

# Having a Meaningful Conversation with Patients about the End of Life

## *Six Tips for Physicians*

BY JULIE BENSON, MD

Physicians receive little training in medical school and residency about how to talk with patients about their end-of-life wishes. Consequently, they often feel uncomfortable discussing the topic, even if the patient brings it up. As the population ages and as patients become more involved in their health care decisions, physicians will need to have more of these conversations. This article provides guidance for having these difficult conversations.

For many physicians, talking to their patients about serious life-limiting illnesses and end-of-life decisions is a struggle. It's a skill not regularly taught in medical school or residency. If they are exposed to training on how to have end-of-life discussions, it's often during clinical rotations and only if the subject comes up. One study found only 17% of medical school faculty reported having taught some aspect of end-of-life care to residents and medical students in the past year.<sup>1</sup> In medical school, students are required to spend four to six weeks doing clinical rotations in obstetrics and gynecology, but only 50% of the population is at risk for obstetric or gynecologic issues. Contrast that with the limited amount of time medical students and residents spend learning about a process that 100% of patients will experience—dying—and it's no surprise that many physicians have difficulty talking to their patients about their end-of-life wishes.

As the population ages, more and more people want to be informed about and involved in their own health decisions. And

that means physicians will need to have conversations with them about planning for the inevitable. In a recent survey of residents in three Minnesota communities, nearly everyone interviewed reported that they would want to talk with their doctor about hospice if they knew that their illness was serious or life-threatening.<sup>2</sup>

The topic of end of life, however, can be the elephant in the exam room. Patients often believe their physician will bring up the subject if and when it is necessary. Yet, physicians worried about taking away their patients' hope may not bring it up unless the patient inquires.<sup>3</sup> Thus, no conversation ensues.

Physicians need to both initiate and skillfully conduct these conversations. The following is some basic guidance to help them sharpen their skills when it comes to talking to patients about their end-of-life wishes.

### **1. Identify the Need for a Conversation**

Ideally, clinicians are talking with their patients about end-of-life issues over the course of their relationship. They especially need to have the conversation with certain patients at certain times. By ask-

ing yourself if you would be surprised if a patient died in the next year, you can often identify patients for whom end-of-life conversations are especially necessary. Ask yourself this question when a patient is admitted to the hospital, in a clinic setting, at the time a serious illness is diagnosed, or during follow up.

### **2. Clarify the Prognosis**

Next, the clinician needs to understand the patient's prognosis and what it means in terms of life expectancy as well as morbidity related to treatment options. Note that understanding the prognosis isn't necessarily the same as predicting life expectancy. These are two different pieces of information. Prognosis speaks to the probable course a disease may take, whereas life expectancy is simply the average time a patient will live given a particular diagnosis. So even if life expectancy is unknown, the course of the illness can be explained by its pattern of exacerbations and possibility of recovery or partial recovery.

Unfortunately, determining the prognosis for many serious illnesses can be difficult. Cancers are the diseases about

which we have the best delineated prognoses (with or without treatment). But that's not the case with progressive end-stage diseases such as congestive heart failure, COPD and dementia. That does not mean you should not have conversations about the end of life with patients who have these conditions.

Be sure to gather the appropriate information before initiating the conversation. Consider the patient's primary diagnosis and comorbid conditions. The Palliative Performance Scale<sup>4</sup> sometimes can help you determine a patient's life expectancy. Also, be cognizant of the patient's current clinical situation. Have they had a repeat admission to an ICU for respiratory failure? Are they in the clinic for follow up for slowly advancing dementia?

### 3. Prepare for the Conversation

If you are struggling with what to say about a patient's prognosis and potential life expectancy, then employ the "mom test." Imagine your mother sitting in front of you. What would you want her to know and how would you want her to hear it? Remember that most patients are emotionally connected to their physician and would rather hear difficult news from him or her than from a consultant they have not yet learned to trust. Honor that relationship.

When planning for such conversations, schedule enough time to have a thorough discussion. Block time for them as you would for a surgery or procedure. If possible, have these conversations earlier in the disease process, when a crisis is not occurring. Also keep in mind that it's better to have a difficult conversation and have the patient improve than to not have it and have to face a patient and family who are unprepared, scared and angry. Having these conversations is never a waste of time, as they lay the groundwork for subsequent talks.

If you feel you do not have the skills or the time or enough information to

proceed with an end-of-life conversation, then a referral to a palliative care service is indicated. Palliative care clinicians can aid in complex medical, spiritual or family situations. If a palliative care team is not available, a hospice nurse or social worker may be able to assist even if it isn't time for a hospice referral.

### 4. Determine the Goals of Care

Goals of care often are determined over the course of several conversations. The SPIKES mnemonic can help you share information and elucidate the patient's goals of care:<sup>5</sup>

**S (SETTING).** Make sure the setting in which you're having the conversation is comfortable and private. Limit distractions by turning off cell phones. Include family members and loved ones if the patient wants them present. Consider having another member of the care team, such as a representative from social services, present to answer questions that you might not be able to.

**P (PERCEPTION).** Understand how the patient perceives their condition and their prognosis. Are they in denial? Have they received inconsistent or even conflicting information from other specialists? If so, it might affect their ability to understand their prognosis. Ask the patient to explain their understanding of their medical condition to date. It will give you a chance to hear it from them. You can then use some of their own language and terminology when you share your news.

**I (INVITATION).** Ask the patient if it's all right to share new results. Ask how much he or she wants to hear. You might start with, "Are you the sort of person who...?" Accept the patient's right not to know or to decline details at this time. Some may even defer all information to a family member. If a family member insists that the patient not be told certain information, ask the patient how much he or she want to know. Not every patient wants to know all the details. Cultural differences may influence the way information is shared.

**K (KNOWLEDGE).** Present information in small chunks. Give a warning that bad news is about to be shared. Saying

something like, "I am afraid the results aren't what we were hoping for" allows the patient to prepare for the next piece of information. Disclosing too much at once makes it less likely that the patient will understand and remember the details. Also, speak in lay terms, using some of the same language the patient has used to describe his or her condition. Stop frequently and allow time for everyone to absorb the information. Also check in with patients to make sure they understand what you're telling them. Ask them to repeat what they have heard to make sure they understand it.

**E (EMOTIONS).** Consider the impact on the patient of news about his or her condition. Ask how he or she is feeling and let him or her know you understand how or why they're feeling the way they are. Patients who feel they have been heard and understood are more likely than others to trust you and follow your advice. Offer comfort. It is acceptable for them to know you are struggling with this news as well. Hiding your feelings may actually distance a patient from you.

**S (STRATEGY and SUMMARY).** Conclude the conversation by summarizing the information you've shared and discussing the next step. Keep in mind that any change in the patient's condition requires a review of the goals of care. Goals can change, and you need to be flexible and truthful.

### 5. Create and Document a Plan

Once goals of care have been clarified, you can develop a plan for the patient. The plan should outline how symptoms will be managed, what support services may be needed and when, and who the patient's surrogate decision-maker is should he or she become incapacitated. Fill out an advance directive (AD) form or a POLST (Provider Order Set for Life-Sustaining Treatment) form if appropriate. However, just filling out an AD or POLST form is not enough. The plan needs to be documented so other members of the care

team are aware of it and can follow it. Not documenting these discussions carefully is like not writing an operative or procedure note.

Discussions regarding resuscitation are critical to a plan. Clarifying a code status is not as simple as asking: “Would you like to be resuscitated or not?” To be fair, that is what many of us were taught to do. Patients often believe resuscitation will be successful if it is initiated. They deserve accurate information about the likelihood of a poor outcome in the setting of serious or terminal illnesses. It is imperative that clinicians truthfully share this information in a manner that is compassionate and respectful of the patient’s stated goals of care and in light of their prognosis. Sometimes their code status needs to be revised after a proposed trial of limited therapy. Keep in mind this is often the last decision over which patients feel they have control.

## Resources

### *Improving Generalist Palliative Care.*

A 40-page guidebook published by the Palliative Care Network of Wisconsin that focuses on the education and systems changes necessary to embed goal-of-care conversations into care for seriously ill hospitalized patients. The book includes a step-by-step guide along with a sample EMR template, quality improvement guidelines, clinician communication guidelines, clinician educational resources and more.

[www.mypcnow.org/#!about1/c22s6](http://www.mypcnow.org/#!about1/c22s6)

### *Vital Talks.*

Web-based videos that teach physicians how to navigate tough clinical situations. [www.vitaltalk.org/clinicians/cultivate-your-skills](http://www.vitaltalk.org/clinicians/cultivate-your-skills)

## 6. Offer Support

Never tell a patient there is nothing more you can do. It can send an unintended message of abandonment. There may not be any further treatment to offer, but there is always more you can do in the way of providing support and making your patient comfortable. If you feel you do not have the resources to support the patient, ask for help from a hospice or palliative care team. Supporting the patient, family and care team is what they do.

## Looking to the Future

The Institute of Medicine’s 2014 report “Dying in America” found clinicians’ ability to handle end-of-life matters to be so deficient that it recommended that educational institutions, professional societies, accrediting organizations, certifying bodies, health care delivery organizations and medical centers take measures to expand all clinicians’ knowledge about end-of-life care.<sup>6</sup>

Indeed, with the current focus on the Triple Aim and, in particular, increasing quality in health care, it is likely that institutions will require clinicians to have specific training and competence in end-of-life planning in the near future. The Palliative Care Network of Wisconsin has developed a guidebook focusing on how to embed goal-of-care conversations into routine care for seriously ill hospitalized patients.<sup>7</sup> Some hospitals in Wisconsin and elsewhere in the United States now require all medical staff to receive training on how to have such conversations with patients.

## Conclusion

Medicine is complex. Life is unpredictable. We prepare expectant mothers and their families for the birth of a child with regularly scheduled prenatal visits, birthing classes and opportunities for education. Those with serious life-threatening illnesses deserve to be similarly prepared for dying and offered the same type of longitudinal support. Atul Gawande wrote, “The purpose of medical schooling was to

teach how to save lives, not how to tend to their demise.”<sup>8</sup> It is time for this to change. And it all starts with a conversation. **MM**

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