

suggested phrases and underlying rationales for each one. Additional research that further considers the response of patients to systematic methods of delivering bad news could build the evidence base for even more effective communication procedures.

Continuous Goal Assessment Major barriers to ensuring quality palliative and end-of-life care include difficulty providing an accurate prognosis and emotional resistance of patients and their families to accepting the implications of a poor prognosis. There are two practical solutions to these barriers. One is to integrate palliative care with curative care regardless of prognosis. With this approach, palliative care no longer conveys the message of failure, having no more treatments, or “giving up hope.” Fundamental to integrating palliative care with curative therapy is to include continuous goal assessment as part of the routine patient reassessment that occurs at most patient-physician encounters. Alternatively, some practices may find it useful to implement a standard point in the clinical course to address goals of care and advance care planning. For example, some oncology practices ask all patients whose Eastern Cooperative Oncology Group (ECOG) performance status is 3 or less—meaning they spend 50% or more of the day in bed—or those who develop metastatic disease about their goals of care and advance care preferences.

Goals for care are numerous, ranging from cure of a specific disease, to prolonging life, to relief of a symptom, to delaying the course of an incurable disease, to adapting to progressive disability without disrupting the family, to finding peace of mind or personal meaning, to dying in a manner that leaves loved ones with positive memories. Discernment of goals for care can be approached through a seven-step protocol: (1) ensure that medical and other information is as complete as reasonably possible and is understood by all relevant parties (see above); (2) explore what the patient and/or family are hoping for while identifying relevant and realistic goals; (3) share all the options with the patient and family; (4) respond with empathy as they adjust to changing expectations; (5) make a plan, emphasizing what can be done toward achieving the realistic goals; (6) follow through with the plan; and (7) review and revise the plan periodically, considering at every encounter whether the goals of care should be reviewed with the patient and/or family. Each of these steps need not be followed in rote order, but together they provide a helpful framework for interactions with patients and their families about goals for care. It can be especially challenging if a patient or family member has difficulty letting go of an unrealistic goal. One strategy is to help them refocus on more realistic goals and also suggest that while hoping for the best, it is still prudent to plan for other outcomes as well.

Advance Care Planning • PRACTICES Advance care planning is a process of planning for future medical care in case the patient becomes incapable of making medical decisions. A 2010 study of adults 60 or older who died between 2000 and 2006 found that 42% required decision making about treatment in the final days of life but 70% lacked decision-making capacity. Among those lacking decision-making capacity, around one-third did not have advance planning directives. Ideally, such planning would occur before a health care crisis or the terminal phase of an illness. Diverse barriers prevent this. Polls suggest 80% of Americans endorse advance care planning and completing living wills. However, data suggest between 33 and 42% have actually completed one. Other countries have even lower completion rates. Most patients expect physicians to initiate advance care planning and will wait for physicians to broach the subject. Patients also wish to discuss advance care planning with their families. Yet patients with unrealistic expectations are significantly more likely to prefer aggressive treatments. Fewer than one-third of health care providers have completed advance care planning for themselves. Hence, a good first step is for health care providers to complete their own advance care planning. This makes providers aware of the critical choices in the process and the issues that are especially charged and allows them to tell their patients truthfully that they personally have done advance planning. Lessons from behavioral economics suggest that setting this kind of social norming helps people view completing an advance directive as acceptable and even expected.

Steps in effective advance care planning center on (1) introducing the topic, (2) structuring a discussion, (3) reviewing plans that have been discussed by the patient and family, (4) documenting the plans, (5) updating them periodically, and (6) implementing the advance care directives (Table 10-3). Two of the main barriers to advance care planning are problems in raising the topic and difficulty in structuring a succinct discussion. Raising the topic can be done efficiently as a routine matter, noting that it is recommended for all patients, analogous to purchasing insurance or estate planning. Many of the most difficult cases have involved unexpected, acute episodes of brain damage in young individuals.

Structuring a focused discussion is a central communication skill. Identify the health care proxy and recommend his or her involvement in the process of advance care planning. Select a worksheet, preferably one that has been evaluated and demonstrated to produce reliable and valid expressions of patient preferences, and orient the patient and proxy to it. Such worksheets exist for both general and disease-specific situations. Discuss with the patient and proxy one scenario as an example to demonstrate how to think about the issues. It is often helpful to begin with a scenario in which the patient is likely to have settled preferences for care, such as being in a persistent vegetative state. Once the patient's preferences for interventions in this scenario are determined, suggest that the patient and proxy discuss and complete the worksheet for the others. If appropriate, suggest that they involve other family members in the discussion. On a return visit, go over the patient's preferences, checking and resolving any inconsistencies. After having the patient and proxy sign the document, place it in the medical chart and be sure that copies are provided to relevant family members and care sites. Because patients' preferences can change, these documents have to be reviewed periodically.

TYPES OF DOCUMENTS Advance care planning documents are of three broad types. The first includes living wills or instructional directives; these are advisory documents that describe the types of decisions that should direct care. Some are more specific, delineating different scenarios and interventions for the patient to choose from. Among these, some are for general use and others are designed for use by patients with a specific type of disease, such as cancer or HIV. A second type is a less specific directive that provides general statements of not wanting life-sustaining interventions or forms that describe the values that should guide specific discussions about terminal care. These can be problematic because, when critical decisions about specific treatments are needed, they require assessments by people other than the patient of whether a treatment fulfills a particular wish. The third type of advance directive allows the designation of a health care proxy (sometimes also referred to as a durable attorney for health care), who is an individual selected by the patient to make decisions. The choice is not either/or; a combined directive that includes a living will and designates a proxy is often used, and the directive should indicate clearly whether the specified patient preferences or the proxy's choice takes precedence if they conflict. The Five Wishes and the Medical Directive are such combined forms. Some states have begun to put into practice a “Physician Orders for Life-Sustaining Treatment (POLST)” paradigm, which builds on communication between providers and patients to include guidance for end-of-life care in a color-coordinated form that follows the patient across treatment settings. The procedures for completing advance care planning documents vary according to state law.

A potentially misleading distinction relates to statutory as opposed to advisory documents. Statutory documents are drafted to fulfill relevant state laws. Advisory documents are drafted to reflect the patient's wishes. Both are legal, the first under state law and the latter under common or constitutional law.

LEGAL ASPECTS The U.S. Supreme Court has ruled that patients have a constitutional right to decide about refusing and terminating medical interventions, including life-sustaining interventions, and that mentally incompetent patients can exercise this right by providing “clear and convincing evidence” of their preferences. Because advance care directives permit patients to provide such evidence, commentators agree that