

# **EPEEC for Veterans**

Education in Palliative and End-of-life Care for Veterans

**Trainer's Guide**

Plenary 2

**Ethics and Law  
in End-of-life  
Care in VHA**

**Emanuel LL, Hauser JM, Bailey FA, Ferris FD, von Gunten CF, Von Roenn J, eds. EPEC for Veterans: Education in Palliative and End-of-life Care for Veterans. Chicago, IL, and Washington, DC, 2012.**

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## Plenary 2 trainer's notes

### Principal message

There are important legal principles and precedents that support multiple aspects of palliative and end-of-life care in VHA.

### Plenary overview

A broad legal consensus has developed around issues of end-of-life care in the United States generally and in VA specifically. This plenary discusses the clear and consistent legal principles regarding informed consent, treatment limitation, decision making for Veterans who lack capacity and the use of opioids. Legal aspects of the more controversial issues of physician-assisted suicide and futility are also discussed.

### Preparing for a presentation

#### 1. Assess the needs of your audience

Choose from the material provided in the syllabus according to the needs of your expected participants. It is better for participants to come away with a few new pieces of information, well learned, than to come away with a deluge of information, but remembering nothing.

#### 2. Presentation timing

The suggested timing for this plenary is:

Introduction	2-3 minutes
Presentation	45 minutes
<u>Summary</u>	<u>2-3 minutes</u>
Total	49-51 minutes

#### 3. Number of slides: 20

#### 4. Preparing your presentation

The text in the syllabus was not designed to be used as a prepared speech. Instead, the slides have been designed to trigger your presentation. Although the slides closely follow the text of the syllabus, they do not contain all of the content. Their use presumes that you have mastered the content. You may want to make notes on the slide summary pages to help you prepare your talk in more detail and provide you with notes to follow during your presentation.

Practice your presentation using the slides you have chosen, and speaking to yourself in the kind of language you expect to use, until it is smooth and interesting and takes the right amount of time.

## **5. Preparing a handout for participants**

The syllabus text and slides in the **Trainer's Guide** were designed to be reproduced and provided to participants as a handout, either in its entirety, or module by module. If the entire curriculum is not being offered, please include the following in each handout:

- **EPEC for Veterans Front Cover Page**
- **EPEC for Veterans Acknowledgment Pages** (to acknowledge the source of the material)
- Syllabus and slides for **Plenary 2**

## **6. Equipment needs**

- computer with DVD capability or separate DVD player
- flipchart and markers for recording discussion points

## **Making the presentation**

### **1. Introduce yourself**

If you have not already done so, introduce yourself. Include your name, title, and the organization(s) you work for. Briefly describe your clinical experience related to the information you will be presenting.

### **2. Introduce the topic**

Show the title slide for the plenary. To establish the context for the session, make a few broad statements about the importance of palliative care. Tell participants the format you will use and the time you will take to present the session. Identify any teaching styles other than lecture that you intend to use.

### **3. Review the session objectives**

Show the slide with the session objectives listed. Read each objective and indicate those that you are planning to emphasize.

Then, proceed with the content of the plenary.

## **4. Present the material**

### **Recommended style: Lecture**

This plenary was designed to be presented as a lecture without much audience interaction. Use the slides to trigger the subject. Prepare ahead and practice so that it is smooth and interesting. The use of your voice, body language, and gestures can all add to your presentation and the clarity of the message you are delivering.

## **5. Key take-home points**

1. Clinicians should never feel alone when facing difficult ethical or legal situations: VA's Integrated Ethics initiative offers extensive resources to help resolve challenging legal and ethical issues; in addition, clinicians can consult Regional Counsel at either their facility (if available) or at the VISN level.
2. There is legal precedent to support the rights of Veterans to make decisions regarding the continuation or discontinuation of life-sustaining treatments.
3. Decision-making capacity is determined by assessing a Veteran's ability to understand, evaluate and communicate information.
4. Specific advance directive forms and documentation exist in VA for allowing Veterans to select a durable power of attorney for health care (DPAHC, also often referred to as a health care proxy) and help document their wishes for care in the event that they are no longer able to communicate.
5. By federal law, physician-assisted suicide is illegal in VA. Requests for physician-assisted should still be assessed sensitively and compassionately, but clinicians in VA are legally forbidden from acting on these requests.

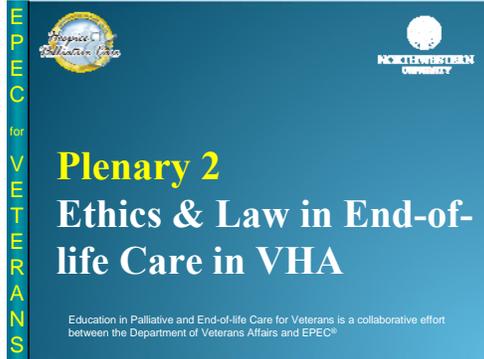
## **6. Evaluation**

Ask the participants to evaluate the session.



# Abstract

Slide 1



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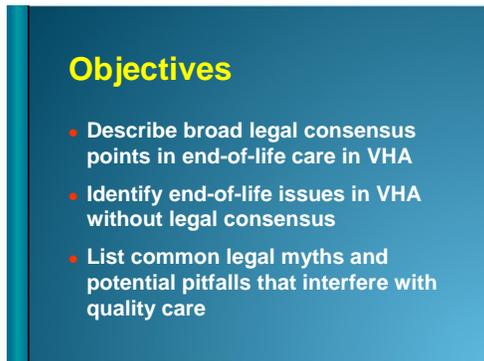
A broad legal consensus has developed around issues of end-of-life care in the United States. The clear and consistent legal principles regarding informed consent, treatment limitation, decision making for patients who lack capacity, the use of opioids are discussed, as well as the legal aspects of the more controversial issues of physician-assisted suicide and futility.

# Cautionary note

This session is intended to present the broad legal consensus in end-of-life care with the understanding that neither the authors nor VHA are rendering specific legal advice to physicians in so doing. Federal law and individual state laws can and do vary on many points, and may change. It is the individual physician's responsibility to be familiar with current laws governing his or her practice and to seek legal counsel if a specific situation requires it.

# Objectives

Slide 2



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The objectives of this plenary are to:

- describe the broad legal consensus that has developed around issues of end-of-life care in VHA;

- identify the end-of-life issues in VHA that lack a legal consensus; and
- list the common legal myths and pitfalls that can interfere with quality care.

## Introduction

Traditionally, questions of end-of-life care were resolved through decision making by physicians in conjunction with patients and families. If the dying patient was a child, such questions were resolved with parents. However, as technologic breakthroughs advanced medical interventions, new questions arose concerning the appropriate use or discontinuation of these interventions. In the absence of other guidance, many of these questions have been brought to courts for resolution. Landmark bioethics legal cases have acted as important benchmarks of the evolving societal consensus within the United States concerning end-of-life care, and case names often act as shorthand regarding the principles for which they have come to stand.

Many clinicians are unfamiliar with these benchmark cases and the principles they have established, and so tend to be more concerned than necessary about legal aspects of decision making at the end of life. Generally, legal precedent follows medical ethical principles in end-of-life care. For instance, physicians are not required to provide treatment that would be ineffective. Nor are physicians required to provide life-sustaining treatment when a patient with the capacity to make health care decisions (or an authorized health care agent) has refused such treatment. In fact, it may be more legally perilous for a physician to continue to treat against patient or surrogate wishes.

## Law and ethics

Slide 3

**Law and ethics**

- Administration system
- Civil system
- Criminal system
- State and federal

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In the U.S., law is created in one of two systems—federal and state—and is made by judges (common law), legislatures (statutory law), and executive agencies empowered by legislatures (regulatory law). Enforcement is either through the administrative system (licensure suspension or revocation), the civil system (most commonly, monetary judgments, but in the medical context, often an order to take an action or to stop treatment, known as “declaratory or injunctive relief”), or the criminal system (fines and/or prison).

End-of-life issues are generally addressed through the civil system — common law (federal or state case law, e.g., landmark bioethics cases) or statutory law (usually state law, e.g., advance directive laws). Some end-of-life issues may be addressed by administrative regulations (e.g., federal drug enforcement or state medical examining board).

In VHA, end-of-life issues are addressed through regulations that govern medical care in VHA. VHA regulations supersede state law. Therefore, it is important for clinicians to familiarize themselves with VHA regulations that apply to end-of-life care. Additionally, although many important legal principles in end-of-life decision making are similar in state law, it is important for practitioners to become familiar with their state’s specific statutes and cases.

## Resolving difficult cases

Slide 4



**Resolving difficult cases**

- Role of law and ethics
- Ethics committees / consultants

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In any discussion of ethical issues in medicine, legal issues may arise. Both ethics and the law set norms or standards for conduct. The law often expresses a kind of minimal ethical societal consensus—one that society is willing to enforce through civil judgments or criminal sanctions. However, there are areas of conduct that the law does not and cannot address well, including important aspects of the relationship with the patient, including providing caring, treating with compassion and engendering trust. Moreover, going to court as a means of dispute resolution is often a slow and expensive process, and in end-of-life cases, it is rarely necessary.

Clinicians facing difficult decisions concerning patients near the end of life may be aided by consultation with ethics consultants and ethics committees. These consultants or committees usually have developed processes to allow clinicians, patients, and families a forum for the discussion of end-of-life decision making and a mechanism to provide recommendations regarding ethically appropriate choices in a given situation. VHA’s IntegratedEthics initiative sets standards for case consultation and resolution of ethical issues within VHA. The IntegratedEthics Program is available through <https://www.ethics.va.gov/integratedethics/index.asp> and includes information about ethics consultation and education throughout VA.

# Key legal topics in end of life care

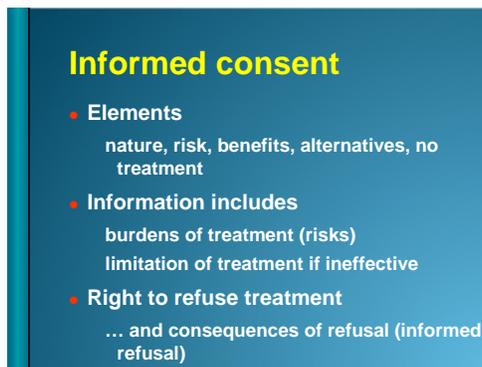
The sections that follow consider the key legal aspects of end-of-life care in VHA. These include;

- Informed consent
- Treatment limitations
- Decision-making in the setting of incapacity
- Appropriate use of opioids
- Physician assisted suicide
- Futility
- Confidentiality

## Informed consent

Informed consent in end-of-life care is a basic legal and ethical requirement for all medical interventions, but it is important for three additional reasons in end-of-life care. First, many patients and families who are facing treatment withdrawal may not have been fully informed of the risks (or burdens) and benefits of the therapy at the time it was begun. Many therapies such as intubation and tube feeding are begun without this critical discussion to which patients are entitled by law and ethics. Knowing the burdens of continued treatment, the fully informed patient or surrogate may not elect further treatment. Second, the related principle of informed refusal requires that patients and families who refuse further treatment should be told the consequences of the discontinuation of treatment, just as they are told the benefits and risks of other interventions. Those consequences may include expected death, but should also include information about the opportunity for palliative care in the dying process. Third, patients should be told at the time of the initiation of a treatment that such treatment may be withdrawn if the treatment is no longer effective. This discussion may well prevent conflicts concerning ineffective treatment.

Slide 5



**Informed consent**

- **Elements**  
nature, risk, benefits, alternatives, no treatment
- **Information includes**  
burdens of treatment (risks)  
limitation of treatment if ineffective
- **Right to refuse treatment**  
... and consequences of refusal (informed refusal)

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Slide 6



**Ethics of informed consent**

- Consent
  - understanding
  - voluntary

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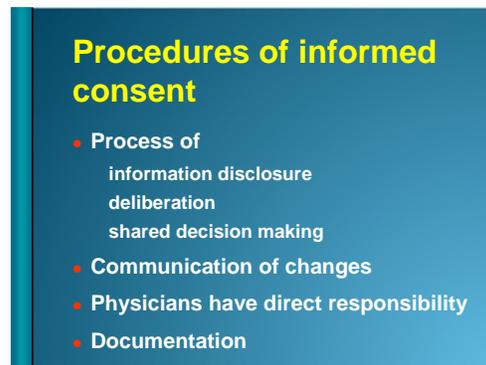
What information should be disclosed during a discussion of medical interventions? Information standards are set in the law of informed consent. VHA’s standards for informed consent are delineated in the VHA Handbook in section 1004.01(13), *The Informed Consent Process*.<sup>1</sup>

In VHA and in the majority of states, the standard of information is judged by what would be material to the decision making of the reasonable person, known as the reasonable person standard. In other states this is judged by the standards of what the prudent professional would disclose. Though not legally required, an important ethical goal would go beyond this to a standard that takes into account what this particular patient would want to know under the circumstances.

Information must include the nature of the procedure, the benefits, the risks, and the alternatives to it, including no treatment. In deciding which of the many risks of any intervention to identify in particular, choose the common ones and the serious ones even if rare.

Consent is as important as information giving, and must involve proper understanding. For instance, does the patient understand that the consequence of declining life-prolonging intervention is probably an earlier death? Consent must also be voluntary and free of coercion.

Slide 7



**Procedures of informed consent**

- Process of
  - information disclosure
  - deliberation
  - shared decision making
- Communication of changes
- Physicians have direct responsibility
- Documentation

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The informed consent process is one of discussion and shared decision making. Ideally it is woven into regular clinical interaction and reflects a deliberative relationship in which the physician fosters and advocates for the well-being of the Veteran, as well as his or her

health care values, goals and specific wishes, as reflected in shared decisions. To attain this, the clinician should bring news and information to the Veteran about his or her disease and its management in as timely and sensitive a fashion as possible, bringing it all into focus before settling on a specific decision together (see EPEC for Veterans Module 3: Breaking Bad News and EPEC for Veterans Module 1: Goals of Care).

Informed consent should be documented, and in most cases in VHA is required to be documented using iMedConsent™ [see VHA Handbook section 1004.01(13)(c) *Documenting the Informed Consent Process*<sup>1</sup>]. However, documentation is of no risk management benefit if the process was absent or ineffective.

## Treatment limitation at the end of life—legal consensus

Slide 8

**Treatment limitation at the end of life**

- Right to refuse any intervention
- All patients have rights, even incapacitated
- Withholding / withdrawing not homicide or suicide orders to do so are valid
- Courts need not be involved

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In the past two and a half decades, federal and state courts have decided a number of cases that have established a consensus of important legal principles in end-of-life care. Though these principles have not been unanimously adopted by all state courts and legislatures, the consensus that has emerged has been broadly accepted with a distinct minority of exceptions, as follows:<sup>2</sup>

**Patients may refuse unwanted treatment:** The most important of these principles is that patients with decision-making capacity may refuse unwanted medical treatment, even if this may result in their death.<sup>3,4</sup> This is based on both the common-law respect for bodily integrity and the liberty interest articulated in the 14th Amendment to the Constitution. The most important expression of this principle was enunciated by the United States Supreme Court in the Cruzan case, where a key question was whether an individual has the right to refuse treatment. Other courts have affirmed this principle; it applies even in cases where the patient does not have a life-threatening illness.<sup>3,4,5</sup>

**Surrogate decision making:** Patients who lack capacity to make the decisions about their medical care have the same rights as those who have capacity. However, the manner in which these rights are exercised is different. Authorized surrogate decision makers may make decisions to limit treatment for patients who lack decision-making capacity using standards as discussed below.

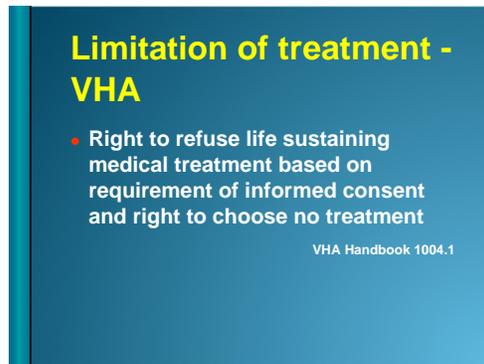
**Withdrawing or withholding treatment:** Withholding or withdrawing life-sustaining medical treatment is considered neither homicide<sup>6</sup> nor suicide.<sup>3</sup> Courts have drawn a

distinction between intentionally causing a patient’s death and allowing a patient to die as a result of the withdrawal or withholding of life-sustaining treatment. In addition, there is a legal consensus that both withdrawing and withholding treatment can be justifiable, if that treatment is not wanted by the patient or is ineffective.

Courts have also upheld the validity of DNR (do-not-resuscitate) and other treatment limitation orders.<sup>7</sup> There are no limitations on the type of treatment that may be withheld or withdrawn—courts have rejected distinctions between “ordinary” and “extraordinary” treatment. Thus, ventilator withdrawal that may result in death is permissible,<sup>3,8</sup> and even parenteral nutrition and hydration may be withheld or withdrawn under the same conditions as any other form of medical treatment.<sup>9</sup> Physicians should provide the patient with information about his or her situation, offer choices about all treatments, assist with decision making, and not automatically assume that ventilators, feeding tubes, or other life-prolonging treatments are required.

These are established legal principles, and physicians should feel comfortable acting in accord with them. There are few situations that cannot be resolved legally and ethically by the physician in collaboration with the patient and family. Only rarely does limitation of life-prolonging treatment at the end of life require court intervention.<sup>10</sup>

Slide 9



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VHA also recognizes that patients have the right to refuse life-sustaining medical treatment based on the requirement of informed consent for treatment, and the right of the patient to choose no treatment [see VHA Handbook section 1004.01(13)(d) *When the Patient Chooses and Alternative Treatment, Including No Treatment or Revokes Consent*<sup>1</sup>].

## Decision-making in the setting of incapacity

Few patients with life-threatening illnesses retain decision-making capacity until the moment of their death. Most patients endure some period of incapacity at the end of their lives. Limitation of life-sustaining treatment is possible for patients who lack capacity to make medical decisions. However, it is necessary to first determine incapacity and have arrangements for proxy decision making.

# Determining and declaring decision-making incapacity

Slide 10



**Determining incapacity**

- Any incapacity in:
  - ability to understand?
  - ability to evaluate information, reason, appreciate the consequences and make a decision?
  - consistent over time?
  - ability to communicate the decision?
  - reassess for each decision?

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Though a court of law may determine a patient to be incompetent and appoint a guardian to make important decisions, including those concerning health care, for the patient, many patients who have not been declared incompetent by a court may nonetheless have problems with their capacity to make health care decisions.

In assessing a patient’s ability to make a decision regarding health care, one must evaluate three elements of the capacity to make health care decisions.

First, the patient must possess the ability to comprehend information about the medical problem as well as to appreciate the impact of the disease and the consequences of various options for treatment, including foregoing treatment. Second, the patient must possess the ability to evaluate options by comparing risks and benefits of each option, to deliberate in accord with the patient’s own values, and to make choices that are not irrational. The patient should also be able to maintain a consistent choice over time. Third, the patient should be able to communicate his or her choice.<sup>11</sup>

Determination of the capacity of a patient to decide on a course of treatment must relate to the patient’s abilities, the requirements of the task at hand, and the likely consequences of the decision. When the consequences for the patient’s well-being are substantial, there is a greater need to be certain that the patient possesses the necessary level of capacity to make the decision.<sup>12</sup>

A lack of decision-making capacity may be caused by any break in the chain of decision making: the ability to understand, to reason and evaluate, and to communicate a decision. Obviously, patients in a coma, infants, young children, and the profoundly mentally disabled lack decision-making capacity for all medical decisions. Some other patients, such as those at the end of life with significant metabolic abnormalities, some disorientation, or early dementia, may yet retain some degree of decision-making capacity. Clinicians taking care of patients at the end of life should make a determination of the patient’s decision-making capacity before each significant health care decision.

Evaluating decision-making capacity can be summarized as follows:

- Ability to understand:

- Does the patient have the ability to understand the basic information needed to make a decision?
- Ability to evaluate:
  - Can the patient reason and weigh the consequences of the decision?
  - Does the patient make a decision? and
  - Is the decision reasonably consistent over time?
- Ability to communicate:
  - Can the patient communicate the decision?

Declarations of incapacity can be done through a formal, legal statement, but usually are done by recording the evaluation of incapacity by the primary physician or a psychiatrist in the medical record. The recorded evaluation should document the basis for declaring the patient incapacitated. A record of the patient’s lack of decision-making capacity as determined by two physicians or a physician and psychologist may be required before a power of attorney for health care can be activated. Most declarations of incapacity should be for the limited scope of the decision at hand, and the record should so indicate. Subsequent decisions will require reevaluation.

Slide 11

**Decision making for the incapacitated - VHA**

- Who should decide (must be ≥ 18 y.o.)
  - health care agent (DPAHC)
  - guardian
  - next of kin, relative
  - close friend
- What standard should be used
  - substituted judgment if wishes known
  - best interest

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In VHA, standards for determining decision making capacity are set for in VHA Handbook section 1004.01(12) *Determination of Decision Making Capacity*.<sup>1</sup>

Once incapacity is determined, practitioners should use one of two criteria or tests that courts have generally recognized as standards for decisions about life-sustaining medical treatment. The first test requires determination that treatment would not be in the *best interests* of the patient. For example, one court applying the test determined that for a patient in a persistent vegetative state, it is not in the patient’s best interest to continue treatment.<sup>13</sup> The second test applies the *substituted judgment* standard to determine whether the patient would have wanted treatment withheld if he or she had been competent.<sup>14</sup> This standard takes into account the patient’s subjective wishes, if known. Decision making that involves the application of advance directives uses the substituted judgment criterion, to which proxies (or health care agents) must adhere.

# Guardianship

Traditionally, if the patient has made no other provisions, the mechanism for making both medical and nonmedical decisions for incapacitated patients has been to establish a legal guardian, that is, a person with legal guardianship. End-of-life decision making for patients who have never had decision-making capacity (e.g., infants and young children, or developmentally disabled adults) generally requires an individual who is legally able to act in the patient’s best interest, such as a parent or guardian. Additionally, federal regulations (so-called Baby Doe regulations) apply to end-of-life decisions made for infants and newborns.<sup>15</sup> However, the guardianship mechanism has a number of disadvantages for the average life-threateningly ill patient. The guardianship process is often slow and costly for the patient or family. Moreover, the guardian is normally expected to make decisions using the traditional best interest standard, which does not necessarily rely on the patient’s previously expressed preferences. For most adult patients at the end of life, legal guardianship is an option of last resort for making health care decisions. It may, for instance, be used if the proxy (or health care agent) is clearly acting against the patient’s interests and needs to be replaced.

## Terminology of advance directives

Slide 12



**Terminology of advance directives**

- Advance care planning  
process of discussion, documentation, implementation

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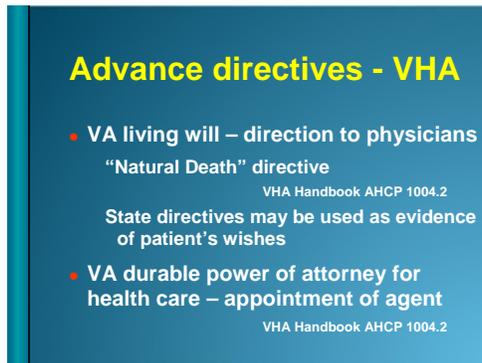
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Slide 13



**Advance directives - VHA**

- VA living will – direction to physicians  
“Natural Death” directive  
VHA Handbook AHCP 1004.2  
State directives may be used as evidence of patient’s wishes
- VA durable power of attorney for health care – appointment of agent  
VHA Handbook AHCP 1004.2

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Over the past two decades, courts and legislatures have recognized advance directives as legally valid indicators of patients’ previously expressed desires to be used in medical decision making. Terminology in this area may be confusing. The process of discussion, documentation, and implementation of wishes is termed *advance care planning*. Advance

directives refer more specifically to the documents that are generated in the process of advance care planning. The most common of the advance directives are the living will (a form of instructional directive to limit life-sustaining medical treatment in the face of a life-threatening illness) and the durable power of attorney for health care (an appointment of a health care agent or proxy to make decisions according to the incapacitated patient's preference). Other types of instructional directive include personal letters, a values history, and a medical directive.

Advance directives typically give immunity from successful prosecution to physicians who, in good faith, follow the directive. Though advance directives are, for the most part, statutory documents created by state legislatures, they can also be advisory documents that act as evidence of patient wishes, and may be recognized under common law beyond state borders. Moreover, state legislatures may direct that health care providers honor other states' advance directives. As a result of the Patient Self-Determination Act, states are required to recognize at least one form of advance directive, and health care institutions are required to inform patients of their right to refuse medical treatment and to make advance directives<sup>16</sup> (see EPEC for Veterans Module 2: Advance Care Planning).

VHA advance directives include the Durable Power of Attorney for Health Care and Living Will. These documents are valid across state lines in any VHA facility [see VHA Handbook section 1004.02 *Advance Care Planning*<sup>17</sup>, and VA form 10-0137 *VA Advance Directive: Durable Power of Attorney for Health Care and Living Will*.<sup>18</sup>]

If a patient does not have a VHA advance directive, but does have a state-authorized advance directive, the information may be helpful as evidence of the patient's wishes. Although some states place restrictions on the content or applicability of advance directives, such restrictions do not apply in VHA. Questions about the validity of a state-authorized advance directive in VHA should be referred to VA Regional Counsel or to the Office of General Counsel (OGC).

## **Choosing a surrogate**

Despite the availability of these documents, the majority of individuals do not complete advance directives.

VHA has a specified process for making decisions for those patients who have lost decision making capacity. It consists of first identifying a health care agent or surrogate. An authorized health care agent has highest priority as a surrogate. When no health care agent is authorized and available, the Veteran's legal or special guardian has next highest priority. If no health care agent is authorized and no guardian is authorized and available, the practitioner must make a reasonable inquiry to identify other possible surrogates, including next-of-kin or, if no next-of-kin, a close friend. The next-of-kin should be a spouse, child, parent, sibling, grandparent, or grandchild 18 years of age or older. The close friend should be someone 18 years of age or older who has shown care and concern

for the patient's welfare and is familiar with the patient's activities, health preferences, religious beliefs, and values.

Where there are multiple surrogates at the same priority level in the hierarchy and they do not agree about the recommended treatment or procedure, the practitioner must make reasonable efforts to reach a consensus. If consensus cannot be reached, the clinician must choose the surrogate who is best able to speak for the patient, and document the reasons for choosing that individual. In cases where the choice is unclear, the clinician must consult with the local ethics program and/or regional counsel [VHA Handbook section 1004.01(14)(a)<sup>1</sup>]. In general, because of this well-defined hierarchy, identifying a surrogate to engage in shared decision making in end-of-life care may be easier in VHA than in many other hospitals controlled by state law that may not have such a hierarchy.

A number of states have enacted surrogacy laws.<sup>19</sup> Under these laws, patients without advance directives who become incapacitated may have a decision maker appointed from a list of eligible individuals, including a spouse, family member, or others as prescribed by statute. The hierarchy of the individual's eligibility may vary from state to state. Surrogacy laws give legal recognition to a process that many physicians used in the past when no one had been appointed as guardian—namely, turning to the person most likely to be recognized as the appropriate representative of the patient. In states that do not have surrogacy laws, physicians often continue to rely informally on the next-of-kin hierarchy from which surrogacy statutes are adapted.

## **Evidentiary support of surrogate decision making**

Once a surrogate is identified, he or she must determine the patient's wishes regarding end-of-life treatment. Where the patient has an advance directive specifying treatment choices, this may only entail interpreting the directive.

VHA requires surrogates to make decisions based on substituted judgment or, if the patient's values and wishes are unknown, on the patient's best interests [VHA Handbook section 1004.01(14)(b)(1)(c) *Patients Who Have a Surrogate*<sup>20</sup>].

Most states require a surrogate to determine that it is more likely than not that the patient would have made a particular health care decision (this standard is known as the preponderance of evidence standard, expressed as "more probable than not"). Some states require a higher degree of certainty (clear and convincing evidence, a higher standard than preponderance of the evidence) that the patient would have chosen a particular course of action. The difficulty in determining whether verbal expressions of health care preferences meet these standards reinforces the importance of written advance directives. For example, a general comment made by the patient that he or she "would never want to live as a vegetable" does not give a great deal of guidance as to whether to discontinue life support after an accident that leaves the individual with significant brain damage, but not in a persistent vegetative state (see EPEC for Veterans Module 2: Advance Care Planning).

# The appropriate use of opioids in end-of-life care— developing consensus

Slide 14

**Appropriate use of opioids in end-of-life care**

- Recognition of role of opioids by regulatory agencies
- Principle of double effect
- VHA initiatives
  - National Pain Management Strategy
  - Palliative Care Consult Teams

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The concepts of palliative care and hospice have developed in response to the ethical mandate that patients and families should receive care to relieve suffering and improve the quality of their lives. Both depend on the appropriate use of opioids to relieve pain, shortness of breath, and other symptoms. The federal Drug Enforcement Agency (DEA) and state licensure and drug regulation agencies are charged with enforcing the laws concerning controlled medical substances, such as opioids. Traditionally, these agencies have monitored physicians’ prescriptions for opioid use.

In the past, many physicians and regulators have been overly concerned about the problems associated with substance abuse and addiction. Today, there is a growing awareness by regulatory bodies of the appropriate role of opioids in end-of-life medical practice. The result is a recognition that quantity and frequency alone are not indicators of inappropriate treatment when physicians prescribe opioids for terminal patients.<sup>21,22</sup>

The principle of double effect differentiates the provision of adequate medication that unintentionally hastens death from the provision of medication that intentionally causes a patient’s death (see physician-assisted suicide below and EPEC for Veterans Module 13: Responding to Requests for Hastened Death). This principle justifying adequate pain relief in end-of-life care has been recognized by the U.S. Supreme Court. Clinicians have a responsibility to be aware of the realistic risks associated with the treatments they offer (e.g., the minimal risk of death associated with opioids when prescribed appropriately for pain relief).

Clinicians should feel comfortable providing medication, including opioids, using accepted dosing guidelines to alleviate a Veteran’s pain and suffering, even if an unintended secondary effect might risk hastening the Veteran’s death (see also EPEC for Veterans Module 4: Pain Management). The fear of prosecution of clinicians for providing appropriate end-of-life care has been disproportionate and should not deter providers from using opioids analgesics to manage pain at the end-of-life, provided that pain has been carefully assessed and treated, and communications with the caregivers and family are thorough.<sup>23</sup> In fact, there are now cases where the treating clinician has been disciplined or successfully sued for under state law for inadequate pain treatment.<sup>24</sup>

The VHA National Pain Management Strategy established pain management as a national priority, with a requirement that a pain management committee be established at each VHA facility.<sup>25</sup> Additionally, each VHA facility must have a Palliative Care Consult Team.<sup>26</sup> Both of these resources are available to VHA practitioners who treat patients for pain in end-of-life care.

## Physician-assisted suicide—a matter of federal law in VHA

Slide 15

**Physician assisted suicide and VHA**

- Prohibited in all federal facilities
- Also in statutory or common law in almost all other states

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Perhaps no other end-of-life ethical issue has generated as much controversy as that of physician-assisted suicide. Although there is an ethical and legal consensus that patient refusal of life-sustaining medical treatment is not suicide, the provision of medication with the intent to produce death is considered to be assisting suicide. All states except Oregon, Washington and Montana have laws that make assisting a suicide by anyone (including clinicians) a criminal offense.

Recently, some patients and physicians have argued that suicide with the assistance of a physician should be available for patients who have advanced life-threatening illnesses and decision-making capacity. In 1997, the United States Supreme Court held that there is no federal Constitutional right to assisted suicide.<sup>27</sup> In doing so, it reaffirmed the distinction between withholding or withdrawing life-sustaining treatment and assisted suicide. The decision leaves open the possibility that state supreme courts will find a state constitutional right, or, more likely, that states will develop a statutory right. For example, Oregon has followed the latter route and has legalized physician-assisted suicide<sup>28</sup> (see EPEC for Veterans Module 13: Responding to Requests to Hasten Death).

Nonetheless, the federal law applicable to VHA is clear. Practitioners in VHA may *not* assist in suicide.<sup>29</sup>

# Futility—lack of consensus

Slide 16

**Futility**

- Futile for what goal?
- Objective determinations of benefit
- Use ethics consultation / committees
- Transfer of care, if possible
- No obligation to offer non-beneficial intervention

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Slide 17

**Futility & DNR – VHA ...**

- DNR orders – authorization  
must get patient, agent, or surrogate
- Exception  
Resuscitation not mandated “where such efforts would be futile or useless”  
VHA Handbook 1004.3 DNR Protocols  
Do-Not-Resuscitate Orders and Medical Futility. Report by the National Ethics Committee of VHA

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Slide 18

**... Futility & DNR – VHA**

“In the exercise of the sound medical judgment of the licensed physician, instruction may be given to withhold or discontinue resuscitative efforts of a patient who has experienced [a cardiac] arrest.

Such cases would involve patients for whom resuscitative efforts are ineffective...”

VHA Handbook 1004.3

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Another controversial issue in end-of-life care is the process for determining when medical interventions are no longer effective, especially when medical personnel and the patient or surrogate disagree about the decision. A number of cases suggest that this issue is still undergoing development in judicial analysis.<sup>30,31,32</sup> In addition, states may have statutes that directly address the issue.<sup>33</sup> To guide the process, some general guidelines can be drawn from medical practice and ethical principles (recognizing that applicable law, if any, may vary by jurisdiction):

Physicians should be careful when thinking that a treatment may be “futile.” In medical decision making when a treatment under consideration may seem to be futile, the physician should ask, “futile for what goal?” That goal should be defined by the patient or surrogate in conjunction with the physician.

Physicians' recommendations for limiting treatment should be based as much as possible on an objective determination of ineffectiveness, for the accepted goal rather than subjective opinions about the worth of the intervention or of the patient's continued life. Where there is a concern or question, a second clinical opinion about the potential effectiveness of treatment may be both beneficial and necessary.

Where the Veteran or family disagree with the clinician's judgment, ethics consultation or committee review may be advisable.

If there is continued disagreement, facilitate transfer of the Veteran when feasible to another health care practitioner or health care facility willing to continue or cease treatment

If transfer to another clinician or institution is not possible, ethical standards support that the practitioner may determine when an intervention is futile and need not be offered.<sup>34</sup> The exception to this general rule in VHA pertains to DNR orders. DNR orders may not be written without the consent of the Veteran or surrogate, although a licensed clinician exercising sound judgment may appropriately give an instruction to withhold or discontinue resuscitative efforts of a Veteran who has experienced a cardiopulmonary arrest, based on the ineffectiveness of resuscitative efforts or efforts being contrary to the Veteran's wishes and interests. [VHA Handbook 1004.3 DNR Protocols (3) (c)<sup>35</sup>].

In cases where futility comes up, there is very commonly a major component of unsuccessful communication and strained relationships. Try to keep communication good, listen well, convey information effectively, and keep an empathic approach. In several studies a correlation exists between quality relationships and reduced malpractice rates, not only in futility cases but in general.

## **Confidentiality**

Confidentiality concerns are not usually different for Veterans facing the end of life. There are no major legal differences. In general, confidentiality should be broken if the absence of information puts an identifiable third party at risk of major damage. Reporting requirements demand that certain infectious disease diagnoses be reported to public health authorities.

# Legal counsel and end-of-life care

Slide 19

## VHA Legal Counsel

- VHA Legal Counsel represents VHA and VHA practitioners
- Responsibility for ethical end-of-life care resides with VHA practitioners
- VHA Legal Council can make the treatment team cognizant of those VHA policies, federal laws, and regulations that support ethical practice in end-of-life care

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Physicians have a responsibility to make ethical decisions in the care of patients at the end of life within the law that governs their medical practice. While ethics committees and consultation may consider legal aspects, they do not act as a legal advisor to the clinician and should not be mistaken as such.

Though there is broad legal consensus on much of end-of-life treatment, some state variations remain (e.g., standards of certainty that surrogates must demonstrate in making decisions) and some difficult legal issues remain unresolved (e.g., futility).

When clinicians are uncertain as to the approaches to resolving a given case, legal counsel may be sought. Clinicians often have high regard for VHA counsel and their legal advice and recommendations may well influence decisions about patient care. In VHA, institutional counsel represents both VHA and the practitioners in VHA. Legal counsel's primary duty is to protect VHA from legal liability, while facilitating practitioners' implementation of the best course of ethical medical practice. In most cases these two goals are compatible, but ultimately the responsibility for ethical end-of-life care resides with VHA practitioners. Institutional counsel can make the treatment team cognizant of those VHA policies, federal laws and regulations that support ethical practice in end-of-life care.<sup>36,31</sup>

# Summary

Slide 20

## Summary

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For clinicians, the management of Veterans at the end of their lives may give rise to legal considerations. However, many of these legal issues have been resolved and a broad legal consensus of the appropriate treatment and limitation of treatment in end-of-life care has emerged. It is important for clinicians who are caring for Veterans at the end of life to understand the ethical and legal consensus, noting where their jurisdiction's laws may differ. As well, clinicians should understand the end-of-life issues that lack a legal consensus. Most importantly, clinicians should remember that the best risk-reduction strategy, from both an ethical and a legal perspective, is effective communication with the Veteran and family. Many of the points in this session can be summarized in the "take-home" list of pearls and pitfalls that follows the list of resources/references.

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