

Ethical and Legal Issues

Ryan Bratcher

James J. Farrell

Kathleen A. Stevens

Kevin W. Vanderground

LEARNING OBJECTIVES

At the end of this chapter, the reader will be able to

- Use the American Nurses Association Code of Ethics and Interpretive Statements as a guide for practice.
- Discuss how nurses apply ethical concepts to decision making in rehabilitation.
- Describe why guardianship is important and when it should be considered in rehabilitation.
- Recognize different types of advance directives and relevance in rehabilitation. Explain key protections within the Americans with Disabilities Act.

KEY CONCEPT AND TERMS

Advance directive	Capacity	Living will
American Nurses Association Code of Ethics	Do not resuscitate (DNR)	Medical power of attorney
Americans with Disabilities Act (ADA)	Guardian ad litem	Nonmaleficence
Autonomy	Guardian	Patient Self-Determination Act
Beneficence	Guardianship	Psychiatric advance directive
Bioethics	Individuals with Disabilities Act	Reasonable accommodations
	Informed consent	Veracity
	Justice	

Ethical issues have been known to cause distress among nurses, resulting in decreased job satisfaction and increased turnover intention (Hart, 2005). This is especially problematic when the ethical concern has some legal consequences. In some cases new laws have been created to provide guidance in response to ethical dilemmas. The two offer different ways of thinking about common problems related to rights of individuals with a disability within our society. For this reason we address both ethical and legal issues in this chapter. The intent is for the reader to appreciate the basis for ethical decision making and utilize resources that can provide guidance in decision making. For more details on ethics and models of ethical decision making for nurses, please see texts on these specific topics.

DEFINING ETHICS

In the course of daily life we make decisions as to the best or morally right action to take. How we make decisions is based on our values and beliefs as well as laws or rules of society. Ethics is the branch of philosophy that deals with the values relating to human conduct and with respect to the rightness or wrongness of certain actions and to the goodness and badness of motives and ends of such actions. These values of human conduct are based on shared beliefs within a society or culture. Ethics most commonly refers to the reasons for decisions about how one should act based on the shared values and beliefs of the group. Ethics refers not to a specific set of principles or rules but rather presents a way of guided thinking.

In our society there are values outlined in the U.S. constitution that provide the foundation for our society. The guiding principles of ethical decision making are autonomy, beneficence, justice, nonmaleficence and veracity (Masters-Farrell, 2007). **Autonomy** is the duty to allow the individual the right to make his or her own decision. Conflicts arise when individuals or persons served make a decision that conflicts with that of the healthcare team, such as refusing treatment or pursuing a discharge plan the team believes is unsafe. The individual's decision may not be what the healthcare team prefers or recommends; however, the principle of autonomy says that professionals must respect the decision made by the person served. Decision making can be problematic when the individual is unable due to illness, functional level, cognition, language, or age to participate in the decision-making process, so a surrogate is used to execute decision making. This has been an important principle in several prominent court decisions and is discussed later in this chapter.

The value of human life and our responsibility as nurses to do good, promote health, and serve as a patient advocate should be the foundation for our practice.

The second principle is **beneficence**, which is the duty to do good. It frequently is paired with **nonmaleficence**, which is the duty to do no harm. So when presented with a choice of treatment options, the nurse is expected to elect to choose the option will do good and cause no harm. A conflict arises when a treatment with a high likelihood for success comes with exceptional risk. Should a nurse recommend a patient take a medication that poses significant health hazards to affect a cure and yet could be potentially lethal for the person? In this case the conflict for the nurse occurs in deciding between the potential for doing good and doing no harm.

The principle of **veracity** refers to the duty to be truthful and provide the person served with adequate information necessary to make an informed decision. This principle is the foundation for **informed consent** in patient care and research studies. In the case of the medication that is beneficial but carries significant risk, the importance of truth telling is key. The clinician would be expected to disclose the risks and benefits to the person in a manner that is understandable and in a language the person can understand. Upon disclosing full information, if the person freely elects to take the medication, then no moral or ethical issue results. In this case the clinician

has provided full disclosure, verified understanding, and allowed the individual to make a choice, supporting the competent person's autonomy. Conflicts arise when before administering a medication the nurse assesses the patient does not have full or adequate knowledge to make a decision or is incompetent to do so.

The last ethical principle is **justice**. Justice is the duty to treat all fairly or act in a manner such that risks and benefits are distributed equally. When healthcare services depend on payer, decisions about type, frequency, and duration of treatment occur. Some clinicians question whether justice is being served. Some have argued that having paid more dollars to an insurance carrier that negotiates a more comprehensive benefits package than the public payer is fair, whereas others see this as preferred treatment. When confronted with an ethical dilemma, rarely does one principle alone provide adequate guidance for decision making. The best decisions occur when all the principles are considered and applied to the thought process.

MODELS FOR ETHICAL DECISION MAKING

Several models for ethical and moral decision making have been developed by nurses. These include the three-step ACT model by Graham-Eason (1996) and the Savage Model for Facilitating Ethical Decision Making (Savage, & Michalak, 1999). These models have several commonalities. First, it is important to gather the facts and engage all stakeholders, including family, healthcare providers, and the healthcare organization early on. Second, identify the ethical principles that are the source of conflict, and, finally, discuss options with key stakeholders. Often, it is helpful to engage the assistance of the organization's ethics committee to serve as a neutral facilitator in these discussions. The cases mentioned here have all led to legal precedents or legislation designed to help guide future decision making, especially in cases when an individual is not able to express their own healthcare wishes.

PROFESSIONAL CODE OF CONDUCT

To provide guidance, many societies or professions have formal written codes of conduct that outline the values of the group and expectations of those that belong to the group. The **American Nurses Association Code of Ethics** (2001) is the code of conduct that guides nursing practice within the United States. In essence, the Code of Ethics (American Nurses Association, 2001) defines

the ethical obligations and duties of individuals who have entered into and practice within the profession of nursing. The Code is based on the shared belief that “nursing encompasses the prevention of illness, the alleviation of suffering, and the protection, promotion, and restoration of health in the care of individuals, families, groups and communities” (American Nurses Association, 2001, p. 5). All nurses are expected to be familiar with the Code and act in accordance with the beliefs and values set forth in the Code.

In the rehabilitation setting, nurses work with colleagues from a variety of different disciplines as a member of the rehabilitation team. Each discipline has a unique set of beliefs and values that underscore the philosophy of the discipline. Each profession also has a code of ethics that serves to guide professionals within the discipline. Although many disciplines share some common values and beliefs related to the value of human life, respect for the humanness, and desires of the person seeking services of the professional, there are also differences in relation to delivery of services that can be a source of conflict (Savage, Parson, Zollman, & Kirschner 2009). For example, a nurse may believe it is important for a physical therapist to treat a patient. If the therapist determines there are no active goals that can be achieved with therapy services, then according to the profession’s code of ethics it would be unethical for the therapist to treat the patient and charge for services delivered. Team members should be

knowledgeable of their code of ethics as well as those of other disciplines (Table 25.1).

Another potential source of conflict in the rehabilitation setting is consumer expectations and beliefs as set forth in regulatory requirements. In particular, the Commission on Accreditation of Rehabilitation Facilities, a regulatory body for rehabilitation, expects the team to include and respect the decisions of the person served throughout the rehabilitation process. When patients and/or family members refuse healthcare provider recommendations or treatments, this can pose a moral dilemma for staff. A moral dilemma occurs when two or more clear moral principles apply but they support mutually inconsistent sources of action (Redman & Fry, 1998). Case Study 25.1 describes how nurses at one facility addressed a conflict with a parent over unsafe oral feeding of a child.

Ethical conflicts can arise when two or more individuals on the rehabilitation team have different expectations of what is right or morally appropriate action. Savage et al. (2009) suggests guidelines for resolving team disagreements regarding patient care during nonemergent situations (Box 25.1).

Although many of these conflicts can be resolved through respectful communication and guidance provided by the discipline’s code of conduct, some require more in-depth discussion to discern appropriate action to be taken. It may be helpful to seek consultation from

TABLE 25.1 Rehabilitation Disciplines’ Web Links to Code of Ethics

Profession	Web Link
Physiatrist	http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/principles-medical-ethics.shtml
Rehabilitation nurse	http://nursingworld.org/ethics/code/protected_nwcoe629.htm
Physical therapy	http://www.apta.org/AM/Template.cfm?Section=Policies_and_Bylaws1&TEMPLATE=/CM/ContentDisplay.cfm&CONTENTID=73012
Occupational therapy	http://www.aota.org/Consumers/Ethics/39880.aspx
Speech-language pathology	http://www.asha.org/docs/html/ET2010-00309.html
Psychology	http://www.apa.org/ethics/code/index.aspx
Respiratory therapy	http://www.aarc.org/resources/position_statements/ethics.html
Pharmacy	http://www.uspharmd.com/pharmacist/pharmacist_oath_and_code_of_ethics
Therapeutic recreation	http://www.atra-online.com/displaycommon.cfm?an=1&subarticlenbr=41
Social work	http://www.naswdc.org/pubs/code/code.asp

CASE STUDY 25.1

The following case study is excerpted from Savage (2005).

An 11-year old girl who is several years post-traumatic brain injured is admitted to the rehabilitation unit after hip surgery. She is nonambulatory, nonverbal, and cortically blind. She has a gastrostomy tube in place; however, at home her mother feeds her pureed foods with a spoon or eye-dropper. It usually takes the mother an hour to feed her daughter about 8 ounces of food. The mother believes her daughter has few pleasures in life and that oral feeding, while risky, provides some degree of pleasure for her daughter. The mother has asked that her daughter be fed by mouth during her hospitalization. Staff members on the unit were uncomfortable with oral feeding and feared potential harm would occur with feeding.

The ethics consultant recommended several actions to the staff. First, approach the mother acknowledging the love and concern she has for her daughter and her willingness to go to great lengths to provide oral feeding in the home. Second, express the shared concern of staff about the safety of oral feedings and concern that they may not be adequately prepared to feed the child safely and in a manner consistent with what the mother has done at home. Third, seek a compromise or common ground. Perhaps offer that for the child's safety staff

provide nourishment via gastrostomy feedings during hospitalization; however, if the mother is present staff would be able to secure a pureed meal so the mother can feed the child. Seek consultation from experts in pediatric feeding who can provide strategies to provide adequate nourishment as the child's needs change as the child matures. Finally, suggest other interventions such as gentle rocking, skin massages, warm showers, or play that offer pleasure to the child but are safer than oral feeding. The ultimate goal according to the consultant is to provide nourishment while maintaining the mother-child bond, respecting the integrity of the nursing staff, and forging an alliance between the mother and the rehabilitation team.

Questions

1. What would the next step be in this process if the mother refuses to heed the advice of the consultant?
2. If this case came before the ethics board of the facility, how would you respond to this dilemma as a rehabilitation nurse? As an ethics board member? As the nurse manager on the unit?
3. What risks are inherent in this situation to the hospital? To the unit? To the patient? To the mother?

BOX 25.1 Suggested Guidelines for Resolving Team Disagreements

1. Clarify the plan of care with other members of the healthcare team.
2. Identify the specific issue that is the source of conflict.
3. State the source of the disagreement and rationale.
4. Propose an alternative action or plan.
5. Determine whether there is agreement, consensus, or acceptance of the new plan that is acceptable for all.
6. Implement the plan of care.

Adapted from Savage et al. (2009).

a hospital ethics committee or ethics consultant in these cases. The latter can serve as objective reviewers and offer alternatives to help the team reach a mutually acceptable decision.

DILEMMAS IN REHABILITATION: WHERE ETHICS AND LEGAL ISSUES COME TOGETHER

Advances in technology and knowledge since the turn of the 20th century allow modern medicine to accomplish feats of supporting birth, sustaining life, and promoting longevity for individuals with chronic illness or disability. Concurrently, the Internet has increased public awareness of healthcare options while creating a forum for dialogue on ideological issues. **Bioethics** is the branch of ethics concerned with issues surrounding health care and the biological sciences. Bioethical issues may occur from before birth, in the case of in vitro fertilization and abortion, to end-of-life decision making and euthanasia. The 20th century began with bioethicists asking how far modern medicine could go in prolonging life, and now the debate has shifted to how far should modern medicine go and how should end-of-life decisions be made.

Some of the most notable cases in bioethics are related to end-of-life decision making and the subsequent legal decisions that have significant relevance for rehabilitation nursing.

DECISION MAKING FOR THE INCOMPETENT AND DYING

Perhaps the most commonly debated ethical and legal dilemma has been when an individual is incapacitated and unable to make healthcare decisions on his or her behalf. How far can a surrogate decision maker go in terms of removing life support devices? In the current era, when modern medicine appears to be at the point of being capable of supporting vital organs almost indefinitely, serious ethical issues have arisen. Should individuals be able to terminate their own existence where no hope of quality or cure exists? Or should the family, acting on behalf of the individual, be permitted to withdraw life-prolonging medical procedures, even when withdrawing life-prolonging procedures will almost certainly cause death? How far can the individual and/or family go in deciding to terminate life? At what point does terminating life become homicide and prohibited by the law? Furthermore, what can be done to prevent some mistakes of the past from being repeated? Three cases, Quinlan, Cruzan, and Schiavo, stand at the crossroads of ethical and legal issues in medical practice. These cases, which started as ethical issues, evolved into legal cases that ultimately set the precedent for the national use of living wills and future advance directive laws. These cases are examined as examples in the following sections.

Quinlan and Advance Directives

The Quinlan case is the landmark case in the patient's right of self-determination. On the night of April 15, 1975, Quinlan ceased breathing for two 15-minute intervals and was transported to the hospital, where it was determined her pupils were unreactive and she failed to respond to deep pain (Karen Ann Quinlan Memorial Foundation, 2010). She was placed on a ventilator at the hospital and received a tracheotomy. In the ensuing days after her respiratory arrest, her parents watched the condition of their daughter further deteriorate. After much discussion and counseling, the family determined that it was in her best interest to remove the ventilator. Whereas the hospital initially consented to authorize removing the ventilator and life support, the hospital would later disagree with the decision and took the case to court (Karen Ann Quinlan Memorial Foundation, 2010).

The case went to the Supreme Court of New Jersey where it was acknowledged that Karen was in a "persistent vegetative state." Her condition was clearly determined to be incurable, and the court was confronted with determining if a person in her position possessed the right of choice regarding the disruption or continuance of life-prolonging medical procedures. The court concluded that the family could, after consultation with the hospital ethics committee, withdraw life-sustaining equipment. The court only required that a responsible physician first determine that there was no possibility of Karen ever coming out of her present condition to a cognitive, functional state (Karen Ann Quinlan Memorial Foundation, 2010).

In the aftermath of this case, several interesting things occurred. Most importantly, living wills evolved from this case as a means of communicating to family members and medical staff the wishes of the competent patients in the event they are unable to make their wishes known.

Cruzan and Schiavo and the Patient Self-Determination Act of 1990

The cases of Nancy Cruzan and Theresa Schiavo are unmistakably linked with the Quinlan case in the public debate over honoring an individual's wishes. Although removing someone from a ventilator in current society appears to a socially acceptable and even a benevolent act, the removal of a feeding tube, as in these cases, raised concern for many individuals, including some healthcare workers. Some even argued that it was cruel and inhuman punishment, because no one would voluntarily choose to "die of starvation."

Nancy Cruzan was born in Missouri and on the night of January 11, 1983 she lost control of her car and crashed into a ditch with the injury resulting in anoxia to the brain (FindLaw, 2010). After determining that her condition was irreversible, the family asked the hospital to cease nutrition and hydration. The hospital refused to grant the family's wishes without a court order requiring them to do so. The family then appealed to a trial court who agreed that Nancy's wishes, as declared in a conversation with a housemate, should be upheld. The decision was appealed to the Supreme Court of Missouri, who reversed the decision, stating they found insufficient grounds for removing the feeding tube.

The case made its way to the Supreme Court, who supported the right of Nancy to have a feeding tube removed once sufficient evidence was found stating this was Nancy's wish. In the aftermath of the Supreme Court

decision, the family found additional witnesses who testified on Nancy's behalf regarding her desires about life-sustaining medical treatment and ultimately the feeding tube was removed. As a follow-up to this case, the **Patient Self-Determination Act** was enacted in 1990 requiring all medical facilities that accept Medicare or Medicaid funding to provide counseling for patients on advance directives.

Most recently, the case of Theresa Marie Schiavo (Cerminara & Goodman, 2010) may have started as an ethical concern about the right to remove a feeding tube, but it would become a legal quagmire and a highly political battle. In this case disagreement among family members would lead to a protracted court battle. Terri Schiavo suffered a cardiac arrest in February 1990. Although her husband sought medical intervention and rehabilitation therapy with the hope of Terri regaining some level of consciousness, he would eventually lose hope and request to have the feeding tube removed.

The legal battles over Terri began in 1998 when her husband asked the court for permission to have her feeding tube removed. Her parents opposed the motion. In February 2000 Judge Greer ruled for the first time that sufficient evidence existed to demonstrate that Terri would want the feeding tube removed.

Ultimately, due to the parents' public statements and widespread discussion in the public media and on the Internet, politicians stepped into the fray over Terri's right to die. Now for the first time the legal debate extended beyond the courts into the political and legislative arena. In October 2003 the Florida House and Senate passed the bill into law, informally known as "Terri's Law," which prohibited the removal of Schiavo's feeding tube. Judge Baird and the Florida Supreme Court declared this law unconstitutional in September 2004. In December 2004 the Governor of Florida asked the U.S. Supreme Court to overturn the Florida Supreme Court's decision, repealing Terri's Law. The Supreme Court rejected this motion (Cerminara & Goodman, 2010).

In 2005 the federal government got involved when a congressional committee subpoenaed Terri's family. The congressional committee asked for a stay on the removal of the feeding tube. The stay was denied, and Terri's feeding tube was removed for the last time on March 18, 2005 (Cerminara & Goodman, 2010). She passed away 2 weeks later on March 31.

The pivotal person in this case was the Circuit Judge, George W. Greer. He presided over this case and made his decision to allow the feeding tube to be removed on 11 February 2000. In his ruling he cited the case of

Guardianship of Estelle M. Browning in which it was determined that every person has the "fundamental right to the sole control of his or her person" (*In Re: The Guardianship of Theresa Marie Schiavo* from the Circuit Court for Pinellas County, Florida Probate Division File No. 90-2988GD-003). Furthermore, he stated the Browning case established this right to reject medical treatment was not "diminished by virtue of physical or mental incapacity or incompetence" (*In Re: The Guardianship of Theresa Marie Schiavo* from the Circuit Court for Pinellas County, Florida Probate Division File No. 90-2988GD-003). To invoke the patient's rights of self-determination, the surrogate or guardian must meet three criteria: (1) the surrogate must be satisfied that evidence in regards to the patient's wishes is uncoerced and reliable, (2) the surrogate must have reasonable assurance that the patient does not have probability of recovering competence, and (3) the surrogate must ensure that any written or oral statements are considered and honored.

The laws regarding end-of-life decisions are not unclear. It is without question that decisions like this one and others related to intensity and use of healthcare interventions are made in hospitals across the nation. When family members disagree, authority for decision making is by state law assigned to the closest next of kin unless the individual has created an advance directive assigning a surrogate to act on his or her behalf. The importance of communication between healthcare providers and family members is often key to resolving ethical dilemmas.

ADVANCE DIRECTIVES

It is important for individuals to make their wishes known before an event occurs. The Quinlan case encouraged individuals and families to have discussions about end-of-life care and encouraged the use of advance directives, such as a living will. After the Cruzan case, the Patient Self-Determination Act of 1990 institutionalized this decision making by mandating that all patients upon entry into a healthcare facility be queried about the existence of an advance directive and if none exists it was the duty of the healthcare facility to offer education and assistance should an individual wish to create an advance directive. There are several types of advance directives, and nurses should be aware of the different types and limitations associated with each type of advance directive.

Advance directives are legal documents that convey an individual's decisions regarding end-of-life care and treatment. These documents are used to direct family members, friends, and healthcare providers' decisions

regarding health care and treatment in the event the patient is unable to make or convey these decisions on his or her own due to some incapacity, such as a coma. In theory, by preparing an advance directive the patient can maintain some control over his or her medical treatment while at the same time relieving family, friends, and doctors of making difficult decisions on behalf of the patient when the patient is unable to express his or her intentions. Often, an advance directive will set forth the patient's wishes depending on the extent of his or her ailment or incapacity. For example, an advance directive could describe what treatment, if any, the patient desires in the event he or she is unlikely to recover or is permanently unconscious. The advance directive can also direct healthcare providers to provide treatment regardless of the severity of the patient's ailment or condition.

Living Will

Generally speaking, there are three types of advance directives: a living will, a power of attorney for healthcare decision making, and a do not resuscitate (DNR) order. A **living will**, otherwise known as a healthcare declaration or healthcare directive, is a written document that sets forth the types of medical treatments or life-sustaining measures the patient wants or does not want in the event the person has a terminal illness and is unable to communicate. This document goes into effect once the patient has been deemed terminal by a duly authorized physician and is unable to articulate his or her own desires regarding treatment. When preparing a living will, a patient can choose the treatments he or she would like to receive if unable to articulate these on his or her own due to an incapacity. Typically, a living will sets forth whether or not the patient would like to receive treatments as described in Box 25.2.

A living will can convey the patient's decision regarding organ donation as well.

It should be noted that a living will does not necessarily convey the patient's decision to obtain or refrain from certain treatments. In some cases the patient, by his or her living will, may expressly state that he or she is intentionally making no decision regarding what treatment to receive. In doing so, the patient is purposely leaving such decisions to family members and doctors. Regardless of the patient's decisions set forth in a living will, it is advisable for healthcare providers to discuss the treatments available. In doing so, the patient can make informed decisions regarding prospective treatments and possible outcomes of those treatments.

BOX 25.2 Sample of Items Addressed by a Living Will

- **Resuscitation.** Resuscitation is the attempt to restart the heart when it has stopped beating. Common forms of resuscitation are by cardiopulmonary resuscitation (CPR) or a defibrillator device that administers an electric shock in an effort to stimulate the heart.
- **Artificial nutrition and hydration.** The patient can express whether or not he or she desires nutritional and hydration assistance via a tube or intravenously. In his or her living will, the patient can express the duration of time he or she would desire life to be sustained by these methods.
- **Mechanical ventilation.** Mechanical ventilation refers to devices that substitute or assist spontaneous breathing. Again, the patient can express the duration of time he or she would desire life to be sustained by mechanical ventilation.
- **Dialysis.** Dialysis refers to artificial replacement for diminished or lost kidney function. In receiving this treatment, machinery will assist the body by removing waste from the patient's blood. In a living will, the patient can determine the duration of time he or she is desirous of this treatment.

Medical or Durable Power of Attorney for Healthcare

A second type of advance directive is a **medical power of attorney**, also known as a durable power of attorney with healthcare powers. The medical power of attorney has broader powers than a living will. A medical power of attorney allows the patient to choose an individual to make medical decisions on his or her behalf when the patient is unable to do it him or herself. This allows the patient to give decision-making powers to a trusted individual in the event the patient's living will does not address a particular situation. This appointed individual acts as the patient's healthcare agent (or proxy) and may make a broad range of healthcare decisions on the patient's behalf. This person is entrusted to make decisions on behalf of the patient that are consistent with the patient's living will or discussed wishes related to healthcare decisions.

For obvious reasons an individual should select a healthcare agent they trust and who is not opposed to the individual's healthcare or end-of-life wishes and desires. In fact, choosing a healthcare agent is perhaps one of the most important decisions in advance directive planning. This person should have the individual's best interests at heart, and most importantly should understand the

individual's wishes. The individual should discuss the issue with the potential healthcare agent to ensure they are willing to serve in this capacity. When choosing a healthcare proxy or surrogate, the individual should choose a person who is mature and capable of making difficult decisions. The person selected need not be a family member, and at times the patient's best interests may best be served by choosing an agent who is not family. In any event the patient should not choose an agent out of a sense of obligation or feelings of guilt. It is also a good idea, for practical reasons, that the agent live near the patient. This allows the agent to more readily consult with the patient's healthcare providers and to make better-informed decisions regarding care. Selecting an alternate power of attorney is also recommended in the event the primary power of attorney is unable or unwilling to serve if the time to do so arises.

It is important to understand the distinction between a power of attorney and a medical power of attorney. With the former, the authority conveyed typically allows the agent to conduct business or financial transactions on behalf of the person who has granted the authority to act in this way. A medical power of attorney conveys specific authority to an agent for the express purpose of making medical decisions on behalf of the grantor. Given this distinction, it is important that the healthcare provider be aware of the extent to which the agent has authority to make decisions on behalf of a patient. A doctor should not look to a patient's agent for medical treatment decisions if the only authority conveyed to the agent by the patient is to sign checks on his or her behalf.

DNR Order

A third common advance directive is a **DNR** order. This is a request by the patient to not receive cardiopulmonary resuscitation in the event his or her heart stops or he or she stops breathing while at the hospital. A DNR order can typically be placed in the patient's chart by the request of the patient. Hospital policy defines the organization's responsibilities for who can request a DNR order and the organization's responsibility for honoring the DNR order.

Typically, the DNR applies only when the individual is undergoing care and treatment at the hospital, but nursing home residents may have a standing DNR on the medical record after going through the proper channels to have this implemented. Within the past few years a select number of states have created a universal or uniform DNR order request that is initiated by the individual

and is carried by them from one healthcare setting to the next (Illinois Department of Public Health, 2005). This order spells out what the individual wants in terms of resuscitation while they are being transported from one facility to another or in the case of some patients in rehabilitation when they are being seen as an outpatient at another hospital or physician office. The nurse should be aware of their hospital policy and state rules and regulations on DNR orders. In addition, residents in long-term care facilities are now urged to place their living wills and DNR orders on their refrigerators so that in the event of an emergency, rescue personnel have ready access to these legal documents that can aid in upholding the person's wishes.

PSYCHIATRIC ADVANCE DIRECTIVE

A relatively new way to deal with mental health decisions in advance is through a **psychiatric advance directive**, sometimes called a declaration for mental health treatment. As the name implies, this legal document can be used to declare in advance one's desires regarding the psychiatric or mental health treatment they wish to receive. A psychiatric advance directive may be used to document a competent person's specific instructions or preferences regarding future mental health treatment. This is done in preparation for the possibility that the person may lose capacity to give or withhold informed consent to treatment during acute episodes of psychiatric illness.

Advance directives can be prepared in a variety of ways. Many times, healthcare professionals have a form a patient can fill out to make known his or her desires. A patient can also write his or her own desires. Another potential resource is also a local health department or other local or state agency that can provide a form. Finally, and perhaps the best resource for preparation of an advance directive, is an experienced, licensed attorney. Although this may be slightly more expensive for the patient, the cost for this type of legal work is relatively small, and counseling offered by the attorney can go a long way in avoiding future complications. The legal requirements for advance directives vary from state to state, and the individual creating the documents should keep this in mind.

Regardless of the source for the advance directive, the preparer should keep in mind that the document need not be long and complicated. A short, simple statement of the patient's desires regarding treatment should suffice. Once an advance directive is prepared, it is advisable to have the

patient review the document with his or her doctor. This will assist the healthcare provider to understand exactly what the patient's intentions are regarding treatment. Any advance directive should be notarized and a copy given to the patient's doctor and any agent appointed in the medical power of attorney document.

The patient should also be aware that an advance directive can be changed at any time as long as the patient is of sound mind. To be of sound mind means that the patient can think rationally and can communicate his or her wishes clearly (i.e., is deemed competent). It is also recommended that the patient periodically review his or her advance directives to ensure the documents still accurately reflect his or her intentions. Any changes should be made known to the patient's doctor and any individuals appointed as a healthcare agent. In the absence of an advanced directive, family members and physicians are left with the unfortunate task of making difficult decisions without the benefit of knowing the patient's wishes and desires. State law dictates the legal order of decision making within the state. The typical order is spouse, parent, child, and sibling. Only a few states have a provision allowing domestic partners to serve as decision makers. At times the order of decision making can be a source of conflict, as in the case of a woman with a traumatic brain injury sustained as a result of domestic abuse. If criminal charges are not filed against the spouse, the spouse will in most states be primary decision maker (see Case Study 25.2). Dealing with such situations is stressful enough, but often the absence of an advance directive can lead to conflict among family members, friends, and healthcare providers. Nurses as patient advocates should encourage individuals to consider preparing an advance directive long before it is actually needed.

GUARDIANSHIP

Safe decision making is part of every day life, yet some patients in rehabilitation are unable to make decisions without jeopardizing their welfare. One of the most common ethical and legal dilemmas in rehabilitation is how to care for those who may not be able to make decisions in a cogent manner. As a result the law has developed a tool called "**guardianship**." The number of guardianships is increasing, and as the so-called baby boomer generation ages, the number of guardianships in the United States is projected to continue to grow.

Rehabilitation nurses should have an understanding of the general principles surrounding guardianship and the specific rules applicable in the jurisdiction you

CASE STUDY 25.2

You are working with a female patient who has sustained a C-5 complete ASIA A spinal cord injury. The patient is dependent for all activities of daily living and has a tracheostomy in place. The patient tells you she wants to die rather than live with this disability. She has been eating poorly and refusing turns and therapy. At team conference several team members are recommending discharge to a skilled nursing facility because the patient has no rehabilitation goals. You and other team members are concerned about her well-being and not comfortable with the discharge plan.

Questions

1. How can this dilemma be resolved?
2. What factors should be considered?
3. What role might the ethics board play in a situation such as this?
4. What legal and ethical factors/principles should be considered?

are working in. Generally, once an individual has been determined to be incapacitated, the court can appoint a guardian to make some or all decisions for that individual.

Identifying a Guardian

A "**guardian**" is a person who has the legal authority and duty to care for another's person or property (Garner, 1999). A guardian or conservator may be appointed for all purposes, for a specific purpose, or a specific period of time. The term includes a temporary guardian, a limited guardian, and a successor guardian but excludes one who is only a guardian ad litem (a **guardian ad litem** usually only appears in court for the incapacitated individual). The guiding principle in all guardianship is that of least intrusive measures to ensure as much autonomy as possible. The guardian's authority is defined by the court, and the guardian may not operate outside that authority. However, guardianship duties are often not clearly defined. A good guardian takes into account the wishes and desires of the incapacitated person, often called a "ward," when making decisions about residence, medical treatments, and end-of-life issues. The courts will remove only those rights that the proposed ward is incapable of handling.

When the courts appoint a guardian, certain rights of the ward are removed. Table 25.2 lists the rights of the

TABLE 25.2 Rights of the Ward Removed During Guardianship

Consent to medical treatment	Make end-of-life decisions, such as the withdrawal of life support or withholding of medical care
Determine place of residence	Possess a driver's license
Manage, buy, or sell property	Own or possess a firearm or weapon
Enter into a contract	Marry
Vote	

ward that are removed during guardianship. These rights are rights typically guaranteed by federal or state law to citizens so any removal of these rights can significantly limit an individual's role within society and thus the process of guardianship is highly regulated.

Capacity Determination

The first step in the guardianship process is to determine "incapacitation." An incapacitated person is a person who is impaired, for any of a variety of reasons, to the extent that personal decision making is impossible (Garner, 1999). Each state has an official legal definition of an incapacitated person. The legal definition is not the same as a medical definition of incapacitation. The legal definition often is based on a determination of an individual's inability to manage his or her own property and/or provide self-care (Indiana Code § 29-3-1-7.5). Several states have very detailed explanations of what a determination of incapacity involves. For example, Virginia defines an incapacitated person as follows (Virginia Code § 37.2-1000):

An adult who has been found by a court to be incapable of receiving and evaluating information effectively or responding to people, events, or environments to such an extent that the individual lacks the capacity to (i) meet the essential requirements for his health, care, safety, or therapeutic needs without the assistance or protection of a guardian or (ii) manage property or financial affairs or provide for his support or for the support of his legal dependents without the assistance or protection of a conservator.

It is important for rehabilitation nurses to know the official definition for their state to articulate the standard by which the capacity of patients will be judged.

Poor judgment does not constitute incapacity. For relatives of elderly individuals, there is a temptation to

have the relative declared to be an incapacitated person when family members perceive the individual is exercising poor judgment. When an elderly person has assets that are desired by his or her heirs, many times the family members attempt to have the individual declared to be an incapacitated person so they can establish a guardianship and control the assets of the individual. As a result, family members will try to attribute what they perceive to be a bad decision to incapacity.

Another common cause for guardianship requests is dementia. Many times the one suffering from dementia is unaware of the seeming absurdity of his or her decisions and will thus fight the guardianship proceedings. In this situation it is often difficult for the court and medical personnel to tell the difference between family and friends of the patient who are acting with the well-being of the patient in mind and those acting in their own self-interest. Some research has indicated that persons with dementia may fluctuate in their decision-making abilities (Menne & Whitlatch, 2007), further complicating the issue. How then should courts and practitioners examine whether an individual is incapacitated? Many courts use some or all of the following criteria in assessing the capacity of an individual:

- What is the current cognitive ability of the patient?
- What is the medical condition that caused the current condition?
- Is it temporary or reversible?
- Can the person perform the activities of everyday living (e.g., grooming, toileting, eating, dressing)?
- What is the risk of harm associated with the least restrictive means available?

Some courts attempt to understand the values or preferences of the incapacitated person. Of course, if the incapacity is mental or psychological, such as dementia, understanding the person's preferences can become rather complicated.

Establishing guardianship is a legal process that involves the removal of an individual's rights. There are several due process hurdles one seeking a guardianship of another must overcome:

- The individual must be notified of all court proceedings.
- The individual is entitled to representation by an attorney.
- The individual can and may be compelled to attend hearings regarding his or her capacity/guardianship unless excused due to physical impossibility.

- The individual is entitled to compel, confront, and cross-examine all witnesses and present his or her own evidence.
- The individual may appeal the determination of the lower court.
- The individual has the right to a jury trial.

The due process required for the removal of an individual's rights may vary from state to state, and as such the state's statutes and case law will be the final authority.

Anyone can act as a guardian. The court will decide who should be the guardian of an incapacitated individual. There may be different types of guardians specified, depending on the patient's condition and needs. For example, a patient with complex needs and a large estate may have a guardian of person (who handles daily affairs including health and home maintenance), a guardian of his or her estate (who handles all financial aspects), and a guardian ad litem (for legal counsel).

As a general rule, courts prefer close relatives to be the guardian (of person) because they are often best prepared to understand the individual's needs and desires. Many community organizations, and some state and national organizations, can connect individuals with volunteer advocates who will act on behalf of the incapacitated individual. When the court appoints a guardian of the person, the responsibilities of the guardian are as follows:

- Determine and monitor the residence of the incapacitated individual
- Consent to and monitor medical treatment
- Consent to and monitor services such as education and counseling
- Consent to and release of confidential information (i.e., healthcare records)
- Make end-of-life decisions
- Act as representative payee
- Report to the court about the guardianship status at least annually

Often, a guardian will have to right to make financial decisions on behalf of the incapacitated person. Practitioners need to be careful as well when deciding for themselves as to the capacity of an individual. Often, physicians and other medical personnel can be called to testify in court as to what they observed and the functionality of an individual. Because so much is at stake for the supposedly incapacitated person and there is so much risk of wrongdoing and potential loss, some laws create a duty to maximize the independence of the individual.

At the very least one could argue for an ethical obligation to entrust as much of his or her own affairs as possible to the individual.

One tool that has been increasing in popularity is the limited guardianship. A limited guardian has only those powers specifically stated in the court order making him or her a guardian. In other words, the court can decide the guardian can only do certain things on behalf of the incapacitated person. For example, an incapacitated individual may be perfectly capable of determining living arrangements or his or her degree of participation in family or religious events, but a court may decide he or she are not currently capable of understanding a new lease agreement on an apartment or making a major purchase. The decision to pursue guardianship is not to be taken lightly. Yet when used properly guardianship can be a valuable resource, allowing the individual to live with a high quality of life.

INDIVIDUALS WITH DISABILITY AND RIGHT TO LIFE ISSUES

A second area where ethical and legal issues merge is related to rights of individuals with disability within society. For many years individuals with disability were denied either by law or societal handicap basic rights as citizens, such as right to a public education or the right to vote. As recently as 1979 it was legal for some state governments to sterilize disabled individuals against their will or prohibit people with certain disabilities from marrying (Regents of the University of California, 2004). In the early 1970s the disability rights movement started at the University of California at Berkley. The disability rights movement asserts that people with disabilities are human beings with rights equal to any American citizen. The movement sought to secure these rights through political action. As a result of their efforts a number of legislative victories have occurred within our society. Table 25.3 outlines 20 years of legislation to secure rights for individuals with disabilities.

One of the first successes was the passage of the Rehabilitation Act of 1973. This federal law for the first time protects individuals with disabilities from discrimination based on their disability. The Act defined qualified individuals with disabilities as persons with a physical or mental impairment that substantially limits one or more major life activities as well as persons who have a history of or are regarded as having a physical or mental disability. According to the Act, major life activities

TABLE 25.3 Federal Disability Rights Laws and Court Decisions

Law	Date	Summary
Architectural Barriers Act (ABA)	1968	Requires that buildings and facilities that are designed, constructed, or altered with Federal funds, or leased by a Federal agency, comply with Federal standards for physical accessibility. Facilities of the U.S. Postal Service are not covered by this Act.
Rehabilitation Act	1973	Prohibits discrimination on the basis of disability in programs conducted by Federal agencies, in programs receiving Federal financial assistance, in Federal employment and in the employment of Federal contractors.
Individuals with Disabilities Education Act (IDEA)	1975	This Act requires public schools to make a free appropriate public education in the least restrictive environment available to all eligible children. It also requires public school systems to develop appropriate individualized education programs (IEPs) for each child. The IEP must be developed by a team of knowledgeable persons and must be reviewed at least annually.
Voting Accessibility for the Elderly and Handicapped Act	1984	This Act requires polling places across the U.S. to be physically accessible to people with disabilities for federal elections. If no accessible location is available, an alternate means of casting a ballot must be offered. States must make registration and voting aids available for disabled and elderly voters.
Fair Housing Act	1988	Prohibits housing discrimination on the basis of race, color, religion, gender, disability, familial status, and national origin. Amendments are applicable to government housing as well as private housing that receives federal assistance. It also requires landlords to allow tenants with disabilities to make reasonable access-related modifications to their private living space, as well as common areas. Any new multifamily unit with four or more units be designed and built to allow access for persons with disabilities.
Americans With Disabilities Act (ADA)	1990	The ADA prohibits discrimination on the basis of disability in employment, state and local government, public accommodations, commercial facilities, transportation and telecommunications. It also applies to the U.S. Congress.
Air Carrier Access Act	1990	Prohibits discrimination in air transportation by domestic and international carriers against qualified individuals with physical or mental impairments. It applies only to air carriers that provide regularly scheduled services for hire to the public.
National Voter Registration Act "Motor Voter Act"	1993	This Act requires all offices of state-funded programs that are primarily engaged in providing services to persons with disabilities to provide all program applicants with voter registration forms, to assist them in completing the forms, and transmitting the completed forms to the appropriate state official.
Telecommunications Act	1996	Requires manufacturers of telecommunications equipment and providers of telecommunications services to ensure that such equipment and services are accessible and usable by persons with disabilities, if readily achievable. The amendments ensure that people with disabilities have access to a broad range of products and services such as telephones, cell phones, pagers, call waiting, and operator services that previously were inaccessible to persons with disabilities.
Civil Rights of Institutionalized Persons Act	1997	This Act authorizes the U.S. Attorney General to investigate conditions of confinement at state and local institutions such as prisons, jails, pretrial detention centers, juvenile correctional centers, publicly operated nursing homes, and institutions for persons with psychiatric or developmental disabilities. The purpose is to all the Attorney General to uncover and correct any widespread deficiencies that would jeopardize the health and safety of the residents.
Olmstead Decision	1999	U.S. Supreme Court affirmed that unjustified institutionalization of people with disabilities is discrimination and violation of the ADA. States are required to provide community-based services for persons with disabilities otherwise entitled to institutional services when the state's treatment professionals reasonably determined that community placement is appropriate; the person does not oppose such placement; and the placement can reasonably be accommodated, taking into account resources available to the state and the needs of others receiving state-supported disability resources.

Source: Adapted from U.S. Department of Justice (2005).

include caring for one's self, walking, seeing, hearing, speaking, breathing, working, performing manual tasks, and learning (U.S. Department of Justice, 2005). Under the Act employers may not deny qualified individuals the opportunity to participate in or benefit from federally funded programs, services, or other benefits. Qualified individuals with a disability could not be denied access to programs, services, benefits, or opportunities to participate as a result of physical barriers and, finally, could not be denied employment on grounds of their disability. The law applied to employers or organizations receiving federal funding, so there were still a number of private entities exempt from the Act. The Act for the first time provided a legal definition of individuals with disability and clearly prohibited discrimination on these grounds.

A second major piece of legislation provided individuals with a disability access to public schooling. The **Individuals with Disabilities Act**, commonly referred to as IDEA, provides eligible children with disabilities a free appropriate public education in the least restrictive environment. Previously, many children with disabilities were segregated in schools dedicated to children with disabilities. Children with disabilities were now accorded public education opportunities equivalent to able bodied children.

Over the next 10 years federal legislation eliminated barriers in voting and housing with federal funding. Although the federal government was moving to eliminate barriers, a number of barriers continued to exist in the private sector. In 1990 President George H. Bush signed the **Americans with Disabilities Act (ADA)**, a landmark piece of legislation often considered the civil rights bill for individuals with disabilities. The ADA is a federal civil rights law that prohibits discrimination in employment, public services, and public accommodations against a person with a disability. According to the Act, a disability, consistent with the Rehabilitation Act of 1973, is a physical or mental impairment that substantially alters one or more major life activities.

Unlike the Rehabilitation Act of 1973, the ADA applies to both governmental and private entities (U.S. Department of Justice, 2005). However, the discrimination is not barred everywhere, only in employment, public services, and public accommodations. In employment, employers are required to make **reasonable accommodations** for a disabled employee. The word "reasonable" has sparked a lot of litigation. Also, the government is not allowed to discriminate against the disabled in the provision of public services. Of particular importance for

healthcare professionals is the prohibition of discrimination against those with disabilities within the realm of public accommodations.

Private hospitals or medical offices are covered by Title III of the ADA as places of public accommodation. Public hospitals and clinics and medical offices operated by state and local governments are covered as programs of public entities. Section 504 covers any of these that receive federal financial assistance, which can include Medicare and Medicaid reimbursements. In other words, if you provide medical care, it is highly likely that you are required to abide by the ADA. The ADA requires that medical care providers provide individuals with disabilities

- Full and equal access to their health care services and facilities; and
- Reasonable modifications to policies, practices, and procedures when necessary to make healthcare services fully available to individuals with disabilities, unless the modifications would fundamentally alter the nature of the services (i.e., alter the essential nature of the services).

Equal treatment for individuals with disabilities can mean an adjustment to the normal practices of healthcare providers. For instance, generally it is not acceptable to examine an individual in his or her wheelchair because the exam would not be as thorough as an exam on an exam table. Thus, accommodations may be necessary to get the patient from the wheelchair to the exam table. Accessible room design, training in proper techniques, and certain equipment (such as adjustable exam tables and medical testing equipment) are likely necessary to ensure equal treatment. For nurses in particular, training regarding the proper techniques for lifting and moving patients is becoming increasingly valuable. Because most medical service personnel are not in control of the equipment or facilities available to them, the most they can do is be sure they are using proper techniques. Because employers have a legal obligation to provide equal treatment, this training often readily available.

OLMSTEAD DECISION: INSTITUTIONALIZATION OR COMMUNITY-BASED SERVICES

In the late 1990s two women in Georgia whose disabilities included mental retardation and mental illness filed suit stating that their institutionalization was discriminatory and in violation of the ADA (U.S. Department of Health and Human Services, 2000). At the time the women were

covered by the state Medicaid program that restricted payments for ongoing health services to payment for services provided during an inpatient stay at healthcare institution. According to the suit, local health professionals involved in the care of the women had determined that appropriate mental health services could be provided in a community setting, yet at the time Medicare and Medicaid funding was not available to provide the support needed for community care. As a result of the court decision the Department of Health and Human Services committed to working with state Medicaid directors to craft fiscally responsible solutions that support compliance with the ADA, including making funding available for individuals with disability to live in the community with the right support (U.S. Department of Health and Human Services, 2000).

INDIVIDUALS WITH DISABILITIES: A GROWING VOICE

Individuals with disabilities were vocal not only about legal issues but also ethical matters related to the value and quality of life associated with disability. One specific concern was the case of Ashley X (Kirschner, Brashler, & Savage, 2007), a young disabled girl diagnosed with static encephalopathy. As a result of the disability she was dependent in all activities of daily living, nonverbal, and received all nutrition through a feeding tube. As Ashley approached puberty her parents were concerned that her physical growth would make it difficult for them to care for Ashley at home. After discussion with her physician, a plan was devised to provide high-dose estrogen to attenuate her growth. Concurrently, Ashley underwent a hysterectomy and breast bud removal. The combination of medication regimen and the surgery was referred to as the “Ashley treatment” (Kirschner et al., 2007). This treatment raised significant concern among individuals with disabilities who viewed the parents’ decision as evidence of an ongoing stigma against individuals with disabilities in society. Did the parents’ decision to have the hysterectomy performed in the absence of disease violate the rights of Ashley as a person? Do cases such as this further the image of life with disability as less than adequate?

Similar concerns have been voiced related to decisions on euthanasia and genetic testing. In the case of genetic testing, if testing reveals gene for one of several diseases that result in severe disability, is it ethical to then proceed with a therapeutic abortion? Is manipulation of genes in utero a violation of the embryo? Does genetic

BOX 25.3 Web Exploration

Code of Ethics for Nursing and Interpretive Statements
http://nursingworld.org/ethics/code/protected_nwcoe629.htm

A Guide to Disability Rights Law
<http://www.ada.gov/cguide.htm>

Stem Cell Research, National Institutes of Health
<http://stemcells.nih.gov/info/defaultpage>

testing reinforce the belief that life is only valued for able bodied children and that children with disability should not be allowed to live?

The therapeutic use of stem cells is a potential ethical concern for many. Scientists postulate that stem cell therapy may be of benefit to patients with a number of chronic illnesses, such as diabetes and Alzheimer’s disease, as well as individuals with disabilities such as spinal cord injury (Chapman, Frankel, & Garfinkel, 1999; National Institutes of Health, n.d.). Currently, there is a limited supply of available stem cells, and it is anticipated that new sources of live stem cells will be needed in the future. Under the Bush administration federal funding for human embryonic stem cell research was limited by presidential order. In March 2009 President Obama revoked this order and removed the limitation on scientific exploration of the use of stem cell therapy to reduce disease and disability (National Institutes of Health, www.stemcells.nih.gov/policy/defaultpage.asp). For some individuals the use of stem cells presents a moral and ethical challenge to their values.

SUMMARY

Perhaps it was inevitable that with the advances in modern medicine since the turn of the 20th century that ethical issues would arise. Where the life expectancy once was in the 40s, modern medicine has increased it to 78 years old. With increased life expectancy came the increase of chronic disease and associative suffering. Also, modern medicine found a way to sustain people on life support nearly indefinitely. Consequently, we began the 20th century asking how far modern medicine *could* go. We ended the 20th century asking how far modern medicine *should* go.

The collision between personal rights and modern medicine continues today. The battle between rights and medicine will likely continue throughout the 21st century. Rehabilitation nurses will encounter some of

the difficult decisions in their practice or work settings. Yet, certain foundational beliefs such as the belief in our society that all life has value and meaning will hopefully underscore ethical decision making in the future. Second, the rights of the individual cannot be infringed upon except when such exercise of those rights endanger others. Third, medical treatment and procedures must be received voluntarily and the medical community must honor all stated wishes except where those wishes violate personal ethical responsibility to do no harm. The value of human life and our responsibility as nurses to do good, promote health, and serve as a patient advocate should be the foundation for our practice.

CRITICAL THINKING

1. Describe how you respect a patient's autonomy in your daily practice as a nurse.
2. Your patient today is a young woman who sustained a traumatic brain injury as a result of an assault. She has significant cognitive impairments and is dependent for most activities of daily living. She has a gastrostomy tube in place for nutrition. Her husband is the suspected assailant; however, criminal charges were never filed against him. The discharge plan is for the woman to return home with the husband as the primary caregiver. What should you consider when preparing this patient for discharge?
3. You are working in the outpatient clinic. Today your patient's family members report her memory is becoming more impaired and they are fearful of her living alone. The physician has recommended the family pursue obtaining guardianship. The family asks you about pros and cons of guardianship. What advice do you have for the family?
4. What are the critical factors to be considered when allowing a surrogate to make healthcare decisions on a patient's behalf?
5. You are a nurse manager. A qualified applicant just accepted a position on your unit. The human resources representative notifies the nurse has a lower extremity amputation and uses a prosthesis. What should you consider when planning the nurse's orientation?
6. Your patient has a medication ordered that is derived from human embryonic stem cells. You believe the use of stem cells is morally wrong. What options are available to you and how will you decide what option to pursue?

PERSONAL REFLECTION

- Do you have an advance directive? If so, why? If not, why not?
- Think about three or four individuals with whom you have had conversations about your end-of-life wishes. How would they represent your decisions when questioned by the court?
- Do you know someone with a disability? When you initially learned about the disability how did you react? How does this person describe his or her life since the onset of the disability? Has this changed your initial perception about the person's life with a disability?
- Can you describe a scenario in a clinical setting when you had a hard time deciding on the right action to take? Think about how you made the decision. What factors did you take into account when deciding?

RECOMMENDED BOOKS ON ETHICS AND NURSING

- American Nurses Association. (2001). *Code of ethics for nurses with interpretive statements*. Washington, DC: Author.
- Bandman, E., & Bandman, B. (2002). *Nursing ethics through the life span* (4th ed.). New York: Prentice Hall.
- Bartter, K. (2001). *Ethical issues in advanced nursing practice*. Philadelphia: Elsevier.
- Beauchamp, T. L., & Childress, J. F. (2001). *Principles of biomedical ethics* (5th ed.). New York: Oxford University Press.
- Bosek, M. S. D., & Savage, T. A. (2007). *The ethical component of nursing education: Integrating ethics into clinical experience*. Philadelphia: Lippincott Williams & Wilkins.
- Danis, M., Clancy, C., & Churchill, L. R. (2005). *Ethical dimensions of health policy*. New York: Oxford University Press.
- Jecker, N. S., Jonsen, A. R., & Pearlman, R. A. (2007). *Bioethics: An introduction to the history, methods, and practice* (2nd ed.). Sudbury, MA: Jones & Bartlett.
- Macrina, F. (2005). *Scientific integrity: An introductory text with cases* (3rd ed.). Washington, DC: American Society for Microbiology Press.
- Morrison, E. E. (2006). *Ethics in health administration: A practical approach for decision makers*. Sudbury, MA: Jones & Bartlett.

REFERENCES

- American Nurses Association. (2001). *Code of ethics for nurses with interpretive statements*. Washington, DC: Author.
- Cerminara, K. A., & Goodman, K. (2010). Schiavo case resources: Key events in the case of Theresa Maria Schiavo. Retrieved May 20, 2010, from http://www6.miami.edu/ethics/schiavo/schiavo_timeline.html

- Chapman, A. R., Frankel, M.S., & Garfinkel, M.S. (1999). *Stem cell research and applications, monitoring the frontiers of biomedical research*. American Association for the Advancement of Science and the Institute for Civil Society. Retrieved September 1, 2010, from <http://stemcells.nih.gov/info/ethics>
- FindLaw. (2010). *Cruzan v. Director, Missouri Department of Health*. Retrieved August 1, 2010, from <http://caselaw.lp.findlaw.com/scripts/getcase.pl?court=us&vol=497&invol=261>
- Garner, B. A. (1999). *Black's law dictionary* (7th ed.). St. Paul, MN: West Group.
- Graham-Eason, C. (1996). Ethical considerations for rehabilitation nursing. In S. Hoeman (Ed.), *Rehabilitation nursing: Process and application* (2nd ed., pp. 34–46). St. Louis, MO: Mosby.
- Hart, S. E. (2005). Hospital ethical climates and registered nurses' turnover intentions. *Journal of Nursing Scholarship*, 37, 173–177.
- Illinois Department of Public Health. (2005). Illinois Department of Public Health announces new uniform do-not-resuscitate order form. Press release June 1, 2005. Retrieved April 15, 2010, from <http://www.idph.state.il.us/public/press05/6.1.05.htm>
- In Re: The Guardianship of Theresa Marie Schiavo from the Circuit Court for Pinellas County, Florida Probate Division File No. 90-2988GD-003.
- Karen Ann Quinlan Memorial Foundation. (2010). Karen Ann Quinlan: She changed the way people looked at life and death. Retrieved July 1, 2010, from <http://www.karenannquinlanhospice.org/history.htm>
- Kirschner, K., Brashler, R., & Savage, T. A. (2007). Ashley X. *American Journal of Physical Medicine and Rehabilitation*, 86, 1023–1029.
- Masters-Farrell, P. A. (2007). Ethical, moral and legal considerations. In K. Mauk (Ed.), *The specialty practice of rehabilitation nursing: A core curriculum* (5th ed., pp. 27–34). Glenview, IL: Association of Rehabilitation Nurses.
- Menne, H. L., & Whitlatch, C. J. (2007). Decision-making involvement of individuals with dementia. *The Gerontologist*, 47(6), 810–819.
- National Institutes of Health. (n.d.) Stem cell information—federal policy. Retrieved September 10, 2010, from <http://stemcells.nih.gov/policy/defaultpage.asp>
- Redman, B. K., & Fry, S. T. (1998). Ethical conflicts reported by certified rehabilitation registered nurses. *Rehabilitation Nursing*, 23(4), 179–184.
- Regents of the University of California. (2004). The disability rights and independent living movement: Introduction. Retrieved from <http://bancroft.berkeley.edu/collections/drilm/introduction.html>
- Savage, T. A. (2005). Clinical consultations: How do we handle conflicts with parents over unsafe oral feedings? *Rehabilitation Nursing Journal*, 30(1), 7–8.
- Savage, T. A., & Michalak, D. R. (1999). Ethical, legal and moral issues in pediatric nursing. In P. A. Savage, T. A., Parson, J., Zollman, F., & Kirschner, K. L. (2009). Rehabilitation team disagreement: Guidelines for resolution. *Physical Medicine and Rehabilitation*, 1, 1091–1097.
- U.S. Department of Health and Human Services. (2000). The Olmstead decision fact sheet. Retrieved December 1, 2010, from <http://www.acf.hhs.gov/programs/add/otherpublications/olmstead.html>
- U.S. Department of Justice. (2005). A guide to disability rights laws. Retrieved December 10, 2010, from <http://www.ada.gov/cguide.htm>