

## **Advocating for a Patient's Self-Determined Autonomy: An Advance Directive Primer**

### **NYSNA Continuing Education**

*The New York State Nurses Association is accredited as a provider of continuing nursing education by the American Nurses Credentialing Center's Commission on Accreditation.*

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The New York State Nurses Association is authorized by IACET to offer 0.4 CEUs for this program. In order to receive contact hours and CEUs, participants must read the course material, pass the examination with 80%, and complete an evaluation. Contact hours will be awarded until July 30, 2022.

NYSNA has been granted provider status by the Florida State Board of Nursing as a provider of continuing education in nursing (Provider number 50-1437).

Declaration of Vested Interest: None

NYSNA wishes to disclose that no commercial support of sponsorship was received.

NYSNA course planners and authors declare that they have no conflict of interest in this course.

## How to Take This Course

Please take a look at the steps below; these will help you to progress through the course material, complete the course examination and receive your certificate of completion.

### 1. REVIEW THE OBJECTIVES

The objectives provide an overview of the entire course and identify what information will be focused on. Objectives are stated in terms of what you, the learner, will know or be able to do upon successful completion of the course. They let you know what you should expect to learn by taking a particular course and can help focus your study.

### 2. STUDY EACH SECTION IN ORDER

Keep your learning "programmed" by reviewing the materials in order. This will help you understand the sections that follow.

### 3. COMPLETE THE COURSE EXAM

After studying the course, click on the "Course Exam" option located on the course navigation toolbar. Answer each question by clicking on the button corresponding to the correct answer. All questions must be answered before the test can be graded; there is only one correct answer per question. You may refer back to the course material by minimizing the course exam window.

### 4. GRADE THE TEST

Next, click on "Submit Test." You will know immediately whether you passed or failed. If you do not successfully complete the exam on the first attempt, you may take the exam again. If you do not pass the exam on your second attempt, you will need to purchase the course again.

### 5. FILL OUT THE EVALUATION FORM

Upon passing the course exam you will be prompted to complete a course evaluation. You will have access to the certificate of completion **after you complete the evaluation**. At this point, you should print the certificate and keep it for your records.

## Course Objectives

At the completion of this course, the learner will be able to:

- Define *advance directive*.
- Discuss the purpose of an advance directive.
- Distinguish capacity from competency.
- Describe methods to test a patient's capacity.
- Discuss various laws dictating a patient's right to autonomy and self-determination.
- Identify the impact of the U.S. Constitution, the Patient Self Determination Act, and common law on nursing practice as it relates to autonomy and self-determination.
- Recognize ethical questions that arise in practice when caring for patients at end-of-life.
- Identify barriers that patients, families and healthcare professionals face in implementing advance directives and end of life decision making.
- Identify problems created by lack of an advance directive.
- Describe ways that nurses can involve patients in advance care planning.

## **Introduction**

Advances in nursing care and healthcare technology have obscured the margins between a quality life and death, and have challenged societal expectations about how patients and their families should experience medical crises and end of life care. Studies have indicated that approximately one in four Americans has multiple chronic conditions (MCC), including one in 15 children (Anderson, 2010). Chronic conditions include both physical conditions such as arthritis, cancer, organ system failure (primarily heart, lung, liver, and kidney failure), stroke, and HIV infection, and mental and cognitive disorders, such as ongoing depression, substance addiction, and dementia. Few Americans die suddenly in today's healthcare environment, rather most will live long, but increasingly disabled lives (Wilkinson, Wenger, & Shugarman, 2007).

Over 60% of deaths occur in hospitals and over 20% in nursing homes in the United States. Often Americans die in a healthcare setting where the provision of high-technology treatment and medical and nursing intervention is aggressive and is capable of sustaining and extending a life that presents in an extremely compromised and fragile state. Nevertheless, when asked, over 80% of Americans would prefer to die at home (MacPherson & Parikh, 2017).

Studies have shown that end-of-life medical care is associated with a substantial burden of suffering among dying individuals (Wildinson, Wenger, & Shugarman, 2007). Older Americans with chronic illness think about how they would prefer their lives to end, and want a "good death" without burdensome pain, symptoms and advanced technology. Seventy percent (70%) of adult deaths occurring in those aged 65 and older want better discussions, information, and a chance to influence decisions about their care — whether to be at home or in the hospital, and whether to have cardiopulmonary resuscitation (CPR), to be placed on a respirator, to be tube fed, or to donate organs after death (American Psychology Association, 2019).

Clinicians may lack sensitivity to the sociocultural beliefs that influence decisions affecting end of life care and may not have the knowledge to increase flexibility in their own practices and standards in the application of advance directives. Inadequate knowledge of patients' cultural values, preferences for communication, palliative care, decision-making, and choices at end of life inhibits the provision of quality care. Unless the patient's preferences are known, they may undergo unwanted, distressing, and costly treatments that impair their quality of life, increase suffering, and distress and financially burden their loved ones. The sociocultural values of many culturally diverse groups conflict with the values on which the use of advance directives is based in American hospitals today (American Psychology Association, 2019).

Advance directives (ADs) were developed to provide a practical approach and process for ensuring patient autonomy and self-determination at the end of life. The principal behind ADs is to integrate patient autonomy and decision-making into treatment and interventional practices performed by nurses and physicians on behalf of the patient who later becomes incapacitated and is no longer able to speak for themselves.

## **About the Author**

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Dr. Esposito has taught Introduction to Law, Civil Litigation, Risk Management, Medical Malpractice, Birth Injuries, Ethics, Introduction to Hospital Management, Collective Bargaining, and Introduction to Research and Writing at various colleges and universities. She has been Of Counsel to Wagner, Doman, & Leto, a Long Island, New York defense firm concentrating in medical malpractice, has worked for several malpractice firms both on Long Island and in New York City, and has worked for the United States Attorney's Office in the Eastern District of New York.

Dr. Esposito has been an honorarium speaker for Catholic Medical Center School of Nursing, Winthrop University Hospital, Sigma Theta Tau, and the American Association of Legal Nurse Consultants. She has authored articles on Informed Consent and Malpractice Insurance, Transcultural Nursing, Patient Satisfaction, Short Term Medical Missions, End-of-Life Care, Continuous Nursing Education, Leadership Development, and Nursing Ethics, and has developed course and text materials for the National Center for Professional Development. Dr. Esposito taught medical/surgical and pediatric nursing through BOCES and has practiced as a medical/surgical and cardiac nurse.

## Definitions

### *Advance Directive*

An advance directive is a written or oral legally binding instruction given by a patient who has the capacity and competency to make medical decisions concerning medical treatment they would or would not want. Advance directives take effect when the patient later becomes incapacitated and is no longer able to speak for themselves. An advance directive remains in effect indefinitely unless the patient cancels it (orally or in writing, upon divorce, or by destroying the instrument), includes an expiration date, or describes the circumstances that trigger expiration. In New York State there are three types of Advance Directives: Health Care Proxy, Living Will, and the Do Not Resuscitate Order (DNR) (James, 2019).

### *Assisted Suicide*

New York law defines assisted suicide as an individual who aids another person to commit suicide. N.Y. Penal Law §125.15(3). Black's Law Dictionary defines "suicide" as "[t]he act of taking one's own life," and "assisted suicide" as "[t]he intentional act of providing a person with the medical means or the medical knowledge to commit suicide" (10th ed. 2014). There is no right to assisted suicide in New York State (*Myers v. Schneiderman*, 2017).

### *Best Interests*

New York State's Department of Health (NYSDOH) defines "best interests" as follows: To figure out what is in the "best interests" of the patient, the decision maker must consider: "the dignity and uniqueness of every person; the possibility of preserving the patient's life and preserving or improving the patient's health; relief of the patient's suffering; and any other concerns and values a person in the patient's circumstances would wish to consider." (NYSDOH, 2018b).

### *Capacity*

Capacity refers to an assessment of the individual's psychological abilities to form rational decisions, specifically the individual's ability to understand, appreciate, and manipulate information and form rational decisions. Capacity is determined by a physician, often (although not exclusively) by a psychiatrist, and not the judiciary. When a patient has been evaluated by a physician to lack capacity to make reasoned medical decisions, the patient is referred to be **de facto incompetent**, i.e., incompetent in fact, but not determined to be so by legal procedures. Such individuals cannot exercise the right to choose or refuse treatment, and they require another individual, a de facto surrogate, to make decisions on their behalf (Dastidar & Oden, 2011, Leo, 1999).

### *Clear and Convincing Evidence*

According to the Supreme Court in *Colorado v. New Mexico* (1984), "clear and convincing" means that the evidence is highly and substantially more likely to be true than untrue, and the fact finder must be convinced that the contention is highly probable.

This is a medium level of burden of proof which is a more rigorous standard to meet than the "preponderance of the evidence" standard, but a less rigorous standard to meet than proving evidence "beyond a reasonable doubt." In order to meet the standard and prove something by clear and convincing evidence, the party alleging the contention must prove that the contention is substantially more likely than not that it is true. This standard is employed in both civil and criminal trials. States vary with regard to which standard of proof they require. However, claims which involve fraud, wills, and withdrawing life support will typically require the clear and convincing evidence standard.

### *Competency*

Competency is an assessment and legal determination made by a judge in court. Competence is strictly a legal term. Every person is presumed to be competent unless a court has determined that an individual is incompetent. A judicial declaration of incompetence may be global, or it may be limited (e.g., to financial matters, personal care, or medical decisions) (Orr, 2004).

### *CPR*

CPR, or cardiopulmonary resuscitation, is an emergency procedure to restart the work of the heart and lungs by compressing the chest overlying the heart and forcing air into the lungs. Additional lifesaving procedures include mechanical ventilation or respirator and intravenous medications to regulate blood pressure and heart rhythms.

### *Do Not Intubate (DNI) Order*

A DNI order is an order that directs practitioners to not intubate (place a tube down the patient's throat) or connect the patient to a ventilator (breathing machine).

### *Do Not Resuscitate Order (DNR)*

A DNR order is a medical order written by a physician. It instructs healthcare providers not to perform cardiopulmonary resuscitation (CPR) or other lifesaving emergency procedures if a person's heartbeat or breathing stops. A DNR is arranged with the patient's physician or healthcare provider before an emergency occurs (James, 2019).

#### **Checklist for a Valid Hospital DNR Order:**

- The patient, the healthcare agent or a surrogate may give written or verbal consent to a hospital DNR order.
- Verbal consent must be witnessed by two adults, one of whom must be a doctor in the facility where the patient is admitted.
- Written consent must be signed by two adult witnesses.
- The patient's physician can issue the DNR order. New York State does not require the patient's written or verbal consent to be recorded on the state form. Facilities may use their own forms or the state specified MOLST form.

#### **Checklist for a Valid Non-Hospital DNR Order:**

- The patient, the health care agent or a surrogate may give written or verbal consent to a non-hospital DNR order.
- If the DNR order is being created before discharge, verbal consent may be given to the attending physician or two adult witnesses, one of whom must be a physician in the facility where the patient is admitted.
- If the patient is out of hospital, at home, it is sufficient to give verbal consent to the attending physician.
- If you are giving consent in writing, it must be signed by two adult witnesses.
- Written or verbal consent must be recorded on New York State Form DOH3474 and signed by your physician.

### *Double Effect*

A negative outcome, when the intended consequence of alleviating pain results in the unintended consequence of hastening death.

### *Durable Power of Attorney for Healthcare*

A **power of attorney** is a legal document that gives someone the patient chooses the power to act in their place. A **durable power of attorney for healthcare** covers all health care decisions, and lasts only as long as the patient is incapable of making decisions for themselves. Patients can set out specific

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provisions in the Durable Power of Attorney telling their agent how they would like them to act with regard to deathbed issues (Rocket Lawyer, 2019). If the decision-maker is not certain of the patient's wishes, the "best interest" standard directs the decision-maker to choose the intervention that will best promote and protect the patient's values, beliefs, morals, and interests. Durable Power of Attorney for Healthcare documents are not recognized in New York State.

### *Five Wishes*

Five Wishes is a nationally recognized (in the United States) advance directive created by the non-profit organization Aging with Dignity. It has been described as the "living will with a heart and soul." This document meets the legal requirements in 42 states, and is useful in all 50.

Five Wishes lets families and doctors know (Five Wishes, 2019b):

- Who the patient wants to make health care decisions for them and when the surrogate can't make them.
- The kind of medical treatment the patient wants or doesn't want.
- How comfortable the patient wants to be.
- How the patient wants practitioners and family members to treat them.
- What the patient wants their loved ones to know.

### *End of Life*

End of life is defined as that time period when healthcare providers would not be surprised if death occurred within about six months (American Psychological Association, 2019).

### *Euthanasia*

Euthanasia, or "mercy killing," is the act of taking someone's life who no longer wishes to live, by engaging in some act to cause the death of a patient, such as administering a lethal dose of medication and typically because the patient has a terminal illness or some other debilitating condition. A distinction can be made between "active" euthanasia, which is acting to ensure death, and "passive" euthanasia, which is the failure to intervene to prevent death. Euthanasia differs from assisted suicide. Euthanasia is illegal in all 50 U.S. states and is treated as a crime in New York State (Find Law, 2019).

### *Health Care Proxy*

The New York Health Care Proxy Law allows patients to appoint someone they trust to make health care decisions for them in the event that they lose the ability to make decisions for themselves. By appointing a **health care agent**, patients can make sure that health care providers follow their wishes. The agent can also decide how the patient's wishes apply as their medical condition changes. Healthcare practitioners and hospitals must follow the agent's decisions as if they were the patient's (New York State Department of Health, 2017). Health care proxies are invoked in all situations when the patient becomes incapacitated, whether the incapacitated state is temporary or permanent, and in all types of cases, such as temporary or permanent illness, or terminal illness. The health care proxy document is the preferred advance directive in New York State.

### *Living Will*

A living will is a written document that specifies what the patient would and would not want under specific and explicit medical scenarios. A living will is limited to deathbed concerns only (Rocket Lawyer, 2019), i.e.: they only come into effect in the case of terminal illnesses. Living wills should be as specific and as detailed as possible. Treatments and aspects of care that were not anticipated and not included in the living will then become the responsibility of the surrogate healthcare decision-maker described under state law (Mayo Foundation for Medical Education and Research, 2019). Under a living will, a health care agent cannot be named. While New York does not have a law governing Living Wills, the Court of

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Appeals, New York’s highest court, has stated that Living Wills are valid as long as they provide “clear and convincing” evidence of the patient’s wishes. Thus, New York State recognizes the living will document. **Five Wishes** (2019a) is one of the most popular living will documents used throughout the states today.

### *Medical Orders for Life Sustaining Treatment (MOLST)*

A MOLST allows doctors to record the patient’s preferences regarding cardiopulmonary resuscitation (CPR), mechanical intervention, and other life sustaining treatments on one form as a physician order. It must be completed by a healthcare professional and signed by a New York State licensed physician to be valid. The MOLST form is the only authorized form in New York State for documenting both nonhospital DNR and DNI orders. The MOLST form has been approved by the New York State Office of Mental Health (OMH) and the Office for People with Developmental Disabilities (OPWDD) for use as a nonhospital DNR/DNI form for persons with developmental disabilities or persons with mental illness, including persons who are incapable of making their own health care decisions or who have a guardian of the person appointed pursuant to Article 81 of the Mental Hygiene Law or Article 17-A of the Surrogate’s Court Procedure Act. The OPWDD has approved a checklist that must be attached to the MOLST form, in order for the form to be used for persons with developmental disabilities who are incapable of making their own health care decisions or who have a guardian of the person appointed pursuant to Article 81 of the Mental Hygiene Law or Article 17-A of the Surrogate’s Court Procedure Act (NYSDOH, 2018a).

### *Medically Futile Treatment*

"Medically futile" treatment means that CPR will be unsuccessful in restoring cardiac and respiratory function or that the patient will experience repeated arrest in a short time period before death occurs (New York State Task Force on Life and the Law, nd).

### *New York’s Palliative Care Access Act (PCAA)*

New York’s Palliative Care Access Act mandates that patients be fully informed of the options available to them when they are terminally ill or have “advanced life limiting conditions or illnesses.” Healthcare practitioners must offer to the patient information and counseling regarding palliative care and end-of-life options. If the patient lacks medical decision-making capacity, then the information and counseling is provided to the person who has authority to make health care decisions.

### *Palliative Care*

Palliative care is a multidisciplinary approach to specialized medical care for people with life-limiting illnesses, focusing on providing people with relief from the symptoms, pain, physical stress, and mental stress of the terminal diagnosis.

### *Patient Self-Determination Act of 1990*

The federal Patient Self-Determination Act of 1990 mandates that all hospitals, nursing facilities, home healthcare agencies, hospices, and HMO’s receiving federal reimbursement under Medicare and Medicaid provide adult clients with information on health care proxies, living wills and other forms of advance directives.

This statute also mandates that healthcare facilities:

- Provide patient’s upon admission with written information about their legal rights to make decisions that can their medical care.
- Maintain written policies and procedures with regard to advance directives and provide written information to patients about such policies.

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- Document in the patient's record the existence, or non-existence, of a completed advance directive.
- Ensure compliance with state law regarding advance directives.
- Educate its staff and the community on issues pertaining to advance directives.

### *Physician orders for life-sustaining treatment (POLST)*

A POLST is intended for people who have already been diagnosed with a serious illness. This form does not replace other directives. Instead, it serves as doctor-ordered instructions (like a prescription) to ensure that, in case of an emergency, the patient receives the treatment s/he would prefer. A POLST details what treatments not to use, under what conditions certain treatments can be used, how long treatments may be used, and when treatments should be withdrawn. A POLST also indicates what advance directives the patient has created and who serves as their health care agent. Like advance directives, POLSTs can be canceled or updated.

Issues covered in a POLST may include (Mayo Foundation, 2019):

- Resuscitation
- Mechanical ventilation
- Tube feeding
- Use of antibiotics
- Requests not to transfer to an emergency room
- Requests not to be admitted to the hospital
- Pain management

### *Surrogate*

A surrogate is a person close to you, as defined by New York state law, who can make decisions on your behalf if you have lost the capacity to make decisions about your medical treatment, and have not appointed a health care agent.

### *Terminal illness*

A terminal illness generally means that a patient has less than six months to live, whether or not treatment is provided (New York State Public Health Law, § 2997-c(d).).

### *The Uniform Determination of Death Act*

The Uniform Determination of Death Act, adopted by the American Bar Association and American Medical Association, and put into law in some form by all 50 U.S. states, provides healthcare facilities and healthcare professionals with some guidance and direction relating to end of life decisions. The Uniform Determination of Death Act defines death as either the irreversible cessation of respiratory and circulatory functions **or** the irreversible cessation of all brain functions including brain stem function. Despite this seeming uniformity in the law, end of life controversies have increasingly been raised, highlighting variations among state brain death laws and their interpretation by courts (Nikas, Bordlee, & Moreira, 2016).

### *The Uniform Anatomical Gift Act of the United States*

The Uniform Anatomical Gift Act of the United States establishes the regulations with respect to organ donations and organ transplantations, including prohibitions against the sale and trafficking of human organs. According to this law, patients can elect to donate one or more of their bodily parts. This federal law also contains mechanisms that enable surviving spouses and other relatives to donate organs after the loss of a loved one when that patient has not made a decision about whether or not they wanted to participate in an organ donation.

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## Understanding Historical Underpinnings of a Patient's Right to Autonomy and Self-Determination

### *In Re Quinlan*

In 1975, 21-year-old Karen Ann Quinlan suffered cardiopulmonary arrest after ingesting a combination of alcohol and drugs. She subsequently was diagnosed with brain damage and went into a persistent vegetative state (PVS).

Dr. Fred Plum, a neurologist, described her as no longer having any cognitive function but retained the capacity to maintain the vegetative parts of neurological function. She grimaced, made chewing movements, uttered sounds, and maintained a normal blood pressure, but was entirely unaware of anyone or anything. The medical opinion was that Quinlan had some brain-stem function, but that in her case, it could not support breathing. She had been on a respirator since her admission to the hospital. Quinlan's parents asked that her respirator be removed and that she be allowed to die. Quinlan's doctor refused, claiming that his patient did not meet the Harvard Criteria for brain death.

Quinlan's father, Joseph Quinlan, went to court to seek appointment as his daughter's guardian (since she was of legal age) and to gain the power to authorize "the discontinuance of all extraordinary procedures for sustaining Quinlan's vital processes." The court denied his petition to have Quinlan's respirator turned off and also refused to grant him guardianship over his daughter.

Joseph Quinlan subsequently appealed to the Supreme Court of New Jersey (*In re Quinlan*, 1976). He requested, as a parent, to have Quinlan's life support removed based on the U.S. Constitution's First Amendment—the right to religious freedom. The court rejected his request.

The court also considered the Eighth Amendment—protection against cruel and unusual punishment—and considered it inapplicable in Quinlan's case, stating that this amendment applied to protection from excessive criminal punishment. The court considered Quinlan's cruel and unusual circumstances not punishment inflicted by the law or state, but the result of "an accident of fate and nature."

The New Jersey Supreme Court stated, however, that an individual's right to privacy was most relevant to the case. Although the U.S. Constitution does not expressly indicate a right to privacy, U.S. Supreme Court rulings in past cases had not only recognized this right but had also determined that some areas of the right to privacy are guaranteed by the Constitution.

For example, the Supreme Court had upheld the right to privacy in *Griswold v. Connecticut* (the right to marital privacy, the right of married persons to use contraception), (1965) and in *Roe v. Wade* (the right to seek an abortion), (1973). The U.S. Supreme Court had further presumed that the right to privacy included a patient's right to refuse medical treatment in some situations.

Balanced against Quinlan's constitutional right to privacy was the state's interest in preserving life. Quinlan's physicians had refused to remove the respirator because they did not want to violate the prevailing medical standards and practices or the state's penal law regarding homicide.

The court observed that life-prolongation advances had rendered the existing medical standards ambiguous (unclear), leaving doctors in a quandary. Moreover, modern devices used for prolonging life, such as respirators, had confused the issue of "ordinary" versus "extraordinary" measures. The court suggested that respirators could be considered "ordinary" care for a curable patient, but "extraordinary" care for irreversibly unconscious patients. The court also suggested that hospitals form ethics committees to assist physicians with difficult cases like Quinlan's. And so began the birth of legally mandated hospital ethics committees throughout the states.

### *Cruzan v. The Director of Missouri Department of Health*

In 1983, Nancy Beth Cruzan, aged 25, was involved in an automobile accident which left her in a "persistent vegetative state." For almost eight years, her body was rigid and her feet and hands contracted and bent. She had occasional seizures and vomited, and while her eyes sometimes opened and moved, she showed no sign of recognizing her family. A month after the accident, a feeding tube was

implanted in Miss Cruzan's stomach to allow her to receive nourishment. She breathed without assistance from a ventilator.

In 1987, after being refused by the Missouri Rehabilitation Center, Miss Cruzan's parents went to court to ask that the feeding tube be removed and that Nancy be allowed to die a dignified death as they said she would have wanted. But a loose coalition of euthanasia and abortion opponents describing themselves as right-to-life advocates quickly took up Nancy's cause. They argued that every life has meaning, even life in a vegetative state, and that removing the feeding tube and starving Miss Cruzan to death devalues life. Although the lower court ruled in the family's favor, the Missouri Rehabilitation Center refused to comply with the court order and appealed the (parent's favorable) ruling to the state Supreme Court level. The Missouri Supreme Court reversed the lower court's ruling on the basis of the State's greater duty to preserve life, a duty that outweighed any right that the parents might have to make decisions for their daughter.

The *Cruzan v. The Director of Missouri Department of Health* case became the centerpiece of a bitter debate about how and when families can decide to withdraw nourishment or medical treatment to bring about the death of an incapacitated loved one.

The case was appealed and decided at the U.S. Supreme Court in 1989. In a 5-to-4 decision, and in its first ruling on the right to die, the U.S. Supreme Court recognized such a right existed under the right of privacy, but said Missouri could nevertheless stop the Cruzan's from withholding food and water from their daughter unless there was "clear and convincing" evidence that she would have wanted to die. Justice Scalia argued in the *Cruzan* case that refusing medical treatment, if doing so would cause a patient's death, was equivalent to the right to commit suicide. He opined that the right to commit suicide was not a due process right protected under the U.S. Constitution. And so the Supreme Court ruling in the *Cruzan* case set no real uniform national guidelines on the right to die, but left it to each individual state to set their own standards and evidentiary levels.

The ruling spurred enormous interest in living wills and other advance directives that allow people to spell out, beforehand, what treatment they want, and who should make decisions for them if they become incapacitated. The case also helped to generate support for Congressional passage of the Patient Self-Determination Act, effective November 1991, under which hospitals and nursing homes that receive Medicaid or Medicare funds must give patients written information about such advance directives, explaining what right-to-die options are available under their state law. All states now have laws providing a way for people to make known, in advance, their wishes about medical treatment. These instruments, then, would satisfy the "clear and convincing" evidence that the U.S. Supreme Court required.

Between 1976 and 1990, due to the influential cases of *Quinlin* and *Cruzan*, courts reached consensus related to matters of end of life. The courts and bioethicists have confirmed a person's right to refuse life-sustaining treatment and determined that this right remains intact even when the person is unable to speak for oneself. These cases also resulted in our legal system endorsing the principle that all persons are presumed both competent and to have the capacity to make reasoned decisions unless demonstrated to be otherwise.

### ***Theresa Marie Schiavo (December 3, 1963 – March 31, 2005)***

Despite this legal consensus, in the spring of 2005, Theresa (Terri) Marie Schiavo became the focus of national publicity as her story became the most litigated medical case in U.S. history. The case constituted a legal struggle over end-of-life care in the United States from 1990 to 2005, and involved a woman in an irreversible persistent vegetative state.

Schiavo suffered a cardiac arrest in her St. Petersburg, Florida, home on February 25, 1990. She was resuscitated, but suffered massive brain damage due to lack of oxygen to her brain and was left comatose. After two and a half months without improvement, her diagnosis was changed to that of a persistent vegetative state. Terri's husband Michael was named guardian over Terri. In November of 1990, Michael Schiavo took his wife to California for experimental "brain stimulator" treatment, and an

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experimental "thalamic stimulator implant" was inserted in her brain. By July 1991, she received continuing neurological testing, and regular and aggressive speech/occupational therapy through 1994. In 1998, Schiavo's husband, Michael, petitioned the Sixth Circuit Court of Florida to remove her percutaneous endoscopic gastrostomy feeding tube pursuant to Florida law. The court appointed Richard Pearse, Esq., to serve as the second guardian ad litem for Ms. Schiavo.

Terri's husband argued that she would not have wanted prolonged artificial life support without the prospect of recovery. Attorney and guardian ad litem Pearse attested to the appropriateness of this request. But Schiavo's parents argued in favor of continuing artificial nutrition and hydration, challenged Terri's medical diagnosis, and demanded that another guardian be appointed. The second guardian ad litem reported that Michael's decision-making and court requests may have been influenced by his potential inheritance.

Petitions went back and forth through the courts through November 2003, with the court ultimately ruling to remove the tube feeding, and the parents petitioning for a stay on the order. During his tenure as Florida governor, Jeb Bush decided to challenge his own state courts and tried to override the decision to allow Terri to die. In November 2003, Governor Bush intervened in the case by filing a brief in the federal district court in support of Terri's parent's wishes, arguing that the feeding tube should remain. The federal district court ruled that the Governor lacked jurisdiction to intervene or to bring the case. "The Florida Constitution prohibits the Governor's intervention in matters that should be resolved through the court system," ruled the court.

But Governor Bush was determined and wrote to a local publication: "As a concerned citizen, you have the opportunity to influence legislation pertaining to guardianship matters in cases similar to Terri's." The Florida legislature responded and enacted "Terri's Law," which would allow a Governor to issue a "one-time stay in certain cases." With this newly declared authority, the Governor issued an executive order to have the feeding tube reinserted. As a result, a third guardian ad litem was appointed, a physician, who concluded that Terri was in a persistent vegetative state with no chance of improving. Subsequently, in 2004, the Florida Supreme Court declared "Terri's Law" unconstitutional. Governor Bush next sought review by the U.S. Supreme Court. In 2005, the U.S. Supreme Court refused to grant the review.

President George Bush, in support of his brother, almost created a constitutional crisis between the courts and the executive branch of the U.S. government when he tried to override the Florida courts which had, time after time, supported Michael Schiavo's requests. Responding to the President's wishes, the U.S. House of Representatives issued five separate subpoenas commanding Michael Schiavo to appear and to bring Terri with him, with hydration and nutrition equipment intact; and commanding several physicians and hospice personnel to reinsert the feeding tube and to make an appearance with Terri. In the meantime, President Bush signed a bill which would grant to the federal courts the jurisdiction to hear the case.

With this newly signed law, Terri's parents sought assistance from the federal courts and demanded that Terri's feeding tube be reinserted. The federal court denied this motion. The parents appealed the case to the U.S. Court of Appeals for the 11<sup>th</sup> Circuit. The appellate court upheld the federal court's decision and reaffirmed that the feeding tube was *not* to be reinserted. The case was once again appealed to the U.S. Supreme Court and the court once again refused to hear the case. Similarly, the U.S. Court of Appeals denied a motion brought by the parents for a rehearing.

As a result of all of this litigation, former Senator and surgeon Bill Frist saw his Presidential dream disappear when he, on behalf of the President and Terri's parents, challenged Terri Schiavo's diagnosis in court and in the "court of public opinion" without directly examining her.

This case also spurred the Vatican into action. The Vatican wound up challenging U.S. law which, as the *Schiavo* case affirmed, allowed the withdrawal of artificial food and hydration under certain circumstances. The Vatican declared that food and water must not be stopped, thereby, leaving many

Catholic healthcare institutions and Catholics in this country — and others — uncertain as to how to manage requests to let a patient die by removing a feeding tube.

In all, the *Schiavo* case involved 14 appeals and numerous motions, petitions, and hearings in the Florida courts; five suits in federal district court; extensive political intervention at the levels of the Florida state legislature; then-governor Jeb Bush, the U.S. Congress, and President George W. Bush; and four denials of certiorari from the Supreme Court of the United States (Columbia Electronic Encyclopedia, 2012).

### ***Roe v. Wade***

*Roe v. Wade* (1973) is a landmark decision by the United States Supreme Court on the issue of abortion. It was decided simultaneously with a companion case, *Doe v. Bolton* (1973). The Court ruled 7–2 that a right to privacy under the Due Process Clause of the 14th Amendment extended to a woman's decision to have an abortion, but that this right must be balanced against the state's two legitimate interests in regulating abortions, i.e.: protecting women's health and protecting the potentiality of human life. Arguing that these state interests became stronger over the course of a pregnancy, the Court resolved this balancing test by tying state regulation of abortion to the third trimester of pregnancy.

### ***Planned Parenthood v. Casey***

Later, in *Planned Parenthood v. Casey* (1992), the Court rejected *Roe's* trimester framework while affirming its central holding that a woman has a right to abortion until fetal viability. The *Roe* decision defined "viable" as "potentially able to live outside the mother's womb, albeit with artificial aid." Justices in *Planned Parenthood* acknowledged that viability may occur at 23 or 24 weeks, or sometimes even earlier, in light of medical advances. In brief, the *Roe* and *Planned Parenthood* decisions established that, as a matter of law, there was no **absolute** constitutional guarantee of a "right to abortion (death of fetus)". Each state, however, can make law with regard to the right to abortion.

### ***Vacco v. Quill***

*Vacco v. Quill* (1997), is a landmark decision of the Supreme Court of the United States regarding the right to die. The Supreme Court ruled 9-0 that a New York ban on physician-assisted suicide was constitutional, and preventing doctors from assisting their patients, even those terminally ill and/or in great pain, was a legitimate state interest that was well within the authority of the state to regulate. In brief, this decision established that, as a matter of law, there was no constitutional guarantee of a "right to die." Each state, however, can make law with regard to the right to die.

## Advance Directives: Protecting Patients Right to Self-Determination

At present, New York law does not permit the withdrawal or withholding of life-sustaining treatment from an incapacitated adult patient who has neither created a health care proxy nor left written or oral treatment instructions that satisfy New York's "clear and convincing evidence" of a patient's wishes standard. Therefore, the ultimate purpose of advance directives (ADs) is to guide professional decision making and to direct the patient's care and treatments at the end of life.

Advance directives also provide the legal underpinnings for all patients to accept or reject care as they wish because they have the constitutionally, statutorily, and judicially provided privilege (hereinafter, "right") to autonomous decision making and self-determination, without coercion, even when they are no longer have the capacity to do so. Modern day ADs have become increasingly detailed and specific and often contain patient preferences for a variety of hypothetical healthcare scenarios and for a variety of physician and nursing treatments and interventions (Wildinson, Wenger, & Shugarman, 2007).

### Capacity is the Key to Self-Determination

The term **capacity** is frequently mistaken for **competency**. Capacity is a functional assessment regarding a patient's ability to make a particular decision. Capacity is not static. Although capacity usually is defined by state law and varies by jurisdiction, practitioners generally can assume it includes one or more of four key components. The four key components to address in a capacity evaluation include: 1) communicating a choice, 2) understanding, 3) appreciation, and 4) rationalization/reasoning (Dastidar & Odden, 2011) (Table 1).

- **Communicating a choice.** The patient needs to be able to express a treatment choice, and with determination. A patient who changes his/her decision in itself would not bring a patient's capacity into question, as long as the patient was able to explain the rationale behind the altered decision. Frequent changes back and forth in the decision-making, however, could be indicative of an underlying psychiatric/medical disorder or extreme indecision, which could bring capacity into question (Dastidar & Odden, 2011).
- **Understanding the nature and consequences of one's decisions.** The patient needs to be able to recall and provide the sum and substance of conversations about treatment choices, to make the link between causal relationships, and to process probabilities for outcomes. Problems with memory, attention span, and intelligence can affect one's understanding (Dastidar & Odden, 2011).
- **Appreciation of the medical situation and present condition.** The patient should be able to identify their illness, treatment options, and likely outcomes as things that will affect him/her directly. A genuine and factual lack of appreciation usually stems from a denial based on intelligence (lack of a capability to understand) or emotion, or a delusion that the patient is not affected by this situation and will have a different outcome (Dastidar & Odden, 2011).
- **Rationalization or reasoning.** The patient needs to be able to weigh the risks and benefits of the treatment options presented and come to a conclusion in keeping with their own culturally and spiritually based goals and best interests, as defined by their personal set of values. This can often be affected in psychosis, depression, anxiety, phobias, delirium, and dementia (Dastidar & Odden, 2011).

**Table 1. Components of Capacity Assessment**

Component	Patient's role	Physician's approach	Sample questions	Impaired in
Communication	Express a treatment choice	Ask patient which treatment option they prefer	Have you decided whether to get X or Y treatment?	Psychiatric disorders; extreme (pathologic) indecision
Understanding	Recall information, link causal relationships, process general probabilities	Ask the patient to paraphrase their view of the situation	Can you tell me how you view the current situation? How likely do you think that X will happen to you?	Problems with memory, attention span, intelligence
Appreciation	Identify illness, treatment options, and probable outcomes as it relates to them	Ask patient to describe disease, treatment, outcomes, and probabilities as they apply to them	What do you think is wrong with your health? What treatments do you think would help? What do you think is your alternative?	Denial; delusional disorder
Rationalization	Weigh risks and benefits to come to a conclusion in keeping with patient's goals	Ask the patient to compare risks vs. benefits of the proposed treatment and alternatives	What made you choose option X? Why do you think option X is better than option Y?	Depression, psychotic thought disorder, depression, anxiety, phobia, delirium, dementia

Capacity Assessments: Use and Misuse

Nurses and physicians are not automatically authorized to initiate and perform medical treatment on behalf of a patient when the practitioner personally believes the patient has become incapable of making reasoned medical decisions. Requests for a capacity assessment must first be made, and when made, suggests that practitioners may be uncertain about, and perhaps overwhelmed by, the complexities encountered when addressing issues pertaining to medical decision making. The literature denotes myths about capacity that may trigger an otherwise inappropriate request for a capacity assessment by a practitioner.

Those myths include (Ganzini, Volicer, Nelson, Fox, & Derse, 2004; Leo, 1999):

- Decision making capacity is the same thing as competency.
- A patient deciding against medical advice means there is a lack of decision making capacity.
- There's no need to assess decision making capacity unless a patient goes against medical advice.
- Decision making capacity is all or nothing.
- A cognitive impairment automatically means there is no decision making capacity.
- A lack of decision making capacity is permanent.
- Patients who have not been given relevant information about their condition can lack decision making capacity.
- All patients with certain psychiatric disorders lack decision making capacity.
- All institutionalized patients lack decision making capacity.
- Only psychiatrists and psychologists can assess decision making capacity.

Requests for consultations to assess a patient's capacity arise most often in the literature for patients who refuse treatment that the physician and/or nurse deems rational. Often, practitioners think that a patient who refuses a recommended and/or standard treatment is "incompetent" unless proven otherwise. Such posturing is not only inaccurate by legal (and moral/ethical) standards, it is also considered to be inappropriately paternalistic. Paternalism in medicine has become unpopular because it entails practitioners telling patients what is, or is not good for them, without regard to the patient's own needs and interests. The fact that patients have the right to self-determination and the principle of respect for self-autonomy imposes on the attending practitioners and other health workers a duty to respect this right (Ilemona, Bolatito, John, & Ikeoluwapo, 2012; Leo, 1999). Respect for autonomy in healthcare, therefore,

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obligates professionals in healthcare to disclose information, investigate a patient's illness, and ensure understanding in order to facilitate adequate decision making.

Moreover, constitutional, statutory, and common law decrees that individuals possess autonomy and self-determination rights, which encompass the right to accept or refuse medical treatment. It is the right to self-determination in treatment, and not the mere refusal of the proposed treatment, that warrants an assessment of the patient's capacity to make reasoned treatment decisions. When carefully explored and appropriately employed, the capacity assessment ultimately serves to protect the practitioners rendering treatment from legal liability in cases being brought for invasion of privacy. A guide for when to assess the capacity of patients to make medical decisions follows in Table 2 (Leo, 1999).

**Table 2. Guiding the Legitimate Request for Capacity Assessment**

Criteria	Yes	No
Does the patient understand the current medical condition?	Capacity assessment likely not needed	Capacity assessment may be needed
Does the patient understand the natural course of the condition?	Capacity assessment likely not needed	Capacity assessment may be needed
Does the patient understand the proposed treatment intervention?	Capacity assessment likely not needed	Capacity assessment may be needed
Does the patient understand the risks/benefits of the proposed treatment/intervention?	Capacity assessment likely not needed	Capacity assessment may be needed
Does the patient understand what might happen if the proposed treatment/intervention is refused?	Capacity assessment likely not needed	Capacity assessment may be needed
Does the patient understand whether there are any viable alternatives to the proposed treatment/intervention?	Capacity assessment likely not needed	Capacity assessment may be needed
Does the patient understand the potential risks/benefits of the alternative treatments?	Capacity assessment likely not needed	Capacity assessment may be needed

#### When a Capacity Assessment is Warranted

Several clinical tools have been developed to assess the capacity of patients. As capacity is not static, the decision usually requires more than one assessment. These assessment tools include (Dastidar & Odden, 2011):

- **The Mini-Mental Status Examination (MMSE)** is a bedside test of a patient's cognitive function, with scores ranging from 0 to 30. Although it wasn't developed for assessing decision making capacity, it has been compared with expert evaluation for assessment of capacity. Specifically, a MMSE >24 is associated with having capacity, while a MMSE <16 is associated with a lack of capacity. Scores from 17 to 23 is associated with undetermined capacity, and further testing would be necessary. This examination is easy to administer, requires no formal training, and is known by most hospitalists. However, it does not address any specific aspects of informed consent, such as understanding or choice, and has not been scientifically validated in patients with mental illness. The MMSE is an attractive alternative assessment because of its widespread use and familiarity; however, it is imprecise with scores from 17 to 23, limiting its applicability.
- **The MacArthur Competence Assessment Tools for Treatment (MacCAT-T)** is regarded as the gold standard for capacity assessment aids. It utilizes hospital chart review followed by a semi-structured interview to address clinical issues relevant to the patient being assessed. The interview and assessment takes 15 to 20 minutes to complete. The test provides scores in each of the four domains (choice, understanding, appreciation, and reasoning) of capacity. It has been scientifically validated in patients with dementia, schizophrenia, and depression. The MacCAT-T has been validated in the broadest population and is probably the most clinically useful tool currently available. Limiting its clinical applicability is the fact that the MacCAT-T requires training to administer and interpret the results, though this training is a relatively brief process.
- **The Capacity to Consent to Treatment Instrument (CCTI)** uses hypothetical clinical vignettes in a structured interview to assess capacity across all four domains. The tool was developed and

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scientifically validated in patients with dementia and Parkinson's disease, and takes 20 to 25 minutes to complete. A potential limitation of this assessment is the relevancy of the CCTI's use of vignettes as opposed to a patient-specific discussion, which could lead to different patient answers regarding the present situation and a misunderstanding and false assessment of the patient's capacity to render decisions about the current clinical situation.

- **The Hopemont Capacity Assessment Interview (HCAI)** utilizes hypothetical vignettes in a semi-structured interview format to assess understanding, appreciation, choice, and likely reasoning. The HCAI is limited in that it is not modified for individual patients. Rather, it uses clinical vignettes to gauge a patient's ability to make decisions. The test takes 30 to 60 minutes to administer and performs less well in assessing appreciation and reasoning than the MacCAT-T and CCTI assessments.

Dastidar and Odden (2011) have provided a comparison of the most widely used standard Competency Evaluation Tools (See Table 3).

**Table 3. Competency Evaluation Tool Comparison Chart**

Tool	Validated populations	Length to administer	Strengths	Limitations
MacCAT-T	Dementia, depression, schizophrenia	15-20 minutes	Broadly validated, well-established	Requires formal training, does not specify a passing score
CCTI	Dementia	20-25 minutes	Standardized format	Vignettes are hypothetical, might not be applicable to a specific clinical decision
MMSE	Dementia, delirium, psychosis	10-15 minutes	For most, requires no additional training, can give rapid information at the extremes of scores	Psychosis under-represented in the validation study, does not address informed consent
HCAI	Dementia, nursing home residents	30-60 minutes	Might be good for screening	Length, poor performance of reasoning and appreciation assessments

It is not necessary to perform a formal assessment of capacity on every patient. For most patients, there should be no reasonable concern for impaired capacity, obviating the need for formal testing. Likewise, in patients who clearly lack capacity, such as those with end-stage dementia or those with established guardians, formal *reassessment* usually is not required. Formal testing is most useful in situations in which capacity is unclear, disagreement amongst surrogate decision-makers exists, or judicial involvement is anticipated (Dastidar & Odden, 2011).

In the *psychiatric* setting, severe suicide attempts along with suicidal ideas, intent, or plans constitute prima facie evidence for a psychiatric disorder and the lack of capacity to make reasoned decisions

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regarding interventions, such as the need for psychiatric hospitalization and treatment. However, in **medical** settings, a patient's refusal of potentially lifesaving measures cannot necessarily be equated with suicidal intent (Dastidar & Odden, 2011).

The patient exhibiting a psychosis may have a preexisting psychotic disorder or may have regressed under the stress of illness and/or hospitalization and become psychotic. Despite the presence of bizarre behaviors, inappropriate affect, and disturbances in thought processes or content, such patients may nevertheless retain the cognitive abilities to understand, recapitulate, and appreciate those factors required to make treatment decisions. The practitioner wishing to override a refusal of treatment must prove the incapacity of the patient with a reasonable degree of medical certainty. If the patient has incurred a crisis prompting the questionable decision making, all steps must be taken to restore autonomy, even if it is for a short time, and respect the wishes of the patient. Thus, the capacity assessment must take into account the patient's appreciation of the meaning of his/her decision, comprehension, retention of information, and the assigning of weight to available treatment options (Dastidar & Odden, 2011).

Deciding that a patient lacks capacity is not an end in itself. Practitioners should search for and address the underlying cause of incapacity. Certain factors, such as infection, medication, time of day, language used, and relationship with the practitioner doing the assessment, can affect a patient's capacity. These should be addressed through treatment, education, and social support whenever possible in order to optimize a patient's performance during the capacity evaluation. If the decision can be delayed until a time when the patient can regain capacity, this should be done in order to maximize the patient's autonomy (Dastidar & Odden, 2011).

Practitioners should be thorough in documenting details in coming to a capacity determination, both as a means to formalize the thought process running through the four determinant components of capacity, and in order to document for future reference. Cases in which it would be reasonable to call in a consultant to administer the assessment for those who are familiar with the assessment basics and who would otherwise administer the assessment include (Leo, 1999) (See Table 4):

- Cases in which a determination of lack of capacity could adversely affect the practitioner's relationship with the patient;
- Cases in which the practitioner lacks the time to properly perform the evaluation;
- Particularly difficult or high-stakes cases (e.g. cases that might involve legal proceedings); and
- Cases in which significant mental illness affects a patient's capacity.

**Table 4. Requests for Capacity Assessment as a Function of Patient Decision and Benefits/Risks Associated With an Intervention**

<b>Decision</b>	<b>High beneficial outcome and/or low risk of intervention</b>	<b>Poor outcome and/or high risk of intervention</b>
<b>Patient accepts the intervention</b>	Requests for capacity assessment are low	Requests for capacity assessment are high
<b>Patient refuses the intervention</b>	Requests for capacity assessment are high	Requests for capacity assessment are low

Practitioners need to recognize that capacity to make reasoned and medical decisions are task specific. Therefore, a patient might lack capacity to make reasoned medical decisions, but may be fully capable of selecting an agent under the Health Care Proxy Law. Thus, practitioners should direct the inquiry about an agent designee to the patient in most situations. If the patient is incapable of expressing a preference about an agent designee or cannot select or refuses to select an agent, then the practitioner must defer to the law on the available substitute decision makers (Leo, 1999).

Early involvement of potential substitute decision makers should be sought for patients in whom capacity is questioned, both for obtaining collateral history as well as initiating dialogue as to the patient's wishes. When a patient is found to lack capacity, practitioners should incorporate the use of all available

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resources to help make a treatment decision. Resources include looking at an existing advance directive and initiating conversation with substitute decision-makers, such as health care proxy agents, guardians, and surrogates. In those rare cases in which practitioners are unable to reach a consensus about a patient's capacity, the facility ethics committee should be consulted.

## Ethics in End of Life Decision Making

### Immanuel Kant's Ethical Theory

Kant's ethical theory is a deontological theory as it focuses on the intrinsic nature of an action itself, rather than the consequences of the action. Kant's ethics can be subdivided into three categories, namely the concept of Goodwill, the concept of Duty and the concept of Categorical Imperative.

According to Kant, **goodwill** is the only one thing that is good and without qualification. Other things considered to be good are not unconditionally good inasmuch as their goodness can be bad when misused. For example, a practitioner can use his/her knowledge about the adverse effects of a drug to harm a patient. Therefore, the implication of Kant's concept of goodwill in medical practice is that practitioners and healthcare workers are charged to always have goodwill in their dealings with their patients. It is only by doing so that any actions taken can always be justified as good (Ilemona, Bolatito, John, & Ikeoluwapo, 2012).

When espousing the concept of **duty**, Kant distinguishes two types of duty: "acting for the sake of duty" and "acting according to duty". Kant regards the former as perfect duty and the latter as imperfect duty. To take action in the name of duty is to perform one's duty not because of the hope of personally or professionally gaining anything from one's actions, or because one "just feels like doing it", or because one has a natural inclination to do such things. Rather, it implies doing one's duty purely out of reverence for the moral law and ethical rightness. In other words, for an action to have moral value or to be morally praiseworthy, it must be done strictly for the sake of duty, or out of respect for the moral law (Ilemona, Bolatito, John, & Ikeoluwapo, 2012).

Kant's ethics also distinguishes right from wrong actions by means of the principle of *universalization*, which is the first formulation of his **Categorical Imperative**. To know whether an intended action is morally right, the underlying principle of the action should be considered and universalized. The second formulation of Kant's Categorical Imperative is that we should always act to ensure *humanity* as an end, and not as a means to an end. According to Kant, every rational creature possesses an autonomous self-legislative will. This, including the rationality they possess, enables them to make rules for themselves, direct their actions, and consider the consequences of their actions. In the context of the healthcare setting, practitioners must, therefore, never undermine the patient's self-respect or humiliate them for that would violate the requirement that the healthcare provider treat people with respect and humanity (Ilemona, Bolatito, John, & Ikeoluwapo, 2012).

Applying Kant's ethics to the issue of advance care directives, practitioners and other healthcare workers owe patients a duty to first and foremost, inform them about living wills and encourage them to make one. For those who have made living wills or advance directives, there is a duty to treat them as rational, autonomous beings that are ends in themselves, by respecting and implementing every instruction contained in the advance directives, whenever the need arises. Of utmost importance is that practitioners should ensure that all rules made and all issues handled in advance care directives are such that can be universally applied to each and every individual as the need arises.

### Utilitarianism

Within the context of the healthcare system, this is an ethical theory which suggests that an act should be judged to be either right or wrong according to the pleasure produced and the pain avoided. According to the principle of utility, the moral end that should be sought in all that we do is the greatest possible balance of good over evil; thus, the end justifies the means. John Stuart Mill, a notable philosopher, formulated 'the Greatest Happiness Principle', which holds that actions taken are right if they tend to promote happiness, wrong as they tend to produce the reverse of happiness. Happiness is defined as pleasure, and the absence of pain; unhappiness is defined as pain, and the deprivation of pleasure (Stokes, 2006, p. 115). Similarly, Jeremy Bentham, another notable philosopher, formulated a principle which insists that the good for man is the attainment of pleasure and the absence of pain. Bentham was a hedonist who believed that individual happiness is based upon pleasure and pain: increased pleasure and decreased pain bring happiness while decreased pleasure and increased pain bring unhappiness. He

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believed that what is greatest in an individual's self-interest is to have pleasure rather than pain, and that the total happiness of the community is nothing but the sum of the individual happiness of its members (Barclow, 1994).

Thus, based on the utilitarian ethical theory as advocated by Mill and Bentham and those other philosophers who think in a like manner, the pleasure principle is the key to happiness, and the individual must decide what gives them happiness, or pleasure. Moreover, paternalism in medical practice would be morally acceptable if it produces pleasure or reduces pain for the greatest number of people. According to this ethical theory, if a practitioner or healthcare worker forced his or her own ideas on a patient, treated or carried out a procedure on a non-consenting patient, or outrightly disregarded a patient's feelings, idea or wishes, it would be **morally** (but **not legally**) acceptable so long as it was to the benefit of a greater number of people such as the patient's family or relatives, or the government at large. Juxtaposed to this position, if paternalistic actions by practitioners and other healthcare workers resulted in pain or sadness for the patient, then it would be morally wrong. For example, disregarding the wishes of a dying patient thereby causing displeasure for that patient would be, according to utilitarian ethical theory, morally wrong.

The utilitarian ethical theory is extremely problematic as it is based on Libertarian principles, is confusing, is difficult to employ, and as it is, in some instances, antithetical to the legal rights of the patient's advance directive. First and foremost, we cannot say for sure what the consequence of a particular action will turn out to be. That is, it would be difficult to predict whether an action will produce the greatest balance of good over evil. The utilitarian theory also does not assign intrinsic rightness to the action itself that was chosen. It only considers the consequence of an action and cannot say specifically what actions it would permit and what actions it would want practitioners to desist from. Utilitarianism does not consider the intention of the agent. Another problem with utilitarianism is that it permits the suffering of the few for the benefit of the majority.

One potential advantage of utilitarianism in medical practice, however, is that it can discipline a practitioner to be cautious before taking or performing an action. The practitioner is constrained to act more cautiously by calculating the consequences of an intended action (Ilemona, Bolatito, John, & Ikeoluwapo, 2012), particularly when the practitioner is only allowed, in accordance with current law, to educate the patient and not make decisions on their behalf.

### A Critique of Paternalism in Medicine

Paternalism in medicine has become antithetical to current law because it entails practitioners telling patients what is good for them, without regard to the patient's own needs, interests, cultural values, and self-determination. Paternalistic approaches to medicine could also be construed as abuse of the power entrusted to practitioners. Characterized as the antithesis of autonomy, it is therefore widely now thought not to have any acceptable role in medicine, and is often expressed as being in conflict between the principles of autonomy and beneficence. Paternalistic practitioners may be intending to act in the patient's best interest, but may not be fully considering how their perception of those best interests could be changed or modified if the practitioner had a fuller understanding of the patient's values and views. According to Mills, and in defense of his ethical philosophy, "the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to self or others. His own idea of good, either physical or moral, is not a sufficient warrant".

Contrary to the idea of paternalism is that of patient autonomy. **Autonomy** refers to the capacity to be one's own person, to live one's life according to reasons and motives that are taken as one's own, and not the product of manipulative or distortive external forces. John Stuart Mill describes autonomy as one of the elements of wellbeing. This view allows one to adopt a generally **consequentialist** moral framework while paying heed to the importance of self-government to a fulfilling life. To what extent is it morally required to allow individuals to act in pursuit of their own aspirations? Does an individual with self-destructive aspirations thereby lose the right to autonomy generally enjoyed by others? Should freedom to act include freedom to follow a foolish or tragic course or events, or is it justifiable to override another's autonomy paternalistically, as well as for reason of social benefit? Does respect for a patient's autonomy

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require honesty on the part of the physician, even when deception seems medically prudent? These are some of the difficult ethical questions that arise in practice when caring for patients at end-of-life.

## End of Life Medical Decisions

In helping a patient to determine their end of life wishes, nurses and physicians should discuss the patient's cultural, moral, and ethical values. Practitioners should help patients to consider how important it is to them to be independent and self-sufficient, and to identify what circumstances might make them feel like their life is no longer worth living.

Some basic questions a practitioner can ask the patient include:

- (1) Would you want treatment to extend your life in any situation?
- (2) Would you want treatment to extend your life in all situations?
- (3) Would you want treatment only if a cure is possible?
- (4) What would you want or not want in the event of a critical illness, a terminal illness, or permanent unconsciousness?

Patients should address a number of possible end-of-life care decisions before executing an advance directive. The following medical decisions should be considered (Mayo Foundation for Medical Education and Research, 2019):

- **Cardiopulmonary resuscitation (CPR).** The patient should determine if and when they would want to be resuscitated by CPR or by a device that delivers an electric shock to stimulate the heart.
- **Mechanical ventilation.** The patient should consider if, when, and for how long they would want to be placed on a mechanical ventilator.
- **Tube feeding.** The patient should determine under what circumstances they would want to be supplied with nutrients and fluids intravenously or via a tube in the stomach. Considerations include if, when, and for how long they would want to be fed and hydrated in this manner.
- **Dialysis.** Dialysis removes waste from the blood and manages fluid levels if the kidneys no longer function. The patient should determine if, when and for how long they would want to receive this treatment.
- **Antibiotics or antiviral medications.** Medications can be used to treat many infections. The patient should determine if they were near the end of life, would they want infections to be treated aggressively or would they rather let infections run their course?
- **Comfort care (palliative care).** Palliative care includes any number of interventions that may be used to keep a patient comfortable and manage pain while abiding by other treatment wishes. The patient should determine if they want to die at home, get pain medications, be fed ice chips to soothe mouth dryness, avoid invasive tests or treatments, etc.
- **Organ and tissue donations.** Donation of organs and tissues for transplantation can be specified in the living will. If organs are removed for donation, the patient will be kept on life-sustaining treatment temporarily until the procurement procedure is completed. To help the health care agent avoid any confusion, the patient should state in his/her living will and/or proxy document that they understand the need for this temporary intervention.
- **Donation of the whole body.** The patient should determine if they want to donate their body for scientific study. Practitioners can help the patient to contact a local medical school, university or donation program for information on how to register for a planned donation for research.



## **Lack of Confidence in and Limited Knowledge of Advance Directives Law is a Barrier to Implementation**

Less than 30% of older adults have a written advance directive. Only 18% to 36% of younger adults have a written advance directive. Only one out of three primary care providers are aware of whether their patients have or have not initiated an advance directive instrument. Fewer than one out of three primary care providers gives assistance to their patients to create an advance directive, primarily due to the fact that the directives tend to be disregarded in practice. Today's advance directives are rooted in the concept that an "irreversible condition" exists, and physician perceptions of the reversibility of the medical condition is a major factor in the decision to disregard the advance directive (Nelson & Nelson, 2014). Although most healthcare providers support the use of advance directives, industry practices, such as paternalism (the idea that the provider knows best), and ethical principles, such as beneficence (the promotion of well-being) and nonmaleficence (the avoidance of harming a patient), as well as legal ramifications are perceived as conflicting with the patient's right to autonomous decision making. In the absence of an expressed waiver of liability against criminal, civil, or disciplinary sanctions written into the law, most practitioners tend to aggressively treat their patients. Similarly, practitioner knowledge of advance directives and separating limited knowledge of advance directives from personal values tend to limit patient autonomy in practice (Miller, 2018; Nelson & Nelson, 2014).

Multiple studies have documented that completing advance directives does not effectively reduce surrogate decision maker stress or enhance communication between patients and surrogates. This is due, in part, to the struggle patients undergo in identifying their own goals and values related to end of life care. Moreover, some practitioners believe that since the advance directive is made in advance of an actual medical crisis, the patient is acting without the benefit of informed consent and is, additionally, making decisions without knowledge or understanding of the underlying legal, social, physical, or emotional conditions that may influence the decision making at the time it is required. Thus, current thoughts documented in the literature indicate that even in those circumstances where the patient is communicating with their surrogate decision maker, the directives given to the surrogate are rooted in a lack of informed consent (Miller, 2018; Nelson & Nelson, 2014).

## Problems Created by Lack of Advance Directive

Unless there is an advance directive in existence, physicians are generally dissuaded from following the directives of a surrogate for fear of possible civil litigation and/or criminal liability. This fear, in part, is manifested by inconsistencies in the law, misunderstanding of the law, misapplication of the law, and by political and ideological resistance by a few interest groups that attempt to characterize surrogate decision-making as a pretext for denying treatment to vulnerable persons or for actively hastening death in vulnerable persons (Kapp, 2016). The inconsistencies in the law, and the claims of these interest groups have been rebutted by various New York State Task Forces. This will be further discussed in the section below **“Medically Futile Criteria Abolished in New York State by the FHCDA”**.

### The New York State Family Health Care Decisions Act (FHCDA)

Up until 2010, New York law did not permit the withdrawal or withholding of life-sustaining treatment from an incapacitated adult patient who has neither created a health care proxy nor has left written or oral treatment instructions that satisfy the clear and convincing standard. The New York State Court of Appeals had explicitly held that no one, not even a close and concerned family member, could refuse life-sustaining treatment for another person without clear and convincing evidence of the patient’s own wished (*In re Storar*. 420 N.E.2d 64, 52 N.Y.2d 363, 438 N.Y.S.2d 266, 1981).

Presently, the Family Health Care Decisions Act (FHCDA) allows family members to make healthcare decisions, including decisions about the withholding or withdrawal of life-sustaining treatment, on behalf of patients who lose their ability to make such decisions and have not prepared advance directives regarding their wishes. This law establishes procedures authorizing family members, or other persons close to patients who lack decision-making capacity, to decide about treatment, based upon the “best interests” of the patient, in consultation with health care professionals and in accord with specified safeguards. It includes procedures and standards for decisions about life sustaining treatments. There must be a determination by the patient’s attending physician that the patient lacks capacity before this law is triggered. In a residential health care facility, at least one other health or social service practitioner must concur. In a general hospital, this concurrence is required for a surrogate decision to forgo life-sustaining treatment. Hospitals must adopt written policies identifying the training and credentials of professionals qualified to provide the concurring opinion. Notably, if there is any indication that the patient can understand the information, then he or she must be informed of the determination of incapacity. If the patient objects, then the patient’s objection prevails, unless a court determines otherwise.

The list of persons under the FHCDA who may act as a surrogate are in order of priority:

A court-appointed guardian, the spouse or domestic partner, a child older than 18, a parent, a sibling or a close adult friend or relative familiar with the patient’s personal, religious and moral views regarding health care. Administrators, employees and independent contractors of the hospital caring for the patient are excluded, unless they are related to the patient, or were a close friend of the patient before the patient’s admission to the facility.

Under this law, the surrogate has authority to make all health care decisions for the patient that the patient could have made for himself or herself. The surrogate will be given medical information and records necessary to make an informed decision.

Another section of the law establishes a procedure for making health care decisions for adult patients who have lost decision-making capacity and have no available family member or friend to act as a surrogate. It applies the same standards and safeguards. Under these circumstances, the FHCDA authorizes the *attending physician* to decide about routine medical treatment for patients without surrogates. For decisions about major medical treatment, the attending physician must consult with hospital staff directly involved with the patient’s care and at least one other physician selected by the hospital must concur in the appropriateness of the decision. However, in these instances there are

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special requirements for withholding or withdrawing life-sustaining treatment: The law requires approval by a court or the attending physician to determine that life-sustaining treatment offers the patient no medical benefit because the patient will die imminently, and the provision of life-sustaining treatment would violate acceptable medical standards. Where there is no court approval, one other physician must concur in this determination for life sustaining treatment to be withdrawn or withheld.

If the patient has a health care proxy designating an agent, then the health care proxy law prevails and is applied. Similarly if there is a guardian (appointed in the Surrogate's Court) for someone with Developmental Disabilities, then decisions for that patient are governed by the guardianship law before looking to the FHCDA directives. Differences between the Health Care Proxy Law and the FHCDA appear in Table 5.

**Table 5. Differences between New York Health Care Proxy and Surrogate Law**

<b>Query</b>	<b>Health Care Proxy Law</b>	<b>Surrogate Law</b>
<b>Who appoints the agent/surrogate?</b>	The patient via a properly executed health care proxy form	The Family Medical Decisions Act establishes who may act as a surrogate
<b>Who can serve as an agent/surrogate?</b>	Anyone over the age of eighteen (18)	In priority order: Article 81 guardians, spouses, children (over 18), parents, siblings (over 18), close friends
<b>When does agent/surrogate make decisions?</b>	When you lose capacity (established by MD)	When you lose capacity (established by MD)
<b>When does agent/surrogate stop making decisions?</b>	When you regain capacity, when the appointment expires, or under conditions specified in writing on the health care proxy form	When you regain capacity
<b>What decisions can agent/surrogate make?</b>	Any decision specified on the health care proxy form or living will, any decision in the best interests of the patient, decisions about withholding hydration and nutrition if the agent knows what the patient would have wanted. Agent's decision <b>takes precedence</b> over all surrogate decisions	Any decision
<b>Are there any limitations in decision-making?</b>	Limitations that are specified in the written document, withholding hydration and nutrition if not known.	Surrogates may only make decisions based on the patients moral or religious beliefs, or in the absence of these beliefs, in the patients best interest

### Patient Objections

Under the FHCDA, the patient has the authority to object to:

- The (negative) determination of their incapacity;
- The choice of surrogate; and
- The health care decision made by the surrogate.

In the event the patient disagrees with any of these determinations, the patient's wishes must be followed by all practitioners. However, if a court determines that the patient lacks capacity and (if applicable) authorizes the treatment decision, the patient cannot override these court determinations. Further, if there is some other legal basis for overriding the patient's decisions, s/he will be subject to the choices made by the surrogate (James, 2019). For example, if a wife who is hospitalized in a mental facility objects to the determination of incapacity and, out of delusional thoughts, objects to the husband-appointed surrogate, the healthcare law will override these objections.

## Medically Futile Criteria Abolished in New York State by the FHCDA?

Prior to the passage of the FHCDA, decisions about orders not to resuscitate were guided by Article 29-B of the New York State Public Health Law. Article 29-B provided definite procedures for consent to and for the issuance of DNR orders. Since the passage of the FHCDA, orders not to resuscitate are considered to be one type of decision about withholding or withdrawing medical treatment, as opposed to simply a physician's order. Thus, physicians have become anxious about criminal, civil, or disciplinary sanctions associated with a decision to withhold or withdraw life sustaining medical intervention, including the DNR order (Kapp, 2016).

In accordance with the New York FHCDA, decisions by surrogates to withhold or withdraw life-sustaining treatment are authorized only if at least one of the following two conditions is satisfied:

1. "Treatment would be an extraordinary burden to the patient and an attending physician determines, with the independent concurrence of another physician, that, to a reasonable degree of medical certainty and in accord with accepted medical standards, (A) the patient has an illness or injury which can be expected to cause death within six months, whether or not treatment is provided; or (B) the patient is permanently unconscious."
2. "The provision of treatment would involve such pain, suffering or other burden that it would reasonably be deemed inhumane or extraordinarily burdensome under the circumstances and the patient has an irreversible or incurable condition, as determined by an attending physician with the independent concurrence of another physician to a reasonable degree of medical certainty and in accord with accepted medical standards."

Although this language is seemingly clear, physicians, nurses and other healthcare personnel continue to disagree about the meaning of this language and the implementation of the process. This is due, in part, to the changes in past practices, and to the "removal" of the criteria for "medically futile" patients from the FHCDA language and the FHCDA's concomitant removal of the physician's ability to determine whether to write a DNR order on the patient's behalf (See Table 6) (Karmel, 2010).

**Table 6. Differences between the PHL Article 29-B and the FHCDA**

Query	Article 29B	FHCDA (Effective June 1, 2010)
<b>Where is the law applicable</b>	<b>Article 29-B Orders Not To Resuscitate only applies to DNR orders</b> issued in certain "mental hygiene facilities" licensed by the Office of Mental Health (OMH) or Office for People with Developmental Disabilities (OPWDD), residential care facilities, and general hospitals	A new article of the Public Health Law ( <b>Article 29-CC: Family Health Care Decisions Act</b> ) applies to all health care decisions for patients of general hospitals and residents' of nursing homes, <b>including DNR orders</b>  <b>FHCDA is not applicable if:</b> <ul style="list-style-type: none"> <li>– a health care agent under a health care proxy has authority to make decisions</li> <li>– a SCPA Article 17-A guardian (§ 1750-b) has authority to make decisions (for a person with a developmental disability)</li> <li>– Surrogate decision-making is provided for by MHL Article 80 and 14 NYCRR Part 710 (Surrogate Decision Making Committees), 14 NYCRR §§ 633.10, 633.11 (OPWDD facility patients), 27.9 or 527.8 (OMH facility patients)</li> </ul>
<b>Who can consent to a DNR</b>	<ul style="list-style-type: none"> <li>– Adults with capacity who consent</li> <li>– Adults without capacity when a surrogate consents from the surrogate list, and the surrogate is available</li> <li>– Adult patients without capacity for whom no surrogate is available if</li> </ul>	<ul style="list-style-type: none"> <li>– Adults with capacity who consent</li> <li>– Agent under a healthcare proxy takes precedence over surrogate</li> <li>– A surrogate in accordance with the list under FHCDA</li> <li>– Even if the patient lacks capacity, there is no surrogate decision-making permitted where the patient has previously made a decision about the healthcare prior to losing capacity and the decision is:               <ul style="list-style-type: none"> <li>o in writing or orally</li> </ul> </li> </ul>

	CPR would be <b><u>“medically futile.”</u></b> (MD makes the decision)	<ul style="list-style-type: none"> <li>○ with respect to a decision to withhold or withdraw life sustaining treatment, such oral consent must be during <ul style="list-style-type: none"> <li>– hospitalization in the presence of two witnesses eighteen years of age or older, at least one of whom is a health or social services practitioner affiliated with the hospital</li> </ul> </li> </ul>
<b>What decisions can be made</b>	<ul style="list-style-type: none"> <li>– Applies to <b>DNR orders only</b></li> <li>– Patient is presumed to be competent and can make a DNR order</li> <li>– Surrogate consent to a DNR order is based on <b>“patient’s wishes,”</b> or if they’re unknown, <b>“best interests.”</b></li> </ul>	<ul style="list-style-type: none"> <li>– <b>Applies to all healthcare decisions</b> for patients of general hospitals and residents of nursing homes, <b>including DNR orders.</b></li> <li>– Patients are presumed to have medical decision making capacity unless a physician (with the concurrence of another health or social service Practitioner) determines that the patient lacks capacity In a general hospital, the concurring determination is only required for decisions to withhold or withdraw life-sustaining treatment</li> <li>– If patients lack capacity, there is a surrogate list.</li> <li>– Decisions based on <b>“patient’s wishes,”</b> or if they’re unknown, <b>“best interests”</b></li> </ul>
<b>What if there is no surrogate</b>	<ul style="list-style-type: none"> <li>– A facility can put a DNR order in place on his/her own</li> <li>– The clinical requirement is that “resuscitation would be <b><u>“medically futile”</u></b>”</li> </ul>	<ul style="list-style-type: none"> <li>– <b>Routine medical treatment:</b> attending physician can decide on his/her own</li> <li>– <b>Major medical treatment:</b> 2nd physician must concur (note: includes an HIV test)</li> <li>– <b>Only applies to health care, not providing nutrition or hydration</b></li> <li>– Decisions to withhold or withdraw life sustaining treatment (including DNR orders) made by: <ul style="list-style-type: none"> <li>○ a court may make a decision to withhold or withdraw life-sustaining treatment; or</li> <li>○ the attending physician, with independent concurrence of a second physician, determines to a reasonable degree of medical certainty that <ul style="list-style-type: none"> <li>▪ life-sustaining treatment offers the patient no medical benefit because the patient will die imminently, even if the treatment is provided; <b>and</b></li> <li>▪ the provision of life-sustaining treatment would violate accepted medical standards</li> </ul> </li> </ul> </li> </ul>
<b>What about a non-hospital DNR</b>	<ul style="list-style-type: none"> <li>– Must be on the regulatory form (DOH-3474 form)</li> <li>– Use of an “alternative form,” which may also include a do not intubate (DNI) order, must be approved by the Commissioner. The <b><u>Medical Orders for Life-Sustaining Treatment (MOLST)</u></b> form was approved for use only in non-hospital DNRs</li> </ul>	<ul style="list-style-type: none"> <li>– Similar to the provisions that were previously in Article 29-B</li> </ul>
<b>Clinical criteria to withhold or withdraw life sustaining treatment, including DNR orders</b>	<ul style="list-style-type: none"> <li>– Patient has a terminal condition: an illness or injury from which there is no recovery, and which reasonably can be expected to <b><u>cause death within one year</u></b></li> </ul>	<ul style="list-style-type: none"> <li>– Treatment would be an extraordinary burden to the patient and an attending physician determines, with the independent concurrence of another physician that, to a reasonable degree of medical certainty and in accord with accepted medical standards:</li> </ul>

	<ul style="list-style-type: none"> <li>- Patient is permanently unconscious</li> <li>- Resuscitation would be <b>medically futile</b></li> <li>- Resuscitation would impose an extraordinary burden on the patient in light of the patient's medical condition and the expected outcome of resuscitation for the patient</li> </ul>	<ul style="list-style-type: none"> <li>o Patient has an illness or injury which can be expected to <b>cause death within six months</b>, whether or not treatment is provided</li> <li>o Patient is permanently unconscious</li> <li>- The provision of treatment would involve such pain, suffering or other burden that it would reasonably be deemed <b>inhumane or extraordinarily burdensome</b> under the circumstances <b>and the patient has an irreversible or incurable condition</b>, as determined by an attending physician with the independent concurrence of another physician to a reasonable degree of medical certainty and in accord with accepted medical standards</li> </ul>
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\*Adapted from Karmel, J. (May, 2010). Family Health Care Decisions Act. Retrieved from <https://molst.org/wp-content/uploads/2018/03/FHCDAEMSBriefing.pdf>.

As a result of the confusion created by the differences in these two laws, New York Senators Gottfried (D) and Abinanti (D) have proposed Bill No. NY A01203: AN ACT to amend the public health law and the surrogate's court procedure act, in relation to **restoring medical futility** as a basis for both surrogate consent to a 'do not resuscitate' order, and for a 'do not resuscitate' order for a patient without a surrogate. This bill was referred to the New York State Assembly Health Committee on January 14, 2019. To date, and until this bill becomes a law, the FHCDA does not have a standard specifically relating to medically futile resuscitation. Similarly, to date, the Surrogate's Court Procedure Act §1750-b does not have a standard specifically relating to medically futile resuscitation for developmentally disabled patients (A01203 text, 2019).

## Involving Patients in Advance Care Planning

Provision 1.4 of the American Nurses Association's *Code of Ethics* (2015), in addition to federal and state laws, dictates the ethical and legal obligation of the nurse to educate patients, assist them in creating an advance directive, and advocate for their legal right to self-determination and autonomy (Miller, 2017).

Nevertheless, nearly thirty years have passed since the enactment of the federal Patient Self-Determination Act, and the literature has shown that this legislation has fallen short in making any significant impact on advanced health care planning or on patients. Patients simply do not foresee the need for an advance directive. One reason for this finding is that many Americans are reluctant to discuss their mortality, and hospital admissions, where advance directive discussions are raised for the first time, are not the ideal time to discuss end-of-life wishes. This reason, combined with the belief that loved ones will make the best decisions on the patient's behalf, has created a false security, particularly in view of the finding that most patients perceive medical interventions as an "absolute good" and without the possibility of failure (Kroning, 2014).

Research has indicated that educating patients about advance directives using the Knowles Andragogical Model is highly effective. The Knowles model identifies six assumptions about adult learners (Kroning, 2014):

1. They need to know why learning should occur
2. They need to be responsible for their own learning
3. The learners' previous experiences are the foundation for learning activities and acquiring new knowledge
4. The learners must be ready to learn
5. Adult learners have a problem-centered orientation to learning
6. Internal motivators to learn are more influential than external motivators

In accordance with Knowles' theories and model, nurses can help involve patients in advance care planning by initiating the following educational plan (Kroning, 2014):

1. Explore previous end-of-life experiences with loved ones with the patient
2. Discover patient cultural beliefs and values
3. Explore patient current level of knowledge of advance directives
4. Identify knowledge deficits
5. Present new information via discussions, questions and answers, review of pamphlets, videos, etc.
6. Apply learning through role play using scenarios from previous discussions

This education should also include the benefits and risks associated with the patient's choices in the same manner that is done with all informed consent conversations.

One of the most important conversations nurses should have with patients that may be highly useful to them and their healthcare decisions makers is a values history. Although not mandated by law, value histories are recommended and highly beneficial when it comes to end of life care and decision making, particularly when a person is appointed as a health care agent. Values histories contain and consist of the patient's general basic beliefs, values, opinions and principles relating to the following concepts:

- The quality of life versus the quantity of life
- The management of pain even if it may shorten the duration of life
- Surgical procedures and associated alterations of the body image
- "Being a guinea pig" (involving oneself in research trials)
- Dignity and maintaining dignity at the end of life

Prior to initiating conversations with patients about advance directives, nurses should reflect on their own beliefs and values and understand that their primary duty, despite their own personal belief, is to (1)

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ensure that treatment is consistent with the patient's wishes; (2) ensure effective communication of the patient's wishes; (3) ensure the healthcare team is aware of the advance directive; (4) advocate for the patient whenever a practitioner or agent or surrogate is directing care in opposition to the patient's wishes.



## **Conclusion**

This program describes some of the current ethical and legal issues surrounding advance directives and the role of nurses and other healthcare practitioners regarding their application. In addition to this resource, nurses are encouraged to turn to other resources, such as the Code of Ethics for Nurses, nursing colleagues, ethics committees, management, facility policies, and nurses associations, in supporting the nurses' ethical and legal commitment and obligations to the patient's wishes, choices, dignity, and rights.

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## Advocating for a Patient's Self-Determined Autonomy: An Advance Directive Primer

### Course Exam

After studying the downloaded course and completing the course exam, you need to enter your answers online. **Answers cannot be graded from this downloadable version of the course.** To enter your answers online, go to the e-leaRN web site, [www.elearnonline.net](http://www.elearnonline.net) and click on the Login/My Account button. As a returning student, login using the username and password you created, click on the "Go to Course" link, and proceed to the course exam.

**Note:** Contact hours/CEUs will be awarded for this online course until July 30, 2022.

1. An advance directive is all of the following EXCEPT:
  - A. An instruction given by a person while they still have decisional capacity concerning medical treatment they would or would not want.
  - B. Typically consists of either a living will or a written health care proxy.
  - C. Always written by the primary health care provider.
  - D. Legally required to be discussed with patients at the time of hospital admission.
2. Prior to making an advance directive, the individual should discuss their health care wishes with the person of their choice and confirm that person's willingness to act for you.
  - A. True.
  - B. False.
3. Once you have completed your advance directive, it is important to provide copies to your health care provider, your agent, close relatives and friends who may be involved in your care.
  - A. True.
  - B. False.
4. The Patient Self-Determination Act of 1990 specifies that adult patients receive written information on advance directives at the time of admission to hospitals, nursing facilities, home health care agencies, hospices and HMOs receiving federal reimbursement.
  - A. True.
  - B. False.
5. The American Nurses Association's Position Statement: Nursing and the Patient Self-Determination Act recommends:
  - A. That each nurse know the laws of the state in which she/he is practicing pertaining to advance directives.
  - B. That nursing's role in the implementation of this act includes: public education, research, patient care, advocacy, education and of the profession and other health care providers.
  - C. That questions about advance directives be part of the nursing admission assessment.
  - D. All of the above.
6. The purpose of an advance directive is all of the following EXCEPT:
  - A. Communicate and control healthcare decisions when the person is unable to because of a temporary or permanent illness or injury.
  - B. Appoint an agent to represent you in treatment decisions when you do not have the capacity to decide for yourself.

- C. Relieve family/friends/healthcare providers of the burden of struggling to decide what you would want.
  - D. To provide a monetary benefit to your heirs.
7. Dignified death:
- A. Is accompanied by respectful and skillful care giving.
  - B. Places focus on patient autonomy.
  - C. Is free from dependency or physiologic affronts not usually perceived as dignified.
  - D. All of the above.
8. The nurse should not hesitate to use full and effective doses of pain medication for the proper management of pain in the dying patient, even if this may affect a patient's capacity.
- A. True.
  - B. False.
9. Prior to making an advance directive, it is not helpful to determine the specifics of treatment you do or do not want.
- A. True.
  - B. False.
10. Competencies that insure quality care to patients and families regarding end of life care include all the following EXCEPT:
- A. Effective and compassionate communication with patient, family, and health care team.
  - B. Assistance to patient, family, colleagues and one's self in coping with suffering, grief, loss and bereavement.
  - C. Denial of feelings regarding one's own mortality.
  - D. Application of legal and ethical principles in the complex issues regarding end of life care.
11. New York State recognizes a patient's right to assisted suicide when the patient has a terminal illness.
- A. True
  - B. False
12. Competency is an assessment and legal determination made by a judge in court, whereas capacity refers to an assessment of the individual's psychological abilities to form rational decisions, specifically the individual's ability to understand, appreciate, and manipulate information and form rational decisions.
- A. True
  - B. False
13. Methods to test a patient's capacity include all of the following EXCEPT:
- A. The Mini-Mental Status Examination (MMSE)
  - B. The Capacity to Consent to Treatment Instrument
  - C. The Informed Consent Document
  - D. The Hopemont Capacity Assessment Interview
14. Five Wishes is a globally recognized advance directive created by the non-profit organization Aging with Dignity. It has been described as the "living will with a heart and soul."

- A. True
  - B. False
15. A MOLST allows doctors to record the patient's preferences regarding cardiopulmonary resuscitation (CPR), mechanical intervention, and other life sustaining treatments on one form as a physician order. It must be completed by a healthcare professional and signed by a New York State licensed physician to be valid.
- A. True
  - B. False
16. The research proves that the impact of the U.S. Constitution, the Patient Self Determination Act of 1991, and common law on nursing practice as it relates to the autonomy and self-determination of the patient is highly positive. Most hospitals and practitioners listen only to the patient when the patient has capacity.
- A. True
  - B. False
17. Since the passage of the FHODA, the circumstances of medically futile treatment have become controversial, and physicians have become anxious about criminal, civil, or disciplinary sanctions associated with a decision to withhold or withdraw life sustaining medical intervention, including the DNR order.
- A. True
  - B. False
18. Problems associated with a lack of an Advance Directive include all of the following EXCEPT:
- A. Healthcare practitioner fear of possible civil litigation and/or criminal liability
  - B. Healthcare practitioner misunderstanding of the law and misapplication of the law
  - C. Political and ideological interference by a few interest groups that attempt to characterize surrogate decision-making as a pretext for denying treatment to vulnerable persons or for actively hastening death in vulnerable persons
  - D. Reluctance of the courts to rule in these cases
19. Nurses can involve patients in advance care planning by doing all of the following EXCEPT:
- A. Educating patients about advance directives using the Knowles Andragogical Model
  - B. Advocate for the agent whenever a patient is directing care in opposition to the patient's best interests.
  - C. Initiating and educational plan with a discussion of the benefits and risks associated with the patient's choices in the same manner that is done with all informed consent conversation
  - D. Initiating a value's history conversation
20. Utilitarianism as an ethical theory in nursing holds that actions taken are right if they tend to promote happiness, wrong as they tend to produce the reverse of happiness. Therefore paternalism in medical practice would be morally acceptable if it produces pleasure or reduces pain for the greatest number of people. This principle is consistent with current law in New York State.
- A. True
  - B. False