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# 6

## End-of-life Issues

*Decision making at the end of life*

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III Mr. Tofer is a 77-year-old man admitted for resection of a squamous cell carcinoma of the tongue. The surgery was successful but, on the following day, he experienced respiratory distress that required intubation. Because he was not able to be weaned from the ventilator after three weeks, a tracheostomy was performed to place the ventilator tube directly into his trachea, which would be safer and more comfortable than continuing to pass the endotracheal tube down his throat. He has had two subsequent episodes of low blood pressure and is experiencing progressive renal failure. His mental status has deteriorated during the four weeks he has been in the ICU and he is responsive only to painful stimuli, such as suctioning of his tracheostomy.

Mr. Tofer's only family is his nephew, Lawrence. Although they have not had a close relationship, they have maintained contact over the years and Lawrence appears concerned about his uncle. Lawrence is not Mr. Tofer's appointed health care proxy agent and they have never had discussions about care at the end of life.

The renal team met with Lawrence to discuss the plan of care. Dr. Cooper, the renal attending, said that, although dialysis might improve Mr. Tofer's mental status, it would not change his overall grave prognosis. The consensus of the renal team is that the patient is a poor candidate for dialysis and has less than a one percent chance of surviving this hospitalization. Given the considerable risk and the slight benefit, the team would consider dialysis only if the family insisted. Dr. Cooper also recommended a do-not-resuscitate (DNR)

order so that, if Mr. Tofer experienced a cardiopulmonary arrest, resuscitation would not be attempted.

What should Lawrence consider in making decisions about his uncle's care? What are the team's responsibilities?

#### DECISION MAKING AT THE END OF LIFE

If you were wondering when we would get to the really tough issues, the ones that make up the bulk of your ethics committee agenda and clinical consults, this is it. Not surprisingly, some of the most difficult health care choices take place at the end of life. Like much in bioethics, the issues related to dying and death are relatively new and would not have been raised a few generations ago when the health care focus was on attempting to cure or control disease. The response to illness and injury was to try all available measures and hope that something would be effective. Questions about whether the patient was receiving too much treatment or whether life was being unnecessarily prolonged would not have been asked.

Since then, we have managed to greatly expand both our treatment options and our ethical dilemmas. We have witnessed the development of medical and surgical interventions that can often return critically ill patients to health; they can also prevent death, even when improvement is not feasible. Decisions about end-of-life care now require greater scrutiny of the likely outcomes of therapy, including the important distinction between physiologic effectiveness (will the treatment work?) and therapeutic benefit (will the patient be better off because of the treatment?). Recognizing that cure-oriented and life-sustaining measures are not always medically appropriate for or even wanted by patients, bioethics works to facilitate decisions about when to deliver the patient from death and when to let death deliver the patient from us.

Sometimes, dying patients are capable of making or at least contributing to decisions about their care. More often, end-of-life decisions are made when the patient is no longer able to participate in deliberations. As a result, they typically involve efforts by others to determine the care plan that would most effectively meet his clinical needs and promote his well-being. As discussed in chapter 2, any decision making on behalf of an incapacitated patient requires that professionals, families, and other surrogates try to identify what his care wishes would be or determine what would be in his best interest. You already know from your experience in the clinical setting and on the ethics committee that these decisions become infinitely more difficult when the stakes are life and death.

Faced with the need for substitute decision making at the end of life, clinicians routinely turn to family members, who are presumed by tradition, and often by law, to know and act in the patient's best interest. As a rule, both medicine and law are more comfortable providing than withholding treatment, and considerable authority is customarily granted to family in *consenting* to treatment. Decisions about *limiting* treat-

ment are far more problematic, however, and some states restrict the ability of non-appointed surrogates, even next of kin, to authorize the withholding or withdrawing of life-sustaining treatment.

The profound consequences of the choices, uncertainty about decision-making authority, lack of clarity about patient wishes, and lack of consensus on goals of care make end-of-life decisions among the most challenging in the clinical setting. For this reason, ethics committee consultations are frequently requested as death approaches.

#### DEFINING DEATH

Ill Gary, a 9-year-old, was admitted to the hospital after infection from an abscessed tooth spread to his sinuses and eventually to his brain. Despite aggressive treatment, his brain swelled in response to the infection, causing increased intracranial pressure. Ultimately, clinical examinations and tests revealed that he met the criteria for brain death. The attending pediatrician and the pediatric neurologist met with Gary's parents to tell them that the massive infection had destroyed his brain and that the condition was irreversible. In an extended discussion, the doctors explained that, because their son's brain had completely stopped functioning, he was no longer alive. His devastated parents refused to accept the determination of death. His mother cried, "Look at him. His eyes are closed and he doesn't answer us, but he's still breathing and his heart is still beating. He just needs more time to get better. You can't take away the machines that are keeping him alive."

What are the obligations of care professionals in planning for care at the end of life? How can the care team help families accept irreversible deterioration, dying, and death?

Although some things should be relatively straightforward, like knowing when a person is dead, this is not always the case. When science was less precise, death was generally agreed to have occurred when the heart and lungs ceased functioning. By the late 1960s, advances in resuscitative techniques and artificial respirators enabled cardiopulmonary function to be maintained even after the brain had stopped working. Ultimately, the traditional definition of death—irreversible cessation of cardiopulmonary function—was supplemented by a definition that accounted for cessation of entire brain function.

The first well-accepted definition of brain death was the product of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death. The committee defined brain death as irreversible loss of total brain function, including "unreceptivity and unresponsivity . . . no movements or breathing . . . no reflexes . . . [and] . . . flat electroencephalogram" (Ad Hoc Committee, 1968, pp. 85–86). By the time the committee published its report in 1968, the sophisticated medical technology that permitted measurement of brain waves also enabled organ harvesting and transplantation. The generally recognized motivation for developing brain death criteria was the ability to perfuse organs, the only way to keep them viable for transplantation. Thus,

the advances in medical and surgical techniques, the need for transplantable organs, and the unacceptability of taking them from a still-living person prompted a new definition of death.

The Uniform Determination of Death Act (UDDA), adopted in 1980 by the National Conference of Commissioners on Uniform State Laws, expanded the definition of death to include both cessation of circulatory and respiratory function *and* brain death. That dual standard was endorsed in 1981 by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research in its report, *Defining Death*, which encouraged all states to adopt the UDDA.

While the brain death definition may have clarified and simplified some clinical determinations, it has also created a category of potential confusion. Terminology is critical and, especially in dealing with families, clinicians should clearly distinguish brain death and other conditions in which the patient is unresponsive.

Brain death is the irreversible cessation of the *entire* brain's ability to function, including the upper brain, which controls the higher functions of cognition and memory, and the brainstem, which controls the body's automatic functions, such as breathing and heartbeat. Because the brain's regulation of vital functions has shut down, the person is considered both clinically and legally dead. While the family comes to terms with the death and considers possible organ donation, mechanical supports may temporarily continue to perfuse the organs and maintain cardiac and respiratory function. It is, however, counterintuitive for grieving families to accept that death has occurred when looking at a body that is warm, is healthy-colored, has a heart beat, and appears to be breathing because the cardiopulmonary system is being mechanically supported.

In contrast to brain death, the patient in a vegetative state has suffered profound *upper* brain damage and has lost cognitive function; yet she retains the *lower* (brainstem) function that controls the systems essential to life. The vegetative state has been further defined as persistent or permanent (PVS), depending on its duration and irreversibility. "When a vegetative state continues beyond thirty days, it is described as 'persistent.' A vegetative state is generally considered permanent three months after anoxic injury and twelve months after trauma" (Fins, 2005, p. 22). The patient has no awareness of herself or her surroundings and no ability to think or interact, but she is alive and not dependent on machines to maintain life. Indeed, as the case of Terri Schiavo demonstrated, if nutrition and hydration are maintained and no additional illness or injury intervenes, patients can live for years in PVS.

The minimally conscious state (MCS) has been described as a condition in which people who have been in a vegetative state for less than a year occasionally progress to demonstrate "unequivocal, but fluctuating evidence of awareness of self and the environment" (Fins, 2005, p. 22). Finally, coma is a label used for temporary or permanent unresponsiveness that may result from a variety of conditions, including illness, injury, or chemically induced unconsciousness.

Because these conditions have such different courses and outcomes, clearly distin-

guishing among them with careful language is essential to helping families adjust their expectations to the clinical realities. For example, describing a patient in PVS as being "comatose" may unfairly encourage the belief that the responsiveness will return. Likewise, it is extremely unhelpful to tell a family, "Your loved one is brain dead, but we are keeping him alive on machines." Saying this is confusing and hinders acceptance of the patient's death. The term *life support* is also counterproductive in this context because it implies that machines are supporting life. It is more honest and compassionate to explain, "Although your husband is no longer alive, these machines are perfusing his organs and supporting his heartbeat and respirations. Now that death has been confirmed, these mechanical supports are no longer necessary because they are no longer sustaining his life. Unless you are considering organ donation, the mechanical supports should be discontinued so that his body can rest."

Although families often have difficulty accepting the death of their loved ones, some families have specific moral or religious objections to cessation of brain function as a determination of death and may insist that mechanical supports not be discontinued. While brain death regulations are state-specific and institutions adopt their own protocols, in these cases reasonable accommodations should be made for an explicitly specified period of time. These accommodations (e.g., continuing ventilation, nutrition and hydration, and/or medications) should take place in a quiet private room, if possible, but not in the Emergency Department or the critical care unit. Such placement would be counterproductive to the family's acceptance of the death and an unwise use of resources. The clinical staff should emphasize that the accommodations are for the benefit of the *family*, not the now-deceased patient.

If a family without specific moral or religious objections to the brain death determination is still unable to accept the death, reasonable accommodations may be appropriate for a specified time. In this case also, it should be made clear that nothing more can be done for the patient and concern is now focused on the family's adjustment. Efforts to help the family come to terms with the loss may include bioethics consultation, social service intervention, psychiatric counseling, and pastoral care.

## ADVANCE HEALTH CARE PLANNING

### Advance Directives

The 1976 case of Karen Ann Quinlan raised what came to be known as the "right to die"—actually, the right to refuse treatment—and brought to national attention the risks to a patient whose treatment wishes are unknown in a high-tech, aggressive, cure-oriented health care environment. Although physicians determined that the 21-year-old was in a persistent vegetative state (PVS) and would not recover, they were reluctant to agree to her family's wishes and discontinue life-support measures. In a unanimous landmark decision, the New Jersey Supreme Court held that if there were "no reasonable possibility" that she would ever return to a "cognitive, sapient state," her ventilator

could be removed without fear of criminal or civil liability. The *Quinlan* case highlighted the potential for incapacitated patients to be burdened with unwanted treatment, providing the impetus for the development of advance directives that could guide care according to patient wishes.

Subsequent cases, most notably the 1990 case of Nancy Cruzan, sharpened the focus on determining the prior wishes of the incapacitated patient as the guide to making authentic health care decisions. After the 25-year-old woman had been in PVS for seven years, her parents petitioned for an order to discontinue artificial nutrition and hydration. The U.S. Supreme Court, in its only such decision, recognized the protected interest of a capable individual in refusing unwanted treatment, including measures necessary to maintain life. The Court also held that, when life-sustaining treatment is refused on behalf of an incapacitated patient, states may insist that these decisions be based on clear and convincing evidence of what the *patient* wanted, not what others want *for* her.

The cases of Karen Anni Quinlan and Nancy Cruzan, discussed at greater length in part VI, captured national attention for two reasons. First, these were young women in devastating conditions from which they would not recover. Second, and perhaps more significant, decisions about their care were not automatically considered to be the responsibility of those closest to them. In addition to sympathy, these stories prompted many people to say, "Hey, wait a minute. This could happen to me or someone I love. What if no one knows what I would want? What if these decisions are made by doctors or courts or other strangers?"

The answer seemed to be some method of prospectively documenting care instructions to provide clarity and legal authorization for later decision making. Advance directives were developed to provide for treatment preferences, values, and directions to be articulated by a capable person so that they could be communicated and implemented after capacity has lapsed. As discussed in chapter 2, the most common types of directives are living wills and health care proxy appointments.

III Mr. Jennings is a 24-year-old man who has just been brought to the ER after a traffic accident. He has been receiving regular care in the HIV clinic since his initial diagnosis three years ago and, with a CD4 count of 460, his HIV is under good control. He is physically active and was on his way home from playing basketball when his bike was struck by a car. He is unconscious and suffering from a dislocated shoulder and a collapsed right lung.

As the ER team is preparing to intubate Mr. Jennings, his mother and sister arrive with his living will, which says, "If I am ever unresponsive and in respiratory failure, I do not want to be maintained on life support, including ventilatory support." His sister insists, "That may be what he wrote, but it's not what he meant. He's not ready to die. You must do everything to save his life, even putting him on a respirator."

The care team knows that short-term ventilatory support will permit the resolution of the pneumothorax and that Mr. Jennings' chances are excellent for full recovery from his injuries and return to baseline function. The team is concerned that a living will is a legal expression of

the patient's wishes and that respecting his autonomy requires that it be honored, even though his clinical condition would benefit from intubation.

And you thought that a living will was the answer to uncertainty about patient wishes.

A living will is a list of instructions reflecting the individual's wishes about the treatments he does or does not want, usually at the end of life. A health care proxy appointment enables a capable person to appoint an agent to make health care decisions whenever capacity has been lost, either temporarily or permanently. The features of both types of advance directive are often combined in one document that provides for the appointment of a primary agent and an alternate agent, as well as the optional articulation of specific treatment wishes.

While advance directives, especially health care proxies, may be used to guide care at any time the patient has lost capacity, they figure prominently in planning care at the end of life. As discussed in this chapter and chapter 7, the approach of death prompts consideration of life-sustaining treatment, palliation, futility, and quality-of-life judgments. Because these issues are most often addressed when the patient is least able to participate, decisions with lasting consequences must be made on his behalf by others based largely on what they believe he would want. Advance directives can provide surrogate deciders with the insight and confidence to act in ways that are consistent with his preferences and/or best interest.

What could be simpler or clearer? As you well know, clinical ethics consultations are often requested to help the care team, families, and health care agents interpret and implement advance directives. Confusion usually concerns the authority of the directives and the meaning of their provisions. Several points should be emphasized. First, both living wills and health care proxies take effect only when the patient has been determined to have lost decisional capacity. The existence of an advance directive, therefore, does not alter the capable patient's decision-making rights; its authority lies dormant unless or until the patient is deemed unable to make health care decisions.

Second, even when decisional capacity has been lost, treatment instructions are implemented only if the patient meets the criteria specified in the directive. Take, for example, a living will that states, "If I am ever terminally ill, permanently unconscious, or unable to recognize or interact with my family, I do not want to be maintained on ventilatory support, dialysis, or artificial nutrition or hydration." Before even considering withholding or withdrawing these life-sustaining measures, a clinical determination would have to be made that the patient is in one of the specified medical conditions.

III Mrs. Becker, an 82-year-old woman, has been sent by the nursing home to the hospital for replacement of her pacemaker. Her significant dementia prevents her from understanding her clinical condition and health care decisions are made for her by her daughters, who are her

proxy agent and alternate agent. When the daughters arrive at the hospital, they tell the care team that they will not consent to replacing the pacemaker because they are honoring what they believe to be their mother's wishes. "Our mother was an elegant, fastidious, and very private person. She always said that, if she were ever incontinent and had to wear diapers, she would not want to live. We know that, if she could appreciate her situation now, she would be humiliated and would not want to continue this way."

Mrs. Becker, however, does not realize that she is incontinent or that her condition would have been a source of embarrassment. At the nursing home, she greets everyone with a smile, enjoys eating lunch in the garden and listening to opera, and loves visits from her grandchildren, even if she does not remember their names. Should her previous wishes limit care that would allow her to continue what appears to be an enjoyable quality of life? On the other hand, does her dementia deprive her of the right to determine how she will be remembered?

Third, inconsistencies between the provisions of a living will and the decisions of a health care agent should be assessed in terms of the patient's current and projected clinical status, and the relationship between the patient and the agent. Because advance directives are executed before the medical condition that will trigger their use, they try to anticipate what the patient would want under circumstances that have not yet occurred. Commentators such as Dresser and Robertson (1989) and Blustein (1999) have suggested that patients with dementia may have interests that differ markedly from those they had when they were capable. The argument offered is that they are in effect different people for whom decisions should be based on their current needs rather than their prior wishes.

Mrs. Becker's daughters and caregivers are struggling with this very dilemma. Her incontinence, while previously a distressing notion to her, does not threaten her health or interfere with a current quality of life she appears to find pleasant. Given her otherwise good level of comfort and function, it would be hard to justify forgoing a life-sustaining measure at this time. Yet, her daughters feel that they will have betrayed the trust she placed in them if they disregard her wishes.

One important thing for Mrs. Becker's daughters to clarify is whether they believe that her comments were to be taken literally as instructions or figuratively as an expression of her distaste for the condition of incontinence. In other words, what do they think she would have wanted if she could have envisioned her current, otherwise pleasant, situation? Here, it is useful to consider Dworkin's (1993) distinction between experiential and critical interests. The former are interests in having experiences of certain kinds; the latter are more central and important interests that concern one's long-range goals and the shape of one's life over time. How Mrs. Becker's daughters decide may depend on whether they regard her interest in not being incontinent as so critical to her sense of self that she would not have been able to tolerate her current condition.

The health care proxy is the recommended advance directive because it employs the agent's knowledge of the patient and her authority to interact with the care team and respond to changing clinical conditions. She is able to consider unanticipated or evolving situations, as well as the clinical judgment of the professionals. Precisely because the agent has the advantage of assessing current medical information in light of the patient's values and wishes, her decisions may exceed or even differ from the living will. Even though the living will may be silent about a specific choice, even though the patient may never have discussed her present medical situation, substituted judgment allows the agent to say, "If the patient knew what we know about her condition and prognosis, this is what she likely would decide."

This means that the spirit, as well as the letter, of the directive should be considered in interpreting the instructions and determining whether they apply to the current circumstances. Mr. Jennings' living will, for example, specifies that he would not want ventilatory support if he were "unresponsive and in respiratory failure." Given his HIV status and his reference to being "maintained on life support," it is probable that he was anticipating an end-of-life scenario, permanent unconsciousness rather than an acute event that would respond to a short course of ventilatory support. This assessment is supported by his mother and sister, whose knowledge of his values and preferences is a valuable resource. Thus, the patient's prior wishes as expressed in a living will must be considered in light of the current clinical realities, the expected outcomes, and additional insights about what matters to him.

Two important caveats are in order. Despite early enthusiasm for advance directives, the percentage of people implementing them remains low and, when they are used, their effectiveness in the clinical setting is less than optimal. One problem appears to be the unfortunate link between advance directives and dying. While advance directives are often very helpful in end-of-life decision making, the emphasis should be that they can guide care *whenever* the patient is unable to make his own decisions. Indeed, it is recommended that, when advance directives are discussed with patients, they *not* be presented as end-of-life planning, which may discourage their use. In a perfect world, care professionals would raise the issue as a routine part of the clinical interaction, saying, "I have this discussion with all my patients because I believe that advance directives are an important part of total health care planning. This is not a matter of how old you are or how sick you are; this is a matter of being responsible for how your health care decisions are made." Uncoupling advance directives from end-of-life considerations is likely to make them less threatening, more accessible, and ultimately more useful.

The second barrier to the effective use of advance directives is the lack of understanding about them displayed by patients, families, and care professionals. People often mistakenly assume that, by itself, a detailed list of treatments they do or do not want or the appointment of a proxy agent will get the job done. In fact, what they believe to be informed prospective decisions are likely to be counterproductive if they do not discuss their care preferences with their doctors, families, or proxy agents. People frequently

refuse treatments in advance without understanding what they are or how they work. They leave instructions that do not apply to the medical situations in which they ultimately find themselves. They authorize proxy agents who have no idea of their authority, the types of decisions they may have to make, or how to interpret patient preferences. In some instances, agents do not even know that they have been appointed until it is too late to ask the patient, "What would you want?"

Lack of communication and coordination has also been shown to interfere with advance directives accurately influencing care. Even when directives have been executed, they often do not make their way to the acute care hospitals when patients are admitted. Professionals are uncertain how to interpret advance directives and when their provisions are applicable. Physicians are sometimes unable to predict accurately patient treatment preferences and are often unaware that their patients even have advance directives. Research reveals the need for earlier, more frequent, and better doctor-patient communication, focusing on the goals of care rather than specific interventions (Teno et al., 1998; Fischer et al., 1998; Prendergast, 2001; SUPPORT investigators, 1995; Morrison et al., 1995).

Even a carefully executed advance directive is not sufficient if the patient's values and wishes are unknown or unexplained to those who will base decisions on them. People need to talk with their families, caregivers, and trusted others about what is important to them, allowing their values, rather than their scant knowledge of medical interventions, to be the guide. For example, knowing that Mama would agree to temporary treatment but would not want to be permanently dependent on mechanical supports is more useful than a statement about "no dialysis." Understanding that Dad's notion of an acceptable quality of life is being able to interact with others is more helpful than a statement about "no heroic measures."

More often, the explicit authorization and guidance of an advance directive is lacking and treatment decisions require inferences based on recalled comments or behaviors. Unfortunately, these conversations typically take place in the least opportune circumstances—in the acute care setting at the time of a critical event when the unresponsive patient is in multiorgan system failure, the family is under enormous stress, and professionals seek direction in care planning.

#### **Do-not-resuscitate (DNR) Orders**

III Mrs. Marcus is a 72-year-old woman with multiple medical problems, who was admitted from a nursing home after being found unresponsive and hypotensive. This is the second time in recent weeks that Mrs. Marcus has been admitted. She was hospitalized for eighteen days with pneumonia and a massive stroke. During that hospitalization, a feeding tube was placed. She was discharged to the nursing home and now readmitted seventeen days later with aspiration pneumonia. She was intubated in the ER and successfully extubated several days later.

Mrs. Marcus's daughter, Deborah, is her health care proxy agent. A living will, executed on

the same date as the proxy appointment, stipulates that, if Mrs. Marcus's "brain has ceased to function," she would not want a variety of potentially life-sustaining interventions, including respiratory support, artificial nutrition and hydration, and antibiotics. Although Mrs. Marcus responds only to deep pain and her physicians do not expect her condition to change, Deborah is in favor of continued aggressive treatment, which she hopes will result in her mother's improvement. The attending believes that, if Mrs. Marcus suffers a cardiopulmonary arrest, she could survive a resuscitation attempt but would almost certainly be left in a much worse condition. For that reason, the care team has recommended a do-not-resuscitate (DNR) order to spare Mrs. Marcus an intervention that would increase her suffering without providing benefit.

Deborah refuses to consent to a DNR order because the wording of the living will does not clarify what is meant by the "brain has ceased to function," and she does not think that forgoing resuscitation reflects her mother's wishes. She says that the living will is clear that her mother would not want to linger in a coma. Because she is not yet in that condition, however, Deborah is unwilling to consent to a DNR order or consider less-than-aggressive treatment at this time.

Another type of advance decision making is the do-not-resuscitate (DNR) order. A DNR order means that cardiopulmonary resuscitation (CPR), including mouth-to-mouth resuscitation, external cardiac massage, and/or stimulants, will not be attempted if the patient suffers a cardiopulmonary arrest. Consent to a DNR order can be given either by a capacitated patient or by someone authorized to consent on the incapacitated patient's behalf.

The ethical dilemma is that CPR's ability to prevent death can greatly benefit some patients and greatly burden others. In a young and/or otherwise healthy person, if cardiopulmonary function can be restarted within approximately four minutes, avoiding irreversible damage to brain and other organs, CPR can give back a life. In an elderly, demented, terminally ill person, one who has multiple serious health problems or has suffered severe and permanent damage, CPR can deprive the individual of a peaceful death.

Unfortunately, reports of successful resuscitations and dramatic television and film depictions of heroic rescue have played into popular belief in CPR's life-saving certainty. In fact, the brutal procedure is rarely effective on frail, debilitated, or terminally ill patients and may simply impose suffering and prolong dying. The critical distinction between attempting and successfully achieving resuscitation accounts for efforts to change the term from DNR to the more accurate DNAR (do not *attempt* resuscitation). Because of its profound implications, consent to forgo CPR is explicit and limited, not inferred or automatically transferred from one setting to another. Thus, DNRs must be renewed periodically, a separate nonhospital DNR is agreed to upon discharge to home or another care facility, and a specific discussion is necessary to suspend a DNR order during the perioperative period.

Even experienced physicians know that advising patients or, more often, families

that CPR is not recommended is among the most difficult discussions in the clinical setting. No matter how sensitively it is presented, suggesting that life-saving efforts not be undertaken is distressing and frightening, an index of just how hopeless the patient's condition has become. All the physician's judgment, skill, and compassion are required and ethics consultations are often requested to assist in the process.

Rather than an isolated conversation, the DNR discussion should be part of the overall review of the patient's changing clinical condition. Just as other interventions are evaluated in terms of whether they promote the patient's well-being, resuscitation should be subjected to a benefit-burden analysis. Patients, families, and staff should clearly understand that it is the futile or clinically inappropriate *attempt* rather than successful resuscitation that will be withheld. Discussions with Deborah should balance the benefits and burdens of resuscitation to help her view a DNR order as a way to *protect* her mother from a painful but ineffective intervention, rather than *deprive* her of potentially beneficial treatment. Unfortunately, family members like Deborah are not entirely wrong when they fear that consenting to a DNR order signals to the care team that they have given up hope that the patient will improve and are willing to accept less attentive care. Efforts should be directed toward convincing families and educating caregivers that a DNR order permits the forgoing of a single ineffective intervention but will not affect any other treatment, define the goals or plan of care, or limit the team's attention to the patient.

It is unfair to ask families to take full responsibility for the difficult and painful decision to forgo resuscitation. If CPR is not clinically indicated, the physician's clear recommendation, rationale, and support should be central to the discussion. Once the decision has been made, it is often the consent document that may be most distressing, as if putting pen to paper is the act that seals the patient's fate. The most common expression is, "I feel like I'm signing the death warrant." In many cases it is more compassionate to avoid that trauma by obtaining verbal and witnessed consent.

Finally, there are times when, even though the disadvantages of attempting resuscitation have been explained, families cannot or will not authorize a DNR. However well intended, repeated efforts to obtain consent begin to feel like harassment. The issue risks becoming the focus of the clinical interaction and the signed consent perceived as a trophy. In these circumstances, it may be necessary to redirect attention to other care goals that are more important and achievable.

#### GOALS OF CARE AT THE END OF LIFE

III Mrs. Diller is an 86-year-old woman admitted from home after suffering her second stroke. Following her last stroke, she recovered some mobility and could enjoy some of her favorite activities, such as Bingo. The attending physician, Dr. Tanner, has discussed the case with the neurologist, Dr. Moon, who thinks that it is still too early to predict the potential for recovery

because, when strokes are this deep, patients may take longer to improve. She recommends tissue plasminogen activator (TPA), a complex and potentially dangerous therapy that should be instituted immediately. Based on his prior experience with Mrs. Diller and familiarity with her priorities, however, Dr. Tanner favors a care plan that focuses on comfort.

On this admission, Mrs. Diller was responsive and, although she had great difficulty speaking, she insisted that she did not want to "be like this again." Since then, her level of consciousness has deteriorated and she is largely unresponsive, although her family insists that she squeezes their hands when asked. Dr. Tanner has observed the patient squeezing a hand placed in hers, but believes that this is reflexive rather than a response to command.

Before her initial stroke, Mrs. Diller had appointed one of her daughters, Lila, as her proxy agent. Additional instructions in the proxy document include her wish not to be resuscitated if she has a cardiac arrest and not to receive artificial nutrition and hydration if she has a terminal condition or is in an irreversible coma.

Her family describes her as a very independent woman who would be distressed by her current disability but disagrees about the appropriate care plan. Although Lila feels obligated to honor her mother's expressed wishes, she does not want the responsibility of forgoing life-sustaining treatment. Another daughter notes that Mrs. Diller improved considerably after her last stroke and insists that the same thing could happen this time. The patient's brother argues for the TPA advocated by Dr. Moon, while one granddaughter insists that she would not want to be "tortured" with tubes and machines and should be allowed to die in peace. Another granddaughter pleads that, as long as her grandmother can squeeze her hand, she should be kept alive as long as possible.

Perhaps the single most important question in clinical decision making and the one that is central to any ethics analysis is, "What are the goals of care for this patient?" or "What do we intend to accomplish with our diagnostic and therapeutic efforts?" Identifying the care goals, especially at the end of life, requires professionals, families, and, when possible, patients to clearly articulate what they understand and expect. If recovery or substantial improvement is unrealistic in light of a terminal diagnosis and steady deterioration, the goals and plan of care should be revised. If the aim is to relieve suffering and not prolong the dying process, then interventions aimed at cure are inconsistent and serve only to distract from the primary objective.

Regularly reassessing the goals in response to clinical changes permits the care plan to reflect accurately what is both feasible and desirable, especially as death approaches. Critical considerations during this time include the determination that the patient is dying, the initiation or forgoing of particular interventions, and the involvement of additional resources, such as palliative care. As discussed in chapter 7, the relief of pain and suffering is a moral imperative central to the entire clinical interaction, which becomes more prominent at the end of life.

Focusing on the goals of care guards against the risk of resorting to interventions

because they are available rather than clinically indicated. The temptation to use everything in the therapeutic arsenal makes it easy to justify this treatment, which triggers that one and then, of course, the one that follows. Rather than asking, "What is the goal of this particular intervention?" the patient is better served by asking, "Where does this intervention fit into the overall plan of care? If it advances the agreed-upon goals, we may appropriately begin or continue it. If not, it is probably not indicated."

Keeping the goals at the center of care planning also permits a wider range of treatment options, which is especially important at the end of life. Interventions should be evaluated in terms of what they can accomplish for the patient rather than categorized according to conventional labels. For example, surgery, radiation, or antibiotics can be appropriately considered for a dying patient when it is clear that the goal is comfort rather than cure.

Clarifying *whose* goals are being considered is a key element in care planning. A frequent source of ethical tension is the presumption of consensus on care goals when, in fact, the patient, family, and care team may not share the same understanding of the clinical picture or possible outcomes. The patient may want to spare his family the pain of seeing him deteriorate and the emotional and financial burden of his care. His children may want him to continue aggressive therapy in hopes of a cure. His wife may want him to come home with the focus on symptom management so that his remaining time can be spent comfortably finishing his work and interacting with his family. His sister may want to protect him from the knowledge that he is dying. His caregivers may feel that he could benefit from a clinical trial of an experimental protocol.

Mrs. Diller's family and care providers find it hard to agree on a plan of care because of their differing perceptions of her condition, prognosis, and wishes, as well as their own notions of what is in her best interest. Dr. Moon and the patient's brother believe that not pursuing aggressive treatment would be giving up prematurely. Dr. Tanner and one granddaughter urge a focus on comfort measures to protect the patient from treatment that would increase and prolong her suffering. As the health care agent, Lila feels bound to honor her mother's expressed preferences, which appear to be forgoing specific life-sustaining treatments. Finally, while differences between physicians' clinical impressions are not uncommon and can be useful in arriving at accurate prognoses, families often find their lack of agreement frustrating.

How the goals of care are articulated and justified will influence the therapeutic and interpersonal dynamics. Inconsistent expectations inevitably lead to descriptions of the family as "unreasonable" or "demanding," and charges that care professionals have not been clear and candid in their explanations or responsive in their treatment. Insufficient attention to what is really being communicated or avoided permits people to mistakenly believe that what they have said has been heard and understood. Your involvement through bioethics consultation can be especially helpful when the parties need to clarify the clinical realities, identify the patient's interests and values, and focus on the goals in developing an appropriate end-of-life care plan.

III Mr. Giles is a 58-year-old man who has had AIDS for fourteen years, apparently the result of a long history of intravenous drug abuse. He has multiple medical problems, including hypertension, asthma, chronic obstructive pulmonary disease, panic disorder, colitis, stroke, meningitis, and multiple pneumonias, two episodes of which required ventilation. He has been receiving hemodialysis for one year to treat end-stage renal disease. He was admitted from a long-term nursing facility with seizures and changes in mental status. He is nonverbal and only intermittently responsive.

An MRI revealed a brain tumor. Given Mr. Giles' AIDS status, he faces specific risks. Surgery carries a high risk of hemorrhage, which could leave an immediate, severe, and permanent neurologic deficit, such as hemiplegia (one-sided paralysis). Without surgery, his seizures and cognitive changes can be controlled with anticonvulsant medication, but he faces progressive decline in mental status, as well as a slow evolution of hemiparesis (one-sided weakness). Mr. Giles has no family or others involved in his care. Despite encouragement from the nursing facility, he has not completed an advance directive.

An important consideration in setting end-of-life care goals is the quality of the patient's remaining time. For example, it is not uncommon for an intervention to be recommended because it will "improve the quality of life" or for a prognosis to be described in terms of a "poor quality of life." It is worth noting that these subjective, value-laden conceptions are important *personal* evaluations for the patient, family, or other agent, not *medical* assessments for clinicians. Defining beneficence and best interest remains the responsibility of the patient and his surrogates, for whom the requested interventions have the most significance. While the physician can describe the likely range of comfort and function that the patient will experience, it can be argued that only the patient or those who know him well can assess how those projections will be perceived in terms of life quality. When, as in Mr. Giles' case, the patient is without capacity, surrogates, or advance directives, the care team has no insight into his values, wishes, or the quality of life he would consider acceptable. Only in these circumstances are clinicians justified in using the best interest standard to try to assess what plan might benefit the patient.

Setting therapeutic goals should be a fully collaborative effort by the patient or trusted surrogates and the care team, reflecting not only what is possible but what is desirable. This balance calls for articulation and periodic review of the meaning of success, recognizing the subjective nature of quality-of-life assessments. Despite the superiority of professional medical knowledge and skill, the perspective that matters is that of the patient who will experience the life and death that are achieved.

#### FORGOING LIFE-SUSTAINING TREATMENT

III Mrs. Lewis is a 72-year-old woman with progressive dementia of unknown etiology, progressive renal failure, and hypertension, admitted with an acute gastrointestinal (GI)



bleed. She has been living at home with her daughter and has received care through the family practice group. She has neither a living will nor a health care proxy.

Prior to admission, Mrs. Lewis could use a walker and a bedside commode. She has not been hospitalized recently and generally manages well at home. While her renal failure has been progressive, her current deterioration may be the result of her acute GI bleed and might be reversible, although the renal attending thinks this is unlikely. Her primary care physician favors a trial of dialysis to see if her renal function improves and her mental status clears, but he doubts the utility of chronic dialysis. Mrs. Lewis's acute bleeding has stopped, but she is not eating and the gastroenterologist has placed a temporary nasogastric tube to provide nutrition. He says that, shortly, a more permanent feeding tube will be necessary for continued nourishment. The chief resident describes Mrs. Lewis as "a little old lady curled up in bed who responds only to noxious stimuli and occasionally utters a single word." He is concerned that dialysis and tube feeding will prolong her dying and increase her suffering.

Her daughter is anxious about making decisions without knowing what her mother would want. In particular, she is concerned about eliminating dialysis from consideration without knowing whether it would be effective.

It's a safe guess that much of your ethics committee agenda and consultation requests concern withholding or withdrawing life-sustaining treatment, especially from patients without capacity. Decisions about deferring or permitting death are difficult for clinicians and administrators; they are painful and often paralyzing for those who act on behalf of their loved ones. If abandoned to make these choices alone, the family or other surrogate is likely to feel solely responsible for the outcome. The lingering regret is likely to be, "If only we had insisted on continued treatment, Mama would be with us today." Clinicians can help make the process more bearable by sharing the burden of making these hard decisions.

Whether end-of-life care choices are made by capable individuals or surrogates, using a benefit-burden analysis as the decision-making model can provide structure, consistency, and support for patients, families, and staff. Central to this analysis is the overarching goal of providing only care that benefits the patient without increasing suffering or prolonging the dying process. When the burdens of an intervention or a course of care are shown to outweigh its benefits, the decision to look for alternatives is more easily and comfortably justified.

One useful strategy is a therapeutic trial. A treatment plan with potential benefits is implemented for a specified period of time, after which its effectiveness is evaluated and it is either continued or discontinued. The key is clearly setting out in advance the proposed length of the trial, as well as the goals, limits, and criteria for success. For example, "Let's try three dialysis treatments during the next seven days. If Mrs. Lewis's renal function and mental status improve, we can consider the benefit of further treatments. If she shows no improvement, we'll know that dialysis is ineffective for her and should not be continued." Consensus on the goals and indices of success encourages

the trial of appropriate interventions without the fear that, once begun, they cannot be stopped. Therapeutic trials also provide important reassurance that no potentially beneficial treatments have been left untried.

Productive end-of-life decision making depends on clarity and candor. As discussed in chapter 3, offering false choices when there are no real alternatives frustrates patients and families, and diminishes their exercise of genuine autonomy. Asking, "Should we continue your husband's antibiotics?" or "Do you want us to resuscitate Mama if her heart stops?" is not helpful if it is clear that these interventions are not clinically indicated. It is more responsible and compassionate to say, "The antibiotics we tried are no longer fighting your husband's infection. Because they're not helping him and may be creating other problems, they should be discontinued," or "Let me tell you why we believe that, if Mama's heart stops, attempting resuscitation will not benefit her."

These discussions are never easy, but they can be made less threatening with reassurance that the patient will not be abandoned. When specific interventions will be withheld or withdrawn, the focus should be on those that will be continued or added. It is critical to emphasize that, while the goals of care may change to reflect a greater priority on comfort than cure, the team's commitment to the patient's well-being remains unaltered.

#### PROTECTING PATIENTS FROM TREATMENT

Decisions about forgoing life-sustaining measures usually arise when death is imminent and continued intervention will not improve the clinical condition but may contribute to suffering. How these issues are resolved depends greatly on how they are framed. Withholding or withdrawing treatment can be seen either as *depriving* the patient of needed care or *protecting* the patient from the burden of ineffective or harmful interventions. When continued treatment will only prolong dying or increase suffering, it is appropriate to help the patient's loved ones give themselves permission to make hard choices, within applicable state law, that will be in his best interest.

An example is considering artificial nutrition and hydration (ANH) at the end of life when the burdens of the intervention will outweigh the benefits. Research has shown that patients with advanced dementia typically stop eating as the end of life nears because their bodies are shutting down and no longer need the nutrition. For these patients, continued tube feeding often creates considerable discomfort, including bloating, gas, nausea, cramping, and diarrhea (Huang and Ahronheim, 2000; Ahronheim, 1996). When the dying process cannot be reversed and an intervention imposes only pain or other distress, it can be argued that discontinuing the treatment—even nutrition and hydration—protects the patient from harm and promotes comfort as death nears.

The frustration and despair of those closest to the dying patient are directly related to their feelings of helplessness as his condition deteriorates. No matter what they do, they cannot prevent the inevitable. But, while they cannot determine *whether* he dies,

they can influence *how* he dies. Assessing the care plan according to its relative benefits and burdens, they are able to make decisions that shield their loved one from interventions that create more harm than good. At the end of life, the notion of family as protector can be a powerful and comforting one that can and should be reinforced.

#### REJECTION OF RECOMMENDED TREATMENT AND REQUESTS TO "DO EVERYTHING"

III Mrs. Abrams is a 70-year-old woman who came into the hospital for surgical closure of her colostomy. She had been living independently at home and, on admission, she was interactive and fully capacitated. Her medical history includes emphysema from years of cigarette smoking. The surgery was successful but, shortly thereafter, Mrs. Abrams developed abdominal fistulas that required another operation. She was so weakened by her multiple surgeries that she required ventilatory support. Despite strong initial resistance to intubation, she reluctantly agreed to it after discussion with her pulmonologist.

The following day in the ICU, Mrs. Abrams let it be known in no uncertain terms that she wants to be extubated. Her surgeon is playing a marginal role in her care and all important medical decisions are being made by her pulmonologist. Mrs. Abrams' three daughters are deeply troubled by their mother's decision to refuse further intubation. The house staff caring for Mrs. Abrams do not know how to proceed or what is legally and ethically appropriate. They believe that removing the vent would mean almost certain death, which they find personally and professionally very disturbing.

When patient or family decisions conflict with physician recommendations, clinical judgment and skill are tested. Patients often reject proposed interventions likely to be beneficial or even life-saving. While respect for patient autonomy requires that capacitated care decisions be honored, the refusal of treatment should be the beginning, not the end, of the discussion. As discussed in chapter 3, the professional obligation is to ensure that all consents and refusals are informed and thoroughly considered. Because of their profound implications, however, refusals of life-sustaining treatment should receive heightened scrutiny. Special attention should be given to the adequacy of the information presented and the quality of the explanation, possible language or cultural barriers to understanding, and the patient's capacity and appreciation of the consequences of forgoing treatment.

In addressing Mrs. Abrams' request for extubation, the care team should clarify the length of time ventilatory support is recommended, the anticipated benefits, and the likely outcomes of premature vent removal. Carefully probing her concerns should reveal fears and misconceptions that can be addressed. For example, she may be afraid that she will be permanently dependent on ventilatory support, when, in fact, her doctors anticipate that she should be weaned from the ventilator within a few weeks.

Although Mrs. Abrams' ability to communicate will be hampered by the endotra-

cheal tube, adequate time and effort should be invested in assessing her capacity, her goals for care, her expectations, and the consistency of her wishes. Throughout the process, which may take several days, she should be reassured that her request is being carefully considered, especially in light of its significant consequences. A bioethics consultation, including Mrs. Abrams, her daughters, and the care team, can facilitate a clinically, legally, and ethically acceptable resolution. If the patient remains committed to discontinuing ventilatory support, the care plan should focus on promoting her comfort, including measures to minimize air hunger, anxiety, and other symptoms of respiratory distress.

Physicians may also be faced with patient or family instructions to "do everything," including requests for specific interventions judged to be therapeutically inappropriate or otherwise not indicated. At the end of life, family members often feel the need to be good advocates, to ensure that their loved ones are not neglected and that no potentially beneficial treatment is left untried. Especially when they do not know what to anticipate or how much confidence to place in the care professionals, they may insist on all available therapies in the hope that one of them will be effective.

Is the customer or, in this case, the patient or family always right? The short answer is, of course not. Because there is no obligation to provide treatment just because it is requested and because physicians must be guided by their clinical judgment and professional integrity, they should not comply with requests that fall outside the standard of care. That position, however, is only the beginning of the ethics analysis. Like treatment refusals, insistence on inappropriate treatment should trigger further discussion and clarification.

These requests should be seen as an important signal that the parties to the interaction may not share the same understanding of the patient's condition and prognosis, goals of care, available treatment options, and expected outcomes of the proposed interventions. The first question should be, "What does 'everything' mean to you, and what do you expect to happen if we do it?" The focus should be on identifying unrealistic expectations, clarifying the goals of care, the potential for the proposed treatments to achieve those goals, the obligation to prevent suffering without benefit, and further explanation of the recommended plan of care.

#### MEDICAL FUTILITY

III "He never had time to even catch his breath and already it's come to this." Ari was talking about his father, Dr. Dole, a 54-year-old physician who had diagnosed his own pancreatic cancer just nine weeks ago. He was found to have significant metastases and his condition has deteriorated very rapidly. Now he is in the ICU, intubated and comatose, and his colleagues are finding it increasingly difficult to keep his organ systems from failing. Even with aggressive management, there is reluctant consensus within the medical team that the therapeutic options are running out and nothing further can be done to stem multiorgan failure.

When the critical care team met this morning to discuss Dr. Dole's care, several suggestions were offered for continued and even accelerated interventions. Finally, Dr. Birch said quietly, "Let's face it. This is medically futile."

Judgments about providing or limiting treatment frequently invoke the notion of medical futility. Despite vast literature and vigorous debate, efforts to agree on a determination of futility have been largely unsuccessful. Its narrowest and most useful definition describes the *physiologic impossibility* of an intervention achieving its therapeutic objective. In that strict sense, physicians are excused—even precluded—from burdening patients with treatment that will be clinically ineffective or even harmful.

This narrow and value-neutral definition does not apply, however, to the vast majority of cases in which the notion of futility is raised. Far more often, interventions or care plans are labeled "futile" when they are expected to produce a clinical effect that falls below a specified standard. For example, dialysis may successfully assume the function of failing kidneys, but not contribute to returning the patient to an acceptable overall health status. Depending on the long-range clinical goals, the intervention may be considered futile in achieving the desired objective. Moreover, the differing values and expectations of the patient, family, and care team may prevent consensus on the definition of success, contributing to confusion and conflict in determining the meaning of futility. Finally, notions of futility may have more to do with perceived acceptable quality of life than actual clinical effectiveness.

Care providers faced with new and often competing pressures may misuse the notion of futility in the service of what they see as their ethical responsibilities to patients, families, and society. Mindful of their conflicting obligations to promote the best interests of patients by providing only beneficial treatments, not raise unrealistic expectations, and provide cost-effective care, physicians may label questionably effective interventions "futile" as a way of withholding them. Futility can also function as the trump card to discourage families from insisting on treatment that care providers consider inappropriate. While some physicians see futility determination as the ethical way to manage end-of-life care, others see it as a way to take control of decisions from demanding families.

Labeling inappropriate interventions "futile" distorts the meaning of the term and obscures the message that should be communicated. The more accurate and accessible approach might be to explain that, regardless of what is done, the patient is dying and what matters is the quality of that dying. Invoking futility as a frame for end-of-life issues should be replaced with reality checking—clarifying that the patient is dying, reassessing the goals and expectations of care, defining benefit and burden, and identifying ways to promote physical and emotional comfort.

Seen in this light, further efforts to reverse Dr. Dole's clinical course can be considered medically futile because the interventions are not meeting their physiological

objectives and he is dying regardless of treatment. Continued cure-oriented measures would not only be ineffective, they would be counterproductive and, as discussed in chapter 7, the goals of care are now more appropriately palliative than curative. In other cases, discussion might well reveal that, rather than strict futility, decisions for the dying patient concern quality of life and death.

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