

Module # 21: Ethics

Geriatrics, Palliative Care and Interprofessional Teamwork Curriculum

Module # 21: Ethics

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I. Overview

The delivery of ethical patient care is a goal of all health care providers, but this objective can be more challenging when the patient is older with an array of conditions and diseases. An interdisciplinary health care team may have an advantage in dealing with these issues because of the multiple perspectives brought to bear in case discussion. However, a possible disadvantage to the resolution of ethical issues in a team context is a tendency for “groupthink”, with the strongest team members dominating the discussion.^{1,2} Advance care planning is an ongoing process that offers the patient the opportunity to have a dialog with his or her family members and physician regarding the choices for care at the end of life. During this process, the patient's questions, fears and values are explored. As the important issues are uncovered, the information can be translated into a plan of action, called the advance directive. Ultimately, advance care planning is designed to clarify the patient's questions, fears and values, and thus improve the patient's well-being by reducing the frequency and magnitude of over treatment and under treatment as defined by the patient.

II. Learning Objectives

1. Define and describe ethical principles within a health care setting.
2. Compare personal values and professional codes of ethics.
3. Describe a seven-step process for ethical decision-making.
4. Delineate the role of the health care team in ethical decision-making.
5. Define Advance Care Planning.
6. Describe the benefits and barriers to Advanced Care Planning and Directives.
7. Describe the purpose and health care responsibilities related to the Patient Self-Determination Act.
8. Discuss informed consent, including definition, importance, related procedures, and influence of age.
9. Identify the legal consensus on treatment limitations.
10. Discuss the issue of physician-assisted suicide.
11. Discuss medical futility.

III. Definitions

The following two definitions are important for an understanding of ethics in health care:

- A. **Ethics** can be defined as declarations of what is right or wrong and what ought to be. Ethics is a specialized area of philosophy with origins dating back to ancient Greece. The ethical principles enunciated by Hypocrites still serve as the underpinnings of many of today's ethical issues. ³ In an ethical decision making process, one asks in a systematic way, "what do dignity and respect demand in terms of response from others?" Following are some questions that may follow from this initial question:
1. Do our values, behaviors, and character traits pass the test of further examination when measured against this standard?
 2. Which values, duties, and other guidelines are the most important in situations where conflicts arise?
 3. When situations present uncertainty, what aspects of present moralities will most reliably guide individuals on a path of survival?⁴
- B. **Ethical dilemma** can be defined as 1) a difficult problem seemingly incapable of a satisfactory solution, or 2) a situation involving choice between equally unsatisfactory alternatives. This is not to suggest that all dilemmas in life are ethical in nature; rather, that ethical dilemmas arise when moral claims conflict with each other. ⁵

IV. Ethical Principles Within Health Care ⁶

- A. **Autonomy**: the right to self-determination, independence, and freedom. Involves the provider's willingness to respect a patient's right to make decisions about and for him or herself, even if the provider does not agree with the patient's decision.
- B. **Justice**: the obligation to be fair to all people, regardless of race, sex, marital status, medical diagnosis, social standing, economic level, or religious belief. It is sometimes expanded to include equal access to health care for all.
- C. **Beneficence**: requires that providers do good for patients under their care. Good care requires that the provider understand the patient from a holistic perspective that includes the patient's beliefs, feelings, and wishes as well as those of the patient's family and significant others. Involves acting in ways that demonstrate caring; listening, empathizing, supporting, and nurturing.
- D. **Nonmaleficence**: requirement that providers do not harm their patients and opposite of beneficence. Also requires that providers protect those individuals from harm if they cannot protect themselves.

- E. **Veracity:** “truthfulness” requires that providers not intentionally deceive or mislead patients. Based on mutual trust and respect for human dignity. As with other rights and obligations, there are limitations to this principle; an example would be a situation where telling the patient the truth would seriously harm or produce greater illness or go against the cultural mores of the patient.

V. Framework For Ethical Analysis

There are several frameworks to analyze an ethical dilemma in a health care setting. (Refer to Figure 1, a modified case analysis structure originally developed by Jonsen, Siegler, and Winslade.)⁷ This framework is useful when discussing a particular case in a health care team setting.

VI. Personal Values vs. Professional Code Of Ethics⁸

- A. Personal values are generally derived from society. Providers need to know the patient’s values about life, health, illness and death. Some important ethical issues include:
1. Individual’s right to make decisions for self
 2. Euthanasia (active and passive)
 3. Blood transfusions
 4. AIDS/HIV
 5. Withholding fluids and nutrition
 6. Cultural differences
 7. Spiritual and religious differences
- B. Professional Values are often a reflection and expansion of personal values. They may come from ethic codes, healthcare experiences, teachers, and peers.
- C. A Code of Ethics is a formal statement that sets standards of ethical behavior for a group of people. Professional societies have developed codes of ethics for their members. It reflects the groups’ moral judgments over time and serves as a standard for their professional actions. Please go to the following sites to review professional codes of ethics:
1. National Association of Social Workers
<http://www.socialworkers.org/pubs/code/code.asp>
 2. American Pharmacists Association
http://www.aphanet.org/AM/Template.cfm?Section=Pharmacy_Practice_Resources&Template=/CM/HTMLDisplay.cfm&ContentID=2903
 3. American Nursing Association
<http://www.nursingworld.org/ethics/chcode.htm>
 4. American Medical Association
<http://www.ama-assn.org/ama/pub/category/2512.html>

VII. When The Provider Cannot Support The Patient's Decision ⁹

- A. Typically occurs when goals are unreasonable or illegal.
- B. Provider must set limits on what he or she will do without implying abandonment or destroying the relationship with the family.
- C. Provider should make the conflict explicit and offer to help find an alternate solution.

VIII. Overview Of Advance Care Planning

- A. Advance Care Planning is the process of planning for future medical care, particularly for the event when the patient is unable to make his or her own decisions. It also involves the patient deciding and designating whom they would like to make those decisions on their behalf in the event they cannot make them for themselves. ¹⁰
- B. Advance care planning involves decision making and the communication of those decisions between the person and their family, friends, physicians and other health care providers that ensure that patient's choices are known, preferably long before a crisis situation or when they can no longer communicate their wishes. The process helps patients identify and clarify their personal values and goals about health, medical treatment, and how, where, and with whom they want to live the end of their lives and puts in place concrete arrangements for services. ¹¹

IX. Definitions ¹²

- A. The **living will** (or "medical directive" or "declaration" or "directive to physicians") is a written instruction spelling out any treatments you want or don't want if you are unable to speak for yourself and terminally ill or permanently unconscious. A living will says in effect, "Whoever is deciding, please follow these instructions!" On its own, a living will is very limited—it usually applies only to end-of-life decisions, and standard instructions tend to be general.
- B. A **health care power of attorney** (or health care "proxy," or "medical power of attorney") is a document that appoints someone of your choosing to be your authorized "agent". You can give your agent as much or as little authority as you wish to make health care decisions. The decisions are not limited to just end-of-life decisions. Appointing an agent provides someone with authority to weigh all the medical facts and circumstances and interpret your wishes accordingly. A health care power of attorney is broader and more flexible than the living will.

- C. A comprehensive **Health Care Advance Directive** combines the living will and the health care power of attorney into one document. In addition, you may include any other directions, including organ donation or where and how you prefer to be cared for. Because it is more comprehensive and more flexible than the other tools, it is the preferred legal tool.

X. Why Have Advance Care Planning?

- A. States have laws supporting the appointment of a health care proxy.
- B. All states but New York and Michigan have a living will statute, but these documents are still recognized as a matter of practice in those states.
- C. The Patient Self-Determination Act (1990) requires all health care facilities that receive Medicare payments inform patients of their rights to complete advance directives under their state law.
 - 1. Insurance companies and regulatory agencies see advance directives as quality indicators.
 - 2. We will all die someday from a variety of disease for which there is a wide spectrum of treatments.
 - 3. Many of us will achieve advanced age and mental incapacity, where others will be deciding medical treatments for us.

D. Benefits and Barriers to Advanced Care Planning and Directives

A. Benefits

- 1. Advance Directives allow the individuals to exercise control over their bodies and direct health care in the event that they will lack decision-making capacity at the time a medical decision needs to be made. Older adults are more likely to develop impaired decision-making capacity than are younger people.¹³
- 2. When patients communicate these wishes ahead of time, it decreases the chance of conflict in future decision making, decreases the potential for ethical dilemmas, and takes the burden of the family and healthcare team when the patient can no longer communicate for him/herself. The sense of control and peace of mind that this process fosters in the patient and the reduction in anxiety of proxy decision-makers are important benefits.

B. Barriers

- 1. Vague language.
- 2. They do not guide treatment decisions by physicians - (SUPPORT Study).

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3. Surrogate decision makers often unaware of patient wishes, or unwilling to support them.
4. Physicians do not bring them up, and patients feel it is the physician's responsibility to do so.
5. Physicians have difficulty with truth-telling and breaking bad news.
6. Physicians want to maintain "hope".
7. Problems with prognostication.
8. Anticipated disagreement between physician and patient or family over appropriateness of specific treatments.
9. Physicians' fear of death.
10. Medical-legal concern
11. Physicians feeling advance directives not appropriate for healthy patients.
12. Time.

XI. Preparing A Living Will ¹⁴

- Prepared while the patient has decisional capacity.
- Describes the patient's preferences in the event they become incapable of making decisions or communicating decisions.
- Usually describes what type of life prolonging procedures the patient would or would not want and circumstances under which they would want these procedures carried out, withheld, or withdrawn.
- Documentation of living will - Copy should be in patient's home, physician's record, hospital record, outpatient record and with surrogate/proxy.
- Variations exist by state so professionals must be familiar with state laws.

XII. Patient Self-Determination Act

- A. The Federal Patient Self-Determination Act (PSDA): (enacted by Congress in 1991) creates obligations for health care facilities participating in the Medicaid and Medicare program to: 1) ask patients whether they have an advance directive and to record this information in the medical record; 2) to honor advance directives; 3) to educate patients about advance directives; and 4) to conduct community education. ¹⁵
- B. The Patient Self-Determination Act requires providers to tell patients what their state provides in the form of an advance directive, and hospitals are required to inform patients of their right to accept or refuse medical treatment and to make advance directives. The Act is intended to protect the views and choices of patients when they become incapacitated to make decisions. ¹⁶

XIII. Informed Consent

A. Definition

Informed consent is a legal doctrine requiring the disclosure of information about a proposed treatment before obtaining consent for its performance. Informed consent involves providing factual information, including the benefits and burdens of an action, and determining a person's understanding of that information. After being given information, a person is thought to be able to give informed consent if they can: a) evidence a choice; b) understand and appreciate the issues; c) rationally manipulate information; and d) make a stable and coherent decision.¹⁷

B. The Importance of Informed Consent

Many patients and families who are facing treatment withdrawal may have not been fully informed of the risks and benefits of the therapy at the time it was begun, nor, often are they told that treatment could be withdrawn if no longer effective. Patients and families who refuse further treatment should be told the consequences of the discontinuation of treatment.

C. Procedures of Informed Consent¹⁸

1. The informed consent process is one of discussion and shared decision making.
2. It is ideally woven into regular clinical interaction.
3. The health care provider should bring news and information to the patient about his or her disease and its management in as timely and sensitive a fashion as possible.
4. Age Changes Which May Influence Informed Consent in Older Adults¹⁹
 - a. Sensory deficits in hearing and vision.
 - b. Adult learning needs for both written and verbal information presented slowly with opportunities to repeat and clarify content.
 - c. Values and beliefs about making health care choices (i.e., "let the doctor decide).
 - d. Decision-making capacity that fluctuates or is diminished.

XIV. The Steps Of Advance Care Planning²⁰

(Refer to Figure 2 : ‘Your Life, Your Choices- Planning for Future Medical Decisions: How to Prepare a Personalized Living Will’. By R. Pearlman, H. Starks, K. Cain, W. Cole, D. Rosengren, D. Patrick (2001). A publication Health Services Research and Development, Veterans Health Affairs. [www.hsrd.research.va.gov/publications/your life/](http://www.hsrd.research.va.gov/publications/your_life/))

A. Preparing for the Discussion

1. Discussions can never be all-inclusive.
2. Discussion should be directed toward expected clinical situations whenever possible.
3. Appointment of a surrogate is an important first step for both patients with and without identifiable risk factors for specific treatment issues.
4. Discussion must address patient values - prolong life or comfort care.
5. Discussions should take place over time, whenever possible.
6. Information should be presented in a thorough and unbiased fashion.
7. The physician needs to recognize that some patients do not want to have these discussions - may or may not be based in culture - need to ask.
8. Must address medical uncertainty - concept of time-limited trials.
9. Directives must be well documented and available.
10. The possibility that the patient may change his or her mind must be anticipated, and wishes periodically reviewed, as long as the patient retains decisional capacity.

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B. Introducing the Topic

1. Be straightforward and routine: whenever possible, routinely initiate the advance care planning process with every adult patient, regardless of age or current state of health
2. Determine patient familiarity: some patients may already have advance directives. If this is the case, review the documents and amend if appropriate.
3. Explain the process: before beginning, explain the goals and the process. Literature or validated worksheets may be helpful.
4. Determine the patient's comfort level: be aware of the patient's comfort level during the introduction of the topic. If a patient does not seem comfortable, be supportive and provide information, but do not force the conversation.
5. Identify a proxy: ask the patient to identify a possible- proxy decision-maker who might act on his or her behalf, to be involved in subsequent conversations.

C. Surrogate Issues

1. Surrogates should be chosen who are familiar with and willing to support the patient's wishes and values.
2. Surrogates must be decisional capacity.
3. Directives should address if surrogate has discretion to override previously stated wishes.
4. Surrogates must be informed and reachable.

D. Engage in Structured Discussions

1. Proxy decision-maker(s) should be present: potential proxy- decision maker should be present at the discussions and planning so that he or she can have a thorough and explicit understanding of the patient's wishes.
2. Describe scenarios and options for care: this will provide insight as to scenarios that might arise and the types of decisions that proxies most commonly face.

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3. Elicit patient's values and goals: this can be done by asking about past experiences and describing possible scenarios.
 4. Specific issues that ought to be discussed include: the patient's choice of a spokesperson; beliefs; health conditions; life-sustaining treatments; vision of a good death; organ donation; and funeral arrangements.
 5. Use a worksheet: worksheet should include a range of potential scenarios that patients should consider. It should elicit the patient's values and goals related to health and medical care in general terms and should include the most common life-threatening interventions.
- E. Treatments to be Covered in Discussion
1. Resuscitation
 2. Mechanical breathing (intubation)
 3. Surgery
 4. Chemotherapy
 2. Dialysis
 3. Blood transfusion
 4. Artificial nutrition and hydration
 5. Diagnostic tests
 9. Antibiotics
 10. Pain medication
- F. Document Patient Preferences
1. Formalize the directives: check for inconsistencies and misunderstandings. Have the patient sign the directives.
 2. Enter directives into the medical record: directives should be formally documented into the patient's medical record.
 3. Recommend statutory documents: One or more statutory documents that comply with state statutes can be completed for added protection.
 4. Distribute the directive: the records should be available wherever the patient may receive care.
- G. Review and Update the Directive
1. Follow up periodically.

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2. Note major life events: such as illness, marriage, birth of a child, which may affect a person's attitude.
 3. Discuss changes: ensure patient, provider, and proxy understand the new wishes.
 4. Document changes: documents should be updated and shared appropriately.
- H. Apply Prior Directives to Actual Circumstances
1. Determine the patient's capacity to make decisions
 - a. *Decision-making capacity* is a clinical determination as to whether a person possesses a set of values and goals, the ability to communicate and understand information, and the ability to reason and deliberate about their choices.
 - b. *Competency*: a legal determination (by a judge) as to qualified to give testimony or execute legal documents (in the law with regard to health care decisions there is no definitive test for competency).²¹
 - c. Questions for Determining Decisional Capacity²²
 - Can the person make and express personal preferences at all?
 - Can the person give reasons for the alternative selected?
 - Are the supporting reasons rational, in the sense that he patient begins with a factually plausible premise and reasons logically from that premise to the result?
 - Does the person in fact comprehend the implications?
 - d. Because a substantial number of older adults have altered decision-making capacity, it is an issue every time an older adult is asked to consent to treatment or execute a Health Care Proxy or living will.²³
 - e. Cognitive impairment does not automatically constitute decisional incapacity. Widely used tests of mental status assessment (e.g., Mini-Mental Status Assessment of MMSE) are NOT good measure of an individual's ability to make health care decisions.²⁴

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2. Read the advance directive: never assume its content.
3. Interpret the advance directive: should be interpreted in view of the clinical facts of the case. No matter how thorough they are, advance directives cannot anticipate all possible circumstances.
4. Consult with the proxy: whenever significant interpretation is necessary.
5. Use ethics committee: for cases in which disagreements cannot be resolved.
6. Carry out the treatment plan.

(Refer to Figure 3, “Instructions and Definitions for VA Advanced Directives)

XV. Legal Consensus On Treatment Limitation

- A. Patients May Refuse Unwanted Treatment: Patients with decision-making capacity may refuse unwanted medical treatment, even if this may result in their death.²⁵
- B. Surrogate Decision-Making: Patients who lack capacity to make the decisions at hand have the same rights as those who have capacity. Authorized surrogate decision-makers may make decisions to limit treatment.²⁶
- C. Sustaining medical treatment is considered neither homicide nor suicide. There are no limitations on the type of treatment that may be withheld or withdrawn. This may arise more frequently with older adults where the potential benefits of a treatment are unclear.²⁷
- D. Legally (and ethically) there is no difference between never starting therapy and discontinuing therapy.²⁸
 1. State laws can vary from the prevailing legal consensus on end-of-life care (e.g., in the degree of certainty that a surrogate should have about a patient’s wishes).²⁹

XVI. Issue Of Physician-Assisted Suicide³⁰

- A. In 1997, the US Supreme Court held that there is no federal Constitutional right to assisted suicide. In doing so, it reaffirmed the distinction between withholding or withdrawing life-sustaining treatment and assisted suicide. Some professionals do have difficulty distinguishing professionally sanctioned end of life interventions from those that are not. This is partially

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due to imprecisely defined or understood terms used in end of life interventions. For purposes of clarification, the use of the following definitions are recommended:

1. Assistance in dying: is an act that directly and intentionally brings about the death of a capable adult who voluntarily requests such assistance to end suffering.
 2. Suicide: is the act of taking one's own life, and the act of doing so was decriminalized in 1961.
 3. Assisted Suicide: is the provision of the means to end life, such as through the prescription for a lethal amount of drug, the lethal drug itself, or other measures) to an adult who is capable of ending life, with knowledge of that person's intentions.
 4. Voluntary Active Euthanasia: is a deliberate and intentional act that causes death, often by lethal injection, at the voluntary request of an adult who is capable of causing his or her own death.
 5. Non-voluntary Euthanasia: is the deliberate and intentional act that causes the death of a person who is incapable of expressing his or her own wishes about dying.
 6. Involuntary Euthanasia: is the direct and intentional killing of a competent person who explicitly refuses receiving euthanasia.
- B. Provision of medication with the intent to produce death is considered to be assisting suicide.
- C. All states except Oregon, which has developed a state statutory right, have laws that make assisting a suicide by anyone a criminal offense. In the first and second year after the physician assisted suicide (PAS) law was passed in Oregon, 16 and 27 terminally ill patients, respectively, ingested lethal amounts of drugs. According to preliminary information, the reasons these individuals gave for requesting PAS was loss of personal autonomy and control of body functions, inability to participate in activities of daily living that made life enjoyable, and desire to control the manner of dying. The experience of unmanaged pain was not a factor.

XVII. Medical Futility ³¹

- A. There are times when there are conflicts regarding belief of the beneficial nature of a treatment. These situations are referred to as "medical futility" and are common reasons for ethics consults or ethics committee presentations. These conflicts often involve failure in communication or misunderstandings over prognosis or benefits versus burden of treatment options. There are also important cultural and religious influences in these matters.
- B. By asking the fundamental question, "Who are we doing this for?" many futile interventions can be avoided. The answer should be guided by the patient's values. Often, interventions (e.g. daily weights, mobilizing patients, continuing dietary supplements) may become questions to involving futility.
- C. Many institutions have developed futility policies and have advocated the use of prognostic data to assist in determining when a treatment is futile. Such efforts alone rarely solve the fundamental disagreements about quality of life, meaning and decision making authority.

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Learning Resource A

Case Studies

Case # 1: Mr. Lewis*

Mr. Lewis, age 71, has been a patient in the hospital for three weeks after suffering a very severe stroke. He has a tracheostomy (not ventilator dependent) and rarely leaves his bed. He has several infections that respond well to therapy. He communicates by whispering and writing. Many staff members observe that Mr. Lewis seems depressed. He has never been treated for clinical depression. His spouse of nearly 50 years, Mrs. Lewis, visits him faithfully during hospitalization. She feeds him his lunch and dinner by spoon. She is a much-admired visitor and brings gifts for the staff. She is a “lovely woman, truly devoted to her husband,” in the words of the staff social worker.

Mr. Lewis was offered an opportunity to complete an advance directive. He chose to fill out only a durable power of attorney for health care (health care proxy). He named his wife as his surrogate decision-maker should he lose decisional capacity. Mr. Lewis’s health care proxy was filed in his chart. In a subsequent discussion with his physician, he requested that no cardiopulmonary resuscitation be attempted were he to suffer an arrest. The Do Not Resuscitate order was also appropriately charted.

Later, however, Mr. Lewis told his primary nurse “when the time comes, I don’t want one of them feeding tubes. I would rather starve to death.” The nurse reported this statement to the physician. The physician brought up the matter the next day with both Mr. Lewis and his wife. This time Mr. Lewis said nothing. His wife stated, “Well, you know, his mind wanders sometimes. I know that he would not want to die without food or water.” Later, outside of the patient’s room, she told the nurse and doctor, “I don’t really care what he says. He doesn’t know what he wants. I could never let him die that way. We would both go straight to hell. If he does have another stroke, I will become the decision-maker. So it really doesn’t matter anyhow.”

Focus Questions:

1. What are some ethical issues introduced in this case study?
2. Who could be involved in assisting in this situation?
3. How would you plan care for Mr. Lewis based on the information outlined here?
4. What are any thoughts/feelings that you have about this care situation?

* Mariano C, Gould E, Mezey M, Gulmer T, eds. Best Nursing Practices in Care for Older Adults: Incorporating Essential Gerontologic Content into Baccalaureate Nursing Education. 2nd ed. New York: The John A. Hartford Foundation Institute for Geriatric Nursing, Division of Nursing, School of Education, New York University; 1999. Topic 15, pp14 –16.

Case # 2: Mrs. Rodriguez

Mrs. Rodriguez, a 79 year old widow with a history of diabetes mellitus, breast cancer, poor vision and gait instability, lived in a senior housing facility in the inner city. Eight months prior to her death she was diagnosed with a recurrence of her breast cancer. This time the cancer was found to be widely metastasized. She was advised by her primary care physician that there was no hope of cure. She continued to live in the senior housing facility. Soon thereafter her health began to decline.

Three months after being diagnosed with the recurrence of breast cancer, Mrs. Rodriguez fell at home. She was taken to the emergency room by her daughter-in-law, and was subsequently hospitalized at an academic medical center with a fractured arm. Due to Mrs. Rodriguez's decline in functional status, the medical center's inpatient social worker recommended that Mrs. Rodriguez be aced in a nursing home. The patient and her close confidant, a local pastor, were very clearly against her being placed in a nursing home. A nurse who had become quite close to Mrs. Rodriguez during her inpatient stay also tried to advocate on Mrs. Rodriguez' behalf against nursing home placement in heated discussions with the inpatient social worker, but was unsuccessful in her efforts. Based on the evaluation of the inpatient social worker, the social worker at Mrs. Rodriguez' senior housing facility steadfastly refused to allow Mrs. Rodriguez to return to her home, citing liability restrictions of the housing facility.

Mrs. Rodriguez was sent to a nursing home to convalesce while efforts continued on the part of the pastor to get her adequate home attendant services so that she could be returned to the senior housing facility. The nursing home's chief geriatrician as well as its social worker took up the cause at the pastor's behest. Medicare personnel would only approve nine hours of home attendant services, however, and neither the staff of the nursing home nor the senior housing social worker would accept this as adequate for her care.

An interdisciplinary meeting was held at the nursing home. The senior housing social worker, the pastor, the patient's daughter-in-law, and the nursing home's geriatrician and social worker were in attendance. This pastor, the nursing home's social worker, and the patient's daughter-in-law continued to press for discharge to the senior housing facility in keeping with the patients wishes, while the housing facility's social worker reluctantly continued to deny permission. It was noted at this meeting that Mrs. Rodriguez had become much more withdrawn and depressed at the nursing home. At the end of this meeting he nursing home social worker promised to push Medicare for round the clock home attendance care for the patient, which the senior facility social worker agreed would be adequate for her return. Mrs. Rodriguez also signed a health care proxy form naming her daughter-in-law as proxy. Four days prior to Mrs. Rodriguez's death she was approved for 24-hour home attendant care. She was transferred to the senior housing facility where she died in her sleep soon after.

Mrs. Rodriguez Case Analysis

A. Patient and Family Preferences

The patient desires to be returned to their apartment in senior housing. She appears to have capacity to make this decision as she is allowed to sign a health care proxy form, and the inpatient nurse's notes indicate that she is "alert and oriented x 3." The patient's daughter-in-law and pastor want Mrs. Rodriguez to be allowed to return to her apartment.

The foremost ethical issue in Mrs. Rodriguez' case is the conflict between autonomy and beneficence: the desire to respect the patient's wishes and right to self-determination balanced with the desire for health professionals to act in what they perceive to be the patient's best interest. Here, several of Mrs. Rodriguez' healthcare providers emphasize finding the optimal care setting for the preservation of her life, giving the issue of beneficence more primacy than the stated desire of both Mrs. Rodriguez and her confidants to have her back in her home. Ethically, patients should be considered to have the capacity to make their own decisions unless there is a compelling reason to question their decision-making ability.

In this case the patient appears to have the capacity to make her own decisions, as evidenced by the fact that she is alert and oriented and retains the legal right to assign her own proxy. Her confidants also agree with the patient's choices. Nevertheless, Mrs. Rodriguez is kept out of her home until four days prior to her death. A better compromise between autonomy and beneficence might have been worked out had round-the-clock home attendant care been readily available.

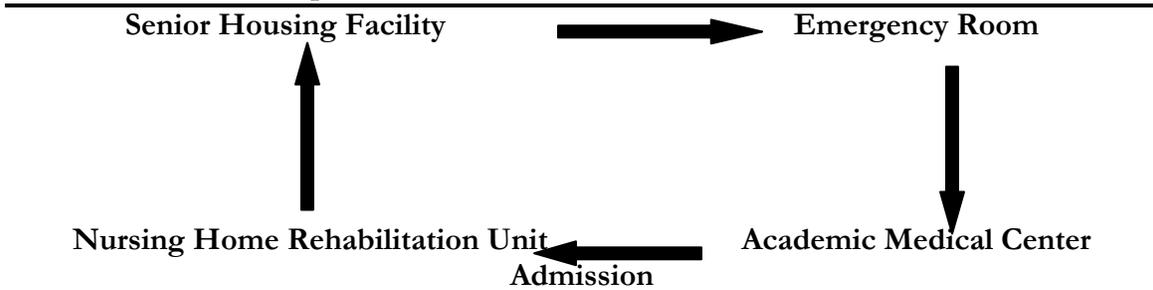
B. Quality of Life Issues

Mrs. Rodriguez will be unable to return to normal life in the senior center housing facility without round-the-clock care; however, the patient still desires this option over life in a nursing home.

C. Contextual Factors: Teams and Transitions

See next page

Transition in Clinical Settings



Parties involved with the care of Mrs. Rodriguez:

Primary care physician
Family: Mrs. Rodriguez's daughter-in-law and pastor
Inpatient social worker, Inpatient nurse
Senior housing social worker
Nursing home: geriatrician, social worker, nurses
Medical personnel

Collegiality. Another facet of team dynamics that can complicate decision-making is that of colleagues waiting to respect each other's decisions. In order for a team to function effectively it is necessary for team members to behave toward each other in a manner that is consistent with how the team members behave toward the patient – ideally, by respecting autonomy. A premium is placed on colleagues respecting each other's autonomy and decision making capacity: just as patients with capacity must be permitted to make poor choices. Thus the desire not to affect the group dynamic of a team adversely may prevent team members from confronting each other when they encounter what appear to be poor judgment calls by their colleagues. This may be the case with the senior housing facility social worker, who appears to lack sufficient knowledge about the importance of respecting patient autonomy. Other members of the team, had they felt comfortable educating the social worker in this regard, may have been able to convince her that transfer back to the adult home was indeed appropriate. When team members do not know each other very well, which is often the case of multiple-institutional teamwork, there is a greater reluctance to disagree with a colleague.

Legal implications. Team effectiveness can be comprised by influences entirely outside their control. One example is the senior housing social worker's refusal to permit re-entry into the housing. Her hands were in fact tied by her duty to heed regulations of the housing facility. Here it could be argued that the senior housing social worker – or those who initially determined the housing policies – are violating Mrs. Rodriguez' right to autonomy. This argument must be weighed against the legal liability of the housing facility should Mrs. Rodriguez have an accident upon her return or cause accidental injury to others through fire, etc. An ethical dilemma arising during Mrs. Rodriguez' transitions is whether persons living in a housing facility have less right to autonomy than persons living in a private home; i.e., a conflict between patient autonomy and housing facility liabilities.

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From the point of view of clients in need of long-term care most likely for the rest of their lives but wishing to live at home as long as possible, as in Mrs. Rodriguez' case, a single agency responsible for providing all care and assuming complete accountability is preferable to the patient being shuttled from setting to setting. A model of care such as PACE's may have prevented unnecessary hospitalization and avoided this particular ethical dilemma from arising.

Allocation of Resources. Another contextual feature of this case is Medicare's unwillingness to provide more hours of daily home attendant care makes what could have been a logical team compromise – for Mrs. Rodriguez to remain at home with extended home attendance – an impossibility. Medicare personnel, presumably for cost control reasons, block the way for this compromise by only approving nine hours of daily home care. Medicare regulations and personal play an important role in this case, yet no Medicare representatives are part of the team. Managed care administration may very often play a central role in a team's decisions without actually being a physical part of the team. This can engender frustration from care providers, patients, and family members alike. Here again, a mega-team model is instructive, where those parties responsible for making cost-decisions are actively involved in team decisions for each patient. In the case that follows, how the PACE accomplishes this goal will be discussed.

Team composition. Team composition is blurry. There are several care providers, but it is not clear if there are teams at all. Certainly the provision of care is not coordinated. The patient's primary care physician who originally diagnosed the cancer is not actively involved throughout the transitions. The health care providers at the hospital, including the hospital's inpatient nurse and social worker, do not play an active role once the patient make a transition beyond the hospital doors. Yet the inpatient social worker's evaluation of the patient has such primacy that it continues to directly affect the patient by forming the basis on which Mrs. Rodriguez is prevented from returning home.

The patient might better have been served had members of the hospital involved Mrs. Rodriguez's care – or at the very least the inpatient social worker – stayed involved in the case until its resolution. It is not known, however, what other burdens these providers faced and whether continuing involvement was even a possibility given other time and staffing constraints at the hospital. The interdisciplinary meeting involving professionals from the nursing home and senior housing facility as well as the patient's confidants is an attempt on the part of these providers to function as a single team. In fact this meeting did serve to accomplish the patient's goal, albeit too late to be of benefit to her.

Team management. Even if all the various health professionals involved in this case are regarded as functioning as a single “mega-team”, lack of clear team management still obscures what should be the central role of the patient being able to make her own choices about living arrangements. Until the last days of the patients life when she signs a proxy form, no one on this “team” appears to take responsibility for ensuring that an assessment of the patient's decision-making capacity is carried out in an explicit manner such that the entire team is aware of whether or not the patient is able to make her own decisions. Without a person with the needed combination of awareness of the importance of patient

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autonomy and the power to return her to her apartment, several members of the team appear to operate under the assumption that the patient lacks decisional capacity.

The de facto leader in coordinating the team's decisions could be viewed as the senior housing social worker in that she is able to block transfer of Mrs. Rodriguez, or as the pastor in that he is consistently involved throughout the various transactions. A case manager is badly need here, whether it be the patient's primary car provider, someone from the hospital who had the patient's trust, such as the inpatient nurse, or any of the other professionals involved in Mrs. Rodriguez' care, preferably one upstream in the transition process.

Role of Family and Confidants on Team. The Pastor and the daughter-in-law both have the desire to follow the patients wishes, but they are powerless to convince the senior housing social worker who doe not place as great an emphasis on the patient's decisional capacity. Here the role of the family on the team and what level of involvement in decision-making should be afforded the family members and patient confidants is another central team issue.

Learning Resource B

Template For Ethics Case Analysis

1. Gather the Clinical Information
 - a. What is the patient's medical problem? History? Diagnosis? Prognosis?
 - b. Is the problem acute? Chronic? Critical? Emergent? Reversible?
 - c. What are the goals of the treatment and care?
 - d. What are the probabilities of success?
 - e. What are the plans in case of therapeutic failure?
 - f. In sum, will medical and nursing care benefit the patient and harm be avoided?
2. Identify Patient and Family Preferences
 - a. What has the patient expressed about preferences for treatment?
 - b. Has the patient been informed of benefits and risks, understood, and given consent?
 - c. Is the patient mentally capable and legally competent? What is evidence of incapacity?
 - d. Has the patient expressed prior preferences (e.g. advance directives)?
 - e. How does the patient want to include family or friends in the decision-making process?
 - f. If the patient is incapacitated, who is the appropriate surrogate? Is the surrogate using appropriate standards?
 - g. Is the patient unwilling or unable to cooperate with medical treatment? If so, why?
 - h. Are there family issues that might influence treatment decisions?
 - i. In sum, is the patient's right to choose being respected to the extent possible in ethics and law?
3. Evaluate Quality-of-Life Issues
 - a. What are the prospects, with or without treatment, for the patient to return to a normal life?
 - b. What biases might prejudice provider evaluations of the patient's quality of life (i.e., is the patient's or family's definition of quality of life or the provider's definition used?)
 - c. What physical, mental, and social deficits is the patient likely to experience if treatment succeeds?
 - d. Is the patient's present or future condition such that, if it continues, he or she might judge life undesirable?
 - e. Is there any plan and rationale to forgo treatment?
 - f. What are the plans for comfort and palliative care?
4. Consider Contextual Factors
 - a. Are there provider (physician, nurse, etc.) issues that might influence

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- treatment decisions?
 - b. Are there financial and economic factors?
 - c. Are there religious or cultural factors?
 - d. Is there any justification for breaching confidentiality?
 - e. Are there resource allocation problems?
 - f. What are the legal implications of treatment decisions?
 - g. Is clinical research or teaching involved?
 - h. Is there any provider or institutional conflict of interest?
5. Resolve the Ethical Issues and Create the Plan
 6. Implement the Plan
 7. Evaluate the Plan

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Learning Resource C

Your Life/Your Choices: Choosing A Spokesperson

Who should speak for me?

Instructions This exercise will help you choose the best spokesperson for you. On the top of each column, write in the names of one or more people you're considering to be your spokesperson. Place a check mark (✓) in the column for that person if the following statements are true. The first two statements must be true for your spokesperson to have legal authority to represent you. You should weigh how important the other attributes are to you in deciding your first choice.

| | | | |
|---|--|--|--|
| Meets the legal criteria in my state for durable power of attorney for health care (see the instructions in the back pocket). | | | |
| Would be willing to speak on my behalf. | | | |
| Would be able to act on my wishes and separate her/his own feelings from mine. | | | |
| Lives close by or could travel to be at my side if needed. | | | |
| Knows me well and understands what's important to me. | | | |
| Could handle the responsibility. | | | |
| Will talk with me now about sensitive issues and will listen to my wishes. | | | |
| Will be available in the future if needed. | | | |
| Would be able to handle conflicting opinions between family members, friends, and/or medical personnel. | | | |

What makes your life worth living?

Instructions This exercise will help you think about how you would feel about your life if each factor **by itself** described you.

Life like this would be:

| | Difficult, but acceptable | Worth living, but barely | Not worth living | Can't answer now |
|--|--|---|---------------------------------|---------------------------------|
| a. I can no longer walk but get around in a wheelchair. | | | | |
| b. I can no longer get outside - I spend all day at home. | | | | |
| c. I can no longer contribute to my family's well being. | | | | |
| d. I am in severe pain most of the time. | | | | |
| e. I have severe discomfort most of the time (such as nausea, diarrhea, or shortness of breath. | | | | |
| f. I rely on a feeding tube to keep me alive. | | | | |
| g. I rely on a kidney dialysis machine to keep me alive. | | | | |
| h. I rely on a breathing machine to keep me alive. | | | | |
| i. I need someone to help take care of me all of the time. | | | | |
| j. I can no longer control my bladder. | | | | |
| k. I can no longer control my bowels. | | | | |
| l. I live in a nursing home. | | | | |
| m. I can no longer think clearly - I am confused all of the time. | | | | |
| n. I can no longer recognize family/friends. | | | | |
| o. I can no longer talk and be understood by others. | | | | |
| p. My situation causes severe emotional burden for my family (such as feeling worried or stressed all the time). | | | | |
| q. I am a severe financial burden on my family. | | | | |
| r. I cannot seem to "shake the blues". | | | | |
| s. Other (write in): | | | | |

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Instructions. To help others make sense out of your answers, think about the following questions and be sure to explain your answers to your loved ones and health care providers. If you checked “worth living, but just barely” for more than one factor, would a combination of these factors make your life “not worth living?” If so, which factors? If you checked “not worth living,” does this mean that you would rather die than be kept alive?

If you checked “can’t answer now,” what information or people do you need to help you decide?

Your Beliefs and Values

In

Instructions. Circle yes, not sure or no to indicate whether you agree with each statement. If you do not agree with the “always” statements, this could mean that you agree with these statements some of the time, but not always. You can use the space at the bottom of the page to explain and clarify your beliefs.

Personal and spiritual beliefs.

Many people have special personal or spiritual beliefs that they want respected in decision making about life-sustaining treatments? What are yours?

| | | | |
|--|------------|-----------------|-----------|
| I believe that it is <u>always</u> wrong to withhold (not start) treatments that could keep me alive. | Yes | Not sure | No |
| I believe that it is <u>always</u> wrong to withdraw (stop) treatments that could keep me alive after they’ve been started. | Yes | Not sure | No |
| I believe it is wrong to withhold (not provide) nutrition and fluids given through tubes, even if I am terminally ill or in a permanent coma. | Yes | Not sure | No |
| I do not wish to receive a blood transfusion or any blood products, such as plasma or red blood cells. | Yes | Not sure | No |
| I would like to have my pastor, priest, rabbi, or other spiritual advisor consulted regarding any difficult health care decision that must be made on my behalf. (write in name) _____ | Yes | Not sure | No |
| I believe in other forms of treatment, such as healing through prayer, acupuncture, or herbal remedies. I want the following treatments included in my care: _____ | Yes | Not sure | No |

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I believe that controlling pain is very important, even if the pain medications might hasten my death. **Yes Not sure No**

I believe that my loved ones should take their own interests into consideration, as well as mine, when making health care decisions on my behalf. **Yes Not sure No**

I believe that it is acceptable to consider financial burden of treatment on my loved ones when making health care decisions on my behalf. **Yes Not sure No**

I believe that my loved ones should follow my directions as closely as possible. **Yes Not sure No**

Additional beliefs and/or explanations for my beliefs:

I

Hope for recovery

People have different feelings about hope that influence what health care they want. What are your feelings about hope?

Imagine that you are very sick and have been told that you will very likely die soon.

I would want all possible treatment, even though my doctors don't think they will help me, because I would hope for a miracle cure that would prolong my life. **Yes Not sure No**

Imagine that you have been in a coma for three weeks. The doctors think that the chance that you will ever return to your previous state of health is very small.

I would want to be kept alive indefinitely because I would still hope for a new medical development that would help me to recover. **Yes Not sure No**

Weighing pros and cons of treatment for different chances of recovery

People evaluate the pros and cons of medical treatments in very personal ways. This explains why some people choose a treatment and others reject it. A big question is, how

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much would you be willing to endure if the chance of regaining your current health was high? What if the chance was low? Answer the questions below to carefully evaluate your own willingness to take such risks.

Imagine that you are seriously ill. The doctors are recommending treatment for your illness, but the treatments have very severe side effects, such as severe pain, nausea, vomiting, or weakness that could last for 2-3 months.

I would be willing to endure severe side effects if the chance that I would regain my current health was:

| | | | |
|-------------------------|------------|-----------------|-----------|
| high (over 80%) | Yes | Not sure | No |
| moderate (50%) | Yes | Not sure | No |
| low (20%) | Yes | Not sure | No |
| very low (less than 2%) | Yes | Not sure | No |

From a research workbook entitled “*Your Life, Your Choices*”. An updated version, “*If I Can’t Speak for Myself...*”. 1999, published by Patient Decision Support (www.patientdecisions.com).

How would you like to spend your last days?

Many people have strong opinions about what would be important to them at the very end of their lives. For some, they want to express things they would like to have happen. Others want to be sure that certain things they dislike or fear will be avoided. What are some of the things that you would hope for that could make your last weeks, days, or hours the most peaceful?

Instructions. For each row, check (✓) one answer to express how important these issues would be to you if you were dying.

| | Not Important | Moderately Important | Very Important | Extremely Important |
|---|---------------|----------------------|----------------|---------------------|
| a. Avoiding pain and suffering, even if it means that I might not live as long. | | | | |
| b. Being alert, even if it means I might be in pain. | | | | |
| c. Being around my family and close friends. | | | | |
| d. Being able to feel someone touching | | | | |

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| | | | | |
|---|--|--|--|--|
| me. | | | | |
| e. Having religious or spiritual advisors at my side when I die. | | | | |
| f. Being able to tell my life story and leave good memories for others. | | | | |
| g. Reconciling differences and saying “good-bye” to my family and friends. | | | | |
| h. Being at home when I die. | | | | |
| j. Being kept alive long enough for my family to get to my bedside to see me before I die, even if I’m unconscious. | | | | |

k. What are your biggest hopes about the end of your life?

l. What are your biggest fears about the end of your life?

Other related matters

The topics that have been covered up to this point have related to decisions about your health care in the event you could not speak for yourself. Your decisions about the next topics would go into effect after your death. We include them here because they are related issues that you may want to communicate to others.

Organ donation and autopsy

Sometimes after death, organs and tissues can be used to help other people who need them. Family members must give consent to transplant your organs. You can help them make this decision by letting them know how you feel about this. After an autopsy, the body can be shown and buried.

Instructions. Circle one word to express how you feel.

I want to donate any viable organs/tissues. **Yes Not sure No**

If yes, have you filled out an organ donor card?
Have you told your family?

I consent to the use of all or part of my body for medical research. **Yes Not sure No**

If yes, do you have a preference for a research institution?
Have you told your family?

I permit an autopsy. **Yes Not sure No**

Burial arrangements.

People often leave instructions about what they want done with their bodies after they die. Some want to be buried in a particular place, perhaps in a cemetery with other family. Other people would prefer to be cremated and have their ashes put or scattered in a special place. You can indicate your preferences by answering the questions below.

I would prefer to be: (circle one) **Buried** **Cremated** **No preference**

I would like my remains to be placed: _____

Other preferences: _____

Funeral or memorial services

People have different ideas about funerals and memorial services. These services are often very comforting to family and friends as they celebrate and honor the life of their loved one. Services also can make a statement about one's religious faith. Write in below any thoughts about a funeral or memorial service such as where it should be held, songs or readings to be included, where donations should be sent, information for an obituary notice, or other wishes.

Learning Resource D

Instructions And Definitions For VA Advance Directives

The new advance directive form 10-0137 expands veterans' opportunity to express their wishes about end-of-life care and is structured to prompt veterans to give careful consideration to the care they would like to receive in different clinical circumstances. The form also encourages veterans to provide guidance for decision makers to help ensure that the treatment preferences they set out in their advance directive are appropriately interpreted.

The National Center for Ethics in Health Care anticipates that the new form will prompt veterans to ask more questions of their practitioners and that it will generate productive discussions and a better understanding of patients' wishes regarding care at the end of life. Practitioners looking for a guide to help veterans complete the new advance directive may wish to refer to "Your Life, Your Choices" (<http://vaww.ethics.va.gov/pubs/ylyc.pdf>). This PDF booklet offers a step-by-step discussion guide to end-of-life planning that veterans can use on their own or together with a health care practitioner. An interactive version of "Your Life, Your Choices" will be available through the MyHealtheVet portal in the future.

1. VA Advance Directive: Living Will & Durable Power of Attorney for Health Care (VA Form 10-0137)

This combined Durable Power of Attorney for Health Care and Living Will permits you to specify certain treatment you may or may not want. With this form, you can:

- a. Appoint someone to make health care decisions for you if, in the future you become unable to make those decisions for yourself and/or
- b. Indicate what medical treatments(s) you do or do not want if in the future you are unable to make your wishes known.

2. Instructions:

- a. Read each section carefully.
- b. Talk to the person(s) you plan to appoint to make sure that they understand your wishes, and are willing to take the responsibility.
- c. Place the initials of your name in the blank before those choices you want to make under part 1 and 2 of VA Form 10-0137.
- d. Add any special instructions in the blank spaces provided. If you need more space for additional comments, you may use a separate sheet of paper; but you must indicate on the form that there are additional pages to your advance directive.

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- e. Sign the form and have it witnessed.
- f. Keep the original for yourself.
- g. Give a copy of this entire form to all of the following people: your doctor or your nurse, the person you appoint to make your health care decisions for you, your family, and anyone else who might be involved in your care.
- h. Remember that you may change or cancel this document at any time.

3. Definitions (Words you need to know.)

- a. **Advance Directive:** A written document that tells what you want or do not want, if you become unable to make your wishes about health care treatments known.
- b. **Artificial Nutrition and Hydration:** When synthetic food (or nutrients) and water are fed to you through a tube inserted through your nose into your stomach or into the intestine directly or into a vein.
- c. **Comfort Care:** Care that helps to keep you comfortable but does not cure your disease. Bathing, turning, pain medication, keeping your lips and mouth moist and pain medications are examples of comfort care.
- d. **Cardiopulmonary Resuscitation (CPR):** Treatment to try and restart a person's breathing or heartbeat. CPS may be done by breathing into your mouth, pushing on your chest, by putting a tube through your mouth or nose into your throat, administering medication, giving electric shock to your chest, or by other means.
- e. **Durable Power of Attorney for Health Care:** A document that appoints a specific individual to make health care decisions for you if you become unable to make those decisions for yourself.
- f. **Life-sustaining Treatment:** Any medical treatment that is used to delay the moment of death. A breathing machine (ventilator), CPR, and artificial nutrition and hydration are examples of life-sustaining treatments.
- g. **Living Will:** Instructions you have made in advance that tell what medical treatment you do or do not want if you become unable to make your wishes known.
- h. **Permanent Vegetative State:** When a person is unconscious with no hope of regaining consciousness even with medical treatment. The body may move and eyes may be open, but as far as anyone can tell, the person can't think or communicate.
- i. **Surrogate Decision-maker:** This is an individual, organization or other body authorized to make health care decisions for you if you are unable to do so yourself.

YOUR RIGHTS REGARDING ADVANCE DIRECTIVES

Advance Directives. Advance directives are legal forms that state your preferences about future health care. If you become too ill to make decisions about your care, an advance directive can help your doctors and family members understand what you want. It is up to you to decide if you want an advance directive. Your decision must not affect your access to health care or other VHA services. There are two types of advance directives. In the Department of Veterans Affairs (VA), the two types are in one form. You may complete neither, one, or both of the following: Durable Power of Attorney for Health Care. In this type of advance directive, you name a person as your Health Care Agent who is to make health care decisions for you if you are not able to do so. Your Health Care Agent is the first person your health care team contacts for decisions about your care.

Living Will. In this type of advance directive, you state your preferences about treatments you want, or don't want, in different situations when you cannot make treatment decisions yourself. A living will helps your Health Care Agent or others know what treatments you would choose. Your Rights: 1. You have the **right to accept or refuse any medical treatment**. 2. You have the **right to complete a durable power of attorney for health care**. 3. You have the **right to complete a living will**. Your Responsibilities: 1. If you have an advance directive, it's important to give the Veterans Health Administration (VHA) a copy for your health record. 2. If you'd like more information about advance directives, or help filling out the forms, please call to schedule an appointment.

VA FORM

10-0137A

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WHAT YOU SHOULD KNOW ABOUT ADVANCE DIRECTIVES

As a VA patient you have a say in the health care you receive. When you are ill, your doctor should explain what treatments there are for your illness so that you can decide which one is best for you. But if you were too ill to understand your treatment choices or to tell your doctor what treatment you want:

Who would you want to make decisions for you?

What type of health care would you want?

What health care wouldn't you want?

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Questions like these may be hard to think about, but they're important. That's why VA wants you to know about a legal form you can complete. It's called an advance directive.

What is an advance directive?

An advance directive is a legal form that helps your doctors and family members understand your wishes about health care. It can help them decide about treatments if you are too ill to decide for yourself. For example, if you are unconscious or too weak to talk. There are two types of advance directives: durable power of attorney for health care and living will.

What is a durable power of attorney for health care?

This form lets you name the person you trust to make health care decisions for you if you can't make them yourself—your “health care agent.” He or she will have the legal right to make health care decisions for you. You can choose any adult to be your agent. It's best to choose someone you trust, who knows you well and who knows your values. You should make sure the person is willing to serve as your agent. If you don't choose an agent, your doctor will choose someone to make decisions for you in the following order: legal guardian (if you have one), spouse, adult child, parent, sibling, grandparent, grandchild, or a close friend. Your health care team, or a court, will make decisions for you in accordance with VA policy if none of the above is available.

What is a living will?

A living will is a legal form that states what kinds of treatments you would or wouldn't want if you become ill and can't decide for yourself. It can help your health care agent and your doctor make decisions the way you want them to. Writing down what kind of treatment you would or wouldn't want can help make it easier for those who are asked to make decisions for you. Talk with your family, your health care agent, and your doctor about your wishes so they won't have to wonder what you want and if they're doing the right thing. If you don't have a living will, decisions will be made for you based on what is known about you in general and about your values. That's why it's important to discuss your wishes with your loved ones, your doctors, and your health care team.

Must my health care agent always follow my living will?

Most of the time, yes. Your health care agent should try to respect your wishes. But it can be hard to imagine future health and say just what treatment you would want at that time, so sometimes your agent may have to interpret your wishes. In a VA advance directive, you can say if you want your agent to do just what your living will says, or if they may make the decision they think is best for you at that time, even if it isn't what you said you would want.

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Should I have an advance directive?

Yes, it's a good idea to have one. An advance directive helps protect your right to make your own choices. It helps make sure people respect your values and wishes if you can't speak for yourself. *Your advance directive is used only when you aren't able to make decisions yourself.*

How do I complete an advance directive?

Fill out VA Form 10-0137, "VA Advance Directive: Durable Power of Attorney and Living Will." Or use any valid state advance directive form. Talk to a health care professional at your local VA health care facility. This might be a social worker or your primary care doctor. Or talk to your spiritual advisor or attorney. Your VA health care team can make your advance directive part of your medical record.

Do I need to fill out a durable power of attorney *and* a living will?

No. Even though the VA form contains both, it's up to you whether you complete the durable power of attorney for health care, the living will, or both.

Can I change my advance directive?

Yes, you may change or cancel your advance directive at any time. In fact, you should review your advance directive periodically, especially if there is a change in your health, to make sure it's up to date. If you change it, be sure to tell your health care team and have them put it in your health record. Share your new directive with your family members and other loved ones.

Other resources for advance directives:

Your Life, Your Choices has exercises to help you think about important questions. It's available on MyHealth_eVet at <http://www.myhealth.va.gov>.

VA Form 10-0137B
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OMB Approval Number 2900-0556 Estimated Burden Avg: 30 minutes

Learning Resource E

VA ADVANCE DIRECTIVE: DURABLE POWER OF ATTORNEY FOR HEALTH CARE AND LIVING WILL

This advance directive form is an official document where you can write down your preferences about your medical care. If some day you become unable to make health care decisions for yourself, this advance directive can help guide the people who will make decisions for you. You can use this form to name specific people to make health care decisions for you and/or to describe your preferences about how you want to be treated. When you complete this form, it is important that you also talk to your doctor, your family, or others who may be involved in decisions about your care, to make sure they understand what you meant when you filled out this form. A health care professional can help you with this form and can answer any questions you might have. If more space is needed for any part of this form, you may attach additional pages. Be sure to initial and date every page that you attach.

PART I: PERSONAL INFORMATION

SOCIAL SECURITY NUMBER

NAME (*Last, First, Middle*)

STREET ADDRESS

CITY, STATE AND ZIP CODE

HOME PHONE WITH AREA CODE

WORK PHONE WITH AREA CODE

MOBILE PHONE WITH AREA CODE

Privacy Act Information and Paperwork Reduction Act Notice

The information requested on this form is solicited under the authority of 38.C.F.R. §17.32. It is being collected to document your preferences about your medical care in the event you are no longer able to express these preferences. The information you provide may be disclosed outside the VA as permitted by law; possible disclosures include those described in the "routine uses" identified in the VA system of records 24VA19, Patient Medical Record-VA, published in the Federal Register in accordance with the Privacy Act of 1974. This is also available in the Compilation of Privacy Act Issuances via online GPO access at

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<http://www.gpoaccess.gov/privacyact/index.html>. Completion of this form is voluntary; however, without this information VA health care providers may have less information about your preferences. Failure to furnish the information will have no adverse effect on any other benefits which you may be entitled to receive. The Paperwork Reduction Act of 1995 requires us to notify you that this information collection is in accordance with the clearance requirements of section 3507 of this Act. The public reporting burden for this collection of information is estimated to average 30 minutes, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. No person will be penalized for failing to furnish this information if it does not display a currently valid OMB control number.

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FOR HEALTH CARE AND LIVING WILL**

NAME (*Last, First, Middle*)

SOCIAL SECURITY NUMBER

PART II: DURABLE POWER OF ATTORNEY FOR HEALTH CARE

This section of the advance directive form is called a Durable Power of Attorney for Health Care. This section of the form allows you to appoint a specific person to make health care decisions for you in case you become unable to make decisions for yourself. This person will be called your Health Care Agent. Your Health Care Agent should be someone you trust, who knows you well, and is familiar with your values and beliefs. If you become too ill to make decisions for yourself, your Health Care Agent will have the authority to make all health care decisions for you, including decisions to admit you to and discharge you from any hospital or other health care institution. Your Health Care Agent can also decide to start or stop any type of clinical treatment, and can access your personal health information, including information from your medical records. **NOTE: Information about whether you have been tested for HIV or treated for AIDS, sickle cell anemia, substance abuse or alcoholism cannot be shared with your Health Care Agent unless you give special written consent. Ask your VA health care provider for the form you must sign (VAForm 10-5345) if you wish to give permission for VA to share this information with your Health Care Agent.**

A - HEALTH CARE AGENT

Initial the box next to your choice. *Choose only one.*

Initials

I do not wish to designate a Health Care Agent at this time.(Skip this section and go to Part III, page 3.)

Initials

I appoint the person named below to make decisions about my health care if there ever comes time when I cannot make those decisions.

Name (*Last, First, Middle*)

Relationship

Street Address

City, State and Zip Code

Work Phone with Area Code

Mobile Phone with Area Code

Home Phone with Area Code

B - ALTERNATE HEALTH CARE AGENT

Complete this section if you want to appoint a second person to make health care decisions for you in case the first person you appointed is unavailable.

Initials

If the person named above cannot or will not make decisions for me, I appoint the person named below to act as my Health Care Agent.

Name (*Last, First, Middle*)

Relationship

Street Address

City, State and Zip Code

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Home Phone with Area Code

Work Phone with Area Code

Mobile Phone with Area Code

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PART III: LIVING WILL

This section of the advance directive form is called a Living Will. This section of the form allows you to write down how you want to be treated in case you become unable to make decisions for yourself. Its purpose is to inform the people who will be making decisions about your care.

A - SPECIFIC PREFERENCES ABOUT LIFE-SUSTAINING TREATMENTS

This section gives you a place to indicate your preferences about life-sustaining treatments in particular situations. Some examples of life-sustaining treatments are CPR (cardiopulmonary resuscitation), breathing machine (mechanical ventilation), kidney dialysis, feeding tubes (artificial nutrition and hydration), and medicines to fight infection (antibiotics). Think about each situation described on the left and ask yourself, "In that situation, would I want to have life-sustaining treatments?" Place your initials in the box that best describes your treatment preference. ***You may complete some, all, or none of this section. Choose only one box for each statement.***

Yes. I would want to have life-sustaining treatments.

It would depend on the circumstances.

No. I would not want to have life-sustaining treatments.

If I am unconscious, in a coma, or in a persistent vegetative state and there is little or no chance of recovery

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Initials

Initials

Initials

If I have permanent severe brain damage (for example, severe dementia)that makes me unable to recognize my family or friends

Initials

Initials

Initials

If I have a permanent condition that makes me completely dependent on others for my daily needs(for example, eating, bathing, toileting)

Initials

Initials

Initials

If I am confined to bed and need a breathing machine for the rest of my life

Initials

Initials

Initials

If I have pain or other severe symptoms that cannot be relieved

Initials

Initials

Initials

If I have a condition that will cause me to die very soon, even with life-sustaining treatments

Initials

Initials

Initials

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PART III: LIVING WILL (Cont'd)

B - ADDITIONAL PREFERENCES

You may use this space to write any other preferences about your health care that are important to you and that are not described elsewhere in this document. This may include general preferences about how you would like to be cared for, or specific requests. For example, you might have clear opinions about whether you would want a particular treatment (for example, a feeding tube or blood transfusions). You might want to comment on treatment of pain, or whether you would want life-sustaining treatments on a trial basis. Or you might want to write about your preferences regarding treatment of mental illness.

C - HOW STRICTLY YOU WANT YOUR PREFERENCES FOLLOWED

Initial the box next to the statement that reflects how strictly you want your preferences to be followed. *Choose only one.*

Initials

I want my preferences, expressed above in this Living Will, to serve as a *general guide*. I understand that in some situations the person making decisions for me may decide something different from the preferences I express above, if they think it is in my best interest.

Initials

I want my preferences, expressed above in this Living Will, to be followed strictly, even if the person who is making decisions for me thinks this is not in my best interest.

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FOR HEALTH CARE AND LIVING WILL**

NAME (*Last, First, Middle*)

SOCIAL SECURITY NUMBER

PART IV: SIGNATURES

A - YOUR SIGNATURE

By my signature below, I certify that this form accurately describes my preferences.

SIGNATURE

DATE

B - WITNESSES' SIGNATURES

Two people must witness your signature. VA employees of the Chaplain Service, Psychology Service, Social Work Service, or non clinical employees (e.g., Medical Administration Service, Voluntary Service or Environmental Management Service) may serve as witnesses. Other individuals employed by your VA facility may not sign as witnesses to the advance directive unless they are your family members.

Witness #1

I personally witnessed the signing of this advance directive. I am not appointed as Health Care Agent in this advance directive. I am not financially responsible for the care of the person making this advance directive. To the best of my knowledge, I am not named in the person's will.

Date

SIGNATURE

Name (*Printed or Typed*)

Street Address

City, State and Zip Code

Witness #2

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I personally witnessed the signing of this advance directive. I am not appointed as Health Care Agent in this advance directive. I am not financially responsible for the care of the person making this advance directive. To the best of my knowledge, I am not named in the person's will.

SIGNATURE

Date

Name *(Printed or Typed)*

Street Address

City, State and Zip Code

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PART V: SIGNATURE AND SEAL OF NOTARY PUBLIC (*Optional*)

This VA Advance Directive form does not have to be notarized to be valid in VA facilities. However, you may need to have this document notarized for it to be recognized outside the VA health care setting. Space for a Notary's signature and seal is included below.

On this day of, in the year of, personally appeared before me known by me to be the person who completed this document and acknowledged it as their free act and deed. IN WITNESS WHEREOF, I have set my hand and affixed my official seal in the County of, State of, on the date written above. Notary Public Commission Expires.

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[SEAL]

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