Respecting Choices®

Advance Care Planning Facilitator Course

Chapter 4
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Chapter 4

Facilitating Advance Care Planning Discussions with Adults with Chronic, Progressive Illness

While many of us may prefer to die suddenly and avoid end-of-life treatment decisions, most of us will die after a long history of chronic illness interspersed with periods of increased symptoms and gradual loss of function. This slow illness trajectory allows individuals time to make their own choices, although most do not quickly reach clearly formed preferences about the end of life. Opening the door to discussion, addressing barriers to information, reflection, and discussion may take months. Each episode of exacerbation provides an opportunity to move patients slowly along in the process, but these discussions will typically not occur unless they are initiated by a health professional.

There are many challenges to advance care planning for patients with chronic, progressive illness. Due to incomplete and inaccurate prognostic information, many of these patients do not view themselves as dying or in need of making contingency plans for their medical decisions. Many have been “rescued” several times by advances in medical science and technology and do not contemplate the potential complications that may occur. They experience a slow, progressive decline in function, and often learn to adapt to their changing functional status and adjust goals for living well accordingly. When patients with chronic, progressive illness experience sudden, but not unexpected, complications that render them unable to make their own healthcare decisions, responsibility for making these decisions falls to loved ones, who are often unprepared and uninformed. It is crucial to include designated healthcare agents and other loved ones in advance care planning discussions, although initiating these types of family discussions can be very difficult.

Initiating a discussion about end-of-life issues for patients with chronic, progressive illness and their families need not focus initially on making decisions or on forgoing treatment. It can be a time simply to explore attitudes and provide information. Beginning advance care planning early in the course of chronic, progressive illness can provide opportunities for
ongoing and gradual conversations to slowly engage patients and their loved ones in participating in the planning process.

This chapter will begin by reviewing the interview skills for facilitating advance care planning discussions for adults with chronic, progressive illness. Implementing these skills effectively into practice, however, requires facilitators have additional knowledge about the types of medical choices individuals may face, the benefits and burdens of life-sustaining treatments, how to discuss withholding or withdrawing treatment, and about how and when to maintain comfort.

**Advance Care Planning Interview Skills for Adults with Chronic, Progressive Illness**

1. Assess motivation, knowledge, and beliefs. Begin advance care planning discussions slowly and over time. Initially, these conversations can be a time to explore goals, values, and beliefs without focusing on withdrawing or withholding treatment (e.g., “I know that many patients have concerns about controlling the use of a medical treatment if things got worse. Are there issues or concerns you want to talk about with me?”).

2. Explore understanding of health condition. Assist patients in understanding the progression of their illnesses and related treatment decisions likely to be faced in the future. Begin by assessing the patient’s current level of understanding, identifying gaps in knowledge, and developing a list of questions to ask the physician.

3. Explore experiences. These may be experiences with family or friends who became seriously ill and life-sustaining treatment decisions were made, or experiences with the last hospitalization for an exacerbation of the illness. Clarify the meaning of patient responses and phrases, such as “I want to die with dignity,” or “God will take me when He’s ready.” Ask patients what they learned through these experiences that may help clarify their own goals, values, and beliefs.

4. Explore the concept of *living well* (to be further explained in chapter 5).

5. Explore understanding of potential complications related to the patient’s health condition.

6. Explore patients’ understanding of healthcare decisions based on their own specific chronic illness. Provide information based on this understanding. For example,

   - cancer patients are more likely to need to make decisions regarding pain management and cardiopulmonary resuscitation (CPR).
• patients with lung and neuromuscular diseases will need to discuss decisions related to intubation and mechanical ventilation.

• cardiac patients need to decide if CPR will be performed if their heart stops.

• patients with chronic renal failure dependent upon dialysis need to consider if dialysis should continue if they suffer permanent, serious neurological injury.

• patients with progressive dementia need to consider if artificial nutrition should be provided if swallowing difficulties occur and, in the case of severe dementia, how life-threatening infections should be treated.

7. Develop a list of questions or concerns, and involve others as necessary.

8. Explore individuals’ perspective on comfort care.

Some advance care planning facilitators, because of their knowledge, experience, or role, will feel comfortable and competent to provide detailed information on disease progression, benefits and burdens of life-sustaining treatment, and outcome statistics. However, others may not have the requisite knowledge and experience, or they may feel it is inappropriate to provide information. These advance care planning facilitators can use the interview skills of assessment, exploring the need for information, and assisting in the development of questions, among others, to refer the patient to other qualified professionals who can provide more focused assistance.

All advance care planning facilitators, therefore, must become familiar with the resources available (e.g., palliative care team, financial advisors, physicians, or other healthcare specialists) to develop an appropriate follow-up plan of action to assist the patient in making individualized and informed treatment decisions.

The following scenario provides examples of facilitation skills for advance care planning with adults who have chronic, progressive illness.

Scenario: Mr. Dawson is a 78-year-old man with severe chronic obstructive pulmonary disease (COPD). He is in the hospital for the second time in two months. After the last admission to the hospital, he spent two weeks in a long-term care facility to regain his strength. He has no advance directive and appears to have done no advance care planning. The patient’s current medical condition and his evaluation and treatment plan are reviewed.

“Mr. Dawson, I see that you have been having a difficult time lately with your lung disease. Can you tell me what you understand about what’s been happening with your lungs? If needed, I’d like to keep a list of questions you may have for your doctor.”
“What has the experience this time in the hospital meant to you?”

“As you know, you have an illness that makes it difficult to predict when a complication may occur, and decisions may have to be made on your behalf. I’d like to begin to help you think about the situations that may occur because of your lung disease and about what decisions may need to be made. If we start to help you think about these decisions now, you can take the time you need to learn more, talk to loved ones, and make plans for what you might want.”

“Can you tell me what you know about complications that may happen because of your lung disease?”

“What activities or experiences are most important for you to live well? The reason I ask some of these questions is that when you think about what you might want for your future medical care, it may be helpful to weigh these choices against what is important to you to live well, to enjoy life.”

“What fears or worries do you have about your illness or medical care?”

As illustrated, initiating advance care planning discussions with adults with chronic, progressive illness begins by exploring, assessing, and identifying the needs of the individual. This approach can set the stage for future, more specific discussions about life-sustaining treatment, talking to loved ones, and developing written plans.

**Helping Patients Understand the Benefits and Burdens of Life-Sustaining Treatment**

The life-sustaining treatment choices we ask people to consider are difficult and have become increasingly complex as medical “miracles” have continued to evolve. A common example is the introduction of CPR in the early 1960s. CPR made it possible to resuscitate individuals whose heartbeat and respiration had stopped. CPR obviously helped many people recover, but it also resulted in people who met brain death criteria, who were severely brain injured, or whose lives could be sustained for only a short time. For the first time in history, it became necessary to allow people to die who initially had been spared death. Such decisions are now faced on a daily basis in healthcare facilities around the country.

As people begin to discuss advance care planning, they will need assistance in understanding life-sustaining treatment options and in deciding whether the treatments will assist them in achieving their goals, values, and beliefs. Determining the value of any intervention involves a decision-making process that clarifies
1. the goals of each treatment (e.g., “If you wanted CPR if your heart or breathing were to stop, what would your goals be? What would you hope for?”).

2. the benefits and burdens of each treatment (e.g., “In order for you to make an informed decision about CPR, it is important that you understand the risks involved in attempting CPR and the side effects that may occur”).

3. whether the benefits and burdens are compatible with the individual’s goals (e.g., “What would an unacceptable outcome of CPR look like for you? How can I assist you in weighing the potential benefits of CPR against the risks and consequences I have just described?”).

This decision-making process, therefore, provides a framework within which an individual can make more informed choices. Individuals can make general assessments about future medical care in terms of goals that might be possible without knowing a great deal about the specific pathophysiology of the disease process or the specific technologies that might be used. When thinking about the goals of treatment, a person considers how it might help and might harm them under a particular circumstance. Typically, if a treatment does not provide benefit, or if it is believed to do more harm than good, people refuse it.

The variables involved in analyzing benefits and burdens of life-sustaining treatments are individual, contextual and may be influenced by religious or cultural beliefs. For example, life-sustaining treatments may be viewed as beneficial if they are effective in prolonging life, effective in restoring function or relieving suffering, if they promote a person’s goals, values, and beliefs, and are consistent with religious or cultural beliefs. Conversely, life-sustaining treatments may be viewed as burdensome if they result in more or intolerable pain or suffering, are damaging to body image or functioning, are psychologically harmful, are physically or emotionally restrictive, or are expensive to the ill person.

Unfortunately, in many cases, no obvious preference exists because a person experiences some benefit but also some burden. For example, it might be possible to prolong biological function but not restore consciousness, or function may be maintained but with unrelieved pain and suffering. Patients then face confusing choices and find themselves in a position of weighing the benefits against the burdens and how this analysis impact goals, values, and beliefs.

There are some important concepts to remember when assisting individuals in determining their goals for healthcare at the end of life:

- Preferences and goals may change as illness progresses. Certain goals may assume higher priorities over time, or short-term goals may be balanced against long-term goals.
• Individuals may, at times, need the assistance of others in determining their goals. Those who might provide assistance may include pain management specialists, spiritual counselors, or social workers, among others.

• Other individuals may have the goal of deferring as much decision making as possible to others (e.g., the physician, hospice team, or family).

• In order for an individual’s goals to be honored, an effective mechanism for communicating them to all members of the healthcare team must be established.

• In developing interviewing techniques for assisting with goal setting, health professionals must adapt and be sensitive to the cultural differences related to decision making that exist within their communities.

• Initiating discussions with individuals regarding goal setting as early as possible and in non-stressful situations respects the need to reflect on these issues and to take adequate time to make decisions. Health professionals may mistakenly avoid proactive discussions, missing opportunities for individuals to communicate preferences.

What Treatments Might Need to be Discussed?

To assist individuals in making informed medical decisions and in analyzing the benefits and burdens of these decisions, they will need basic information about and understanding of the most common end-of-life choices. These choices fall into three categories:

1. choices to initiate life-sustaining treatment

2. choices to withdraw or withhold life-sustaining treatment

3. choices related to comfort care

The term life-sustaining treatment can be confusing, meaning different things to different people depending on their knowledge, experience, and religious and cultural beliefs. For some, life-sustaining treatment means only interventions that are highly technical, invasive, or complicated, such as ventilators and kidney dialysis machines. In providing information on end-of-life decisions, people often need clarification and assistance in understanding that life-sustaining treatments include any intervention that prolongs life, and are not highly technical, invasive, or complicated (e.g. antibiotics, IV fluids, and tube feedings). These may be difficult distinctions for people to grasp if they believe that some treatments must be provided because they represent “ordinary” care.
**Choices Related to Initiating Life-Sustaining Treatment**

To effectively assist an individual in making life-sustaining treatment choices, an advance care planning facilitator must have an understanding of the treatment and related benefits and burdens or refer the individual to an appropriate healthcare provider to obtain this information. Armed with this information, the advance care planning facilitator can develop strategies for discussion that are sensitive to the individual’s goals, values, and beliefs. When helping an individual make specific decisions regarding a life-sustaining treatment, it is important to always begin by assessing the individual’s understanding of the treatment, goals for treatment outcomes, and what has been discussed with the physician or healthcare provider.

**Cardiopulmonary Resuscitation**

**Facts:**
People should understand that it is routine practice in hospitals and most other healthcare organizations to start CPR if a patient suffers a cardiac or respiratory arrest unless there are clear medical orders not to start (e.g., a physician’s order that CPR not be attempted). In the case of a cardiac arrest, emergency personnel cannot rely upon an advance directive to decide not to attempt CPR.

CPR is attempted when a person’s breathing and heartbeat have stopped or have become ineffective. Basic CPR involves pressing on the chest and blowing air into the lungs. CPR typically lasts for 15 to 30 minutes. It may require administration of medications, insertion of a tube to assist with breathing (intubation), and electrical stimulation of the heart.

Individuals who are at clear risk for requiring CPR include those with heart disease and those who are frail, especially those in long-term care facilities and those with end-stage diseases.

**Benefits:**
CPR is most beneficial for a healthy person whose heart has stopped suddenly from an accident or heart attack, or for a person whose underlying condition can be effectively treated. CPR can prolong life with good functioning, especially in patients who are healthy and younger, if it is initiated within 5 minutes of arrest.

**Burdens:**
Many patients mistakenly believe that CPR is successful in nearly half of all attempts. When patients and families understand that CPR is not likely to lead to survival and could lead to a technological death, they can make more informed decisions.
Fewer than 17% of hospitalized patients survive CPR and are discharged. CPR is successful in fewer than 5% of people who have end-stage chronic illness and in fewer than 2% of frail elderly living in long-term care facilities.

In addition, the complications of CPR include the need for mechanical ventilation and corresponding intensive care unit (ICU) stay, a decrease in mental functioning, and broken ribs or collapsed lungs.

**Strategies for Discussion:**

Asking patients if CPR should be attempted if their heart stops can be difficult. For those involved, it may sound or feel as if all interest in caring for a patient is gone. Asking this question in isolation of the patient’s treatment goals may deliver the wrong message to the patient: that nothing more can be done. Additionally, obtaining a Do-Not-Resuscitate (DNR) order independent of assessing goals and options for end-of-life care may be interpreted too broadly by health professionals who may make the assumption the patient does not want or require other end-of-life treatments. Avoid asking questions such as “Do you want us to do everything, including CPR?” This type of question implies that nothing will be done if the patient decides against CPR.

Therefore, a discussion of the patient’s medical condition and goals for care should precede the question regarding CPR status. Moreover, CPR should be discussed in conjunction with the range of choices for end-of-life care. The common practice of obtaining a DNR order on admission without placing the decision within the context of the patient’s goals and medical conditions and without relation to all end-of-life issues is simply unethical and borders on abandonment. In certain cases, it is appropriate for the physician to make a recommendation against CPR with associated rationale.

**Scenario:** The following provides some examples of how to place the CPR decision within the context of the patient’s illness:

“*Mrs. X, you are being admitted for the fourth time in 6 months due to complications from your heart disease. Do you understand what these complications are and why they are happening? What information can I give you to help you understand how your medical condition has changed and what that might mean for you?*”

“There are a number of decisions regarding your care and the many choices you can make, depending on your goals and wishes. I’d like to start to talk about them now so we can have plenty of time to help you understand your choices, discuss them with your loved ones, and then make sure we follow your wishes. I’d like to begin to talk today about whether or not you would want CPR attempted if your heart or breathing were to stop.”
“What is your understanding of CPR?”

“What, if anything, have you discussed with your physician about CPR?”

“Many people make the CPR decision without understanding the risks involved. What do you think the success rate of CPR is for someone like you who has been living with heart disease for a long time?”

“What goals do you have if you wanted to have CPR attempted? What would you expect to happen?”

“I’d like to give you some information about CPR that most people are unaware of (or, I’d like to develop a list of questions regarding CPR for you to discuss with your physician in order to help you make an informed choice). We want to respect your decision, but we want to make sure you understand what’s involved. Unfortunately, CPR is not as successful as most people think, and there are complications from CPR as well. CPR is less than 5% successful for people who have end-stage chronic illness, and less than 2% successful for the elderly who are living in long-term care facilities. I realize these odds don’t sound good, and only you can decide if they are odds you are willing to take. In addition, the complications of CPR include the need for a breathing tube and a stay in the ICU, broken ribs that can prolong recovery, and some people lose mental abilities.”

In discussing CPR, it is may be necessary to review the following options:

**Do Not Resuscitate (DNR) or Do Not Attempt Resuscitation (DNAR):**
In the event breathing or heartbeat stops, there will be no attempts at assisted ventilation or external cardiac massage. It is important to remember that this order says nothing regarding other aspects of care, which will require further discussion and clarification.

**Do Not Intubate (DNI):**
In the event breathing begins to fail or heartbeat stops, resuscitation will be started, but without intubation. It may be important to write a DNI order in cases where respiratory failure is likely to occur first and intubation is not desired by the patient.

**Out-of-Facility DNR Orders:**
Some patients wish to have their DNR order respected and communicated when they are outside of a healthcare facility. This may be accomplished by either a DNR bracelet or physician order form, depending on state law or local/regulatory standares.
Artificial Ventilation

**Facts:**
Unlike cardiac arrest, respiratory arrest often occurs with some time to consider whether intubation and ventilation should be provided. Nevertheless, patients with advanced lung disease, pulmonary infections, and neuromuscular disorders who could become ventilator-dependent should consider the type of medical interventions they would want if they experience respiratory failure.

Intubation involves the insertion of a tube through the mouth or nose into the lungs. This tube can then be connected to a breathing machine, or *ventilator*, to artificially support breathing.

**Benefits:**
A variety of temporary and reversible conditions can interfere with adequate breathing or respiration, which is the process of providing oxygen to the body and removing carbon dioxide. These conditions include pneumonia, the need for support following surgery, or a collapsed lung resulting from an accident. The breathing tube and artificial ventilator provide adequate respiration while the lung is healing or the body is recovering from another illness.

For patients with chronic pulmonary diseases, artificial ventilation can be used on a trial basis to determine if patients can improve enough to adequately breathe on their own. Artificial ventilation has the benefit of allowing the lungs to rest while other elements of patients’ conditions are being managed.

In both situations, artificial ventilation may prolong life.

**Burdens:**
The breathing tube causes coughing, throat irritation, and the need to suction secretions from the airway. The artificial ventilator may require some getting used to while the patient learns to let the machine do part, or all, of the breathing. Psychologically, the patient may be afraid or suffer sleep disturbances.

To treat the discomfort caused by the breathing tube, the patient may require medications, such as morphine and sedatives, which may alter level of consciousness.

When using artificial ventilation for chronic pulmonary situations, it may be difficult or impossible to later remove the ventilator. In these cases, patients are never able to resume breathing on their own and become ventilator-dependent for the rest of their lives.

Artificial ventilation may prolong dying.

**Strategies for Discussion:**
While most people would choose the use of artificial ventilation in situations of expected total recovery, patients who have underlying pulmonary problems have a different set of circumstances to consider. Again, patients' goals of care need to be determined and information regarding trials of intervention be discussed. Making a decision to select a trial of artificial ventilation to see if patients can recover and breathe on their own need not be translated into a life-long sentence of dependency on the ventilator. Short-term goals can be discussed with patients with the intent that if the ventilator is no longer producing the intended results, it can be removed. Moreover, the process of compassionate ventilator removal may need to be discussed to allay concerns of discomfort or suffocation. Ventilator removal should follow established protocols that include time frames for withdrawal, appropriate methods for withdrawal, symptom management during withdrawal, and patient and family support.

**Artificial Nutrition and Hydration**

**Facts:**
Artificial nutrition and hydration involves the short-term or long-term administration of a balanced mix of nutrients and fluids via tubes (nasogastric, gastrostomy, jejunostomy, intravenous) placed directly into the stomach, intestine, or vein. Short-term administration is needed to temporarily support a person while the cause of the inability to take nutrition is corrected (e.g., recovery from surgery). Long-term administration permanently sustains nutritional needs in patients who will never recover the ability to take nutrition on their own (e.g., persistent vegetative states, irreversible neurologic disorders).

**Benefits:**
Life may be prolonged.

Patients' personal and/or religious preferences are honored.

Administration prevents weakness, dry mouth, and thirst related to dehydration.

**Burdens:**
Feeding tubes are often associated with the aspiration of nutrients into the lungs, causing pneumonia (in 30% of cases) or irritation and discomfort of the throat, esophagus, and stomach.

Intravenous fluids increase the volume of secretions in the lungs, making breathing more labored and necessitating more frequent suctioning. Intravenous fluids increase congestion in other parts of the body, such as around tumors and organs, causing pain and discomfort, as well as increased production of urine requiring frequent elimination and linen changes.
For some confused patients who are in danger of self-harm from pulling at tubes, physical or chemical restraints may be required.

**Strategies for Discussion:**
There are a variety of reasons why decisions regarding artificial nutrition and hydration are difficult, and it is often helpful to explore fears with patients and their families. Providing food and water may symbolize basic care and compassion; there may be fear that the patient will experience pain and suffering, or there may be religious or personal views to consider. In providing information about the benefits and burdens of artificial nutrition and hydration, it may be helpful for patients and families to learn what professionals have experienced when caring for patients who have artificial nutrition and hydration withdrawn. These professionals report observing a more peaceful, comfortable death after nutrition and hydration are stopped. There is evidence that this withdrawal also produces a release of naturally occurring chemicals (endorphins) that act as natural pain relievers. Death can be expected within 3 to 14 days, with the patient moving quickly into a coma and becoming unaware. The side effects of dry mouth and thirst are alleviated by providing sips of water, ice chips, lubricants, meticulous oral care, and sedation or analgesia.

**Scenario:**

“Mrs. Jones, I’ve been asked to talk with you about one of the choices you seem to be struggling with. One of the nurses told me you were very concerned about artificial nutrition and hydration. Could we talk about that issue now?”

Mrs. Jones: “Yes, I would like to talk. I’ve been told that I must continue food and water no matter what. Otherwise, I would starve to death and be uncomfortable.”

“I know this issue is full of emotion as well as some common misunderstandings. I’d like to help you sort it out. We will respect the decision you make, but I want to discuss some issues so that the decision you make is really the one that best reflects your wishes.”

“First, can you tell me where you received this information about starvation?”

“Have you had any experiences with this issue in the past?”

“Do you have any religious/spiritual or cultural beliefs that would affect your decision on continuing artificial nutrition and hydration?”

“Do you understand what artificial nutrition and hydration is and how it is delivered?” [Provide information as needed.]
“The word starvation is a powerful one, full of emotion. But it is also an inaccurate one. Starvation describes a situation when our bodies desire food and water and are deprived of it. While it may seem natural to you to continue to receive nutrition and hydration, there are some side effects and situations when our bodies do not benefit from it and would actually be more comfortable without it.”

“To assist you in making this decision, I’d like to give you some examples of the side effects that can occur because of receiving artificial nutrition and hydration. First, the artificial nutrition that is delivered through tubes often moves out the stomach and slips into the lungs, causing pneumonia. This is called aspiration. The artificial hydration that is delivered may also increases the amount of fluid the body has to absorb, causing extra fluid in the lungs, making it more difficult to breathe. The extra fluid also causes congestion in other parts of the body, causing pain and discomfort as well as the need to urinate more frequently.”

“There is also a fear that withholding nutrition and hydration is uncomfortable. The experiences of professionals who care for the dying tell us that when artificial nutrition and hydration are stopped, the person appears more comfortable and peaceful. People often die in 3 to 14 days, but slip quickly into unconsciousness and become unaware.”

**Antibiotics**

**Facts:**
In the past, infections were the cause of death for many people, both young and old. Today we have sophisticated antibacterial agents that can often prevent death, even in the case of serious infections.

**Benefits:**
Antibiotics eliminate the source of infection and, therefore, the accompanying side effects of an infectious process such as fever, chills, and discomfort.

Antibiotics may prolong life.

**Burdens:**
Many antibiotics to treat infection need to be administered intravenously, thus requiring initiating an IV site, with the potential discomfort associated with starting the IV and maintaining patency.

Antibiotics may delay the dying process by temporarily reversing a fatal event in an incurable illness (e.g., a person who has pneumonia due to end-stage lung cancer).
Strategies for Discussion:
While antibiotics may be viewed as non-invasive and, therefore, a treatment that should be given, health professionals can help patients and families evaluate this choice in light of their situation and goals of care. There can come a time when death is acceptable and may be welcomed, particularly when the patient is permanently unable to interact, will surely get worse, and will die within the next months or year. Treating an infection may only delay death without particular benefit to the individual being treated. Conversely, antibiotics may be needed to treat discomfort during the dying process, even for situations where death is inevitable.

Dialysis

Facts:
Dialysis is a treatment provided to an individual whose kidneys have stopped working. The kidneys take the waste out of the bloodstream put there by the body’s cells. If this waste is not removed, it will build up and ultimately cause death.

Benefits:
Dialysis removes toxic waste products, allowing a person’s other vital organs to function more normally.

Dialysis may prolong life.

Burdens:
Dialysis involves the insertion of catheters into the bloodstream and up to several hours of removing and filtering the patient’s blood several times a week.

Once kidney function is gone, patients are dependent on dialysis for the rest of their lives, or they may receive kidney transplants.

Expense

Dialysis may prolong the dying process.

Strategies for Discussion:
Patients need to understand that making a decision for dialysis may be a long-term commitment unless kidney function can be restored or a transplant obtained. For some patients, the choice of dialysis is temporary and has few burdens; however, for patients who determine that their quality of life has been permanently and seriously compromised, dialysis may have little value and continue to be a significant personal burden. For those who are contemplating the withdrawal of dialysis, it is necessary to explain the process of withdrawal and how the side effects of the build-up of toxins from the kidney can be managed.
successfully with the use of analgesics and sedatives. With the build-up of toxins in the bloodstream, patients typically go into a coma, become unaware, and their heart stops beating. Once dialysis is stopped in patients with no kidney function, death usually occurs in 5 to 8 days.

**Other Treatments**

There are many other medications or treatments that prolong life and maintain function—for example, insulin, blood or blood products, and medications or devices that control blood pressure or heart rhythm. While it may at first seem unusual to consider stopping treatments that normally serve to benefit the patient, when a decision has been made to withdraw life-sustaining treatment and allow death to occur, all medications and treatments can be evaluated to determine their continued effectiveness in providing benefit or comfort in the dying process.

In addition to making choices regarding which life-sustaining interventions to accept or withhold, patients may also need to decide when and if these same interventions should be withdrawn.

**Choices Related to Withdrawing Life-Sustaining Treatment and the Use of Time-limited Trials**

There is a common fear that once a life-sustaining treatment is started, it can or will never be withdrawn. This may lead individuals to make statements such as “I don’t want to be hooked up to machines” or “I don’t want any tubes.” Indeed, these fears may be translated into decisions that make it more difficult for health professionals and healthcare agents to attempt short-term trials of interventions that could be beneficial and consistent with established goals. However, individuals may need reassurance that after a trial of aggressive treatment that is not serving the purpose for which it was started, it can be compassionately withdrawn.

In addition to needing help understanding that there is no moral or legal distinction between withholding treatment and withdrawing treatment, individuals may also need help reconciling the emotional differences between the two actions. Both actions—withstanding treatment and withdrawing it—result in the same outcome of allowing the person to die of their underlying disease process. The central moral question is whether or not there is justification to start or continue a treatment for a patient given the circumstances of the situation (e.g., the person’s diagnosis, prognosis, and goals and values, as well as the benefits and burdens of treatment).

It is useful to describe a scenario that helps the patient understand that a treatment that is started for a perceived benefit can later be removed if the burden becomes unacceptable (i.e. time-limited trial). A common example is the patient with chronic obstructive pulmonary
disease who is willing to be placed on a ventilator to see if pneumonia can be effectively treated, but has concerns about being maintained on the ventilator if there is not an acceptable recovery. It would be important to discuss the expected goals for recovery, the length of time the patient is willing to wait and the extent of burden the patient is willing to accept. The criteria for withdrawing the ventilator can be discussed prior to initiation and written in the advance directive. In considering such time-limited trials of life-sustaining treatment, it is critical to adequately prepare the healthcare agent and other loved ones for the potential reality of withdrawing such treatment.

**Choices Related to Comfort Care**

“Please make me comfortable” is a phrase expressed by healthy adults as well as dying patients and is an important objective of care for health professionals. However, what does comfort care mean? Consistent with the decision-making process for other end-of-life decisions, the patient’s goals for comfort care need to be determined. Professionals can take an active role in providing information on comfort care options, assessing current state of comfort, and implementing effective interventions as desired by the patient to relieve distressing symptoms.

Healthcare agents, loved ones, as well as health professionals are often concerned about shortening a patient’s life through the administration of medications to control the physical symptoms of the dying process. This fear is often unwarranted and may result in less than optimal symptom control. Health professionals must understand that all medical interventions have potential risks and benefits and that the patients themselves should decide what they are willing to accept based on adequate information and evaluation of their personal goal, values, and beliefs. It is the primary intent of the medical intervention that must be clarified. If administering enough morphine to control pain causes the patient to become more somnolent and unable to interact with family and friends, it is the patient who must decide if the primary intent, that of relieving pain, is more important than the unintended effect of somnolence. The ethical concern exists only when the primary intent is to cause death, as in requests for physician-assisted suicide. Uncomfortable physical effects of the dying process can be adequately managed without causing death.

In addition, options for addressing the psychological comfort of the patient should include such interventions as offering spiritual counseling, utilizing complementary coping tools of music and massage, providing privacy, and supporting loved ones.

In providing comfort care interventions, several actions are indicated:

- Assess the patient’s perception of what comfort care means.
• Remind the patient that choosing comfort care measures does not mean giving up or not providing potentially therapeutic medical treatment. Comfort care measures can and should be offered and provided at any stage of the patient’s illness.

• Provide information regarding the risks and benefits of medications available to control the unwanted symptoms of dying. In essence, provide informed consent related to the intended and unintended consequences of measures to provide comfort.

• Assess patients’ goals related to how they want to experience the dying process.

• Develop clinical practice guidelines on comfort care that include physician order templates and standards of practice on physiological and psychological interventions for comfort care.
Chapter 4: Exercises


2. What are the three categories of end-of-life treatment choices?

3. You need to determine a patient’s wishes regarding CPR. Describe how you would begin the discussion and what information you would give regarding benefit and burdens of CPR.
Chapter 4: 
Further Reading


