Advance Care Planning in Palliative Care

Josephine M. Clayton, Tim Luckett, and Karen Detering

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Abstract

Advance care planning is a patient-centered process to enable a person to express his or her preferences for future healthcare. Advance care planning is an integral component of palliative care for people at various stages in the illness trajectory. This chapter provides an overview of advance care planning; the potential benefits, barriers, and facilitators; the key components of advance care planning at various stages of health; strategies for the advance care planning conversation; and areas for future research.

1 Introduction

Advance care planning is a process of supporting a person to express his or her preferences and priorities for future healthcare in consultation with healthcare providers, family members, and other people who are important to him or her. It typically includes a discussion about end-of-life care. It’s a patient-centered initiative that facilitates shared decision-making. It is highly relevant to palliative care and core business for palliative care providers.

Advance care planning as a concept has been around for decades, initially developing in the USA as a legal mechanism to guide use of end-of-life care interventions. Legally binding documents such as advance directives were established to allow a person to specify his or her preferences for medical treatments prior to losing capacity. However, various factors have limited the uptake of advance care planning.

This chapter explores definitions of various terms relevant to advance care planning, the benefits and evidence supporting advance care planning, the gaps in evidence and barriers to uptake of advance care planning, the advance care planning over the trajectory of health/illness, and the tips for advance care planning discussions in palliative care settings.

2 Definitions

2.1 What Is Advance Care Planning?

Two recently published international Delphi studies have been conducted to establish consensus around the definition of advance care planning. A European consensus process defined advance care planning as “the ability to enable individuals to define goals and preferences for future medical treatment and care, to discuss goals and preferences with family and health-care providers, and to record these preferences if appropriate” (Rietjens et al. 2017). Another international consensus process was led from the USA and defined advance care planning similarly as “a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness” (Sudore et al. 2017).
2.2 What Is an Advance Care Plan?

An advance care plan is the ideal outcome of an advance care planning discussion. Regardless of whether or not the person wishes to formally document his or her preferences in a legal way, the outcomes of advance care planning discussions should be documented to inform care provision. Advance care plans “state a person’s preferences about health and personal care, and preferred health outcomes. They may be made on the person’s behalf and should be prepared from the person’s perspectives to guide decisions about care” (Australian Commission on Safety and Quality in Health Care 2015).

2.3 What Is an Advance Directive?

An advance directive is a type of advance care plan. It is a formal document signed by a competent adult. It can record the person’s preferences for future care and include specific instructions, such as refusal of certain interventions. Other names used in various jurisdictions include advance health directive, advance care directive, living will, and medical directive. The legal standing of advance directives varies from country to country and state to state. In some Western countries, advance directives are supported by specific legislation (statutory advance directives) and are legally binding. In other jurisdictions advance directives may be recognized under common law. Advance directives only come into effect when the person loses capacity to make his or her own decisions.

3 Appointment of a Substitute Decision-Maker or Legal Healthcare Proxy

In many countries, people can formally appoint a trusted person to make medical decisions on their behalf should they lose capacity to do so. Substitute decision-makers have legal authority to make medical decisions on behalf of a person whose decision-making is impaired, with legislation varying between different jurisdictions. Various names are used for this role, such as enduring guardian, health attorney, medical agent, and guardian. This is usually different to a person appointed to make financial decisions (for whom terms include power of attorney).

4 Evidence/Benefits for Advance Care Planning

Patients cite the benefits of advance care planning as including preparation for end-of-life care and death, greater personal empowerment and hope, better medical care, avoidance of prolongation of dying, strengthening of personal relationships, and relieving burdens placed on family (Davison and Simpson 2006; Singer et al. 1995, 1999). Studies conducted in a range of healthcare settings suggest that advance care planning may improve patient and family satisfaction with care (Detering et al. 2010; Molloy et al. 2000), increase the likelihood of medical staff and family members’ understanding and complying with patients’ wishes for end-of-life care (Rietze and Stajduhar 2015; Houben et al. 2014; Martin et al. 2016), reduce hospitalization and aggressive medical care near death (Rietze and Stajduhar 2015; Martin et al. 2016; Khandelwal et al. 2015; Robinson et al. 2012), and increase palliative care and hospice use (Rietze and Stajduhar 2015; Robinson et al. 2012) and the likelihood of a person dying in his or her preferred place of care (Martin et al. 2016). Furthermore, advance care planning may also reduce levels of stress, anxiety, and depression in surviving relatives (Detering et al. 2010; Molloy et al. 2000; Silveira et al. 2010; Wright et al. 2008). At a clinician level, advance care planning can reduce moral distress related to decisions to withdraw treatment (Elpern et al. 2005). At a health system level, advance care planning has potential to increase cost-effectiveness by ensuring resources are not misspent on care that is unwanted or likely to be futile (Klingler et al. 2016; Dixon et al. 2015). Although evidence for benefit at a societal level is limited, improved bereavement outcomes in relatives.
seem likely to translate into quicker return to productivity both economically and socially.

5 Facilitators and Barriers to Advance Care Planning

While the range and extent of benefits demonstrated across the literature as a whole is impressive, there has been significant heterogeneity between studies. This finding has refocused attention away from the overarching question of whether advance care planning can have benefits toward a more nuanced analysis of which advance care planning elements may be more or less effective and in what contexts. Advance care planning is a “complex intervention,” as defined by the UK Medical Research Council, in that it has multiple interacting components, and is dependent on contextual factors for successful implementation (Medical Research Council 2006). Untangling the contributions of each component and contextual factor is challenging. However, research has identified a number of ingredients for success, as well as key problems.

5.1 Organizational Support

At the organizational level, systematic reviews suggest that advance care planning needs to be assigned due priority in terms of training, resources, and time and supported by an appropriate administrative system for communicating and reviewing advance care plans and monitoring adherence during end-of-life care (Gilissen et al. 2017; Travers and Taylor 2016; De Vleminck et al. 2013; Lovell and Yates 2014). Transitions between care settings (e.g., aged care and hospital) are especially disruptive to communication about advance care planning and other aspects of care (Coleman 2003). Ensuring advance care plans are kept up to date improves clinicians’ confidence that they represent the person’s current wishes; as concern that the person may have changed his/her mind since the plan was written is a common barrier to adherence. Other system-level approaches to advance care planning include embedding it into routine care (e.g., on admission) to ensure it is consistently offered; however, care is needed to ensure advance care planning is individualized to each person’s needs rather than takes a “one-size-fits-all” approach. A further “double-edged” system-level approach is to defer advance care planning within an organization to one or more highly trained advance care planning specialist rather than allocate time and training to all clinicians. Although cost-effectiveness analyses are lacking, this approach may be less sustainable in cost terms and overlooks the importance of advance care planning occurring opportunistically within a trusting therapeutic relationship (Lund et al. 2015).

5.2 Clinician-Patient/Family Interaction

At the clinician level, good relationships with the patient and family involved are important, as are motivation, confidence, knowledge, and communication skills (Gilissen et al. 2017; Travers and Taylor 2016; De Vleminck et al. 2013; Lovell and Yates 2014). Clinicians may be uncomfortable with having “difficult conversations” about end-of-life care, even when they are competent communicators more generally. Difficulty with prognosticating often leaves clinicians uncertain about the best time to initiate advance care planning, with many concerned that they will undermine hope if they commence too soon. Even in the later stages of illness, clinicians may worry that patients aren’t psychologically “ready” to discuss end-of-life care, so they wait for patients to initiate the discussion rather than doing so themselves. In fact, research suggests that patients typically welcome the opportunity to take an active role in deciding future care, but may not be sufficiently aware of advance care planning to request it. Patients and families may also have limited knowledge about their disease and available treatments and be unaware that they have management choices, including the option to have no treatment at all. Limited health literacy and low education in general have been found to be barriers to advance care planning (Lovell and Yates 2014), requiring...
communication to be appropriately tailored for content, timing, quantity, and form, as well as checking for comprehension (Dy and Purnell 2012).

5.3 **Patient and Clinician Characteristics Associated with Increased Likelihood of Advance Care Planning**

The likelihood of advance care planning being undertaken is associated with higher patient age and having a cancer diagnosis (Lovell and Yates 2014), perhaps reflecting clinician assumptions about conditions under which a conservative care pathway may be more or less desirable. While advancing age may increase the likelihood of cognitive decline and need for health-related decision-making, age alone should not influence decisions to forego life-sustaining treatments. Similarly, while religious views, family roles, and community support may confer genuine reasons why advance care planning is less attractive to people from certain cultural backgrounds (e.g., African Americans (Sanders et al. 2016)), care is needed to ensure that mistrust in the health system is not a reason for exclusion, and concerns that advance care plans may be used to reduce costs are addressed where these exist. Culture may influence the attitudes not only of patients but also of clinicians, making them more or less likely to offer advance care planning (Frost et al. 2011). An experiential approach to advance care planning training may help clinicians reflect on their own attitudes and values to limit bias in their practice, as well as develop empathy for patients and skills for sensitive communication (Weiner and Cole 2004). Clinicians’ perceived norms may also be determined by their clinical experience, in turn dependent on their discipline and specialty. Multidisciplinary team meetings and case conferences have been used to ensure a diversity of professional perspectives, especially where considerations are complex, as in the context of multi-morbidity (Phillips et al. 2013).

5.4 **Substitute Decision-Maker Considerations**

With notable exceptions, patients typically prefer their substitute decision-maker to be a close family member (Kelly et al. 2012). However, the role can be burdensome, especially when the decision-maker is uncertain of his or her loved one’s preferences or feels unable to enact known preferences because of emotional ties, or when there are divided opinions among the family more generally (Vig et al. 2007; Lord et al. 2015). If decisional conflict is not addressed at the time, it can damage family relationships and complicate bereavement and recovery following the patient’s death. Addressing this problem requires skillful facilitation and support that, wherever possible, should engage with diverse perspectives across the family rather than focus only on the legal obligation to involve the substitute decision-maker.

6 **Who May Benefit from Advance Care Planning?**

Any adult may choose to start advance care planning when healthy before an unexpected health crisis. It may also be relevant for children with a life-limiting illness, although this is beyond the scope of this chapter. Advance care planning may be especially relevant for:

- People diagnosed with a life-limiting or chronic illness
- A person whose doctor would not be surprised if he or she were to die within 12 months
- Any person admitted to a residential aged care facility
- People 75 years of age or older
- Any person requesting to discuss advance care planning
- A person at risk of losing capacity to make decisions (e.g., due to progressive cognitive impairment)
7 Advance Care Planning Across the Trajectory

While advance care planning may be relevant for any adult, the approach and areas to be covered in an advance care planning discussion are different for people at different stages of the illness trajectory. Palliative care providers have various roles in the provision of advance care planning. This includes direct involvement in ongoing advance care planning and goals of care discussions with patients and families referred to palliative care services. Importantly it also includes provision of education and support for clinicians working in other settings to facilitate advance care planning discussions with their own patients, and an advocacy role in education of the public. The following section shows the authors’ recommendations for advance care planning across the trajectory of health.

7.1 Advance Care Planning for a Well Adult, Less Than 75 Years of Age

The main intervention for this population is public education and enabling family discussions about advance care planning. Health professionals do not necessarily need to be involved in the discussion. The key messages for this group are:

1. To prompt the person to consider who he or she would want to make medical decisions for him or her if he or she couldn’t speak for himself or herself in case of a sudden illness or injury. If this person is different from the person who would normally be consulted according to the hierarchy in their jurisdiction, then encourage the person to consider formally appointing a legal medical SDM. In some jurisdictions only legally appointed medical substitute decision-makers can refuse treatment on behalf of the person, which is another reason the person may wish to consider such an appointment.

2. Suggest they have discussions with key family members about the values, goals, and preferences they would want considered if they ever had a serious injury or were in a prolonged period of incapacity. For example, what makes worth living, what level of function and ability to do things would be acceptable to them, their funeral wishes, other things that would be important for their family to know if they died suddenly, and any wishes regarding organ donation.

It is also important for well adults to know they are likely to be called upon to have input into decisions for their family members when they are dying or incapacitated. Resources for enabling early family discussions about advance care planning are shown in Box 1.

Box 1 Advance Care Planning: Example Resources

**Resources for clinicians**

- ACP Australia [www.advancecareplanning.org.au](http://www.advancecareplanning.org.au)  
  - This includes elearning/workshop materials, fact sheets, legal information, webinars
- Canadian ACP website [http://www.advancecareplanning.ca](http://www.advancecareplanning.ca)  
  - Provides range of information and resources and educational materials for health professionals, consumers, and researchers
  - Provides range of information and resources and educational materials for health professionals and consumers
- Singapore ACP website [https://livingmatters.sg](https://livingmatters.sg)  
  - Provides range of information and resources and educational materials for health professionals and consumers

(continued)


7.2 Advance Care Planning for Someone with Chronic Illness or a Well Elderly Person

This group has a greater risk of dying, and/or risk of losing capacity to make healthcare decisions, than a healthy adult younger than 75, but they are not yet likely to be approaching the final months of life. For these patients, health professionals should proactively educate and “plant the seed” about advance care planning. Some key components of advance care planning for this group include:

- Asking the patient about his or her preferred substitute decision-maker; prompting the patient to consider legally appointing a substitute decision-maker, especially if his or her preferred substitute decision-maker is someone different according to the hierarchy in their state; and ensuring there is a record of the patient’s preferred substitute decision-maker in the medical record.

- Encouraging the person to consider an advance care planning discussion with his or her preferred substitute decision-maker, a health professional(s), and any significant others to help him or her reflect on his or her values and preferences if he or she were ever to be unwell to speak for himself or herself.

If the patient is ready to discuss advance care planning, a workbook or web resource (see Box 1) may help patient reflect on his or her wishes and guide the discussion. Regardless of whether or not the patient wants to complete an advance directive, it’s helpful to record a summary of where the discussion is up to in the medical record. It is also important that this documentation is accessible in emergency situations and at the time of transitions between care settings, for example, in the electronic medical record or in a patient-held medical record.

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**Box 1 (continued)**

- Provides training and resources for clinicians working in primary and chronic/complex care setting to initiate discussions about advance care planning and screen for older and/or chronically ill patients’ supportive and palliative care needs

**ACP workbooks or websites for consumers**

*Resources relevant for early discussions about ACP*

- Dying to talk discussion starter [http://dyingtotalk.org.au](http://dyingtotalk.org.au)
- Conversation Project [http://theconversationproject.org](http://theconversationproject.org)
- Singapore Advance Care Planning Workbook [https://livingmatters.sg](https://livingmatters.sg)
- ACP Australia [www.advancecareplanning.org.au](http://www.advancecareplanning.org.au)
  - Includes resources for patients and links to other websites. This includes resources in languages other than English

*Resources for more in-depth discussion about ACP*

- PREPARED [https://www.prepareforyourcare.org/](https://www.prepareforyourcare.org/)
- Canadian workbook [http://www.advancecareplanning.ca/resource/acp-workbook/](http://www.advancecareplanning.ca/resource/acp-workbook/)
7.3 Advance Care Planning for Someone Whose Health Is Deteriorating and Approaching the Last Months (or Weeks/Days) of Life

This is the population where palliative care providers are most likely to be involved in the discussion. If the patient is likely to have only months to live, the clinician should review what advance care planning discussions have already taken place and any advance care planning documents that have been completed. The person should also be provided a further opportunity to reflect on his or her priorities and try to establish a clear plan for the goals of care if/when the person’s health deteriorates. It is important to remember that, even if the patient likely has months to live, he or she may still wish to pursue disease-specific therapies. Questions suggested by Atul Gawande (2014) to help patients consider whether particular treatments are worthwhile for them include the following: “What is your understanding of the situation and its potential outcomes? What are your fears and what are your hopes? What are the trade-offs you are willing to make and not willing to make? And what is the course of action that best serves this understanding?”

If the patient is already in the final weeks or days of life, discuss “good dying” rather than offering interventions like CPR if he or she is unlikely to have therapeutic benefit. Explore the person’s preferred place of care during terminal phase and preferred place of admission if required.

For people whose health is already deteriorating (likely life expectancy is months or less), it is important to translate advance care plans into actionable medical orders that can transition across care settings in case of an emergency, e.g., Physician Orders for Life-Sustaining Treatment (POLST) or Medical Orders for Life-Sustaining Treatment (MOLST) forms, resuscitation plans and/or ambulance plans.

Once a person no longer has capacity to take part in decisions about his or her care, health professionals need to review any previously completed advance care plans and talk with the person’s substitute decision-maker(s) to ensure treatment plans are consistent with the person’s preferences and appropriate to his or her circumstances.

8 Tips for Advance Care Planning Conversations

The general aims of the advance care planning conversation are to:

- Establish who the person would like to speak for him or her, if he or she ever became unable to speak for himself or herself
- Ensure the person understands his or her medical situation to the level that he or she wishes
- Explore the person’s
  - Values, beliefs, goals, fears, and concerns relevant to his or her current and future care
  - Concept of a “reasonable outcome” or health state (if appropriate and the person health is not already approaching the final days of life)
- Determine if there are any treatments that a person does, or does not want now or in the future
- Explore any other wishes the person may have about his or her care in the future and at the end of his or her life
- Facilitate documentation of the person’s wishes in an advance care directive if he or she wishes and/or document any verbal wishes in his or her electronic and paper medical record

General recommendations for advance care planning discussions are shown in Table 1. Further strategies and example questions and phrases for advance care planning discussions are shown in Table 2. Other resources that may be useful are shown in Box 1.

The key to initiating advance care planning is to sensitively offer to discuss the topic. Describe simply and clearly what advance care planning is. Give a rationale for why having these conversations may be helpful for the person, their family, and the healthcare team. While it is important
### Table 1  Summary of recommendations for discussing advance care planning and end-of-life issues with patients with advanced life-limiting illnesses and their families, modified from the PREPARED framework

<table>
<thead>
<tr>
<th>Prepare for the discussion, where possible</th>
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<tbody>
<tr>
<td>Confirm the clinical situation and appropriate treatment options</td>
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<td>Try to ensure privacy and uninterrupted time for discussion</td>
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<td>Mentally prepare yourself</td>
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<td>Gauge the person’s readiness to discuss his or her future care</td>
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<td>Negotiate who should be present during the discussion</td>
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<tr>
<th>Relate to the person</th>
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<tr>
<td>Introduce yourself and explain your role and develop rapport</td>
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<td>Show empathy, care, and compassion during the entire consultation</td>
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<td>Consider cultural and contextual factors which may influence preferences</td>
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<td>Use appropriate body language and actively listen</td>
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<th>Elicit patient preferences</th>
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<tr>
<td>Clarify the patient’s or caregiver’s understanding of their situation, and how much detail they want to know, before giving new medical information</td>
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<td>Identify the patient’s preferred substitute decision-maker (if not already identified)</td>
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<td>Elicit the patient’s goals, values, and beliefs relevant to the discussion</td>
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<tr>
<td>Elicit the patient’s priorities for care and preferences regarding current and future treatment</td>
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<tr>
<td>Explore the family’s concerns and priorities where applicable</td>
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<tr>
<td>Summarize the patient’s (and family’s) most important priorities and check if you have it right</td>
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<tr>
<th>Provide information tailored to the individual needs of both patient and their family</th>
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<td>Ask permission to discuss what to expect</td>
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<td>Pace and tailor delivery of information about the clinical situation and prognosis to the patients’/families’ current understanding and wish for information</td>
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<td>Use clear, jargon-free, understandable language</td>
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<td>Explain uncertainty, limitations, and unreliability of prognostic information</td>
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<td>Consider offering recommendations for the patient’s medical care that are clinically appropriate and align with the patient’s priorities</td>
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<tr>
<th>Acknowledge emotions and concerns</th>
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<td>Explore and acknowledge the patient’s and caregiver’s fears and concerns and their emotional reaction to the discussion</td>
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<td>Respond to the patient’s or caregiver’s distress regarding the discussion, where applicable, and consider their needs for additional support</td>
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<tr>
<td>Acknowledge your own emotions – discussing end-of-life issues is challenging</td>
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<th>Realistic hope should be fostered (e.g., peaceful death, support):</th>
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<tr>
<td>Be honest without being blunt or giving more detailed information than desired</td>
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<td>Do not give misleading or false information to try to positively influence a patient’s hope</td>
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<td>Reassure that all support and care will be given to control pain and other symptoms</td>
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<tr>
<td>Explore and facilitate realistic goals and wishes and ways of coping on a day-to-day basis, where appropriate</td>
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<th>Encourage questions and further discussions</th>
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<td>Encourage questions and information clarification; be prepared to repeat explanations</td>
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<td>Check understanding and if information provided meets needs</td>
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<td>Leave the door open for topics to be discussed again in the future</td>
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<th>Document</th>
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<td>Assist the patient to document his or her wishes in an advance care directive if desired and/or the formal/legal appointment of a substitute decision-maker</td>
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<td>Write a summary of what has been discussed in the medical record</td>
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<tr>
<td>Speak or write to other key healthcare providers involved in the patient’s care. As a minimum, this should include the patient’s general practitioner</td>
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Table 2  Strategies and example questions and phrases for advance care planning discussions

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Example phrase or question</th>
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<tr>
<td>Describe simply and clearly what advance care planning is. Give a rationale for why these conversations can be helpful for families and the healthcare team</td>
<td>“Have you thought about the type of medical care you would like to have if you ever become too sick to speak for yourself? This is the purpose of advance care planning to ensure that you are cared for the way you would want to be, even when communication may be impossible.”</td>
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<td></td>
<td>“Have you ever talked about your wishes, values, and beliefs about medical treatment and care in case you were ever injured or became too ill to speak for yourself?”</td>
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<td>“It’s often easier to talk through tough decisions when there isn’t a crisis”</td>
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<td>“Is this something that you would like to discuss further?”</td>
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<tr>
<td>Involve the potential proxy decision-maker in the discussions and planning so that he or she understands the patient’s wishes</td>
<td>“Sometimes people with your type of illness lose the ability to make decisions or communicate their wishes as the illness progresses. Who would you like to make decisions for you if you were unable to do this yourself?”</td>
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<td></td>
<td>If the person can identify a substitute:</td>
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<td></td>
<td>“Have you spoken to this person about what would be important to you about your care if you were very ill?”</td>
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<td></td>
<td>“Would you like to talk this through with them?”</td>
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<td></td>
<td>“Would you like me to assist you with this?”</td>
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<td>Use open-ended questions to develop an understanding of the patient’s values and to help him/her to work out goals and priorities related to their remaining life and treatment of the illness, and document the patient’s preferences</td>
<td>“What is most important to you now (or regarding your care in the future)?”</td>
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<td>“What aspects of your life do you most value and enjoy?”</td>
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<td>“When you look at the future, what do you hope for?”</td>
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<td>“What concerns you?”</td>
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<td>“Do you have any thoughts about how you would like to be cared for in the future if you became more unwell?”</td>
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<td>“How would you want decisions regarding your care to be made?”</td>
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<td></td>
<td>“Is there a specific person that you would like us to speak to?”</td>
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<td>“Is there anything you worry about happening?”</td>
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<tr>
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<td>“What would you not want to happen to you in terms of your care?”</td>
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<td>“Are there any situations where you would regard life-prolonging treatments to be overly burdensome?”</td>
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<td>“Is there anything else you would like me to know about your values and priorities for care if you were very unwell?”</td>
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<tr>
<td>Consider using clinical scenarios to structure the discussion, particularly if the patient is still at an early stage of his or her illness</td>
<td>Consider referring to an advance care planning workbook; see consumer resources in Box 1</td>
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<tr>
<td>Emphasize that advance care planning is an ongoing process that will need to be reviewed and updated periodically, as the patient’s wishes may change over time, particularly with major health changes</td>
<td>“These are discussions we may need to revisit if there are changes in the course of the illness”</td>
</tr>
<tr>
<td>Ensure that other health professionals who are involved with the patient’s care are aware of the patient’s wishes. If an advance care directive is completed, make sure its</td>
<td>(continued)</td>
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</table>
to be proactive about initiating advance care planning discussions, it is also important to give the patient the option not to discuss it or to defer the discussion to another time if he or she prefers. Not all patients want to discuss and plan for future care. If the patient does not currently wish to discuss the topic, raise it again when the person’s condition or situation changes. Some patients prefer their families to be involved in such discussions on their behalf.

Subsequent steps in the advance care planning discussion include (Johnson et al. 2016):

- Assessing the patient’s and/or family’s readiness to discuss future care
- Exploring the patients’ understanding of their medical situation and any unmet information needs
- Providing information as appropriate to the person’s information needs and medical situation
- Exploring the patient’s values, goals, priorities, hopes, fears, and concerns for the future
- Exploring if there are any situations, treatments, or health states the patient would find unacceptable
- Summarizing your understanding of the person’s most important wishes for future care
- Considering any other specific treatment options relevant to the person’s circumstances that may need to be discussed
- Considering offering to make a recommendation for future medical care, if the person were to become too sick to speak for himself or herself, based on his or her values and wishes
- Helping the patient to document his or her wishes

Discussions about advance care planning can be thought of as a process that unfolds over many conversations and which evolves as the person’s illness progresses. Preferably such discussions should commence prior to illness onset or early in the course of a life-limiting illness and revisited over time. A hypothetical question can be a useful way of gently initiating advance care planning discussions for patients who are still very focused on treatments for their underlying illness, for example, “While we are hoping that things go well with this treatment, if by some chance you didn’t get better, what would be most important to you?” Phrases such as “we can hope for the best at the same time as preparing for the rest” may be useful. When patients or family members ask for treatments that you do not think will be beneficial, the use of an “I wish” statement can allow the clinicians to align themselves with the patient, being supportive as well as being honest (give reference), for example, “I wish that treatment would help. I am concerned in your case that it would make you more unwell rather than better.”

9 Future Research Directions

Much more research is needed to help us better understand how to optimally deliver advance care planning. The following are suggested as topics in particular need of research.

A wide range of tools have been developed to help with clarifying risks and benefits of treatment and eliciting patient preferences based on his or her values, but evidence is limited regarding their efficacy (Cardona-Morrell et al. 2017).
Certain populations have particular advance care planning needs that warrant special attention. For example, more research is needed into ways of involving people with dementia in advance care planning to whatever extent is possible.

While preferences for end-of-life care are relatively stable over time in people with advanced life-limiting illness versus earlier in the disease trajectory (Auriemma et al. 2014), more research is needed to explore why preferences change in a minority of patients and to confirm the utility of written advance care plans for future decision-making. Likewise, further research is needed to determine the best ways to support and prepare substitute decision-makers for their role in future decision-making on behalf of a patient.

Rapid development in information and communications technology (ICT) affords exciting opportunities for advance care planning, including interactive tools to support decision-making and clarify values and preferences, as well as means of digitally recording, updating, and sharing advance care plans (Ostherr et al. 2016; Oczkowski et al. 2016; Luckett et al. 2015). There have even been a number of national initiatives linking advance care plans with electronic health records to improve accessibility at the point of care and enable regular updates (e.g., Australian Government Department of Health 2016). From the clinician user perspective, ICT solutions present an opportunity to see how plans may have changed over time and, when integrated with other electronic health systems, prompt on when to review plans with the patient (Huber et al. 2017). Evidence to date has largely been limited to processes (i.e., whether advance care planning was undertaken) rather than whether interventions improved end-of-life care.

Further evidence is also needed concerning the processes of advance care planning and mechanisms by which these translate into improved outcomes. For example, there is only low-level evidence that documentation of advance care plans or directives prompts clinicians to further discuss end-of-life care with patients rather than assume that no further discussion is needed (Lewis et al. 2016). Recent rhetorical emphasis on the importance of the advance care planning process over documentation has yet to be matched by research showing how the quality of the process – however measured – influences end-of-life care received.

Given established evidence for benefits from advance care planning versus usual care, head-to-head comparisons are now needed to evaluate the most cost-effective approaches in terms of clinician training (Chung et al. 2016), role allocation within multidisciplinary teams (Rietze and Stajduhar 2015), and intensity/frequency of initial advance care planning discussion and review. Evaluations of cost-effectiveness need to take into account the full extent of costs and benefits from the perspectives of the patient, healthcare system, and society, including any impacts on burden for informal carers and requirements for community-based care (Klingler et al. 2016; Dixon et al. 2015; Weathers et al. 2016).

10 Conclusion and Summary

Advance care planning is a core skill for palliative care professionals for direct care provision, to provide support and education for other clinicians involved with caring for patients with life-limiting illnesses, and as part of our role as advocates for improving end-of-life care more broadly in the community. This chapter has provided tips for advance care planning discussions across the disease trajectory. Evidence suggest that advance care planning can improve outcomes for patients and families and improve satisfaction with care. Nonetheless there remain many unanswered questions about the best ways to implement advance care planning in practice. Further work is needed to ensure that patient preferences that are discussed during advance care planning discussions are made readily available and able to assist decision-making at the point of care and to equip caregivers to be adequately prepared for their substitute decision-making role.
References


