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Chapter 2

Facilitating Basic Advance Care Planning Discussions

Developing your skills as a facilitator of the advance care planning process is critical to achieving successful outcomes. Depending on your experience, background, and profession, you may have strengths in certain skills and need improvement in others. Developing competency as a facilitator also takes experience in the application of these skills within the context of real-world situations. It will be necessary to practice new skills by assisting family and friends in having advance care planning discussions. You may also find it helpful to ask a mentor experienced in advance care planning to observe you in action and provide immediate feedback on the effectiveness of your skills.

The development of any skill requires baseline knowledge. This chapter will begin by reviewing the reasons why it is difficult for individuals to participate in advance care planning, why it is an important discussion, and some useful guidelines in assessing decision-making capacity. Next, this chapter will focus on the skills of facilitating basic advance care planning discussions with some reflections on the impact of culture and religion on end-of-life decision making. The chapter will conclude with frequently asked questions.

Advance Care Planning: Why is This a Difficult Discussion?

There are a variety of reasons that make initiating advance care planning discussions difficult. Discussing end-of-life treatment decisions forces us to directly recognize our mortality. For this reason many individuals, including health professionals, would rather avoid the topic. Asking an individual if there might be a circumstance when they would rather be allowed to die than be maintained by medical treatment is difficult to ask and to hear. As health professionals, we may mistakenly focus on dying rather than asking the question, “How would you want to live well near the end of your life?” Ultimately, the fear of death and its unknown cannot be changed, but living as well as possible can be.
Often one of the most challenging issues for an individual is the unwillingness of other family members to discuss end-of-life issues. One of the vital roles of the advance care planning facilitator is to create a climate in which a family unit can comfortably explore goals, values, and beliefs. Another barrier to end-of-life treatment discussions is the fear of intimacy. Revealing one’s thoughts about dying and medical treatment at the end of life quickly reflects one’s central values and beliefs. One could feel forced to reveal a lack of faith in an afterlife, how death would get them out of a desperate situation, or some other private view. For others who have never felt comfortable or safe revealing private beliefs, these discussions may be threatening or impossible. Fear can become a major barrier to sharing preferences about end-of-life treatment choices. Taking time to explore these issues when individuals are relatively healthy is more productive than attempting to do it during a medical crisis.

While we can appreciate that initiating advance care planning discussions may be uncomfortable, we also know that most individuals desire and expect it. With practice and experience, advance care planning facilitators develop a vocabulary for talking about goals, values, and beliefs, and end-of-life decisions. As this vocabulary becomes as natural as the medical jargon used in everyday practice, an environment of support, comfort, and encouragement is created. Individuals are invited to participate in the advance care planning process by taking the time to understand, reflect, and discuss the multiple issues involved. Remember that in order for informed decisions to be made, people must first realize there is a need (readiness to learn), understand the choices unique to their health status (receiving information), and then be able to translate their decisions into specific preferences (advance directive).

Basic Advance Care Planning for Any Adult: Why is it Important?

Many adults do not see the importance of participating in advance care planning if they are healthy. One of the challenges for advance care planning facilitators is to develop strategies to engage and to motivate the healthy adult to view this process as a part of routine planning that everyone should begin.

Although many adults may avoid participating in advance care planning, they express fears and opinions about healthcare decision making. Many people worry about being kept alive if they are in a terminal condition—being kept alive if they will die regardless of what treatments are provided. Two points must be kept in mind when using the term *terminal illness*. First, because of increasing technology, it has become more difficult to determine when someone is going to die, when someone has a *terminal illness*. Often the best that a physician can predict is that it is unlikely that a patient will survive, or that the patient has only a 5% chance of survival. Secondly, if it becomes clear that survival is impossible, and a
patient is not likely to live for a long period of time, advance directives may be helpful, but not as crucial as in situations where an individual’s survival is possible but recovery is not.

Adults may also have opinions regarding loss of function, such as not wanting to live if they became unable to perform some type of daily activity. They may require information on the options and adaptations to living with a disability or in a condition that allows for prolongation of life without recovery, called a persistent vegetative state (PVS). This is a specific clinical diagnosis indicating higher brain function is gone but the brain stem, or lower brain, is intact. The intact brain stem allows for the coordination of basic body functions like heartbeat and respiration, but without the higher brain functions of thinking, feeling, or hearing. Survival for years—or even decades—is possible with 24-hour nursing care and artificial nutrition and hydration.

An additional concern for any adult is the possibility of a devastating stroke, head injury, or other brain disease that results in neither death (by brain death criteria) nor PVS. When questioned about such statements as “Don’t keep me alive if I’m a vegetable,” most people mean that if they were permanently damaged and could not effectively interact with others or their world, they would want all supportive medical treatment to stop. However, some would choose that their biological life be prolonged, regardless of their ability to interact with their environment.

The purpose of basic advance care planning, therefore, is to help adults plan for unexpected events, such as sudden illness or injury, that renders them incapable of making healthcare decisions and from which they are unlikely to recover. This process provides an opportunity for adults to express goals, values, and beliefs about living well and to offer guidance to those who will be making healthcare decisions on their behalf.

**Determining Decision-Making Capacity**

Participating effectively in advance care planning discussions, making informed choices, and executing a written advance directive requires a capable adult. Confusion may exist between the words competence and capacity. Competence is a legal term: an adult is assumed competent unless a court rules he or she is incompetent. Capacity, on the other hand, is a clinical term and is determined by health professionals in the clinical setting by assessing decision-making capacity.

Assessing decision-making capacity is important for three reasons:

1. Capable adults always make their own decisions; it is not their documents that make decisions.

2. An advance directive document is valid only if completed by a capable adult.
3. Advance directive documents become relevant only in the event that patients are determined to have lost the ability to make their own decisions.

The ability to assess decision-making capacity or to recognize when referral for such an assessment is needed is an important responsibility of advance care planning facilitators and other health professionals. This determination is crucial when assisting in the creation of an advance directive document, when assisting patients who do not have advance directives to make healthcare decisions, and when deciding when patient preferences on a written document should be honored.

Assessing capacity is not always easy or straightforward. It may require referral to professionals who have developed considerable skill in this area. However, health professionals and advance care planning facilitators should understand the components of decision-making capacity and learn to gather data from the patient that may assist with this determination. Decision-making capacity includes the following four components:

1. The ability to understand that one has authority—that there is a choice to be made.
2. The ability to understand information (the elements of informed consent).
3. The ability to communicate a decision and the rationale for making it.
4. The ability to make a decision consistent with one’s values and goals that remains consistent over time—or to be able to explain why one’s values have changed.

The implications of the outcomes of this assessment are twofold: (1) As long as people are capable, they will continue to be informed about options and asked to make decisions, even though an advance directive has been completed, and (2) The advance directive will not become relevant unless the patient is assessed as incapacitated. In the first instance, health professionals must remember that an advance directive is a dynamic document that may need revision as changes in medical condition occur or when, as a part of an ongoing conversation, the patient expresses concerns or doubts. The information in the advance directive provides the health professional with the opportunity to continue with the advance care planning process and to honor a patient’s changing preferences.

In the second instance, when the patient is assessed as incapacitated and has completed an advance directive, the document can be activated, meaning the preferences stated in the written document can be applied to treatment decisions. This process requires a determination according to state statute (or regulation/regional standard of care) that the patient is now incapable. Some organizations choose to document this process on an activation form placed in the medical record. The mechanism through which a patient’s decision-making capacity may be reassessed and the advance directive deactivated must also
be clearly defined. It would be a mistake to assume that once a patient is determined to be incapacitated that determination could never be reversed. To optimize the assessment of decision-making capacity, it is important to:

1. Assess for the presence of external factors that may impair capacity (e.g., healthcare environment, pressure from family and friends, and caregiver bias).

2. Assess for the presence of internal factors that may impair capacity (e.g., medications, pain, language barriers, stress, intelligence, and the disease process).

3. Take adequate time for assessment, thus resisting the desire for a quick determination.

4. Correct potential barriers to communication such as hearing difficulties, vision impairment, and language.

5. Remember that patients may be capable of making some decisions, yet not others (e.g., the patient may not be able to make a decision regarding withdrawing or withholding treatment, yet be very capable of naming a surrogate decision maker).

Determination of decision-making capacity, therefore, needs to be ongoing. It will be important to support healthcare agents and/or family and remind them that the purpose of continually assessing decision-making capacity and deactivating an advance directive as appropriate ensures that, whenever possible, patients are allowed to make their own decisions.

**Assessing Capacity to Complete an Advance Directive**

As an advance care planning facilitator, you may be asked to assist in the completion of advance directives for individuals who have decreased mental functioning. They may be confused and disoriented at times and unable to make major treatment decisions without assistance. You may be accountable for assessing their capacity to participate in advance care planning and to complete an advance directive. The capacity to complete an advance directive is more specific than the capacity to consent to treatment. According to Silberfeld (1993), in assessing an individual’s capacity to complete an advance directive that designates another person to make decisions on the individual’s behalf (such as a Power of Attorney for Healthcare), there should be evidence that there is adequate patient understanding. Following is a list of suggested assessment questions:

1. Does the person understand that information in the advance directive contains choices that will be acted upon in the future, not the present?

2. Does the person understand that the preferences in the advance directive will be honored only when the person is no longer capable?
3. Does the person understand the choice to select a surrogate decision maker and/or specify medical preferences?

4. Does the person understand that the choices made can be changed at any time?
Interview Skills for Advance Care Planning

Advance care planning is not a one-size-fits-all process. The advance care planning process must be individualized to meet the needs of the person seeking assistance. The skills of Respecting Choices advance care planning facilitation include:

1. General interview skills for any advance care planning discussion
2. Interview skills for basic advance care planning
3. Interview skills for advance care planning for adults with chronic, progressive illness
4. Interview skills for advance care planning for adults in long-term care facilities or for those who you believe are likely to die in the next 12 months

Advance care planning facilitators must begin by assessing the needs of the individual and identifying when to involve other, more qualified professionals. In this chapter, we focus on general interview skills for any advance care planning discussion and on interview skills for basic advance care planning. These skills provide guidance to a wide range of healthcare providers who participate as members of the advance care planning team. In chapters 4 and 5, we will focus on the interview skills for professionals who care for patients with chronic, progressive illness or who live in long-term care facilities.

General Interview Skills for Any Advance Care Planning Discussion

These general skills are used to initiate advance care planning discussions, emphasize the importance of the process, and aimed at motivating individuals to want to learn more, feel supported, and become active participants. For these interview skills to be effective, the advance care planning facilitator must integrate communication techniques of active listening and exploration. Allowing people to tell their stories will reveal individual perspectives on planning for future medical care, expose gaps in knowledge, and identify fears and concerns. By listening to the individuals’ responses, appropriate replacement information can be given and strategies developed to assist in motivating the individual to continue to participate in the planning process.

1. Affirm your relationship. Assure individuals that you care, will not abandon them, and will assist in developing a plan over time when they are ready.
2. Assure individuals that they will be assisted. Inform individuals that you will be asking questions and listening to their fears and concerns.
3. Inform individuals that these discussions are part of good healthcare for all adults who need to plan for unexpected events (e.g., a car accident) that would render them incapable
of making their own healthcare decisions. This is an opportunity to begin to explore issues, answer questions, and understand preferences.

4. Encourage people to see advance care planning as a process that may change over time.

5. Explore the meaning of statements and phrases, (e.g., “I want to die with dignity”; “I don’t want to be a burden”; “I don’t want to be a vegetable”). Don’t assume to understand the meaning of these statements. Encouraging the individual to express the meaning of words and phrases assists in the clarification of goals, values, and beliefs, and provides an opportunity for improved communication between the individual, the family, and healthcare providers.

6. Schedule adequate time to begin these conversations and determine the type and number of follow-up sessions.

7. Provide information for the individual to take home for further reflection and discussion.

8. Schedule the involvement of healthcare agents and other loved ones.

9. Involve others as necessary, (e.g., physician, social worker, nurse, religious advisor).

10. Document the discussion and follow-up plans.

The following example is intended to illustrate application of some of the general interview skills for any advance care planning discussion.

Scenario: Mr. Fox is a healthy, 56-year-old patient who has hypertension controlled by medication. He is scheduled for a routine physical examination and is experiencing no new problems or symptoms. Initiating advance care planning may resemble the following exchange:

“Mr. Fox, it’s good to see you in such good health. I want to take some time today to begin to discuss some issues that hopefully we will have more conversations about over the next several months and years. Have you heard of advance care planning? I’m here to learn how to best help you and your loved ones understand what’s involved in planning ahead for future healthcare decisions.”

Mr. Fox: “If I am healthy now, what am I planning for?”

“We are trying to provide this type of assistance for all of our patients, so you have time to learn about choices you have about your medical care if you were ever in a condition that would leave you unable to speak and make your own decisions, such as a car accident, or sudden illness.”
“Our discussion today is only a beginning, and we will take this at your own pace. This often takes more time than most people think, so I hope you will consider scheduling more time and perhaps involving more people if needed.”

“We have some materials and tools on advance care planning that you can take home with you that will assist you and your loved ones to start talking and learning together. One of the important decisions I want you to think about is who you would choose to make decisions if you could not speak for yourself. Would you be willing to bring this person back to meet with me so that we can all learn together?”

“Lastly, I have briefly summarized our meeting today and want you to take it home with you to think about. If you have questions before our next meeting, here is how you can reach me” [or “here is another resource for you to use.”]

**Interview Skills for Basic Advance Care Planning Discussions**

The goals of these facilitation skills are to further engage the individual in participating in the advance care planning process and to assist in making three important decisions that any adult should consider: choosing a healthcare agent; exploring goals for medical care in the event of a severe brain injury with little chance for recovery; and exploring religious, cultural, or personal beliefs that might influence treatment choices.

Always begin by assessing the needs of the individual. Begin by asking questions, not merely providing information.

1. **Assess motivation, knowledge, and beliefs.** By allowing and encouraging individuals to tell the story of why they want or need to talk about future healthcare decisions and what experiences they’ve had, a more comfortable environment is created as you begin from the person’s perspective. Individuals will trust that you are there to assist them in understanding and reflecting rather than pressing for immediate decisions.

2. **Explore understanding of the purpose of basic advance care planning.**

3. **Explore experiences with loved ones or friends in making life-sustaining treatment choices.** Explore what was learned from these experiences (e.g., what went well and what did not go well?).

4. **Assist individuals in choosing their decision maker (healthcare agent).** Provide information regarding legal/regulatory guidelines and responsibilities of a healthcare agent.

5. **Provide criteria to consider in selecting the most appropriate healthcare agent:**
   a. Is the person willing?
b. Does the person understand the patient’s goals, values, and beliefs?

c. Can the person make decisions under pressure?

d. Will the person honor or follow the plan?

6. Include the healthcare agent in discussions as soon as possible, and encourage patients to initiate discussions about goals, values and beliefs with their healthcare agents.

7. Explore people’s goals for medical care in the event that sudden illness or injury rendered them incapable of making their own healthcare decisions and unlikely to regain this ability. Would they prefer that life-sustaining treatment be continued, or withdrawn? How serious would this injury or illness have to be for the goals of care to change from prolonging life to focusing primarily on comfort? What types of medical interventions would or would not be acceptable to them?

8. Explore religious, cultural, or personal beliefs that might influence preferences for life-sustaining treatment.

9. Develop a follow-up plan that may include the following:

   a. Provide healthcare agents with information, support, and guidance to understand their role and to promote optimal communication among all parties.

   b. Provide blank advance directive worksheets, asking that individuals and their surrogates begin to discuss and write down the patient’s decisions.

   c. Make referrals to other health professionals as needed to provide more information and counseling opportunities.

   d. Schedule return visits to review information provided and written treatment decisions.

   e. Document all discussions and plans of care. Provide written summaries of the conversations for the individuals to take home.
Scenario (continued):

“Mr. Fox, I’m glad to see you brought your wife and son with you for our continued discussion of advance care planning. If you have had a chance to review the materials you were given, can you tell me what you now understand about the purpose of advance care planning and advance directives? Have you known anyone who became suddenly ill or injured, as in a car accident? What was that experience like for you?”

“You just said you would never want to be kept alive on machines. What do you mean by that?”

“If you were in a car accident, and suddenly lost your ability to know who you were and were unlikely to recover this ability, there is a question for you to answer that could be very helpful to your healthcare agent and loved ones if they had to make decisions for you. In the situation I just described, would you want life-sustaining treatment to keep you alive? Or, would you prefer to have life-sustaining treatment withdrawn or withheld?”

“I see you have decided that your wife will be your decision maker if you cannot make your own decisions. Mrs. Fox, sometimes being the decision maker can be very stressful. Tell us what you understand about your husband’s goals, values, and beliefs. What kinds of discussions have you had together? What would you find most helpful at this point?”
Importance of Healthcare Agency: Strengthening the Process

When individuals are asked to choose someone they would trust to make their healthcare decisions if they become incapable of doing so, they often give a spontaneous answer: “Of course it would be my (name of close relative). Who else would it be?” They are unable to comprehend the impact of this choice, yet it may be the most important one in the process of advance care planning. There are many questions and concerns that should be addressed in choosing and preparing a healthcare agent. What do we know about healthcare agents and the work they are asked to do? How are they prepared to do this work? What type of preparation should they receive? Will healthcare professionals provide them with adequate support when the time comes for them to make some of the most critical and stressful decisions they will ever have to make in their lives? How could they be better assisted in learning their new role? Advance care planning facilitators can play a major role in strengthening the process of healthcare agency.

The ability of the chosen healthcare agent to accurately represent the preferences of the patient has come under intense scrutiny. There are several findings from research that have supported the claim that healthcare agents are neither adequately prepared nor capable of fulfilling their responsibilities:

1. Healthcare agents’ predictions of a loved one’s preferences are no better than chance.

2. Healthcare agents express confidence that they know the wishes of their loved ones, although a high rate of disagreement between healthcare agents and loved ones understanding of preferences has been found. When uncertain about a loved ones preferences, healthcare agents understandably tend to err in favor of more, rather than less, treatment.

3. Concerted efforts to prepare healthcare agents through the use of standardized clinical scenarios and discussions have been found to yield no significant improvement in the accuracy of decision making between healthcare agents and loved ones.

4. Most individuals have had minimal or no discussion regarding their preferences with their chosen healthcare agents.

5. Most individuals have had infrequent or inadequate discussions with their physicians regarding their end-of-life decisions.

6. Despite the lack of discussion, individuals believe that healthcare agents and/or physicians will be able to make decisions on their behalf if needed.
7. Healthcare agents prefer more discussion with loved ones in exploring key issues, such as how to consider the impact of suffering and uncertainty on decision making.

The research, along with clinical experience witnessing healthcare agents struggle with decision making, has led many professionals to be suspicious of decisions that are made and less confident that healthcare agents can be effective in fulfilling their role. Conversely, healthcare agents face several challenges in performing this role. They are often thrown into roles for which they are unprepared and perhaps did not want to accept. They agreed (or were not even asked) to be named on an advance directive document to make healthcare decisions for events that their loved ones do not want to talk about. Healthcare agents often ask few questions for fear of upsetting their loved ones or bringing up an unpleasant conversation about dying. They may receive vague direction from their loved ones such as, “Don’t let me die the way my grandmother died.” When asked to make specific healthcare decisions for a loved one, these types of vague statements are not helpful, and may be confusing. Healthcare agents may be presented with complex medical decisions and asked to provide timely responses during a medical crisis. They are expected to make substituted judgment without imposing personal goals, values and beliefs. Moreover, agents are often asked to relay conversations they may have had with their loved one regarding current clinical dilemmas, providing clear evidence that they are truly acting in their loved ones’ behalf. If the healthcare team suspects that the healthcare agent’s decisions are based on emotional or financial stress, they are viewed with caution. If healthcare agents are unwilling to make decisions based on the recommendations of the healthcare team, they are seen as indecisive and unhelpful. Healthcare agents are expected to be liaisons with the rest of the family, adding the stress of family dynamics to their decision-making process. Adding to the burden of the healthcare agent’s position are health professionals who are ever cognizant of the potential legal risks if the rights of an autonomous patient are not protected. It is no wonder that the challenges faced by healthcare agents in performing their role leads to isolation and ineffectiveness.

Emerging consensus that healthcare agents must be better prepared and supported in their role has led to recommendations regarding a more clear definition of an agent’s responsibilities. Some authors caution against the pitfalls in relying solely on substituted judgment or best interests as standards to judge the quality of a healthcare agent’s decisions. Other authors, such as Fin (1999), Collopy (1999), and Blustein (1999), have offered thoughtful and intriguing insights into this discussion. They suggest that the ability of the healthcare agent to do a good job may be largely influenced by a clarification of the relationship between the patient and the agent and the degree of moral authority the patient grants. Collopy and Blustein emphasize the role that some individuals expect the chosen healthcare agent to fulfill (i.e., to make decisions based on a long and trusting relationship). Healthcare agents are to have the courage to walk with patients and not abandon them, with
the knowledge that whatever decisions they make—because they are made out of trust—will be the ones the patients wanted them to make.

Fin provides a useful model for conceptualizing the role and authority of a healthcare agent. In the traditional view of this role, a contract is formed (i.e. advance directive) that directs a healthcare agent to make decisions consistent with their loved ones known preferences. This type of relationship is advantageous for those who clearly know what their wishes are, are able to articulate them, desire control over their personhood even when incapable, or may be distrustful of the actions of others. As the word contract implies, it is binding and offers little room for interpretation. On the other hand, there is an option to choose a less restrictive relationship that establishes a covenant between two people. In this type of relationship, one person trusts the ability of another person to make necessary interpretations and decisions in any circumstance that may present itself. It is a relationship based on a trusting understanding of the life of another person and a commitment to make decisions most consistent with known values of how best to honor that life. There is evidence that some patients (and professionals) would choose this type of relationship and grant either some or complete leeway to healthcare agents to make decisions in clinical situations that can best be understood only if they happen. Of course, the boundaries of such a relationship would need to be clarified in order for health professionals to honor such a covenant. It would require a level of trust from health professionals that the agent’s authority to have such leeway is, in fact, respecting the patient’s goals, values, and beliefs.

The process of healthcare agency may be strengthened in a variety of ways. Some of these strategies may be easy to implement, others will require a change in attitude and an understanding of the role of the healthcare agent:

1. Develop a standard of including healthcare agents in all advance care planning discussions. Rather than having discussions without healthcare agents, find creative ways to include them.

2. Provide healthcare agents with information regarding their roles and responsibilities. This may be in the form of information cards, booklets, videos, or educational presentations.

3. Send completed or revised advance directive documents to designated healthcare agents. Ask that they read the documents and schedule discussions with patients, families, and other involved parties as needed.

4. Encourage a discussion of the type of relationship and moral authority the patient desires. When asking the patient to choose a healthcare agent, it may be useful to ask exploratory questions, documenting the patient’s responses and communicating the information to the patient’s healthcare agent:
What would you want the healthcare agent you have chosen to do?

- □ Strictly follow your wishes.
- □ Do what he or she thinks is best at the time, even if unaware of your preferences.
Cultural and Religious/Spiritual Perspectives on Advance Care Planning

Increasingly apparent in the United States is the fact that we live in a diverse society with multiple religious, cultural, and ethnic influences that may have a bearing on the process and outcome of advance care planning. While we articulate that we must keep these influences in mind while providing quality healthcare, we remain unclear as to how to effectively manage these influences. A great deal more research is needed to provide better direction.

The facilitation skills and approaches advocated in the Respecting Choices curriculum, when implemented appropriately, are inherently culturally sensitive. By first assessing the needs of the individuals and their families, the advance care planning facilitator can design a process that most appropriately addresses these needs and integrates cultural, religious, and personal goals, values, and beliefs.

Strategies for Communicating Cultural and Religious/Spiritual Sensitivity

Knowledge of cultural and religious perspectives can be extremely useful in predicting potential confusion and determining appropriate interventions, past experience with individuals from these various perspectives should not include automatic assumptions regarding expected behavior. The need for skills in cultural and religious sensitivity will only increase as the population continues to diversify. Come to know the person first, and their religious/spiritual and cultural beliefs, second. Instead of making assumptions, ask the following questions, which may assist in a more accurate assessment of how culture or religion influence healthcare decisions:

1. Is information regarding prognosis openly discussed?

2. If information regarding prognosis is openly discussed, how does this information typically get handled?

3. Are death and dying topics appropriate for discussion?

4. How may this individual’s perspectives vary from those of the stated religious or cultural perspective?

5. Does the patient desire complete disclosure? If not, how should decisions be made?

6. How is quality of life defined?

7. What level of trust does the person have in physicians/other healthcare providers?

   Does the person prefer not to put personal preferences in writing?
8. Offer alternative ways to communicate the person’s end-of-life treatment preferences:
   
a. Focus on the advance care planning discussions rather than on completion of a document.

b. Ask the person who he or she would trust to have these types of conversations and attempt to arrange this facilitation.

General strategies for Sensitivity in Facilitating Advance Care Planning Discussions

1. Assess people individually, avoiding assumptions related to their ethnic affiliation.

2. Listen and explore.

3. Explore how the illness is affecting patients and their families.

4. Explain the purpose of the advance care planning discussion.
   
a. Informed decision making is part of the healthcare professional’s ethical and legal responsibility.

b. Advance care planning is about understanding, reflecting, and discussing individual preferences.

c. Advance care planning is becoming a part of routine care.

5. Identify potential barriers to initiating advance care planning discussions:
   
a. distrust of authority figures, healthcare professionals

b. fear of loss of control over decision making

c. superstitions about discussing prognosis or death

d. reading and language comprehension difficulties

6. Negotiate strategies to address barriers, such as
   
a. Is there a preference for open communication? How does this information typically get handled? Are discussions about illness/prognosis considered off-limits?

b. Assess individuals’ preferences for how decisions should be made. Assure them that their decisions to have family members receive information, make decisions, etc., will be respected if that is what they choose.
c. Offer the use of non-medical advance care planning facilitators.

d. Facilitate the discussion in an unhurried manner. Listen and explore.

e. For individuals who fear the documentation of preferences, focus on the value of the discussion alone, the selection of a trusted decision maker, and the inclusion of this person in informal discussions.

f. For individuals who prefer to document their preferences, take time to verbally review documents. Provide materials in the appropriate language and reading level.

g. Provide community opportunities to learn about advance care planning in a non-stressful environment.
Culture, Religion, and Advance Care Planning

The following section will begin to identify some of the cultural and religious/spiritual factors to be considered. It is meant as a resource for advance care planning facilitators. It is impossible to thoroughly understand all the many differences that may exist; indeed, it may even be undesirable because healthcare professionals could run the risk of assuming what patients would want based on stated religious or cultural beliefs. This type of stereotyping would interfere with assessment of patients within their own social context, with their own unique interpretations of how their religions or cultures affect their current situations, goals, and values.

What remains critical, however, is that advance care planning facilitators be sensitive to all the factors that may influence healthcare decisions while protecting autonomy as defined by the person. This sensitivity also promotes an awareness of one's own biases and how they may influence advance care planning facilitation. Knowledge of religious and cultural influences can help predict what issues may need attention or further exploration, as well as determine the appropriate response of the healthcare professional.

Culture and Advance Care Planning

The United States has moved rapidly to a culturally pluralistic society. There has been a substantial increase in U.S. cultural diversity between 1980 and 1990, due in large part to the increase in immigration and a growing cultural awareness, most notably within Asian, Hispanic, and Native American populations. Conflicts, frustration, and inappropriate medical treatment can result when healthcare professionals have expectations different from those of their patients. For example, advance care planning in Western society makes a variety of assumptions: It assumes that individuals desire information and want to be educated, that they want to participate in their medical decisions, that they want to determine their future care, that they are willing to discuss issues about death and dying, and that their religious/spiritual beliefs exclude medical miracles. Other cultures may make quite different assumptions.

Most of the cultural diversity research that has been done has focused largely on differences among Asian, Hispanic, black, and non-Hispanic white populations. Identified areas of potential differences relating to advance care planning include completion of advance directives, selection of a healthcare agent, willingness to discuss end-of-life issues, and trust in healthcare providers. A few examples will demonstrate these major differences.

Cultural diversity research has found that blacks are less likely than whites to complete advance directives and more likely to choose aggressive end-of-life treatment. Explanations proposed for these tendencies include fear of signing any document, fear of not being adequately cared for, and, in some cases, lower educational levels. Hispanics, too, have been
found to be unwilling to give any type of advance directive and are less likely than whites to choose no resuscitation options. It is speculated that these findings are based on religious beliefs, inadequate access, and language barriers. The influence that language barriers can have may be illustrated by the English term *proxy*, which in Spanish can be translated as *one who has power over another*. There is also belief among some of these populations that completing an advance directive only invites a medical crisis and is, in essence, a bad omen.

As a culture, Asians are known to hold strong convictions regarding the natural course of dying and are hesitant to even discuss the subject of death. They are, therefore, less willing than whites to complete written advance directives; instead, they communicate their desire for less aggressive care verbally. Many relatives act as informal caregivers and become actively involved in medical decisions. They are protective of ill family members, wanting to shield them from potentially harmful and distressing information that might rob them of hope. Therefore, they are offended that healthcare professionals so openly invite conversations regarding end-of-life treatment options.

The role of the surrogate decision maker is also a source of confusion among these cultures. First, many do not understand when the surrogate’s authority becomes effective or the types of decisions the surrogate can make. Second, some believe that the surrogate role places an inordinate burden on the person who agrees to serve in that capacity. Last, in order to avoid conflict it is common for people in these cultures to choose family or group decision makers, which is consistent with their cultural styles.

Trust in healthcare professionals varies between cultures. Hispanics and Asians have faith that physicians will make the best decisions possible, while blacks and whites tend to be less trusting.

In summary, it is important to remember that culture is dynamic and complex. One must avoid assuming that one’s culture automatically determines one’s beliefs, behavior, and preferences. A commitment to listening to people’s stories and to discovering their goals and values within the context of their individual and social situations is essential.

**Religion and Advance Care Planning**

As people begin the process of advance care planning, many will question how their faith fits into the discussion and how their particular church feels about these issues. While it is vitally important for them to understand that religious counseling is beyond the intent of advance care planning, people often ask about religious beliefs and how they relate to advance care planning. Provided here is some general information about the faith traditions that encompass the broadest number of people. This information is by no means comprehensive; rather, it is a summary of the broad, prevailing thoughts of each tradition. These brief summaries are not official rulings, nor do individuals professing a particular faith tradition automatically adhere
to all its beliefs. If patients wish to discuss this information in more detail, encourage them to contact a member of the clergy or someone knowledgeable about these faith traditions.

**For Many, Faith Issues Affect Decisions About the Future**

“What does my religious affiliation say about forgoing life-sustaining treatment?” That’s a question many people will ask as they begin thinking about advance care planning and advance directives. In fact, for many, it would be unthinkable to make life and death decisions without considering theological and ethical positions.

In comparing the ways several prominent religious traditions approach decisions about future medical care, it is apparent that they share a common respect for life, holding it as a sacred gift from a creator. They also recognize that death is an integral part of life. Each religion, for varying reasons and to varying degrees, sees that in holding life sacred, people should not be required to do what is morally unreasonable or what may bring useless suffering to the dying. Defining what is *unreasonable* is what each religion attempts to do.

Discussing future medical care and indicating preferences for end-of-life care through an advance directive is not only acceptable to all of these religious traditions, it is a clear and direct way to clarify a person’s preferences, preferences that may range from withdrawing treatment to requiring that all possible treatments be provided.

While facilitators may find guidelines either here or elsewhere about what is theologically or ethically acceptable for a particular religion, remember that each case must be reviewed based on its own complexities and in light of a person’s own values and faith. Advance care planning is an opportunity for individuals to articulate their personal values regarding end of life care.

**The Roman Catholic Tradition**

**Benefit versus burden**

The Roman Catholic faith tradition affirms the dignity, sanctity, and value of all human life. The church is vitally concerned about protecting the basic right to life of every human being, especially those who are vulnerable as a result of disability or illness. This concern does not require the use of all means possible to maintain physiological existence.

Generally speaking, in Roman Catholic teaching, the decision is made by weighing the benefit against the burden of medical treatment. If a treatment offers a reasonable hope of benefit to the patient without the burden of excessive pain, expense, or other inconvenience, it is acceptable. It is the patient’s right to weigh these factors and decide whether the burden outweighs the benefit, and to decide whether life-preserving measures will be used or
withdrawn. If a patient is no longer capable of expressing these wishes, the patient’s advance directive should be recognized.

According to the Church, the ultimate goal in life is to share in the death and resurrection of Christ. Therefore, there comes a time in every person’s life when he or she should be allowed to die. As a general principle, individuals are not required to accept medical treatment that is useless or presents a grave burden for themselves or others. The focus is on the dignity of the person and compassionate care for the dying.

While the Church prefers that nutrition or hydration support be provided, statements by the Executive Committee of the National Conference of Catholic Bishops and by the Pontifical Academy of Science say there are circumstances in which such treatments are either useless or gravely burdensome and can, therefore, legitimately be refused.

Roman Catholics desiring further information are encouraged to contact their parish priest or a hospital chaplain.

**The Lutheran/Protestant Tradition**

*It’s acceptable to remove treatment deemed futile.*

The Evangelical Lutheran Church of America (ELCA) does not have specific rules regarding advance care planning or advance directives. Members are encouraged to read their Bibles, to think and study, and then to pray, asking God for guidance.

The ELCA accepts the prevailing thought that life—as a gift from the creator—is sacred, but that it is not an absolute value. People are stewards of that gift and are called to protect, care for, and preserve the life they have been given. At the same time, useless or unreasonable efforts to preserve life are unnecessary. If a treatment offers no clear benefit, there is no ethical necessity for a person to receive it. It is, therefore, acceptable for a person to forgo life-sustaining treatment in certain circumstances.

What about treatment that has already been started? Does removing life-sustaining treatment cause a person’s death? The ELCA generally recognizes that it is not the act of withdrawing treatment that causes an individual’s death; rather, the injury or illness that caused the medical crisis in the first place is simply being allowed to take its course. For example, in the case of a stroke victim on a respirator, it is not the removal of the respirator that causes death—it is the stroke itself. Thus, removing treatment can be a morally acceptable act in spite of the fact that it results in the patient’s death. This is also true in the case of artificial nutrition and hydration, which is considered to be a treatment. Nutritional support is initiated in the hope the patient will eventually recover, but if it becomes clear that the patient will not recover, the treatment is no longer ethically indicated, and it may be removed.
The general point of view is that Lutherans live life in relationships—with God and with others. If the capacity for life is so severely diminished that an individual is completely cut off from those relationships and mere unconscious biological survival is left, then human existence—as a Christian in the Protestant tradition understands it—is no longer present, and life-sustaining treatment is no longer required.

Members should contact a member of the clergy or hospital chaplain for more information.

**The Jewish Tradition**

*Nothing may be done that hastens death.*

The Jewish tradition believes God created life by breathing breath into an individual, so one must actively protect this gift by pursuing health and wholeness throughout life and by absolutely not doing anything to end life. For Jewish traditionalists, the source for clarification of theological issues is the rabbinic law, called the *Halakhah*. This law sets up a test to determine what is permissible.

First and foremost, it is forbidden to do anything that may hasten death, actions likened to extinguishing a flickering flame by touching it. For some Jewish people, even removing a pillow or changing the position of a patient may be troublesome if it will hasten death.

Second, and at the other end of the spectrum, it is also forbidden to delay an oncoming death, which the Jewish faith believes is God’s will. Therefore, it is not only permissible to remove an impediment to a natural course of events that leads to death and departure of the soul, it is imperative. Any withdrawal of treatment, however, must always be predicated on knowing that death is at hand—which is almost impossible to discern. The best Jewish legal experts are still undecided about what constitutes *death at hand*, and, for that reason, withdrawing life support is more often an academic discussion than something that can be implemented.

Tension exists between the obligation to remove impediments to death and the prohibition of any move that will hasten it. Attempting to find a reasonable balance between the two, the Jewish Orthodox tradition allows withdrawal of life-sustaining treatments in critical cases. The Reformed Jewish tradition agrees, adding that intravenous apparatus may be discontinued, and the terminal patient may be allowed to die.

It is important to recognize that a decision to withdraw life-sustaining treatment is not based upon a patient’s deteriorating quality of life; rather, the decision is based upon the observable medical criteria that indicate death is at hand, which requires that any impediments to impending death be removed.

The impediments that one might be allowed to remove are those things that sustain life entirely, such as when a patient is completely dependent on a respirator. To determine
whether the patient is completely dependent, trial periods off the respirator may be requested. Again, it is exceedingly difficult to determine when death is at hand.

For more information about this tradition, people should contact their local synagogue or rabbi.

**The Conservative Christian Tradition**

*Quality of life doesn’t affect treatment decisions.*

This summary of the conservative Christian tradition is broad, encompassing information from a group of similar churches.

The conservative Christian tradition views life as a gift from God, and, as such, birth and death are both by God’s design. Life should, therefore, not be prolonged when it is clear that life will end. Neither should life be shortened when it is not specifically terminal, regardless of its quality.

Life-sustaining procedures may be withheld from a patient who has a diagnosis of a terminal illness and for whom death is imminent. But when death is not imminent, it should not be hastened—thus, nutrition and hydration would not be withheld because the withdrawal, rather than the initial illness, would be considered the cause of death.

This tradition believes that God creates life at conception, so it is important that the life of an unborn child be protected. This would be of concern if a pregnant woman were in a terminal situation because the life of her baby would be threatened, as well. This tradition does not believe that the value of life stems from the quality of life as one experiences it, or from one’s activity or effectiveness in society; a patient’s quality of life has no bearing on end-of-life decisions.

If individuals’ faiths lead them to feel strongly about not withdrawing either hydration or nutrition, they should discuss that with their physicians and their loved ones, and they should write it in their advance directives.

**The Jehovah’s Witness Tradition**

*Specific doctrine governs the use of blood products.*

Jehovah’s Witnesses do not object to medical treatment; however, they have specific doctrinal views concerning the use of blood, based on their interpretation of several Bible passages.

Members of this faith are open to receiving medical attention in order to live a full and meaningful life. Specific treatments that they reject include receiving whole blood, packed
red blood cells, plasma, platelets, white blood cells, and autotransfusion of predeposited blood. Individuals may or may not decide to reject albumin, immune globulins, tissue transplants, and hemophiliac preparations. They generally will accept Ringer’s lactate, normal saline, hypertonic saline, dextran, gelatin, hetastarch, perfluorochemicals, and erythropoietin.

Healthcare providers face a challenge when an adult Jehovah’s Witness presents with a major health issue. In order to show respect, blood must not be forced upon the individual. For individuals who believe that receiving blood products will erase all hope of eternal life, treatment against their wishes may have profound effects on their quality of life. Yet the medical community may become uncomfortable when a religious belief compromises the patient’s treatment. It is also difficult if a Jehovah’s Witness comes to an emergency department in an unconscious state and has an unclear social history concerning his or her wishes regarding blood products. The concerns of both Jehovah’s Witness patients and the medical community can be addressed through the use of advance care planning and written advance directives. By putting their wishes in writing and establishing a healthcare power of attorney or proxy, individuals can feel secure, knowing that the tenets of their faith will be observed. Discussing those beliefs with their physician may help the physician reach an understanding of individuals’ choices prior to surgery or an unexpected illness. If physicians feel they cannot accept the Jehovah’s Witness stance, other arrangements may need to be made.

Further, written advance directive cards, prepared in consultation with medical and legal authorities, may relieve physicians and hospitals from liability in situations where blood products are withheld based on the documented decisions of Jehovah’s Witness patients.
Frequently Asked Questions about Facilitating Advance Care Planning Discussions

While each advance care planning session is unique, common problems and questions do arise for advance planning facilitators. The responses to many of these questions are reflections at best. Many deal with complex human, medical, ethical, and legal issues. It is impossible to provide definitive answers for every situation, but by reviewing these examples, you will be better prepared to respond appropriately when you are challenged. It is important that you understand the policies of your organization and the legal/regulatory guidelines in your geographic area.

Do agents or proxies have to be family members?

No. Generally, legal/regulatory requirements allow persons completing a Power of Attorney for Healthcare great freedom in selecting the individual(s) who they feel will best represent them. It is important that the person selected is willing, discusses the person’s values and preferences, can respect these values and preferences, and is able to make difficult decisions in stressful situations.

When people choose healthcare agents who are not close family, it is important to inform family members who would still be included at the bedside. In some cases, individuals are chosen as agents/proxies to exclude family members who are not wanted at the bedside. It may be wise to indicate in the special instructions section of the document that these family members should not be included in decisions or given information.

How do I help someone discuss future life-sustaining treatment when important family members refuse to participate?

Overcoming the numerous barriers to such a discussion can be difficult but is worth attempting. These same barriers are likely to affect end-of-life decision making if not addressed in advance. It would be better to address these barriers early when everyone is less stressed and can participate fully.

Rather than attempting to force a discussion that someone does not want, it may be necessary to find out why having the discussion is so objectionable. In some cases, showing the video may open up feelings or put people in the mood to share their reservations. It might be a big step forward to simply get people to reveal why they are unwilling to discuss this topic. When an individual is strongly opposed to such a discussion, do not expect that change to take place in a few minutes or after one discussion.
If someone is trying to convince another person to complete an advance directive, it is often helpful if he or she completes one first. Modeling the behavior, or *do as I do*, is often more convincing than other reasons.

In some cases, family members simply cannot deal with such a discussion. This information is important to note because individuals who resist discussing end-of-life decisions would be unlikely to be good choices for agent or proxy. However, these family members should be kept informed about what has been decided and about how decisions will be made.

**How do you choose an agent or proxy without causing hurt feelings between family members?**

This worry about hurt feelings is probably caused by two concerns. First, by choosing one family member over others, one might fear that the rest of the family will believe that the chosen family member is more important or better loved than the others. Second, by choosing one person as agent, one might fear that the rest of the family will be excluded from decision making. These concerns are sometimes unwarranted. Loved ones are often quite happy not to be picked. The responsibility of being an agent or proxy is great, and many loved ones are happy not to have it. As for the second concern, one can simply add an instruction to the document. The instruction might read: “While I have picked person X to represent me if I am incapacitated, I expect my agent or proxy to discuss any major medical decisions with the siblings if time permits.”

**What do you do if a family has strong disagreements about the type of instructions that would be acceptable for documents?**

It is not unusual for families to have serious disagreements about when life-sustaining treatment may be forgone. Families can and do reflect wide differences in society. It is because of this pluralism that discussing end-of-life decisions while everyone is still capable is so important.

The goal should not necessarily be to get everyone to agree. First, it is important to work on understanding what individuals believe and why. If there is serious disagreement, determine if people can support and respect each other’s choices. Sometimes individuals in a family cannot support or respect each other. For example, if one family member believes that stopping a feeding tube for someone in a persistent vegetative state is murder, he or she may not respect or support such a decision for another. In such a case, it is important to designate an agent or proxy who will respect and make such decisions. If possible, it would be best to have everyone at least agree to how decisions will be made.

**Will one state/jurisdiction honor the written advance directive from another state/jurisdiction?**
This is a difficult question to answer because legal/regulatory requirements differ, and courts have not ruled to provide direction. In the United States, most states have statutes that say that they will accept documents that are in substantial agreement with their statutes and were legally created in another state.

It certainly is safe to say that having a valid document is better than not having one. There are many legal and ethical reasons to support utilizing a valid written advance directive from another jurisdiction. The real question is not what will happen in another jurisdiction, but what will happen in a health organization in another jurisdiction. If the doctor or institution in another jurisdiction will not recognize a document, the issue may end up in court. Even if the court rules in favor of the legality of the document, you still had to go to court, exactly what the document was meant to avoid.

To avoid putting individuals at risk, institutions should establish their own policies on this matter. Given an adult’s general right to refuse medical treatment, there seems to be little risk by respecting an authentic, valid directive, regardless of in what jurisdiction it was created or what format the document uses. It is not a good idea to have two documents from two different states because the one most recently created will be considered the valid document.
Chapter 2: Exercises

1. Describe how you would assist your healthy 40-year old brother to understand the importance of advance care planning?

2. List the qualities to consider in selecting a healthcare agent.

3. Describe the strategies you would use to initiate an advance care planning discussion with an individual who belongs to a religious group or culture different from your own.
Chapter 2:
Further Reading


