Ethical uncertainties and dilemmas arise routinely in palliative care nursing. Questions about advance directives, refusal of treatment, and the withdrawal or withholding of life-sustaining interventions (such as medically provided nutrition and hydration) can be difficult to address—especially when intense emotions, felt by all involved, cloud decision making.

Such is the case of 88-year-old widow Margaret Joseph, who has been in a nursing home for seven years, following a stroke that resulted in left-sided paresis and dysphagia. Before the stroke, Ms. Joseph exhibited symptoms of moderate dementia and couldn’t make decisions on her own. She has no children but a niece helps out when needed. Ms. Joseph has urinary incontinence, is immobile, needs total assistance for activities of daily living, and receives feedings through a percutaneous endoscopic gastrostomy tube. She has been treated occasionally for urinary tract infections. Otherwise, her condition has remained relatively stable over the years.

Recently, however, when Ms. Joseph became lethargic and developed a fever, she was transferred to an ED for evaluation. Chest X-ray revealed an infiltrate in both lower lobes; a diagnosis of community-acquired aspiration pneumonia was made, and Ms. Joseph was hospitalized and started on parenteral antibiotics. Blood cultures were taken, and she received supplemental oxygen via mask. After four days, she remained febrile with an elevated peripheral white blood cell count. Blood culture results were negative. Her condition continued to decline. She was transferred to the ICU and placed on a ventilator, and her antibiotics were changed. Ms. Joseph showed improvement on the new antibiotic regimen. Now, efforts to wean her from the ventilator have been unsuccessful after a week, and the health care team is concerned that she’ll require prolonged ventilatory support. Given Ms. Joseph’s medical history and the hospitalization’s toll, the team determines it’s unlikely she’ll regain her prior level of functioning.

Although Ms. Joseph’s niece acts as her designated representative at the nursing home, she hasn’t been appointed her health care agent. Ms. Joseph has no advance directives. The team meets with the niece; if long-term ventilatory support is to be provided, she is told, Ms. Joseph will require a tracheostomy. Her nursing home isn’t equipped to care for patients on ventilators, so she’d need to be placed elsewhere. Given her aunt’s poor prognosis, the niece is asked to consider a do-not-resuscitate (DNR) order. Ms. Joseph’s niece, deeply concerned about her aunt, says

Colleen Scanlon is senior vice president, advocacy, at Catholic Health Initiatives, Denver, CO. Contact author: Catholic Health Initiatives, 1999 Broadway, Suite 2600, Denver, CO 80202. This article is the fifth in a series supported in part by a grant from the Robert Wood Johnson Foundation. Betty R. Ferrell, PhD, RN, FAAN (bferrell@coh.org), and Nessa Coyle, MS, NP, FAAN (coylen@mskcc.org), are the series editors.
she recalls only vague discussions about these issues and appears uncertain as to how to proceed. While nurses are familiar with these and other ethical concerns (such as breaches of confidentiality), this doesn’t diminish the distress and tension that can complicate such situations. Improving competency with ethical issues helps nurses promote the highest quality end-of-life care and safeguards professional integrity. This article will outline the various types of advance care planning, discuss ethical decision making at the end of life, and suggest ways in which nurses can become more proficient in this area. (A discussion of another issue, assisted suicide, is beyond the scope of this article.)

**ETHICAL CONTEXT OF NURSING PRACTICE**

Even before graduating nurses first recited the Florence Nightingale Pledge in 1893, promising to “abstain from whatever is deleterious . . . and devote [themselves] to the welfare of those committed to [their] care,” nursing has been based on ethical principles. And it has been ongoing; the ANA’s Code of Ethics for Nurses With Interpretive Statements ([http://nursingworld.org/ethics/code/ethicscode150.htm](http://nursingworld.org/ethics/code/ethicscode150.htm)) not only spells out the standards that have guided nurses but also addresses the complexities inherent in contemporary health care.

In fact, the Code of Ethics explicitly addresses the nurse’s role in end-of-life care, stating:
The measures nurses take to care for the patient enable the patient to live with as much physical, emotional, social, and spiritual well-being as possible. . . . Nursing care is directed toward meeting the comprehensive needs of patients and their families across the continuum of care. This is particularly vital in the care of patients and their families at the end of life to prevent and relieve the cascade of symptoms and suffering that are commonly associated with dying. Nurses are leaders and vigilant advocates for the delivery of dignified and humane care.

The ANA’s position statements on end-of-life issues address pain management, DNR decisions, forgoing medically provided nutrition and hydration, and assisted suicide (see www.nursingworld.org/readroom/position).

The distinctive nature of the nurse–patient relationship also influences nurses’ ability to understand and evaluate ethical issues. The “therapeutic presence” of the nurse is an active intervention that can alleviate feelings of isolation and abandonment in dying patients, who are sustained by the nurse’s willingness to be with them while they are dying.

DECISION MAKING: ‘CAPACITY’

In the past few decades, the physician-dominated approach to decision making has shifted toward one that recognizes a patient’s right to self-determination. Although that shift was warranted, many experts believe that what’s actually best is shared decision making, a model in which providers bring to bear their clinical knowledge, skills, and treatment recommendations, as well as their values, while patients make use of their life experiences, perceptions, goals, and values. Effective shared decision making is built on mutuality (an open and respectful approach), reciprocity (the exchange of information and ideas), and interdependence.

Ultimate control resides with the patient as long as he has capacity. But decision making at the end of life can be particularly challenging; an elderly patient with hypoactive delirium, for example, will be compromised in his ability to participate. In such a case, it’s important to determine what the patient would decide if he were able.

Patients are presumed to have “capacity”—the ability to comprehend information, consider options, evaluate risks, make a decision, and communicate that decision—unless proven otherwise. The capacity to make decisions is necessary for a person to make an autonomous choice. Although health care professionals often use the words “capacity” and “competence” interchangeably, there is a distinction. Competence, a legal term, can only be decided judicially; a person’s competence is frequently declared relevant in areas other than health care (such as financial). Capacity, a clinical term, refers to health decisions and is assessed by clinicians in a health care setting.

Capacity evaluations are not all-or-nothing determinations; they must allow room for changes in cognitive and emotional status and must be done whenever a new decision is to be made. The more serious the potential consequences, the more closely the patient’s capacity should be scrutinized. For example, clinicians may determine that a patient has the capacity to consent to a chest X-ray but not to a thoracotomy. Uncertainty about a patient’s capacity to make decisions can cause anxiety for all those involved and must be addressed aggressively (for example, through psychiatric evaluations). Nurses can increase patient involvement in decision making by encouraging conversation, attending to nonverbal as well as verbal messages, and offering reassurance.

ADVANCE CARE PLANNING

The Patient Self-Determination Act (PSDA), passed as part of the Omnibus Budget Reconciliation Act of 1990 and implemented in 1991, was the first piece of federal legislation aimed at protecting the rights of individuals to make health care decisions. Under the PSDA, all health care facilities receiving federal funding must recognize advance directives—instructions that guide health care decision making in accordance with a patient’s wishes, should that patient lose the ability to speak for himself. Although relatively few patients actually have advance directives (one study found that just 5% of patients older than 65 who were admitted to the ICU had one), the law sets a precedent for how health care decision making at the end of life should proceed. Even so, there are cases in which, in the absence of an advance directive, a clinical situation or a patient’s wishes have been so ambiguous as to require judicial intervention.

Advance directives. There are two basic types of advance directives: living wills (treatment directives) and durable powers of attorney for health care (appointment directives).

A living will is a written document that directs treatment in accordance with a patient’s wishes. A durable power of attorney for health care (also called a medical power of attorney or a health care proxy) designates a spokesperson (who may be called a health care agent, surrogate, or proxy) to represent the patient in decision making. That person must base any given decision on the patient’s known or probable wishes under the circumstances and not on her own preferences.

Of the two types of directives, living wills tend to present greater difficulties in interpretation, and their usefulness can be limited; they may not be clinically specific enough to help in unforeseen circumstances. No document can guarantee that a patient’s
All 50 states and the District of Columbia have enacted statutes to comply with the Patient Self-Determination Act (Omnibus Budget Reconciliation Act of 1990). The federal law requires that all health care institutions receiving Medicare and Medicaid funding must inform patients in writing about their right under state law to accept or refuse medical or surgical treatment before they become incapacitated. The state statutes address both living wills and durable powers of attorney for health care (that is, both treatment and appointment directives). But the statutes vary somewhat from state to state. Instructions and patient forms for each state are available free at the Partnership for Caring’s Web site (www.partnershipforcaring.org/Advance/adconfirm.php).

Many states are now streamlining these laws. Nineteen states have passed comprehensive laws that combine previously separate statutes on living wills and proxies. Seven states have passed laws based on the Uniform Health Care Decisions Act (UHCDA) of 1993, which was created by the Uniform Law Commissioners to serve as a model. The UHCDA recognizes a patient’s written or oral statements as valid. It also recognizes the authority of surrogate decision makers in cases when a patient who lacks capacity has no advance directive. Thirty-seven states and the District of Columbia have specifically included a surrogate provision in their statutes.


Map above shows the 39 states and the District of Columbia that have comprehensive laws (which cover both living wills and durable power of attorney for health care), comprehensive laws modeled after the UHCDA, laws containing a provision for surrogate decision making, or a combination thereof.

BLUE states that have not enacted comprehensive laws but recognize surrogate decision making (19 states and the District of Columbia)

BROWN states that have not enacted laws containing a provision for surrogate decision making but have enacted comprehensive laws (2 states)

YELLOW states that have enacted comprehensive laws (without the UHCDA) that also contain a provision for surrogate decision making (10 states)

RED states that have enacted comprehensive laws modeled after the UHCDA, which contains a provision for surrogate decision making (7 states)

States with NO COLOR have not yet streamlined their existing statutes (12 states)
wishes will be fully known or that appropriate clinical action will be taken. But advance directives can significantly help families and clinicians to understand what a patient would want and thus relieve some of the burden in making decisions.15

All 50 states and the District of Columbia have some type of advance directive legislation, though the specifics can vary greatly. (See U.S. State Laws and Advance Directives, page 51.)

Other ways to discern patient preferences. The absence of an advance directive does not mean that a patient hasn’t thought about or expressed his preferences. For example, oral statements made before losing capacity can be used in decision making, especially if they were documented. Nurses have the most regular, frequent contact with patients, and thus many opportunities to clarify what a patient would have wanted, for example by fostering conversation among family members, friends, and other team members. They can share their knowledge of a patient (particularly valuable when the relationship has been a long one) and can verify that proposed actions reflect the patient’s wishes and preferences accurately.

In some cases, clinicians can turn to others who may be willing to act as the patient’s surrogate decision makers. There’s a longstanding practice of relying on family members in this way, but friends or others who know the patient well may also serve. Many state statutes identify who can serve as a surrogate, in order of priority. When there is confusion or disagreement, the opinions of those who know the patient best, regardless of relationship, should be accorded the most weight. In very difficult situations, it helps to involve your facility’s ethics committee.

Once an appropriate surrogate is identified, decision making can begin. The surrogate must make decisions based on “substituted judgment” (the known or probable wishes of the patient) or “best interests” (the relative benefits and burdens of a given decision for the patient).10, 16 Nurses can help surrogates to share their knowledge of the patient and its relevance to the decision at hand. And by helping surrogates to understand their role, nurses can alleviate the burden of their concern about making the “right” decision. For example, the nurse might say, “We’re hoping you can provide us with a better understanding of what the patient would want.”

Certainly, decisions that others make for someone who cannot participate demand scrutiny. Nurses can help assert the fact that patients who don’t have the capacity to make decisions have the same rights as those who do, though the manner of advancing these rights may differ.16 When the patient has left a living will or named a health care surrogate, that document or person is relied on to express the patient’s wishes. When the patient hasn’t done this, every effort must be made to identify someone who can speak on the patient’s behalf. State laws vary in this regard. In difficult cases, an ethics committee or legal consultation (or both) may be called for.

Ethical and legal issues associated with end-of-life care are often interwoven.17 It’s important to distinguish these two perspectives. Otherwise, providers’ concerns about their legal liability in end-of-life care can become exaggerated. For example, a provider, believing herself legally obligated to continue medically provided nutrition and hydration, might be reluctant to withdraw these interventions even if the patient no longer benefits. An irresolvable conflict may warrant judicial intervention; generally, though, decisions about end-of-life care are best made in the clinical setting.

If everyone agrees, the role of the nurse may be relatively simple: to represent the patient and seek the knowledge of others. But when there is discord, nurses may need additional resources such as ethics committees to arbitrate conflicts and move toward consensus. (Typically, an ethics committee is interdisciplinary and includes physicians, nurses, clergy, social workers, ethicists, and attorneys. It is usually involved in policy review, education, and consultation.)

WITHHOLDING OR WITHDRAWING LIFE-SUSTAINING THERAPIES

The goals of care may change as a patient’s illness progresses and death nears; they can shift from cure to comfort and from extending life to ensuring a humane and “dignity-conserving” death. At times, patients receive an inconsistent combination of therapies because of mixed goals. (For example,
to extend a patient’s life, one clinician may want to continue vasopressors, which will likely require ICU placement. But another clinician, seeing the patient’s comfort as the primary goal, wants the patient to receive palliative care in a non–acute care environment.) Moreover, it’s not always clear how an advance directive applies in a particular situation.

For these reasons, patients and families frequently ask about initiating or discontinuing interventions, particularly when there’s a question of benefit, efficacy, or desirability. Patients have the right to accept or refuse all life-sustaining treatments such as cardiopulmonary resuscitation (CPR), ventilatory support, medically provided nutrition and hydration, blood transfusion, dialysis, and antibiotic therapy.

But undoubtedly, deciding to withhold or withdraw life-sustaining treatment is difficult; to do so means the patient will probably die. Although there is no ethical or legal distinction between withholding and withdrawing a therapy,16, 20 they affect people quite differently. Many clinicians and families find it much harder to discontinue a therapy than to withhold it in the first place. In some cases, it may help to initiate a trial intervention, with a specific time frame to indicate when it should be discontinued if unsuccessful. This lessens the patient’s risk for being “held hostage” if clinicians or family members are later hesitant to withdraw that intervention.

It’s important that nurses be involved in making decisions to withhold or withdraw treatment, not only to represent their professional perspectives, but also to understand those of other team members and patient surrogates and to appreciate how decisions are reached. When those involved trust the integrity of the process, they’re more likely to be more comfortable with the outcome.

Resuscitation and DNRs. A DNR order directs health care providers not to attempt CPR in the event that a patient suffers a cardiac or respiratory arrest. It’s well known that successful outcomes of resuscitation attempts are extremely rare in patients whose health is highly compromised or who are dying: one source estimates that fewer than 5% survive to hospital discharge.21 Family members may interpret a decision to forgo resuscitation as a signal that the patient or the patient’s providers have given up. Nurses should reaffirm that a DNR order does not mean “do not treat”; on the contrary, the team remains committed to providing care that ensures comfort (such as pain management) and preserves dignity. Nurses can also encourage patients or family members to talk about their feelings by offering open-ended comments such as, “This decision seems very hard for you. Can you tell me more about that?”

Ventilatory support. Mechanical ventilation can become permanently necessary if the patient becomes physiologically dependent and can’t be weaned. Withdrawal of mechanical ventilation shouldn’t be viewed differently than withdrawal of other life-sustaining therapies (such as dialysis). However, the withdrawal of ventilatory support usually results in death more quickly than the withdrawal of other therapies,22 and the proximity of the two events can be deeply upsetting for all involved. Occasionally, patients continue to breathe on their own for hours or longer, and this too can be very unsettling. Clinicians need opportunities to discuss the uncertainties and stress that surround such a complex issue.

Medically provided nutrition and hydration. Decisions regarding the administration of medically provided nutrition and hydration also can be difficult. Food and water are literally the sustenance of life, and as the ANA notes, “the symbolism of feeding is intimately linked to caring.”23 Administering medically provided nutrition and hydration to a person who is terminally ill is vastly different: enteral feeding (through a nasogastric, gastrostomy, or jejunal tube) often requires surgery and poses serious risks for patients who are severely ill.24 In the highly publicized case of Cruzan v. Director, Missouri Department of Health, the U.S. Supreme Court ruled in 1990 that nutrition and hydration were medical interventions and as such could be withdrawn.21 Thus, they must be evaluated by the same criteria as any other intervention: benefits, burdens, efficacy, and desirability with regard to goals of care.26 Clinicians have often been hesitant to withdraw these therapies, fearing that to do so would be illegal or analogous to participating in assisted suicide or euthanasia.20, 27, 28 Such misconceptions need to be corrected. Nurses can seek consultation with other colleagues who have experience in these situations and can answer their questions. Professional codes of ethics, practice guidelines, and position statements can also provide guidance.

PROMOTING ETHICAL PRACTICE

Nurses can increase their expertise in ethical practice through varied approaches, including pursuing clinically based ethics education, participating in ethics committees, seeking ethics consultation, and participating in clinical rounds.46

Education in areas such as current ethics trends, ethical inquiry, the discernment process (evaluation of the decision at hand with all those involved) and frameworks for decision making can give nurses a sound foundation in ethics in clinical practice.

Ethics committees, whether nursing-specific or interdisciplinary, allow for the exploration of real clinical situations and the exchange of varied perspectives in a neutral forum. Committees can investigate ethical questions, offer and challenge opinions, and resolve differences, thereby cultivating and
drawing upon the expertise of many. Most nurses will find an ethics committee available at their facility; if one isn’t, nurses can contact ethics centers, schools of nursing, and professional associations for guidance (see Resources, page 52).

Ethics consultants are experts in bioethics and clinical decision making, particularly in ambiguous situations. Using their services can improve communication among those involved, foster conflict resolution, and provide informal education.

Clinical rounds can incorporate review of ethical concerns. Rounds also offer nurses the opportunity to make the team aware of subtle changes in a patient’s condition (such as vacillating capacity) that may affect his ability to participate in decision making.

CASE REVISITED

Ms. Joseph’s condition has continued to deteriorate and now requires vasopressors to maintain her blood pressure. Efforts to wean her from the ventilator continue to be unsuccessful and she requires frequent suctioning. She is unaware of her surroundings and responds only to painful stimuli. Her niece visits daily and feels increasingly burdened by her responsibility as decision maker. Ms. Joseph’s primary nurse has developed a relationship with the niece by updating her on her aunt’s status and listening attentively to her worries. The nurse suggests that meeting with the hospital’s ethics committee and the health care team might help, and the niece agrees.

Present at the meeting are Ms. Joseph’s attending physician, the pulmonologist, an ICU resident, the primary nurse, members of the ethics committee, and Ms. Joseph’s niece. The chairperson of the ethics committee begins by reviewing the ethical and legal principles involved in surrogate decision making. He emphasizes that the surrogate isn’t being asked to make decisions alone, but rather to speak as the voice of the incapacitated patient. The physicians present a review of Ms. Joseph’s clinical course and the grim prognosis. Ms. Joseph’s niece is asked to describe Ms. Joseph before this latest hospitalization. The nurse recognizes that the niece is becoming quieter and more withdrawn in the presence of so many professionals. She offers reassurance and encourages her to take plenty of time in recalling conversations with her aunt.

Ms. Joseph’s niece describes her aunt as an independent, deeply religious woman who worked most of her life as a seamstress before retiring at 65. Devoted to her husband of 48 years, she was devastated when he died suddenly six months after her retirement. They rarely socialized, and after his death she became even more withdrawn. The niece recalls her aunt expressing relief that her husband hadn’t suffered and had died quickly and peacefully at home. She also remembers Ms. Joseph often saying, “When God wants me, He’ll take me.” The niece feels strongly that, if her aunt could communicate, she would not want to continue the current aggressive treatment.

After deliberation, the ethics committee members agree that the niece is indeed giving voice to the patient’s beliefs and wishes and is acting in her best interests. The team reviews the health care decisions that need to be made. The nurse describes the patient’s response to particular treatments and course of care. It’s decided that the goal of treatment is comfort and that only appropriate therapies will be prescribed. Routine blood draws will be stopped and treatment will focus on relieving symptoms. The health care team asks the niece to consent to a DNR order, explaining that given Ms. Joseph’s prognosis, a resuscitation attempt would probably not succeed and would likely cause additional trauma. Team members also reiterate that they will continue all efforts to make her aunt comfortable. The niece consents. She also asks that current treatments (ventilator, antibiotics, vasopressors, and enteral feedings) be continued for one more week to see whether Ms. Joseph’s condition improves; if not, she asks that ventilatory support be discontinued. The health care team agrees. As the meeting ends, the niece tells the primary nurse, “I’m so grateful you were there to support me during the meeting. It helped to think back to the times my aunt and I spoke—I feel surer that we’re doing what she would have wanted us to do.”

A week later, the patient shows no improvement, and the niece asks that all life-sustaining therapies be stopped. The health care team agrees, and members again offer the niece their reassurance and support. Morphine is administered to ease the dyspnea and agitation associated with ventilatory withdrawal, and the ventilator is discontinued. Ms. Joseph dies half an hour later, without apparent distress, with her niece and nurse at the bedside.

REFERENCES
