathing failure, and the disease may continue to progress and the machine may just prolong the dying process.”

“It is not always possible at the beginning of an illness to be sure what the likely long-term outcome is going to be. In such circumstances people may decide to begin treatment with tubes and breathing machines and see how things go. If it then becomes obvious that a reasonable recovery is not possible, it may be reasonable to stop the treatment, and allow death to occur in a peaceful way.”
4.4.4 Tube feeding

Explanation of tube feeding
“It is possible to insert a feeding tube via the nose into the stomach (naso-gastric tube), or directly into the stomach (PEG tube) so as to provide food and water. A chemically balanced mix of nutrients and fluid can then be provided via this tube.”

Likelihood of successful recovery
“There are circumstances where a feeding tube may be of benefit. These include illnesses (such as stroke) where swallowing is affected, either as a temporary measure where recovery is expected, or permanently where the ability to swallow will not improve enough to return to normal eating and drinking. In this circumstance, a person may feel that their quality of life is otherwise reasonable and they would like to have a long-term feeding tube.”

“There are situations where a feeding tube may not be appropriate even if there is a reduced intake of food and water. As part of the natural dying process there is a reduction in the feelings of hunger and thirst, and people may not wish to have much intake. Many people in this circumstance can swallow. This is often the situation in advanced cancer and dementia. In these circumstances the use of a feeding tube may not offer any overall benefit, as it cannot change the underlying disease processes, and usually does not stop death from occurring.”

Potential negative outcomes
“There are also usually side effects associated with tube feeding. These include the need to insert tubes, which can be uncomfortable, and may need to be replaced from time to time. Sometimes (especially in advanced dementia) there is a need to use medication to sedate a person, or physical restraints so that the person does not pull their tube out. Too much tube feeding can cause stomach distension and discomfort, fluid overload, and the risk of developing pneumonia is usually increased when a feeding tube is used. In some circumstances, for example dementia, a feeding tube may prolong the dying process.”

4.4.5 Dialysis (kidney machine)

Explanation of dialysis
“Normal kidney function is important for good health. Dialysis is used to assist and replace the function of failing kidneys by allowing waste products and excess fluid to be removed from the body. Dialysis is often provided through tubes that are surgically inserted into the arm that are then connected up to the kidney machine. This type of dialysis (haemodialysis) usually involves being connected up to the machine for several hours up to three times a week. In some people a tube can be inserted into the abdomen. Fluid is introduced, and then removed, and this allows the waste products to be removed (peritoneal dialysis).”

Likelihood of a successful recovery
“For some people it may be appropriate to commence dialysis, and see how the treatment progresses. If after a period of time their goals are not being met, it is possible for dialysis to be ceased. Upon cessation of dialysis it would be normal for waste products to build up in the body leading to coma and death, usually within one or two weeks. There may be some circumstances where it is expected that the kidneys will improve and dialysis could then be discontinued.”
Potential benefits
“The potential benefits of dialysis include the ability to prolong life, and also it may allow a person to feel better, and to be mentally more alert. It cannot however reverse the underlying abnormality that has caused the kidneys to stop functioning, and for many people is it likely to be a lifelong treatment.”

Potential negative outcomes
“There are a number of potential problems associated with dialysis. It can be time consuming, and cannot completely replace normal kidney function. Despite dialysis many people with kidney failure will have some ongoing symptoms. Often before dialysis occurs the person may feel unwell, and after dialysis occurs they may feel lethargic and fatigued. People receiving dialysis need to be very careful about their diet, and need to control their fluid intake.”

“Dialysis does not keep people alive indefinitely. It can be quite inconvenient for some people, and this can be a bigger issue if there are long distances to travel to dialysis centres.”

“Infection and discomfort at the site of the tube insertion can be a problem. In older people, especially those with other serious illnesses, dialysis may merely prolong the dying process.”

4.4.6 Palliative care

Explanation of palliative care
“Comfort care, supportive care, and palliative care all refer to the types of care that a person may receive. It includes medications such as pain relief and sedation, but may also include things such as attention to the environment (such as surroundings, music), spiritual needs, and social and psychological support, including who might be present to support you through the dying process.”

“Palliative care can begin from the first diagnosis of a non-curative illness. You and your family can begin palliative care when you need and want support. Your needs might change if the disease stabilises and palliative care services might be reduced or stopped until further needs arise.” (Palliative Care Victoria)

Useful considerations
“In treating any symptoms (pain, nausea, dyspnoea, fear, itch) it is important to be aware that all treatments have potential side effects. These can include increased drowsiness, sedation or confusion. These effects can also occur as part of the disease process. For some people this is acceptable, as their main focus is on complete control of their pain, but for other people there may be a preference for less pain control but preservation of alertness and the ongoing ability to fully interact with family and staff.”

“Palliative care has been demonstrated to lead to significant improvements in both quality of life and mood. As compared with patients receiving standard care, patients in one study who received early palliative care had less aggressive care at the end of life, but longer survival.” (Temel et al 2010)