Negotiating goals of care is an example of patient-centered medical decision making, which differs significantly from the problem-oriented method practiced commonly in health care in the United States. A patient-centered approach to medical decisions has proven particularly useful in the setting of advanced or serious illness. This chapter discusses a six-step approach to the goals-of-care discussion, including examples of how the steps can be used and, in a case study, real-world examples of this approach in action. Pearls and common pitfalls are highlighted.

Health care in general aims at preventing or curing disease. When you fracture a bone, you go to the hospital to get it fixed. When you acquire bacterial pneumonia, you take an antibiotic to cure it. However, many diseases cannot be “fixed.” Rather, they are managed; examples are hypertension, diabetes, and congestive heart failure. For most diseases that must be managed, increasing longevity, reducing disease-related symptoms, and maintaining function and quality of life for a maximum period of time until the patient’s death are the objects of medical care. As a patient’s disease progresses, medical decisions are influenced more and more not just by medical information but also by the patient’s underlying values and priorities. For patients living with chronic or life-threatening disease, medical decisions are often not as straightforward as they are for simple problems that can be fixed. Rather, these
patients face several options that may all be reasonable within the breadth of accepted medical practice.

It is therefore crucial for the health care professional who cares for patients with chronic diseases to be able to elicit underlying values and priorities, to set overall goals for care. Mutually agreed on goals will then lead to appropriate decisions to achieve those goals. It is expected that, as the patient progresses along his or her trajectory of illness, goals may change. For example, for the patient discussed in the case study in this chapter, the initial goal is to cure her cancer, then to shrink it, then to keep it from growing too fast. Another goal may be to be as comfortable and functional as possible regardless of the state of the cancer.

Along the trajectory of illness, several trigger situations invite the patient and health care provider to reflect on and discuss goals of care. These include general advance care planning, a new diagnosis, a change in therapy, the transfer to a new health care provider or institution, and, probably most commonly, the point along the disease trajectory when interventions to cure or control the disease are no longer effective or desired. One reason for this may be that the treatment-associated burden seems to outweigh its benefit.

Patients are open to such discussions. Studies show that between 85% and 95% of patients want to have honest discussions with their health care providers regarding life-threatening diseases.1 Health care providers do not adequately meet this need. Studies have shown that doctors and nurses underestimate cancer patients’ concerns, do not elicit the goals and values of seriously ill patients or include them in treatment decisions, and generally fail to address their patients’ emotional concerns.2–4

The three chief reasons that doctors do poorly in communicating honestly with patients and families are as follows:

1. Medical education does not devote much time or attention to the development of good communication skills, and medical students see few role models.5
2. The culture of medicine in the Western world focuses on organ systems rather than on whole-patient care.
3. The physicians’ own attitudes and underlying emotions regarding death and dying also interfere with adequate goals-of-care discussions.6

The importance of good communication has been well recognized in the field of palliative medicine. Major educational initiatives such as Education for Physicians on End-of-life Care and End-of-life Nursing Education Consortium (ELNEC) devote significant time to skills training in this area. Communication is a learnable skill that, like many other skills, requires ongoing practice. Brief educational interventions are likely not sufficient to change physician behavior.7 Intensive communication skills training, however, has been shown in a randomized trial to improve physician communication skills in practice.8

For those physicians interested in skills training regarding the negotiation of goals of care, this chapter summarizes a six-step protocol that can be used as a framework anywhere along the disease trajectory, such as advance care planning, discussing treatment options or resuscitation orders, or introducing hospice care. This protocol was adapted from the SPIKES communication protocol for the delivery of bad news, which is discussed in Chapter 3. It is used in the Education for Physicians on End-of-life Care Project.9

The protocol uses the general principle of shared decision making. This principle is considered the current standard of care for medical decision making in the United
States.\textsuperscript{10} Shared decision making as a process puts great emphasis on patient autonomy while acknowledging the physician’s responsibility to make treatment recommendations that are based both on the patient’s stated overall goals of care and the physician’s medical expertise. The protocol for goals-of-care discussions described here not only reflects common communication styles in the United States but is also strongly influenced by the society’s current bioethical value system. Health care professionals balance the underlying ethical principles of autonomy, beneficence, nonmaleficence, and fairness with a strong emphasis on autonomy.

Studies of health care decision making in other parts of the world show that different cultures prioritize these ethical values differently. It seems most common to place less emphasis on autonomy in favor of beneficence and nonmaleficence. For example, although more than 90% of U.S. physicians share a new diagnosis of cancer with their patients, only 44.5% of competent patients were informed of their prognosis by their physician in a study from southern France. Studies from China indicate that patients there are rarely informed of a new diagnosis of cancer. In African countries such as Nigeria, Egypt, and South Africa, the type and amount of information shared seem to depend on patient factors such as level of education or socioeconomic status. Bruera and colleagues elicited an additional point when studying attitudes and beliefs of palliative care specialists in Canada, South America, and French-speaking Europe. In this study, all clinicians wanted to be told the truth about their own terminal illnesses, but physician predictions about their patients’ wishes differed significantly: Whereas 93% of Canadian physicians thought their patients would wish to know the truth, only 26% of their European and 18% of their South American colleagues thought that most of their patients would want to know about their diagnosis.\textsuperscript{11} These results invite the question regarding the degree to which the perceived differences reflect biases of local health care cultures rather than actual differences in patient preferences.

Attitudes toward truth telling also clearly change over time. In 1961, more than 90% of U.S. surgeons did not share a new diagnosis of cancer with their patients. This finding clearly contrasts with today’s practice.

These trends demonstrate that medical decision making and information sharing are processes guided by values and underlying ethical principles that are influenced by culture and will change over time. The element of the protocol proposed here that helps to assess this is the step of asking the patient how much he or she wants to know. This permits the professional to adjust the approach for a given individual. Over time and according to the needs of individual patients and health care providers in different parts of the world, overall patterns may also change.

**Discussing Goals of Care**

Discussing goals is rarely a one-time event; rather, it is a process that develops over the course of multiple visits. The protocol suggested here can be applied at any stage of this process. The protocol relies on common techniques of verbal and nonverbal communication. Great emphasis is placed on empathic listening, a highly underestimated skill in medical practice. In a patient–doctor interaction, fewer than 25% of patients are provided the opportunity to complete their opening statement of concerns; all others are interrupted in less than 20 seconds. Physicians then tend to focus on closed-ended questions in an attempt to retrieve information as quickly as
possible. This approach risks that patients never have the chance to address their major concerns. As a matter of fact, most patients leave the office without ever having their concerns addressed. Because eliciting patient preferences is at the center of goals-of-care discussions, it is especially important to start out the conversation with an open-ended question, followed by active listening. This allows the patient to focus on his or her major concerns and sets the stage for patient-centered care. Active or empathic listening then includes nonverbal communication skills that show full attention such as good eye contact and leaning toward the patient as well as verbal empathic listening techniques such as reflection, paraphrasing, and validation.

When conveying medical information, it is generally recommended that the information be given in small pieces. The physician should use words that the patient can understand and should pause frequently to check for the patient’s responses. The higher the emotional impact of the given information on the patient, the less likely the patient is to hear what is being said. It may therefore be necessary to repeat the information at a later time. The use of written information, summary letters, or tape recordings improves patient recall and understanding. In a study of 50 cancer patients, use of an informational videotape after a verbal goals-of-care discussion significantly altered patients’ decisions regarding end-of-life care, increasing patients’ choice for comfort care from 22% to 91%.

Stone and colleagues suggest always preparing and having difficult conversations at three levels: facts, emotions, and identity issues involved. An example of this triad regarding goals-of-care discussions is to first spend some time discussing the different clinical options such as further chemotherapy versus hospice care; then look for and validate the patient’s emotional responses such as fear, worry, and sadness. Last but not least, the physician then reflects on what the discussed options will mean for the patient’s and health care provider’s identity. Examples of identity issues that influence goals-of-care discussions are as follows: “I have always been a fighter and now you’re asking me to give up?” or “I am not someone who just gives up on a patient.”

Examples of the communication techniques used in this protocol are given under each step.

### Six-Step Protocol

A stepwise approach to goals-of-care discussions helps to remind the clinician to include all major components of the discussion. This is particularly true for those who are inexperienced or early in their training, in whom this skill has generally not been demonstrated. The six steps include preparing and establishing an appropriate setting for the discussion, asking the patient and family what they understand about the patient’s health situation, finding out what they expect will happen in the future, discussing overall goals and treatment options, responding to emotions, and establishing and implementing a plan (Box 4-1).

#### 1. PREPARE AND ESTABLISH AN APPROPRIATE SETTING FOR THE DISCUSSION

An important part of preparing for a goals-of-care discussion is to assess the patient’s or family member’s readiness to have this conversation and to address cultural or
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personal priorities regarding medical decision making in general. Ask whether your patient would want to have this discussion with you, if someone else should be present, or if your patient would prefer to defer it to someone else such as a family member or designated medical decision maker. A recent study from Australia comparing awareness of treatment goals in patients and their caregivers shows significant discrepancy in nearly half of patient–caregiver pairs, suggesting that you should attempt to include surrogates in as many of these conversations as possible. You can elicit these preferences using the following sentences:

“Some patients like all the information; others like me to speak with someone else in the family. I wonder what is true for you.”
“Tell me how you like to receive medical information.”
“It there anyone else you would like to have present for our discussion?”

When you enter the actual goals-of-care discussion, do it with a clear understanding of the purpose of the meeting and be prepared to discuss information that the patient and family will need to learn. An example could be the outcomes of different treatment options such as chemotherapy, cardiopulmonary resuscitation survival data, and common treatment side effects. In general, patients are more interested in outcomes (“Life is not worth living if I won’t be able to speak”) than in the details of interventions (“That means that we would have to put a tube down your throat that is about as thick as your finger”).

In addition to medical information, it can be helpful before entering the discussion to reflect on expected emotional responses and possible identity issues as discussed earlier. This approach allows you to gain more insight into the patient’s and family’s perspective and to feel prepared, especially when their perspective seems “unrealistic.”

Arrange to have the meeting itself in a private and comfortable place where everyone participating can sit at eye level. The atmosphere should be unhurried and undisturbed. After general introductions, the purpose of the meeting should be made clear. You can introduce the subject by phrases such as the following:

“I’d like to talk to you about your overall goals of care.”
“I’d like to review where we are and make plans for the future.”
“I’d like to discuss something today that I discuss with all my patients.”

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**Box 4-1. Six Steps for the Discussion of Goals of Care**

1. Prepare and establish an appropriate setting for the discussion.
2. Ask the patient and family what they understand.
3. Find out what they expect will happen.
4. Discuss overall goals and specific options.
5. Respond to emotions.
6. Establish and implement the plan.
CHAPTER 4 Negotiating Goals of Care: Changing Goals Along the Trajectory of Illness

2. ASK THE PATIENT AND FAMILY WHAT THEY UNDERSTAND

Start out with an open-ended question to elicit what the patient understands about his or her current health situation. This is an important question and one that many clinicians skip. If the doctor is doing all the talking, the rest of the conversation is unlikely to go well. You could start with phrases such as the following:

“What do you understand about your current health situation?”
“Tell me how you see your health.”
“What do you understand from what the doctors have told you?”

Starting with these questions not only helps to establish trust and set the tone for patient-centered decision making, it also helps to address misconceptions and conflicting or missing information and allows you a quick glimpse into the patient’s emotional response to his or her current health state, such as fear, anger, or acceptance. More time may be needed to clarify the current situation before the patient is able to address future medical decisions.

3. FIND OUT WHAT THEY EXPECT WILL HAPPEN

For patients who have a good understanding of the status of their disease, the third step is to ask them to consider their future. Examples of how you could start are as follows:

“What do you expect in the future?”
“Have you ever thought about how you want things to be if you were much more ill?”
“What are you hoping for?”

This step allows you to listen while the patient has the opportunity to contemplate and verbalize his or her goals, hopes, and fears. This step creates an opportunity for you to clarify what is likely or unlikely to happen. You may need to ask follow-up questions to understand the patient’s vision of the future as well as his or her values and priorities more clearly. If there is a significant discontinuity between what you expect and what the patient expects from the future, this is the time to discover it.

4. DISCUSS OVERALL GOALS AND SPECIFIC OPTIONS

Now that you have set the stage for a joint understanding of the patient’s present and future, you can discuss overall goals of care and specific options. Allowing the patient to reflect on goals that may still be realistic despite reduced functional abilities and a limited life expectancy can be a very effective tool to maintain hope and build trust. Your insight into the patient’s values and priorities should then structure the conversation of medical options and should guide your expert opinion. Use language that the patient can understand, and give information in small pieces. As discussed earlier, you should focus the discussion on treatment outcomes rather than on details of medical interventions.18,19 Stop frequently to check for emotional reactions and to clarify misunderstandings.
It is often helpful to summarize the patient’s stated overall goals and priorities as an introduction to the specific options. Following the principle of shared decision making, after the discussion of the available options, you should make clear recommendations that are based both on the patient’s stated overall goals of care and on your medical expertise. For example:

“You have told me that being at home with your family is your number one priority and that the frequent trips to the hospital have become very bothersome for you. You do have three options at this point (...). Getting hospice care involved seems to be the option that best helps you to realize your goals.”

“If I heard you correctly, your first priority is to live to participate in your granddaughter’s wedding in June. Taking that into account, it may be best to continue the current therapy and try to treat your nausea with a stronger regimen.”

“I heard you say that you are particularly concerned about being a burden to your children. By getting the hospice team involved, your family could get extra support from the nurse, chaplain, and social worker who would come to see you at the house.”

“It is clear you want to pursue all options to extend your life as long as possible. That includes being cared for in an intensive care setting with maximal support. However, if you are unable to communicate, and there is no reasonable chance of recovery, you want life support to be stopped.”

A recent Canadian analysis of expert opinion regarding “code status” discussions suggests that clinicians may initiate them at any point during an illness or even when a patient is in good health. The discussion should be framed as an overall goals discussion. It should distinguish between life-sustaining therapies (LST) and cardiopulmonary resuscitation (CPR); describe a cardiac arrest, CPR, LST, and palliative care; explain outcomes of cardiac arrest; offer a prognosis; and make clear recommendations.20

A study looking at U.S. patient and caregiver preferences regarding end-of-life care conversations shows that these discussions should include different treatment options, future symptoms, a description of the terminal phase, and patient preferences for place of death. Fears about dying should be addressed, and myths dispelled. The needs of patients and caregivers differed significantly when discussing dying: whereas patients emphasized the importance of reassurance that pain would be controlled and their dignity maintained, caregivers often wanted more detail about the terminal phase and practical information about how to look after a very sick person. Both wanted reassurance that their health care professionals would be available.21

5. RESPOND TO EMOTIONS

Patients, families, and health care providers may experience profound emotions in response to an exploration of goals of care. It should not be surprising that patients, when considering the end of their life, may cry. Parents of children with life-threatening diseases are especially likely to be emotional and need extra support from the health care team. In contrast to common worries in the health care community,
however, emotional responses tend to be brief. Respond sympathetically. The most profound initial response a provider can make may be silence and offering a facial tissue. Consider using phrases such as the following:

“I can see this makes you sad.”
“Tell me more about how you are feeling.”
“People in your situation often get angry. I wonder what you are feeling right now.”
“I notice you are silent. Will you tell me what you are thinking?”
“Many people experience strong emotions. I wonder whether that is true for you.”

A common barrier to this step is the physician’s fear to precipitate overwhelming emotional outbursts that they may not be able to handle. Therefore, conversations between physicians and their patients remain in the cognitive realm where emotions are not addressed. The best way to overcome this barrier is to learn how to respond to patient emotions empathically and to learn to be comfortable with silence. Most patients are embarrassed by being emotional and keep their discussions brief. This is because most patients have adequate coping skills and appreciate the presence of a doctor while they work through the experience and their emotions. As with most aspects of being a physician, a sense of competence then leads to a willingness to engage in the challenge.

6. ESTABLISH AND IMPLEMENT THE PLAN

The last step of the goals-of-care discussion protocol involves the establishment and implementation of a plan on which the patient, family members, and physician can agree. You should verbalize a plan that is clear and well understood by everyone involved. Consider using language such as the following:

“You said that it is most important for you to continue to live independently for as long as possible. Because you are doing so well right now and need your current breathing machine only at night, we will continue what we are doing. However, when your breathing becomes worse, you do not want to be placed on a continuous breathing machine. We will then focus on keeping you comfortable with medicines to making sure that you do not feel short of breath.”

“The different regimens we have used to fight your cancer are not working. There is no other anticancer therapy that is known to be effective. We discussed your options at this point including getting a second opinion from one of my oncology colleagues or asking a hospice program to get involved in your care. In light of what you told me about your worries about being a burden to your family, you thought that hospice care may be the best option at this point because you would get extra help at home from the hospice team members that come to see you at your house. I am going to call the hospice team today and arrange for them to call you in the morning so they can see you and explain more about what they offer. We can talk more after you see them.”
It is often helpful to ask patients or family members to summarize the plan and underlying reasoning in their own words to ensure understanding. Especially for emotionally overwhelmed patients, good continuity of care is important. Ensuring this continuity, for example by arranging for follow-up appointments, speaking to the referring physician, or writing the appropriate orders, is part of the clinician’s responsibility. You may want to conclude your conversation with information that gives hope such as a promise of ongoing care.
**PEARLS**

- **Goals are not static and goals-of-care discussions are not a one-time task.**
  
  Many health care providers skip steps 2 and 3 (finding out what the patient understands and expects to happen) and lunge straight into detailed descriptions of medical interventions. These two simple questions set the stage. They show that you are interested in the patient and his or her experience and want to support the patient to achieve his or her goals. Starting from the patient’s perspective is not only an invaluable tool to establish trust and a feeling of safety for the patient, but it also makes giving recommendations much easier for you later. When the “big picture” goals are clearly understood, the discussion of specific medical interventions most commonly falls quickly into place.

- **Deferring autonomy is an act of autonomy.** We often come across situations in which a concerned family member asks us not to disclose health care information to our patient. This can make us very uneasy because it interferes with our understanding of patient autonomy; conversely, do we not want to be accused of “truth dumping.” You can solve this “dilemma” by first verbalizing understanding for the family member’s concern and then conveying that you will need to double check with the patient if this is how he or she would like to proceed (if you have not done that already). When you see the patient alone, ask how he or she would like to handle medical information and decision making. You can use words such as these: “Some people want to know all medical information as we find it and discuss all options with the doctor. Others would rather have their children make decisions and do not want to have to deal with the medical information. Where do you stand?”

- **Cultural competence.** In a multicultural society such as the United States, clinicians are likely to care for patients and families from many different backgrounds. The term culture is used here in the broad sense and includes ethnic, religious, social, and professional cultures such as the culture of the local hospital or another specialty. Each of these cultures has its own values and language. Sensitivity to differences in cultural background helps to facilitate communication and understanding. When inquiring about cultural backgrounds, you can use sentences such as this: “People from different backgrounds handle death and dying very differently. Is there anything that we should be aware of regarding your care?”

- **Validate “unrealistic” or conflicting goals.** Physicians are sometimes frustrated by their patients’ “unrealistic” goals. “They just don’t get it” is a common reason for palliative care consultation requests. Reflecting on our own goals in life, most of us have some hopes that may not be very realistic (“I wish I could win the lottery”) but still valid. The great difference lies in how we handle these hopes: Are we leading our life counting on what seems an unrealistic hope? An often cited example of this is a terminally ill parent who is unable to make the necessary arrangements for his or her minor children. A useful strategy to support hope but at the same time assist in making appropriate plans for the future is the “plan B” approach: “Although we hope for plan A, let’s also prepare for plan B.” Another useful way to validate your patient’s hope is the “I wish” statement. An example could sound like this: “I wish this comes true for you. Whatever happens, we will be there for you.” Intermittent denial of a terminal prognosis verbalized as unrealistic hopes can be a proficient way of coping and should be accepted as such.
### PITFALLS

**Preparation**

- **The goals-of-care discussion happens too late.** We often delay goals-of-care discussions until a catastrophic event makes medical choices no longer meaningful.²³

- **Patient or family readiness is not assessed.** Pushing this conversation upon a patient and family without evaluating their readiness to consider this profound, often highly emotional topic can lead to significant alienation and suffering.

- **The clinician has an agenda.** If you find yourself entering the room with your own agenda (e.g., to “get the DNR” or to “stop this futile treatment”), you may be headed for trouble. Try to understand the patient’s values and priorities first, to assist you in making appropriate medical recommendations that are most likely to achieve the patient’s goals. An awareness of the possible agendas of all parties involved in a goals-of-care discussion, such as yourself, patients and families, consultants, or hospital administrators assists in understanding the different perspectives and prevents adversarial outcomes.

- **The stakeholders are not identified.** You may have facilitated a picture-perfect goals-of-care discussion and thought that everyone agreed on a reasonable plan only to find out that the “cousin from out of town” flew in last night and threw over the whole plan. Before starting a goals-of-care discussion, always make sure that all stakeholders are present, over the phone if necessary, or otherwise represented to the extent possible. Stakeholders also include other health care providers involved in the patient’s care. Consistency among different clinicians, especially regarding prognostication and when suggesting a plan of care, is of vital importance to maintain trust and avoid suffering.

- **Homework is not done.** Be prepared to answer questions regarding the outcomes and evidence of discussion interventions, such as resuscitation survival data, prognosis, and side effects of treatments. Just as in any other informed consent discussion, patients need accurate information to make good decisions.

### Discussion of Overall Goals and Specific Options

- **Information sharing is ineffective.** Each person handles information differently. Although some patients want to understand the numerical probability of success or failure of specific interventions, others do not comprehend statistical information. Many clinicians share an excessive amount of medical details (because it is familiar or interesting to the clinician) using language that the patient cannot understand. Tailor the actual information giving to your patient’s needs. It may be helpful to ask the patient to repeat the information back to you using his or her own words. When discussing options, avoid using diffuse language such as “heroic interventions,” “comfort care,” or “good quality of life” because everyone has a different understanding of what these mean.

- **Care is linked to acceptance of a limited prognosis.** When the clinician unintentionally links the relief of suffering to the demand upon the patient or family to accept a limited prognosis, this may disrupt trust.²³

### Shared Decision Making, Informed Consent, and Decision-Making Capacity

- **The person does not have or is inappropriately denied decision-making capacity.** Before asking someone to make a decision regarding goals of care, ask yourself whether that person has decision-making capacity. This is usually the case if a person can summarize the decision in his or her own words,
Summary

Addressing goals of care periodically over the course of a patient’s illness is an important part of patient-centered care and has been shown to increase patient satisfaction and to decrease stress and anxiety.²⁴,²⁵ The outcome of goals-of-care discussions should guide our therapy and will assist us in supporting our patients through stressful life transitions. In this chapter we have discussed a simple, six-step protocol that can be used to facilitate these types of discussions. It is intended as a road map, highlighting the key components of successful negotiations. It is well known that communication is an important part of medical care. As with any other skill, good communication skills are learned with practice over time. The techniques used in this model can be applied to many other fields of patient care and to personal interaction in general.

Resources

Pal Med Connect. Talk to a palliative medicine expert via a free telephone resource hotline for medical professionals. 1-877-PAL-MED4 (1-877-725-6334) or http://www.palmedconnect.org
American Academy on Physician and Patient: AAPP is devoted to the enhancement of physician-patient communication. This organization hosts an annual course on communication skills training. http://www.physicianpatient.org
OncoTalk: A National Cancer Institute–supported biannual retreat for oncology fellows to improve communication skills at the end of life. http://www.oncotalk.info

References