Mrs. Klein is an 89-year-old woman admitted from home 5 days ago with cellulitis of the legs. Despite her discomfort, she has cooperated with her diagnostic work-up and treatment and consented to all interventions related to the cellulitis. She was able to provide accurate information about her medical history, which was corroborated by her niece. According to both women, Mrs. Klein has been very healthy and self-sufficient all her life, a state she attributes largely to “keeping my distance from doctors and hospitals.” Her goal, expressed repeatedly since admission, is “to go home to my cats.”

Mrs. Klein’s admission blood tests revealed anemia that suggests slow internal bleeding. Despite repeated attempts to explain the dangers of unchecked bleeding and the importance of identifying the source, she has consistently refused consent for a GI series. When asked why she is opposed to a diagnostic work-up, she replies, “Darling, you look, you’ll find. No more tests or treatments. Just get me back on my feet so I can go home to my cats.”

After several days, the attending physician requests a psychiatric consult to do a capacity assessment, suggesting that the patient is not capable of making decisions in her best interest and cannot be discharged under these circumstances.

Why does no one question Mrs. Klein’s capacity to consent to treatment, only her capacity to refuse?

We now embark on a discussion of one of the issues most frequently brought to ethics committee attention—who is morally authorized to make health care decisions for a patient. Ethical principles of respect for patient autonomy, beneficence, and nonmaleficence normally require that decisions about care and treatment be made by the decisionally capable patient and honored by her caretakers, following adequate discussion of the benefits, burdens, and risks of the therapeutic options. When the patient is not able to participate in this process, the responsibility for making care decisions must be assumed by others.

The quality of the decision-making process and the moral validity of the resulting consent or refusal are dependent on the clarity of physician-patient communications;
the patient’s understanding of the information presented and her ability to give
due weight to this information in making a decision; the physician’s attention to
patient values and preferences; and the patient’s trust in the physician that encour-
gages questions and full discussion. Although decisional capacity is required for
morally valid consent, and capacity and consent are inextricably linked, for logistical purposes they are discussed separately in this curriculum. This chapter exam-
ines decision making and capacity, while chapter 3 sets out the ethical basis and
significance of the consent process.

HEALTH CARE DECISIONS AND DECISION MAKING

Health care in general and bioethics in particular deal with decisions requiring
attention to patient needs and preferences in the context of medicine’s capabilities
and limitations. These decisions involve deeply personal ideas about life and
death; the meaning of health, illness, and disability; and the importance of self-
image, self-determination, and trust. While the patient has the greatest stake in
these decisions, and so should be the ultimate decision maker, others, including
family members and care professionals, bring their perceptions and concerns to
the discussion and influence the patient’s assessment of information. Indeed, it
is the value- and interest-based nature of care decisions, and the multiple parties
who have a stake in them, that makes these decisions so complex and often diffi-
cult to negotiate.

DECISION-MAKING CAPACITY

It is tempting to suggest that, like obscenity, decisional capacity is something that
cannot be precisely defined but we know it when we see it. While we may sense that
a patient is or is not able to make decisions, intuition is not enough to guide an eval-
uation with such crucial implications. In the health care setting, the exercise of
autonomy is promoted or hindered by the assessment of decisional capacity, which
effectively includes or excludes patients from making decisions about their care. De-
termining the patient’s ability to understand the issues, consider the consequences
of different options, and communicate these thoughts to professionals is necessary
to supporting autonomy. Without this set of cognitive capacities, patients will need
assistance in making and articulating choices, or others must decide for them. In-
deed, as noted below, even capable patients can benefit from assistance in making
autonomous decisions.

Here, it may be useful to distinguish the principle of respect for autonomy from
another with which it is often elided, the principle of respect for personhood. We
ought to respect the personhood of all patients, regardless of their ability to make
able decisions, and this includes newborns, people with profound cognitive im-
pairment, and patients who are comatose. But, they cannot, nor do we expect them
to, make autonomous decisions because autonomy is a product of maturity, values,
information, experience, and judgment. If a 5-year-old insists that he doesn’t want
to be vaccinated, and he’s very sincere about this, no one should mistake his statement as expressing an autonomous decision. Someone will vaccinate him over his very vigorous objections because we care about him and don’t want him to be the victim of his own non-autonomous choice. Excluding a decisionally capable patient from making choices violates the principle of respect for patient autonomy; treating an incapacitated patient “as if” he were capable makes him vulnerable to the consequences of deficient decision making. Thus, the importance of the clinical assessment of decisional capacity is chiefly explained by its relationship to safeguarding and supporting the autonomy of patients. This assessment is critical to determining whether the patient can participate in care decisions and provide informed consent or refusal.

Capacity and Competence

Although the terms capacity and competence are often used interchangeably, in the health care setting there are important distinctions that go beyond semantics. Competence is a legal presumption that a person who has reached the age of majority has the requisite cognition and judgment to negotiate legal tasks, such as entering into a contract, making a will, or standing for trial. Incompetence is a functional assessment and determination by a court that, because the individual lacks this ability, she should not be permitted to do certain things. Because the legal system is and should rarely be involved in medical decisions, in a clinical context it is customary to refer to the patient’s decisional capacity, a clinical determination of the ability to make decisions about treatment or health care.

Elements of Decisional Capacity

Decisional capacity refers to the patient’s ability to perform a set of cognitive tasks, including

- understanding and processing information about diagnosis, prognosis, and treatment options;
- weighing the relative benefits, burdens, and risks of the therapeutic options;
- applying a set of values to the analysis;
- arriving at a decision that is consistent over time; and
- communicating the decision.

Decisional capacity thus encompasses several skills, including understanding, assessing, valuing, reasoning, and articulating the factors relevant to a choice. Capacity can be seen as an index of a person’s ability to exercise autonomy by making decisions that reflect personal preferences, values, and judgments at a given time. This is not the same, however, as the person’s willingness to make autonomous decisions. Having capacity enables but does not obligate patients to act independently. Despite our good intentions, we cannot force people who are unwilling to exercise their capacity for self-determination to do so. In many instances, insisting that patients make decisions when they are unwilling to do so is a form of patient abandonment that may be psychologically harmful and medically counterproductive.
Frequently, capacitated patients look to family, friends, and trusted others to help them exercise autonomous decision making. Patients demonstrate supported autonomy when they rely on others for advice in making choices (“I want my son to help make the decision”). Some patients, especially those who are elderly or from cultures in which self-determination is not a central value, demonstrate delegated autonomy. These patients often entrust to others the authority to make decisions on their behalf (“Talk to my daughter and do whatever she thinks is right”). Here, autonomy is expressed in the voluntary choice to delegate rather than independently exercise decision-making authority. Patients with capacity who benefit from the advice, guidance, and support of clinicians and trusted others can be said to demonstrate assisted autonomy.

The take-away message is that patients bring to the clinical setting the decision-making dynamics they are accustomed to using and these should not be overridden in the belief that there is one and only one morally proper way for decisions about their care to be made. Rather than insisting on the necessity of independent decision making, patient-centered care planning recognizes and supports the decision-making strategies that most effectively promote each patient’s interests, choices, and abilities. The ethics committee can perform a useful service by clarifying for the care team—through clinical consultations, in-service presentations, or informal conversations—the several ways in which patients can make autonomous decisions.

Decision-Specific and Fluctuating Capacity

Capacity is not global, but decision-specific, referring to the ability to make particular decisions. A patient may have the ability to decide what to have for lunch but may be incapable of weighing the pros and cons of surgery. For this reason, nothing is less helpful than a chart note that says, “Patient lacks capacity to make decisions.” The misleading implication is that the patient lacks the capacity to make all decisions, effectively excluding her from making any decisions.

In fact, many patients have the capacity to make some decisions and not others. For example, a lower level of capacity is required to appoint a health care proxy agent (appreciation of the likelihood that someone will have to make decisions on her behalf and consistent designation of the same person) than to make the often complex decisions the proxy agent will eventually make. Thus, the appropriate response to the question, “Does this patient have capacity?” is “For what decision?” Likewise, a request for a capacity assessment is most helpful when it specifies the decision(s) at issue, such as “Please evaluate the patient’s capacity to make decisions about discharge.” Distinguishing among the specific decisions facing the patient and assessing her capacity to make them offers her the opportunity to make the widest range of choices within her ability.

Just as capacity is not global in its application to all decisions, it is not always constant. Depending on their age, cognitive abilities, clinical condition, and treatment regimen, patients may exhibit fluctuating capacity, demonstrating greater ability to make decisions at some times than others. For example, elderly patients, who are especially prone to “sundowning,” often exhibit greater alertness, sharper rea-
soning, and clearer communication earlier in the day. Recognizing this tendency allows care providers to approach patients for discussion and decisions when they are at their most capacitated, thereby increasing their opportunities for autonomous action. Ethics committees in long-term care facilities, where decisional capacity issues arise regularly, can be very helpful to care teams balancing the relevant interests and obligations.

To return to the case of Mrs. Klein, the 89-year-old patient with cellulitis of the legs, a critical threshold question is whether, in making a decision to refuse the diagnostic work-up and return to her home against medical advice, the patient is demonstrating decisional capacity. If she appreciates the implications and accepts the consequences of her decision and if, moreover, her decision is a voluntary one, it should be honored, despite the caregivers’ concerns that it is not in her best interest. Nevertheless, efforts to persuade her to reconsider and consent to suggested treatments are still appropriate, especially if the potential risks of nontreatment and the benefits of treatment are significant. In this way, her caregivers seek to honor their professional obligations of beneficence and nonmaleficence, as well as respecting her autonomy.

Disagreement with medical recommendations is not by itself evidence of a lack of decisional capacity. Mrs. Klein’s decision may be foolish and ill advised, but it is not necessarily the product of misunderstanding, delusion, or confusion. Continued discussion will be necessary to confirm her understanding and the consistency of her decision with characteristic behavior and prior choices. She has led an independent life that she attributes partly to avoiding doctors and hospitals. Her present decision to refuse the work-up, therefore, conforms to a pattern of life choices that, until now, have served her relatively well.

Practitioners and health care institutions have an ethical and legal obligation to arrange for a safe discharge for their patients. Ethical concerns arise when capable patients make decisions that run counter to their best medical interests. Here, clinicians’ obligations to respect patient autonomy are in tension with their obligation to promote Mrs. Klein’s well-being and protect her from harm.

One way to address these conflicting obligations is to ensure that, when capable patients are discharged, especially under less-than-optimal circumstances, they are encouraged to accept appropriate nursing and other home care services. In contrast, allowing patients who lack capacity to elect an unsafe discharge is a form of patient abandonment. Whatever the patient’s level of decisional capacity, concerned family or other supporters should be encouraged to participate in discharge planning, follow-up care, and advance care planning for future health care decision making. Involving Mrs. Klein’s niece in discussions and decisions would bring the security, support, and perspective of a trusted person to the deliberations.

Intervention by the ethics consultation service or ethics committee is often requested in cases of uncertain patient capacity, usually when questions arise about consent to or refusal of recommended treatment. These issues and the role of ethics intervention in resolving them are discussed further in chapter 3.
ASSESSMENT AND DETERMINATION OF CAPACITY

Mr. Herbert is back again. He is a 38-year-old man who is confined to a wheelchair because of bilateral amputations resulting from untreated leg ulcers. Mr. Herbert has had multiple admissions to treat his repeatedly infected areas of skin breakdown. Once the wounds have been cleaned and repaired and the infection is under control, however, he signs himself out against medical advice (AMA) to return to his fifth-floor walk-up apartment, where he has a thriving business dealing street drugs. He insists that, with his buddies to carry him up and down and his girlfriend to help him with meals and activities of daily living (ADLs), he can manage just fine. He acknowledges that his recovery might be better if he remained in the hospital longer or if he came to the clinic regularly but, if he is not home, his business will be picked up by other dealers. He insists that he is willing to risk future infections, although he is confident that “you guys will always get me back on my game.” Nevertheless, each time he returns, he is in worse shape and it is harder to resolve his medical problems.

The Importance of Determining Capacity

Decisional capacity requires more than the ability to articulate choices. As discussed in chapter 5, young children can be very vocal and sincere in expressing their wishes, but their choices would not be considered thoughtful judgments. The exercise of autonomy and the integrity of the informed consent process depend on the patient’s ability to understand the facts and appreciate the consequences of treatment options. The presumption is that adult patients have the requisite capacity and, absent contrary evidence, decisions about treatment and non-treatment defer to patient preferences. Moreover, this deference usually extends to all capacitated decisions, including those that providers may think reflect poor judgment or are not in the patient’s best interest. Yet troubling and potentially harmful decisions, such as patient rejection of recommended care, must be carefully explored because they may well reflect misunderstanding, lack of trust, or extreme fear and anxiety.

Mrs. Rodriguez is a 69-year-old woman transferred from a nursing home in a semi-comatose state and respiratory failure. She was admitted to the intensive care unit (ICU) and intubated to provide ventilatory support. Her multiple medical problems include congestive heart failure, non-insulin-dependent diabetes, and several prior episodes of pneumonia.

After several weeks, the care team recognized that Mrs. Rodriguez would not be able to breathe without ventilatory assistance and recommended that a tracheostomy be done to promote safety and comfort. Because she was still unresponsive, the procedure was explained to her daughter, who provided consent. The following day, Mrs. Rodriguez unexpectedly became more alert and responsive. The critical care resident expressed concern because he believed the patient was indicating opposition to the tracheotomy.

The ear, nose, and throat (ENT) attending argued that the endotracheal tube made it impossible to determine what, if anything, the patient was trying to communicate and, in any event, she did not have the capacity to make decisions about her
care. He insisted that the trach, which would be in the patient’s best interest, be performed in accordance with the daughter’s consent. The critical care attending asked Mrs. Rodriguez a series of yes-no questions that she could answer by nodding or shaking her head. Her nonverbal but consistent responses, which indicated that she understood the purpose of the tracheostomy and agreed that it should be performed, were considered a ratification of the consent provided by her daughter.

Would Mrs. Rodriguez’s capacity have been considered sufficient for her to consent to the tracheostomy without her daughter’s involvement? Why might a higher level of capacity be required for her to refuse the procedure?

One widely used strategy for approaching decisional capacity employs a sliding scale, which weighs the required level of capacity against the seriousness of the decision. This takes a flexible approach to capacity assessment. As the risks associated with a decision increase, and as these are not offset by the likelihood of greater benefits, the level of capacity needed for the decision to be honored should also increase. For example, a decision about whether to go to physical therapy before or after lunch carries a low risk of harm. This decision could safely be made by a patient with diminished capacity because the consequences of either choice are relatively benign. In contrast, a decision about whether to undergo a life-saving amputation or enroll in an experimental trial of chemotherapy, requires that a higher and stricter capacity threshold be met. Asking a patient with uncertain capacity to take responsibility for a choice this serious would abandon her to the consequences of her deficient decisional ability. Clinically, the sliding scale provides heightened scrutiny when the potential outcomes of decisions require clinicians to be confident that patients fully appreciate the benefits, burdens, and risks of their choices. Mrs. Rodriguez’s low level of capacity was considered sufficient to ratify her daughter’s consent because she concurred with the plan her care professionals and family agreed would benefit her. If she had refused the recommended procedure, however, it is likely that further assessment of her decisional capacity would have been indicated.

The danger in the sliding scale approach is that of paternalism, the tendency to treat otherwise capable adults as though they were children in need of others to make decisions for them. While it is not necessary that the family and care team agree with the patient’s decision, choices considered irrational or harmful to the patient are likely to be challenged or at least closely scrutinized to protect incapable and, therefore, vulnerable patients from making decisions not in their best interest.

The fact is, we only question the capacity of people who do not agree with us. Think about it—when was the last time you saw a capacity consult called to evaluate a patient who had just agreed with the doctor? It is equally important, however, to beware of agreement. If the patient is nodding enthusiastically during discussion, it may signify that he understands and endorses what is being said or it may just mean that he wants to be agreeable. Not uncommonly, a patient who has nodded and said, “Uh huh” during an informed consent discussion turns to the nurse after the doctor has left and asks, “What did he say?”

Capacity assessments require a conscious effort to look beyond the decision we would make for ourselves or even recommend for the patient. If we focus exclusively on the content or the outcome of the decision rather than the decision-making process, we risk disempowering capable people who make risky or idiosyncratic
choices. An important safeguard against this is assessing how the decision is made, evaluating the patient’s ability to manage the several skills required for capable decision making. Likewise, it is necessary to distinguish questioning capacity and finding incapacity. While treatment refusals or other questionable decisions may and often should trigger a capacity assessment, they do not automatically confirm incapacity.

How and by Whom Is Decisional Capacity Assessed?

Especially because the elder population is expected to double during the next 20 years, capacity assessments are likely to be requested and relied on with increasing frequency. Given the importance of assessing decision-making capacity, the desire for a precise method of measurement is understandable. Unfortunately, it is not that simple. Decisional capacity is an index of patient ability to make decisions and, therefore, involves cognitive processes. Nevertheless, its assessment requires more than a test of mental acuity or a psychiatric exam.

In the search for a reliable and easily administered method of determining capacity, various instruments have been developed and tested, with varying results. Ideally, an instrument would be accurate and consistent in evaluating capacity, as well as efficient and uncomplicated to use. Predictably, most scales fail to meet both sets of criteria. For example, the Mini Mental Status Exam (MMSE), designed to assess cognition, is often employed by clinicians to evaluate capacity. While the MMSE has been found useful in gauging “orientation of the subject to person, place, and time, attention span, immediate recall, short-term and long-term memory, ability to perform simple calculations, and language skills” (Lo 2000, pp. 84–85), it is less helpful in assessing an individual’s ability to grasp situations, weigh alternatives, and appreciate consequences—the skills required for capable decision making. At best, very high and low MMSE scores have been found to correlate highly with decisional capacity, making the test most useful as a screening tool rather than a predictor in capacity assessment.

A comprehensive review of several additional capacity assessment instruments (Racine and Billick 2012) concluded that sensitivity and specificity tend to be in tension with efficiency and ease of use. Some can be administered in less than 30 minutes but may be more general, while others, which are more specific and in-depth, require considerably more time and complicated scoring systems. While none of the instruments is considered to be the gold standard, the literature indicates that their use in clinical practice could improve accuracy in capacity determination. Especially in the elder population, where capacity issues may be complex and multifactorial, these tools may be useful adjuncts to clinical interviews, medical record reviews, interviews, neuropsychological testing, and functional assessment.

Calling for a “psych consult” to assess capacity may sometimes be helpful in assessing decisional capacity, but it is not always necessary or sufficient. To be sure, psychiatric intervention can be invaluable in engaging patients in discussion; eliciting and interpreting their concerns; and identifying mental illness, cognitive impairments, and interpersonal conflicts that can mask or interfere with decisional capacity. Even a skillful psychiatric consultation, however, captures only a snapshot of the patient’s thinking at a specific moment rather than over time.
Ultimately, the clinicians who observe and interact with the patient day to day—especially attending physicians, nurses, residents, as well as medical and nursing students—may be in a better position to evaluate the quality and consistency of the patient’s decision-making ability, particularly if they are assisted by reliable and accurate capacity assessment tools. This is especially important in nursing homes, psychiatric hospitals, and facilities for those with developmental delays, where long-term patients and residents are well known to the care team. For this reason, assessing decisional capacity should be considered part of the clinical skill set of care professionals and the responsibility of the medical team. Reinforcing this aspect of the caregiver role can be a valuable ethics committee function in all care-providing facilities, especially those in which decisional capacity assessment is frequently requested.

DECIDING FOR PATIENTS WITHOUT CAPACITY

Usually, health care decisions are made by capable patients with the advice and support of their caregivers, families, and friends. Frequently, however, treatment decisions must be made for patients who lack the capacity to make decisions for themselves. These may be persons who were formerly but are no longer capacitated because of illness, injury, age, or other factors. Or they may be patients, such as newborns and those with profound cognitive impairment, who have never had or have not yet had an opportunity to form values or preferences.

Making medical decisions for others raises a series of questions involving the patient’s clinical needs and treatment options, what is known of the patient’s care wishes, and the appropriate delegation of decision-making authority. Answering these difficult questions is often complicated by disagreements between and among the patient’s family and care providers. Mediating these conflicts and facilitating decision making for incapacitated patients are among the most frequent and effective interventions by health care ethics committee and ethics consultation services. The theory and skills important to clinical consultation are discussed at greater length in chapter 14.

Standards of Surrogate Decision Making

The standards of health care decision making typically rely on the patient’s voice as the central and most authentic source. When that voice is temporarily or permanently unavailable, those who act on behalf of the patient have only indirect access to her wishes and values. Three standards are customarily invoked in attempting to make decisions as the patient would have made them. They vary according to how much direct information the surrogate has from the patient.

- Prior explicit articulation, possibly in the form of an instructional advance directive or a recalled explicit conversation, is the previous expression of a capacitated person’s wishes, the most reliable information about her preferences. “What do we know about this person’s wishes based on what she has said or written?”
• Substituted judgment is a decision by others based on the formerly capacitiated person’s inferred wishes or preferences. “What can we infer about what the patient would choose in these circumstances, based on what we know about her past behavior, values, and prior decisions?” Substituted judgment is commonly thought of as a way to respect the value of patient self-determination, using a constellation of durable and characteristic cues rather than explicit communication as guidance.

• Best interest standard is used to arrive at a judgment based on what a reasonable person in the patient’s situation would want. This standard is invoked when the incapacitated person never had or made known treatment wishes and her preferences cannot be inferred. Others weigh the benefits and burdens to the patient of a proposed intervention or care plan. “What do we believe would best promote this person’s well-being in these circumstances?”

According to the standard approach, a patient’s verbal or written statements of preference reflect autonomous decisions and should be honored whenever feasible, but they may be interpreted in the light of current circumstances that the patient may not have been able to anticipate. There is also consensus that the substituted judgment standard is the most problematic because, as commonly formulated, it requires the intellectually convoluted task of imagining what the now-incapacitated patient would choose if she were magically capable and in possession of all the relevant clinical facts. This has led some commentators to adopt an interpretation of the substituted judgment standard that focuses on a notion of authenticity rather than self-determination. Authenticity expresses the value of having one’s life be a coherent narrative, and surrogate decisions guided by this value seek to maintain the coherence of the patient’s life through the decisions that are made on her behalf, rather than to honor her hypothetical choices (Dworkin 1993; Blustein 1999; Brudney 2009).

Surrogate decision making is a complex process that requires attending to and balancing a number of different factors, and it may not be entirely clear what the surrogate should choose on the patient’s behalf. Surrogate decision making is often a weighty moral responsibility because it happens under conditions of uncertainty and has serious, possibly life-altering, consequences for the patient. Yet decisions must be made and these standards, conscientiously applied, can help surrogates identify the care plan that will most effectively and authentically promote the interests of the incapacitated patient.

Decision Making for the Formerly Capacitated

The notion that only the explicit statement of a capable patient can inform treatment decisions has proved to be double-edged—both a protection of the patient’s right to consent or refuse and a barrier to decision making when the patient has lost the capacity to make decisions. Among the clinical setting’s greatest challenges is the patient who was formerly but is no longer capable and communicative, making it difficult to determine or honor her wishes or to promote authenticity. In this category are the elderly demented and patients of any age with terminal illness or irreversible injury that has impaired their decision-making ability. In order to pro-
tect the interests of the formerly capacitated, reliance on some type of advance directive has become the preferred method of surrogate decision making.

Advance Directives

Mrs. Stern is a 74-year-old woman admitted from home for surgical repair of a hip fracture. Although she is in the early stages of dementia and has mild coronary artery disease, she has been healthy and fairly independent until her recent fall. She has lived alone since her husband’s death three years ago, but her daughter, Mrs. Keller, lives nearby and they either visit or speak daily.

On admission, despite her considerable discomfort, Mrs. Stern was alert, understood her medical condition, and was able to provide consent for the surgery. During the postoperative period, however, she has been increasingly agitated and confused. When recent blood tests indicated anemia, she was unable to discuss the need for a transfusion. She asked that the doctors talk to her daughter, who provided the necessary consent.

Mrs. Stern is scheduled to be discharged to a nursing home for rehabilitation in preparation for her eventual return home. She is expected to make a good recovery from her surgery and should be able to resume her normal activities with some assistance. Her doctors anticipate that, once she is in familiar surroundings, she will be less agitated and confused. Because her dementia is likely to progress, however, she will find it increasingly difficult to make independent decisions, including those related to her health care. For that reason, the care team is encouraging the execution of an advance directive that will enable care decisions to be made on her behalf when she is no longer able to make them herself.

If Mrs. Stern is determined to lack the capacity to make care decisions, is she capable of executing an advance directive? Would different levels of capacity be required to execute a living will and appoint a health care proxy agent?

Advance directives are legal instruments intended to secure an individual’s ability to set out prospective instructions regarding health care. Conceived during the 1970s, they responded to the concern that patients who were unable to speak for themselves might be subjected to unwanted medical interventions, especially at the end of life. The 1990 federal Patient Self-Determination Act (PSDA) requires any health care facility receiving federal funds to offer patients the opportunity to execute advance directives and assistance in doing so. Although all 50 states and the District of Columbia have statutory and/or case law governing advance directives and all states honor them, their standards and restrictions differ (Olick 2012). While advance directives are helpful whenever substitute decision making is required, they are most often invoked in making decisions at the end of life. For that reason, they are discussed further in chapter 9.

Advance directives commonly come in two varieties—instruction directives, also known as living wills, and appointment directives, also known as health care proxies or powers of attorney for health care. In different ways, they provide direct expression of the patient’s wishes, enabling caregivers to rely on the most immediate of the decision-making standards. The living will is a written set of value-neutral instructions about the particular medical, surgical, or diagnostic interventions the individual does or does not want under particular circumstances, usually at the end
of life. The structure of the document generally has a trigger phrase, such as, “If I am ever in an irreversible coma, . . .” or “If I am ever unable to recognize or relate to my loved ones and my doctors say that I will not regain those abilities . . .,” followed by the list of instructions related to the specified circumstances.

Patient wishes may also be communicated orally when the patient is unable to execute a written document. In these instances, the patient’s verbally expressed instructions can be documented by a health care provider or other individual. If properly documented and witnessed, these statements are considered formal advance directives in several states.

Because the living will presents explicit articulation of the patient’s prior incapacitated wishes, it can provide helpful guidance to family and clinicians about what she would or would not want in current circumstances. It is significantly limited by the fact that it is a static document, written when the person could not accurately anticipate her future medical condition. Individual beliefs and preferences change over time, and it is not unusual for patients to change their minds about medical interventions that they thought they would or would never be able to tolerate. In addition, these documents do not always mean what they say. The person whose living will says, “I don’t ever want to be on a respirator” probably does not mean, “I don’t want to be on a respirator for 4 hours if it gives me 10 more years on the tennis court.” What she probably means is, “I don’t want to live out the rest of my life on a respirator.” But living wills typically do not provide for that kind of nuance. Finally, this type of advance directive usually refers only to end-of-life care. The result is a set of instructions that reflect what the patient believed and tried to communicate at a particular time about what she thought she would want under different circumstances at a later time. Because of their limitations, living wills are most useful for someone who does not have trusted friends or family to make decisions in the event of her incapacity.

The preferred advance directive is the appointment directive, also known as a health care proxy or a durable power of attorney for health care. This document enables a capable individual to legally appoint another person—an agent or proxy—to make health care decisions on her behalf after capacity has been lost. The agent is authorized to make any and all health care decisions the individual would make.

The appointment directive is recommended over the instruction directive because it authorizes decision making in the event of temporary or permanent incapacity and permits greater flexibility in responding to unanticipated or rapidly changing medical conditions. The agent is generally required to honor the patient’s previously expressed wishes in making care decisions. If those instructions do not apply to or are inconsistent with the patient’s current health needs, however, the agent is empowered to use his knowledge of the patient’s wishes, values, and decision history to exercise judgment in making choices that promote the patient’s best interest. The agent has the same decisional authority as the patient and may make any and all care decisions the patient could make if capable. Moreover, the authority of the agent supersedes that of anyone else, including next of kin. This scope of authority presupposes a patient-proxy relationship characterized by trust, familiarity with the patient’s wishes and values, and the agent’s willingness to exercise judgment and make hard decisions in the patient’s interest.
There are two important but often misunderstood conditions that your ethics committee can usefully reinforce with your clinicians: (1) As noted earlier, patients deemed incapable of making medical decisions may still have the capacity to appoint an agent to assume this responsibility. (2) The term power of attorney (POA), when applied to advance directives can cause confusion. Powers of attorney are the delegation of authority for specified tasks. Not uncommonly, a well-meaning person will show up in the clinical setting, clutching a document and saying, “I’m the POA so I’m responsible for making decisions.” Encourage the staff to read the document. Very often, it will be a POA for banking or real estate or some other non-medical responsibilities. Unless the document includes “health care decisions” or other similar language, the document should be returned to the person with the explanation that the delegated powers do not include health care decision making.

A hybrid advance directive, Five Wishes, provides the opportunity to communicate decisions about (1) the person I want to make care decisions for me when I can’t; (2) the kind of medical treatment I want or don’t want; (3) how comfortable I want to be; (4) how I want people to treat me; and (5) what I want my loved ones to know. For many people, this frames the issues in an accessible and nonthreatening way. Five Wishes is currently recognized in 42 states (Five Wishes, Aging with Dignity 2013).

Advance directives are statements of patient intention about health care, not medical orders. These statements must be translated by physicians into medical orders in the patient’s medical record before they become operational. Thus, an advance directive that says, “If I am ever terminally ill or permanently unconscious and my doctors do not expect my condition to improve, I do not want resuscitation attempted if my heart stops,” will require the patient’s physicians to determine whether she meets the specified clinical criteria. Only under clinically appropriate circumstances may a do-not-resuscitate (DNR) order be entered in the medical record, which will preclude cardiopulmonary resuscitation.

Mrs. Stern is a good example of a patient who lacks the capacity to make health care decisions, yet is capable of appointing a trusted person to make decisions for her. Her current illness and hospitalization have exacerbated the agitation and confusion of her early-stage dementia, making it difficult or impossible for her to understand and decide about her medical treatment adequately. Moreover, she does not want to assume this responsibility, preferring to delegate decision-making authority to her daughter. Thus, while she may not have the capacity to make decisions about her current treatment or articulate instructions about future care, she does understand the notion that someone will have to make decisions for her and she consistently designates the same trusted person for that task, meeting the criteria for appointing a health care agent.

Deciding for Patients without Capacity or Advance Directives

Advance directives appear to provide all the authorization and safeguards necessary to communicate and implement prior care wishes effectively. You might reasonably think that every capable person would have one. Unfortunately, you would be wrong. Even though people are encouraged to express their health care preferences prospectively through the designation of a health care agent or the execution of a living will, only one-third of adults in the United States have an
advance directive (American Bar Association Commission on Law and Aging 2014). Thus, decisions for most patients who lack capacity are made by unofficial or informal surrogates—people who assume the decision-making role without specific legal appointment or the guidance of documented patient wishes. In some states, a surrogate’s authority to make health care decisions for someone else may be based on statutory or case law. More often, an informal surrogate is asked by the medical team to participate in making treatment decisions. The people who fill this void and act on behalf of incapacitated patients include family, close friends, and trusted others. Many states have approved hierarchies, setting out potential surrogates in order of their relationship to the patient, providing guidance to staff working to identify an appropriate surrogate decision maker. A sample policy in chapter 17 includes such a framework. In the absence of unofficial surrogates, care providers and courts, which are essentially strangers to the patient, may assume this responsibility.

Without the patient’s explicit instructions in an advance directive, health care decisions made by surrogates have traditionally been based on the remaining two decision-making standards—either substituted judgment (when the patient’s wishes can be inferred) or the best interest standard (when the patient did not have or did not articulate treatment preferences). Clinicians and families of patients unable to participate in care discussions or decisions work to determine a course that meets medical, legal, and ethical imperatives.

Goals and plans of care are considered in light of the patient’s condition and prognosis; the benefits, burdens, and risks of the therapeutic options; and what is known about her wishes or best interests. Depending on the laws of the state in which the patient is treated, family and trusted others may have greater or lesser latitude in drawing on their knowledge of and concern for the patient in making decisions on her behalf. In helping to guide substitute decision making, ethics committees and consultants need to be familiar with the scope of authority that their states accord informal surrogates.

Decision Making for Patients Who Never Had Capacity

Those who never had the opportunity or ability to form values or preferences include newborns and adults with severe cognitive impairment. As discussed in chapter 5, decisions for the endangered or profoundly disabled newborn are almost always made by the parents who are presumed, by tradition and law, to act in the best interests of their child. However, the child’s health care providers may disagree with the parents’ decisions, favoring either less or more aggressive life-sustaining treatment, as the case may be. Whenever possible, these disagreements should be mediated without court involvement, but that is not always feasible. Courts tend to override parental refusals of specific life-saving interventions, especially if the child can be returned to reasonable health.

Adults with profound cognitive impairment, much like infants and young children, are considered to need decision making by others because they are and have always been incapable of reasoned judgment. As in the case of salvageable newborns, courts tend to overrule requests to withhold or terminate beneficial treatment.
Addressing the needs of never-capacitated patients does not raise the question, "What would this person want in these circumstances?" Sometimes, in an attempt to represent the patient’s interests, care providers and surrogates create what amounts to a fiction of substituted judgment. For example, they might ask, "What would this imperiled newborn or profoundly impaired adult want if he could want anything?" Careful review of the decision-making standards reveals the fallacy in this approach. Precisely because this patient has no history of expressed preferences or known values that would permit inference about his wishes, substituted judgments cannot be made. Rather, decisions on his behalf must be based on the best interest standard, drawing on what others believe would be best for him.

In these instances, the analysis is based on the objective assessment of what would be most likely to benefit or promote the well-being of a generalized patient in the same circumstances, similar to the legal reasonable person standard discussed in chapter 3. In the clinical setting, the best interest standard might consider mitigating pain and suffering, prolonging life, restoring and enhancing comfort, and maximizing the potential for independent functioning.

REFERENCES


