

EPEEC for Veterans

Education in **P**alliative and **E**nd-of-life Care for Veterans

Trainer's Guide

Module 2

**Advance Care
Planning**

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Module 2 trainer's notes

Principal message

Discussing advance directives with patients can increase the chance that care will be consistent with a patient's goals and values, and enhance quality communication, decision making, and the patient/family's opportunity to come to terms with their illness.

Module overview

Advance care planning is a process for identifying and communicating an individual's values and preferences regarding future health care for use at a time when the person is no longer capable of making health care decisions. It may occur in or outside of health care settings, can be done by anyone with decision-making capacity, and may or may not involve health care professionals directly. Advance care planning may result in a written advance directive document. It can balance the necessary focus on end-of-life planning with current goals of care, especially if encompassed as part of the continuously adjusted goal planning discussions that guide a well-conducted care process.

As with discussions about some other types of goals of care, salient conversations should be conducted with the surrogate decision maker present if at all possible. It is helpful to think of the process as a stepwise approach. The steps include the appropriate introduction of the topic, structured discussions covering potential scenarios, documentation of preferences, periodic review and update of the plans and directives, and conditions under which the advance directive would be implemented. The steps can then be flexibly integrated into routine clinical encounters by the clinician and other members of the health care team. The process fosters personal resolution for the Veteran, preparedness for the surrogate and effective teamwork for the professionals.

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

Allow sufficient time to have participants introduce themselves.

The suggested timing for each part of this module is:

Introduction	2-3 minutes
Presentation	40 minutes
<u>Summary</u>	<u>2-3 minutes</u>

Total

44-46 minutes

3. Number of slides: 24

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 **Module 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 module. To establish the context for the session, make a few broad statements about the importance of advance care planning as a clinical skill. Tell participants the format and 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.

4. Show the trigger tape or present the clinical case

After reviewing the objectives for the session, show the trigger tape that portrays the clinical case below. It has been designed to engage the audience and provide an appropriate clinical context for the session. It was not designed to demonstrate an ideal interaction, but to ‘trigger’ discussion.

Clinical case

Keith Cunningham is a 55-year-old computer salesperson who has diabetes and mild hypertension, but is otherwise in good health. Mr. Cunningham has come in for a routine physical exam. In reviewing the chart, the physician notices that advance directives have not been addressed.

Discussion

If the discussion is slow to start, you may want to ask more direct questions, like:

- Have they had similar patients?
- How did the patient react to the clinician’s questions?
- How did the clinician start? What was well done? What was missing?
- What did the clinician do to foster a comfortable atmosphere?
- How did the physician address the patient’s concerns?

Use the discussion to set the stage for the material to follow. Don’t let the discussion focus on a critique of the technical quality of the trigger tape or how ‘real’ the players seemed. If the participants don’t like something that was said or done in the trigger tape, ask them how they would do it themselves.

Setting limits to discussion time

Limit discussion of each scene of the trigger tape to no more than 5 minutes, then move on to the presentation. To help move on if the discussion is very engaged, try saying something like:

- Let’s hear two last points before we move on.
- Now that you have raised many of the tough questions, let’s see how many practical answers we can find.

5. Present the material

Recommended style: Interactive lecture

An interactive lecture will permit you to engage your audience, yet cover your chosen material within 45 to 60 minutes.

One possibility in this didactic yet interactive approach is to ask participants to consider completing a worksheet, after presenting the principles in the lecture-based format. Present participants with at least 2 scenarios and ask them to consider their choices for each one. After giving participants time to consider the issues and make their own choices, ask for a show of hands to see how much variability there is within the group. After completing the worksheet, ask the group for comments on the exercise. Use the discussion to emphasize the points made during the lecture.

Alternative style: Role-play

Summarize the steps for advance care planning either by using a few slides or by listing them on a flipchart or overhead projector. Then, introduce one of the following role-play exercises and base it on one of the following scenarios: a well-patient visit, a patient with a relatively new diagnosis, or a patient with advanced or metastatic disease who has only recently come into your practice.

Patient, proxy, and clinician role-play

Ask participants to divide into patient, proxy, and clinician trios. Ask the clinicians to introduce the concept of advance planning to the patient and proxy and have the patient respond based on the scenario. Suggest to the proxy that he or she hold a pencil and pencil in the patient's answers on the worksheet. Prompt the clinician to probe for the patient's threshold for intervention, to clarify confusions, and to identify differences that might cause conflict later. Encourage the proxy to listen, clarify if need be, and speak up if serious differences exist or if the role seems too difficult to do.

Continue the interaction for about 10 minutes. Then, stop the advance care planning discussion and ask each participant to comment to his or her partners about one another's handling of the interaction (total of 5 minutes). The following questions may help to guide the feedback:

- What did it feel like for each party to participate in the discussion?
- Did you feel like your issues were understood?
- Were there any expectations you had that were not addressed? How did it feel to have those expectations not addressed?

After the small group discussion (total 15 minutes), lead the larger group in a discussion of their experiences. Ask for comments first from the clinicians and then from the patients. Use the flipchart or overhead projector to capture the important discussion points. Use the discussion to interweave the key take-home points from the syllabus.

6. Key take-home points

1. Make a partnership with the Veteran and the family caregiver; draw them into the interdisciplinary team to foster their active participation in the care plan and developing their advance directive.
2. Conduct advance care planning conversations as a part of routine care.
3. Emphasize that advance care planning is a process and not a document.
4. Advance care planning does not need to be done in one session. It can be started at one appointment or encounter and revisited at a later time.
5. Review advance care planning documents upon a change in the patient's condition to be sure they continue to reflect the patient's preferences.
6. Keep in mind that advance directives are different from life-sustaining treatment plans or medical orders to provide or limit life-sustaining treatment. Advance directives are written by patients to help the patient's family and health care team understand their preferences for how they would want to be treated under hypothetical future circumstances if they were to lose the capacity to speak for themselves. Life-sustaining treatment plans with associated orders are written by health care providers and direct the patient's treatment for their current circumstances.

7. Summarize the discussion

Briefly, review each part of the presentation. Recap 2 or 3 of the most important points that were discussed.

Advance care planning exercise

This is an exercise to help clinicians learn about advance care planning. It is written essentially as a script for a facilitated group process. The educational method is interactive rather than didactic. The scenarios are designed for people in generally good health and would not be duplicated exactly for many of the Veterans we care for. Rather, this exercise allows health care professionals to get used to advance care planning for themselves as a step in the process of becoming competent in assisting patients in the process.

It is helpful to be able to say to Veterans and families that you have done your own advance care planning as a matter of routine care. It is also helpful to have experienced the process of trying to imagine being in a state of serious illness and mental incapacity.

First scenario

We will start by considering a scenario in which you have an advanced illness with a very poor prognosis (less than 3 months if the disease follows its usual course). You are in the

hospital with confusion and are not able to speak for yourself with a poor likelihood of recovery when you develop a fever and signs of small bowel obstruction.

First, consider what you would want to be the *goals* of your care in this circumstance. Would you want: (a) all possible intervention to prolong life, (b) full intervention, but with early reassessment, (c) interventions that may help but that are not too invasive, or (d) noninvasive comfort care only? [*Pause briefly.*]

Now, consider what treatments you would want. Would you want major surgery? [*Pause briefly.*] How about an intermediate option with a nasogastric tube, and no intake by mouth? [*Pause briefly.*] How about only intravenous antibiotics? [*Pause briefly.*] What about only comfort measures with analgesics and sedatives?

Let's look at what goals you selected. How many of you selected all possible interventions to prolong life? [*You may want to list this on the left-hand side of a flipchart or overhead projector. Count hands and record the number.*] How many selected full interventions, but with early reassessment? [*Count hands and record the number.*] How many chose interventions that might help but are not too invasive? [*Count hands and record the number.*] How many chose noninvasive comfort care only? [*Count hands and record the number.*]

Let's look at what treatment options you selected. How many wanted major surgery? [*Count hands and record the number on the right-hand side of the flipchart or overhead projector opposite the corresponding goal.*] How many wanted intermediate interventions with an NG tube? [*Count hands and record the number.*] How many wanted antibiotics? [*Count hands and record the number.*] How many chose noninvasive comfort care only? [*Count hands and record the number.*]

Notice how many of you declined all interventions and wanted only comfort measures. Some of you wanted some noninvasive or minimally invasive measures. Also, notice the inconsistencies. When faced with specific choices, some of you changed to a different "level" as related to overall goals. If we were to move to a scenario with a rosier prognosis, we would still be likely to find a range of choices within the group. Many of you would change your choices.

This process provides an opportunity to think about your own internal inconsistencies, how you might value various options, and how you would set limits. Further, it helps you to be specific about your relationship to death and dying.

Many of the questions in your mind are questions Veterans will have. In fact, lawyers and physicians tend to be either the fastest or the slowest to complete these types of exercises. Most people, regardless of educational experience, find these exercises helpful and doable.

Second scenario

Now, consider a scenario in which you have a mild chronic condition. It affects your day-to-day living to a modest degree. You now contract a life-threatening but potentially reversible condition such as *Staphylococcus aureus* pneumonia. You are barely conscious and cannot make decisions for yourself. Let's go through the same exercise. First, let's discuss goals. Would you want: (a) all possible intervention to prolong life, (b) intervention, but with early reassessment, (c) interventions that may help but that are not too invasive, or (d) noninvasive comfort care only? [*Pause briefly.*]

Now, consider what treatments you would want. Would you want care in an intensive care unit, including pressors and intubation? [*Pause briefly.*] Would you want a more intermediate intervention, such as multiple intravenous antibiotics but no transfer to an intensive care unit and no intubation? [*Pause briefly.*]

Now consider a barely invasive intervention. Would you want IV antibiotics but a limit on the degree of laboratory testing? [*Pause briefly.*] Would you want only comfort care with analgesics and sedatives? [*Pause briefly.*]

Let's look at what treatment options you selected. How many chose all measures to prolong life? [Count hands and record the number on the right-hand side of the flipchart or overhead projector opposite the corresponding goal.] How many wanted intermediate interventions with IV antibiotics, but no ICU care? [Count hands and record the number.] How many wanted only IV antibiotics? [Count hands and record the number.] How many chose noninvasive comfort care only? [Count hands and record the number.]

Notice the changes. Most of you wanted interventions that were much more "aggressive." Contrast your answers to this scenario with the first. Do you have a sense of where your threshold for intervention lies relative to prognosis and disability? Some of you could now move to other scenarios and treatments that would more clearly define your personal threshold for intervention. For many people, it is enough to define where the threshold is, without resolving detailed decisions at the threshold. This is often where clinician recommendation plays a stronger role and proxy discretion comes in. Many Veterans are content with this.

Notice how most of you selected intervention choices that were consistent with your general goal. This is usually the case. However, some of you chose treatments that didn't quite correspond with the overall goal. Research shows that trying to predict intervention choices from stated general goals (such as those in a Living Will) is weaker than extrapolating from specific preferences. While identifying goals provides a reality check and organizes thinking, it is not a substitute for considering specific examples.

Most people, after weighing other scenarios and having fully completed an advance care planning worksheet, will feel that their views are well articulated. Some proportion of Veterans, however, will feel that there is something more that needs to be said. Invite them to give you a statement in their own words, such as in a letter. Ask them to consider

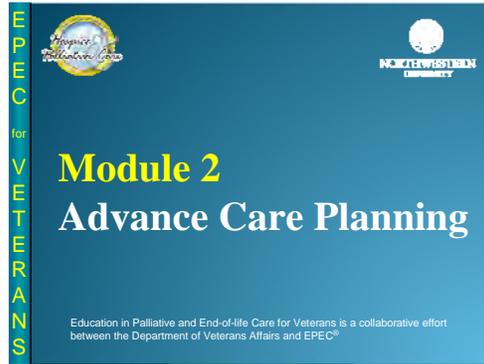
other matters, such as whether they want to die at home, or whether autopsy and/or organ donation is desired. Invite the formal proxy to be designated. If more than one proxy is desired, invite the Veteran to give some sense of order of authority in cases of disagreement.

8. Post-test/evaluation

Ask the participants to evaluate the session.

Abstract

Slide 1



Advance care planning is a process for identifying and communicating an individual's values and preferences regarding future health care. These discussions allow the individual to prepare for decisions regarding their health care that they may need to make and, importantly, clarify and document values and goals of care that can be used at times when the person is no longer capable of making health care decisions. It is helpful to think of the process in a stepwise approach. The steps include the appropriate introduction of the topic, structured discussions of potential scenarios, documentation of preferences, periodic review and updating of the plans and directives, and conditions under which the advance directive would be implemented. The steps can then be integrated into routine clinical encounters by the clinician and other members of the health care team. The process can foster personal resolution for the Veteran, preparedness for the surrogate and effective teamwork for the professionals.

Objectives

Slide 2



Slide 3

... Objectives

- Describe the five steps for successful advance care planning
- Identify pitfalls and limitations in advance care planning

After studying this module, clinicians will be able to:

- define advance care planning and explain its importance;
- distinguish between types of advance directives;
- describe the role of the Veteran, surrogate, and health care providers;
- describe the five steps for successful advance care planning; and
- identify pitfalls and limitations in advance care planning.

Clinical case

Slide 4

Clinical case

Keith Cunningham is a 61-year-old Vietnam veteran who has diabetes and mild hypertension, but is otherwise in good health. Mr. Cunningham has come in for a routine physical exam. In reviewing the chart, the physician notices that advance directives have not been addressed.

Introduction

Slide 5

Advance care planning ...

- Process of planning for future medical care at a time when that person is no longer capable of making health care decisions
- Values and goals are explored, documented
- Surrogate decision maker is named

Slide 6

... Advance care planning

- Builds trust
- Reduces uncertainty
- Helps to avoid confusion and conflict
- Permits peace of mind

What is advance care planning?

Advance care planning is a process, not an event.¹ It is the *process of planning for future medical care particularly in the event that the Veteran becomes unable to make his or her own decisions*. During this process Veterans explore, discuss, articulate, and document their preferences. The process helps Veterans identify and clarify their personal values and goals about health and medical treatment. They identify the care they would like, or not like, to receive in various situations. Veterans also determine who should make health care decisions on their behalf in the event that they cannot make decisions for themselves.

Advance care planning is designed to ensure that a Veteran's wishes will be respected in the event that he or she is unable to participate in decision making. The sense of control and peace of mind that this process fosters in the Veteran and the reduction in anxiety of surrogate decision makers are important potential benefits.

Veterans have a right to participate in the planning of their health care, and advance care planning is an important part of their medical care. Clinicians have a responsibility to ensure that the preferences for care are honored even if the Veteran loses the capacity to make decisions. The process of determining those preferences for treatment builds trust and a sense of teamwork between the Veteran, the surrogate and the clinician in several ways. The invitation to discuss future care permits the Veteran to understand his or her own values, goals, and preferences that govern his or her life. The clinician and surrogate

learn about those preferences and needs. The process helps to relieve anxieties and fears on both sides because a spirit of openness is fostered. Advance care planning is a form of preventive medicine because it may help to avoid future confusion and conflict.

There are cultural and age-related differences in approaches to medical decision making and advance care planning which are vital to consider in the process of advance care planning.² Even in the face of important cultural traditions, it remains important to determine how each individual wants to be treated in the present and into the future. This can be accomplished by developing the therapeutic relationship that will allow Veteran and family to determine how medical information is to be shared and medical decision making handled. See EPEC for Veterans Module 3: Communicating Difficult News for a discussion of how to do this.

Many clinicians are concerned that advance care planning is too idealistic or time-intensive to include in their busy practice. One purpose of this module is to provide a framework for the routine and practical inclusion of the process into practice.

Definitions

Slide 7

Advance directive

- Written statement
- By a person who has decision-making capacity
- Regarding preferences about future health care decisions
- In the event that the individual becomes unable to make those decisions

An **advance directive** is a written statement by a person who has decision-making capacity regarding preferences about future health care decisions in the event that the individual becomes unable to make those decisions. Although verbal statements may also be extremely useful in determining the prior preferences of a Veteran who subsequently loses decision-making capacity, statements that have been committed in writing in a formal advance directive document are accorded special authority, as described in VHA Handbook 1004.02.³

NOTE: *An advance directive is not to be used as the basis for decision-making while the Veteran has decision-making capacity. The existence of an advance directive never precludes the requirement to discuss treatment options with a patient who has decision-making capacity.*

Decision-making capacity is a clinical judgment about a patient’s ability to make a particular type of health care decision at a particular time. In clinical practice (and law), a patient’s decision-making capacity is generally presumed. However, when the patient’s medical condition and/or observed behavior raises questions about the patient’s decision-

making capacity, the responsible clinician must make an explicit determination based on assessment of the patient's ability to:

1. Understand the information that is provided about one's health status and treatment options;
2. Appreciate how this information applies to one's own situation (including the potential consequences of alternative treatment decisions);
3. Manipulate the information in a way that is internally rational or logical to arrive at a conclusion and;
4. Communicate the decision.⁴

This determination of decision-making capacity can be made by any clinician granted privileges to do so. It does not require a psychiatrist or a psychologist. In situations where there is uncertainty about decision-making capacity, it is often helpful to get the assistance of a psychiatrist or other mental health services. This can be particularly helpful if there is concern for the Veteran's mental health or a history of mental health problems. Clearly, individuals with delusions, psychosis or other severe mental illness will lack decision-making capacity unless these problems are treated successfully.

NOTE: *In contrast to "decision-making capacity," "competence" is a legal determination made by a court. Patients who have been judicially determined to be incompetent are incapable of giving consent as a matter of law. Such persons are deemed to lack decision-making capacity for the purpose of giving informed consent. If a practitioner believes that a Veteran who is legally incompetent does in fact have the capacity to make a particular health care decision, the practitioner must discuss this with the legal guardian and seek advice from the local ethics program and/or Regional Counsel (see VHA Handbook 1004.01, Informed Consent for Clinical Treatments and Procedures).*⁵

A Surrogate Decision Maker is a person who is authorized to make decisions about all types of health care on the Veteran's behalf if that person is incapacitated. This is based on a hierarchy of closeness of relationship to the Veteran. An example would be spouse, if available, and then adult children, etc. Individuals can select and designate a surrogate(s) who may or may not be within the hierarchy of relationship. Veterans who would desire an individual outside of the hierarchy to be their surrogate must document this in a Durable Power of Attorney for Health Care (DPAHC) in order to have their preferences honored.

A Health Care Agent (HCA) is a person selected by the patient and named in a **Durable Power of Attorney for Health Care (DPAHC)** to make health care decisions on the patient's behalf if, and/or when, that individual can no longer do so. This is also known in some settings as a **health care proxy**. In VHA, an HCA is first in the hierarchy of surrogate decision makers and is authorized to make decisions about all types of health care on the Veteran's behalf.³

A **Legal Guardian** or **Special Guardian (Guardian)** is an individual appointed by a court of appropriate jurisdiction to make health care decisions for a person who has been declared legally incompetent (the terms “guardian” and “conservator” are used synonymously).

NOTE: *Some state laws may limit the authority of a guardian to specific types of health care decisions. While statutory limitations generally do not apply in VA, specific court-imposed limitations to the authority of a guardian do generally apply. Consult Regional Counsel for questions about the legal authority of guardians.*

Types of advance directives

Slide 8

Types of advance directives ...

- **Durable Power of Attorney for Health Care:** surrogate is designated
- **Living Will:** personal preferences regarding future treatment options are indicated
- **Mental Health (or Psychiatric) Advance Directive:** personal preferences for future mental health care are indicated

Slide 9

... Types of advance directives

- **State-authorized advance directive:** advance directive document legally recognized by particular state
- **DOD Advance Medical Directive:** drafted for members of the armed services and/or military dependents by a military attorney
- **VA Advance Directive:** VA Form 10-0137

There are several types of advance directives. Some of these are general types and some are specific to VA.

Durable Power of Attorney for Health Care (DPAHC)

A Durable Power of Attorney for Health Care (DPAHC) is a type of advance directive in which an individual designates another person to make health care decisions on the individual’s behalf. The individual appointed in the DPAHC is also known in some settings as a **health care proxy**.

Living will

A living will is a type of advance directive in which an individual indicates personal preferences regarding future treatment options. A living will typically includes preferences about life-sustaining treatment, but it may also include preferences about other types of health care (e.g., mental health treatment, blood transfusions, pain management). Some living wills are very specific about certain treatments while others are more general and refer only to overall goals.

NOTE: *Living wills must not be confused with life-sustaining treatment plans or medical orders to provide or limit life-sustaining treatment. Living wills are written by patients to help the patient's family and health care team understand their preferences for how they would want to be treated under hypothetical future circumstances if they were to lose the capacity to speak for themselves. Life-sustaining treatment plans with associated orders are written by a health care provider, directing patient treatment for the patient's current circumstances.*

Mental health (or psychiatric) advance directive

A mental health or psychiatric advance directive is for patients whose future decision-making capacity is at risk due to mental illness. In this type of directive, the individual indicates preferences about future mental health care (e.g., hospitalization, medications, restraints, and/or electroconvulsive therapy). Within, preferences regarding mental health care may be recorded on VA form 10-0137, *VA Advance Directive: Living Will & Durable Power of Attorney for Health Care*.⁶

State-authorized advance directive

A state-authorized advance directive is a non-VA DPAHC, living will, mental health directive, or other advance directive document that is legally recognized by a particular state. Most state-authorized forms include the ability to designate a health care agent or proxy. All state-authorized advance directive forms are available through the National Hospice and Palliative Care Organization (NHPCO) at <http://www.caringinfo.org/AdvanceDirectives>. The validity of the state-authorized advance directives is determined by applicable state law which can mean either the law of the state where the advance directive was signed, the state where the Veteran resided when the advance directive was signed, the state where the Veteran now resides, or the state where the Veteran is receiving treatment.

VA works to resolve any conflict between those state laws regarding the validity of the advance directive by following the law of the state that gives effect to the wishes expressed by the Veteran in the advance directive. Although some states place restrictions on the content or applicability of advance directives, such restrictions do not apply in VA. Questions about the validity of a state-authorized advance directive in VA need to be referred to VA Regional Counsel or to the Office of General Counsel (OGC).

Department of Defense (DoD) advance medical directive

A Department of Defense (DoD)-authorized advance directive is drafted for members of the armed services and/or military dependents by a military attorney. This may include a DPAHC and/or living will. Federal law exempts such advance directives from any requirement of form, substance, formality, or recording that is provided for under the laws of an individual state. Federal law requires that this type of advance directive be given the same legal effect as an advance directive prepared and executed in accordance with the laws of the state concerned (see Title 10 United States Code (U.S.C. §1044c⁷, and DoD Directive 1350.4).⁸

VA advance directive

VA has a specific advance directive form, VA Form 10-0137, *VA Advance Directive: Living Will & Durable Power of Attorney for Health Care*. VA Form 10-0137 may or may not be recognized by non-federal health care facilities.⁶

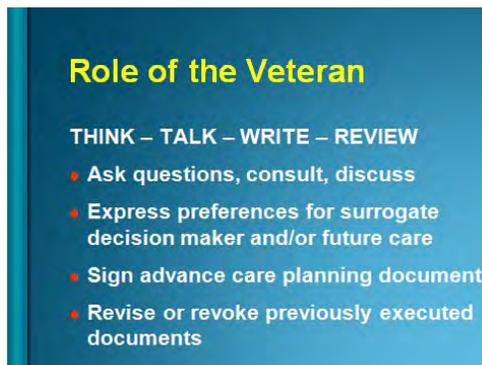
VA advance directive and the DoD advance medical directive are recognized in *all* federal facilities, regardless the state in which that facility is located. In addition, VA will recognize any state-approved advance directive. However, an individual state may not recognize VA advance directive in a non-federal facility (see POLST.org for examples).

Roles in advance care planning

The above sections have described the forms and the definitions that are important in advance care planning. With these as a foundation, the next step is to consider the important roles that the Veteran, his or her family, and clinicians take in the process of advance care planning. These are discussed below.

Role of the Veteran

Slide 10



Role of the Veteran

THINK – TALK – WRITE – REVIEW

- Ask questions, consult, discuss
- Express preferences for surrogate decision maker and/or future care
- Sign advance care planning document
- Revise or revoke previously executed documents

The Veteran is responsible for asking questions, talking to loved ones, and documenting values and preferences for future care. To prevent any misunderstanding, remind the Veteran that the goal of advance care planning is to reflect and make plans about their future health care. This process can help Veterans have the time to carefully make

decisions as they come up. When advance care planning is documented, it can guide family, friends and providers as they honor their preferences for care in the event of loss of capacity to make decisions, either temporarily or permanently.

When discussing advance care planning, convey the health care team's commitment to help the Veteran understand treatment options, develop a shared plan and goals of care, and follow the preferences. It is important that Veterans understand that VA has a commitment to provide excellent care, and that the goal of advance care planning is to ensure that the Veteran receives the type and level of care that he or she desires. All discussions with the Veteran and his or her surrogate regarding advance directives and care planning should be documented in the Veteran's medical record.

Role of the surrogate

Slide 11

Role of the surrogate

- Surrogate = person who is authorized to make health care decisions when patient lacks decision-making capacity

ask questions
keep a copy of advance care planning documents
be ready to serve as surrogate decision maker and follow the Veteran's preferences

The **surrogate decision maker (surrogate)** is the individual authorized to make health care decisions on behalf of a patient who lacks decision-making capacity. The authorized surrogate may be the health care agent/health care proxy named in the Durable Power of Attorney for Health Care, the legal guardian, or the next-of-kin (see VHA Handbook 1004.01 for information about surrogate selection, hierarchy, and the surrogate's role in health care decision making).⁹ In cases where a health care agent has not been selected in advance and the patient does not have a legal or special guardians, clinicians caring for Veterans who lose decision-making capacity will need to turn to a surrogate who is named from a hierarchy that includes: spouse, adult child, parent, sibling, grandparent, grandchild, and close friend.

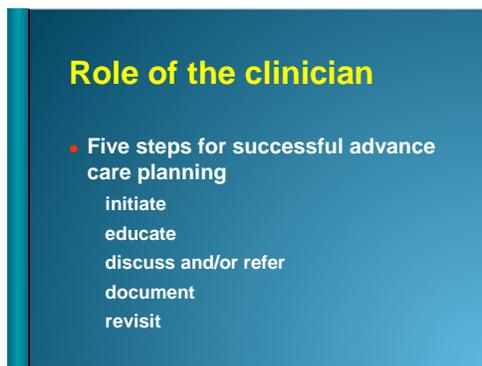
Involve the potential surrogate in the discussions and planning so that he or she can have a thorough and explicit understanding of the Veteran's wishes. Usually, the appropriate role for the surrogate during the initial discussions is to listen, perhaps take notes, and ask questions for clarification. A joint meeting including the Veteran, his or her surrogate and clinician can be invaluable in ensuring common understanding of the Veteran's values and preferences. In the general population, there are data to suggest that surrogates and patients do not always discuss wishes for treatment together.¹⁰

An advance directive is activated when a Veteran loses decision-making capacity. At this point, surrogates should be counseled that decisions about care should be based on any

oral or written documentation (such as a living will) and on the basis of his or her knowledge of the Veteran’s values and preferences for care. Another way of thinking of this is the substituted judgment standard (“What would the Veteran want if he or she could speak?”) or the best interest standard (“What is in the best interest of the Veteran?”). Often, these are the same, but not always. The surrogate will need to work with the clinician and, in general, should have the same participation in decisions that the Veteran would have had. VHA Handbook 1004.01, *Informed Consent for Clinical Treatment and Procedures*, outlines the role of the surrogate in Section 14, item b: Patients Who Have A Surrogate.^{11,12}

Role of the clinician

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Role of the clinician

- Five steps for successful advance care planning
 - initiate
 - educate
 - discuss and/or refer
 - document
 - revisit

The primary care provider plays an important role in initiating and guiding advance care planning. The primary care provider will often need to work with a specialist, such as the surgeon, oncologist or other specialists and subspecialists, to ensure that both they and the Veteran have the information and expertise needed as they guide the advance care planning process. Other appropriate clinicians need to be involved in some, but not all, stages of advance care planning in order to understand the Veteran and establish a trustworthy, shared decision-making process.

Additional clinicians on the team also play important roles in assisting Veterans with advance care planning. Each member of the team brings his or her own expertise and advance care planning is enhanced with an interdisciplinary approach.¹³ However, as the physician will be responsible for the actual medical orders, sufficient involvement is necessary among the primary care provider, other health care providers, the Veteran and his or her surrogate for the physician to feel comfortable that all treatments and care plans are consistent with the Veteran's goals and priorities. For a Veteran without a primary care provider, the primary treating provider assumes responsibility for initiating and guiding the Veteran through the advance care planning process.

Steps in advance care planning

Step 1: Initiate

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Who

VA system primary care providers are responsible for raising the issue of advance care planning with all Veterans who have decision-making capacity, explaining that they do this with all their patients. The primary care provider should involve the interdisciplinary members to facilitate completion of advance care planning. In addition, Veterans admitted to the hospital are asked by admissions clerks and nursing staff whether they would like information about or assistance with advance care planning. Health care providers in other settings may also recommend advance care planning to their patients.

When

Advance care planning discussions are to be done at intervals no longer than three years, whenever the primary care provider observes a significant change in the Veteran's health status and at the earliest opportunity after a new or revised advance directive is entered into the Veteran's record. In addition, primary care providers need to initiate these conversations more frequently with patients who are at high risk of losing decision-making capacity. It is important to revisit the subject of advance care planning on a periodic basis to review the Veteran's preferences and update the documents. Major life events such as illness, marriage, the birth of a child, or the death of a loved one should be reviewed by health care providers, as these events may affect a Veteran's attitude toward future health care decisions. Advance directive notification and screening is required at:

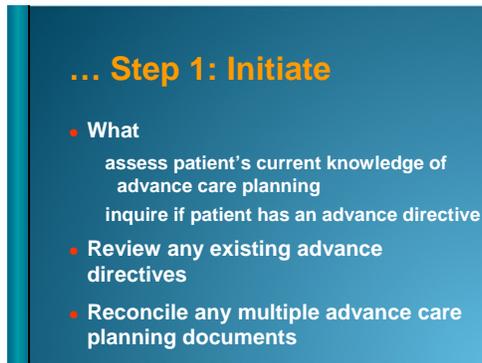
- check in for a Veteran's first primary care appointment,
- each admission to a VHA inpatient facility (including hospital, nursing home, or domiciliary facility), and
- each admission to home care or hospice care.

Where

Advance care planning should be conducted:

- in primary care settings (preferably),
- in other outpatient settings as appropriate, and
- at the bedside if the Veteran is at home or being cared for in an institution.

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... Step 1: Initiate

- What
 - assess patient's current knowledge of advance care planning
 - inquire if patient has an advance directive
- Review any existing advance directives
- Reconcile any multiple advance care planning documents

Introduce the topic

Research has shown that most patients believe it is the physician's responsibility to start advance care planning and will wait for the physician's initiative.¹⁴ Advance care planning is most easily accomplished during stable health, since changes often require a period of adjustment before the patient will have stable goals again.¹⁵

Often, the most difficult part of the advance care planning process is introducing the topic. Clinicians may have a number of concerns that make them reluctant to do so. Some clinicians may be concerned that the subject of advance care planning will frighten the Veteran or send the wrong message. Others may be uncertain about the most effective approach to use. In fact, most Veterans welcome the opportunity to discuss their preferences with their providers, and providers who routinely engage in the process find it helpful and not too time consuming.

While most Veterans will welcome the opportunity to discuss these matters, be aware of the Veteran's comfort level during the introduction of the topic. If a Veteran does not seem comfortable talking with you, be supportive and provide information, but do not force the conversation. It may happen later when the Veteran is ready. You should, if possible, talk about the decision-making process when a Veteran loses capacity to make health care decisions. In particular, Veterans who have never married or are widowed, divorced or have a domestic partner, should be informed of the hierarchy of surrogacy in the absence of advance care planning documents (see VHA Handbook 1004.01).¹² This can encourage advance care planning when the Veteran understands that the people closest to them may have no standing to participate as surrogate decision makers should they become incapacitated.

As Veterans frequently wish to minimize the decision-making burden for their families, suggest that the Veteran include family members, friends, and even members of the community to explore how to best manage potentially difficult decisions. Ask the Veteran to identify a possible surrogate decision maker to be involved in subsequent conversations. The best surrogate decision maker is not always a family member or significant other. Sometimes, the decisions are too difficult for people close to the Veteran, who may be overly influenced by their attachment or by burdens of care.

Whether close or not so close, the surrogate should be someone the Veteran trusts and who would be willing and able to represent the Veteran's wishes. Encourage the Veteran to bring that person, or persons, to the next visit. Ideally, clinicians providing specialty care will find that Veterans referred for consultation come with documentation of prior advance care planning discussions fostered by the primary care provider. If this is the case, and the Veteran is not actively adjusting to a change in health status, it may be possible to note the presence of an advance directive document and confirm with the Veteran whether preferences stated in it are, or are not, in need of review. However, clinicians should be aware that Veterans may have declined advance care planning in the past, and the topic may need to be reintroduced. After this introduction and acknowledgement of the topic, it is possible to note that it is recommended to revisit these plans periodically as part of normal care and indicate roughly when you would advise doing so. Then, after the therapeutic alliance is well established, everyone involved is usually comfortable enough to return to the topic to revisit and revise any items as necessary.

Inquire whether Veteran has an advance directive

After inquiring how familiar the Veteran is with advance care planning overall, ask whether the Veteran has an advance directive.

Review any existing advance directives

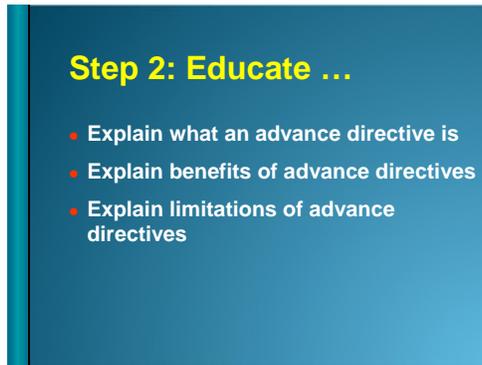
For Veterans who already have an advance directive, review the document and determine whether the Veteran's preferences have changed. If the Veteran wishes to update or revise his or her VA advance directive, a new document must be created and the old document(s) must be rescinded.

Reconcile multiple versions of advance directives

VA recognizes the Veteran's right to have more than one advance care planning document, e.g., VA and state-authorized advance directives. If the Veteran has more than one advance care planning document, review them to be sure they do not contain conflicting information. If the documents are not consistent, determine which document reflects the Veteran's current preferences, and inform the Veteran that the outdated document(s) should be rescinded.

Step 2: Educate

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Step 2: Educate ...

- Explain what an advance directive is
- Explain benefits of advance directives
- Explain limitations of advance directives

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... Step 2: Educate

- Encourage patient to appoint a Health Care Agent through a Durable Power of Attorney for Health Care document
- Encourage patient to involve loved ones
- Educate patient about available resources

Explain to the Veteran that an advance directive is a written document which provides information to clinicians, surrogate, and family members about the types of treatment the Veteran would or would not want if he/she becomes unable to speak for him- or herself.

Explain that the document allows the Veteran to extend his or her autonomy into a time in which he or she is unable to make decisions, and helps the surrogate make decisions that are consistent with the Veteran's values and preferences. Advance directives can help reduce conflict in families and ease the mind of the surrogate, who otherwise may have less information about what the Veteran would have wanted in the situation at hand. A copy of the advance directive document, which can be used as a worksheet, encourages and fosters discussions between the Veteran and family/surrogate both during the meeting with the clinician as well as between meetings.

Explain to the Veteran that there are limitations to advance directives. Not every clinical scenario can be anticipated, so the advance directive may not contain specific information about some situations that might arise. A person may complete an advance directive to express a preference for a certain type of care, but may have changed his or her mind once in the situation. If a person does not update the advance directive as their health status changes, the document may not reflect their current preferences.

At the core of advance care planning is the empowerment and preparedness of the Veteran and surrogate. Both usually require some education, time for reflection, and discussion. In order to make informed choices, the Veteran must understand the meaning

of various clinical scenarios under discussion, as well as the benefits and drawbacks of various treatment options. The discussion should provide insight into the types of clinical scenarios that might arise and the types of decisions that surrogates most commonly face.

Define key medical terms using words the Veteran and surrogate can understand. Explain the benefits and burdens of various treatment options, e.g., life support on a ventilator may only need to be used for a short time if the underlying problem is reversible. Remind them that any intervention can be refused or stopped if it is not meeting overall treatment goals (see EPEC for Veterans Module 10: Life-Sustaining Treatments). Because recovery cannot always be predicted, help Veterans to consider a range of possible situations.¹⁶

It is appropriate for clinicians to help Veterans and surrogates understand the treatment options and provide recommendations when appropriate. For instance, feeding tubes in advanced dementia have not been demonstrated to improve survival or enhance comfort and have a predictably high complication rate.¹⁷ It would be appropriate for clinicians to propose a plan of hand feeding and supportive care as a preferred option if, in their medical judgment, they believe it is appropriate. In other circumstances, clinicians may recommend a feeding tube when it could help to maintain nutritional status until the time when the patient is able to eat again, for example for patients about to undergo certain radiation therapy protocols.

Step 3: Discuss and/or refer

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Step 3: Discuss and/or refer

- Assist in completing worksheets
- Refer if Veteran has questions you cannot answer
- Refer for help in completing advance care planning document(s)

Any clinician may help with the advance care planning process. Primary care providers may discuss the issues with the Veteran and family, and then refer to a social worker for assistance in completing the documents or to a chaplain for help with related spiritual issues. Non-primary providers who are helping Veterans with advance care planning may refer to the primary care provider or a specialist to address specific medical questions. Sometimes, Veterans need time to think about information that has been provided before they are ready to document their preferences. As for the initial discussion, evidence that an advance care planning discussion occurred must be documented in the “Advance Directive Discussion” progress note along with a summary of the significant content.

Veterans who have experienced combat may have strong emotions about death or suffering related to traumatic military experiences. Discussions about end-of-life care

may provoke unresolved grief over fellow service members who were lost in combat, or may reveal fears of death as an experience of violence and suffering. Clinicians should recognize and explore this possibility with their Veterans, demonstrating sensitivity to the topic, addressing ways in which a peaceful death can be achieved, and referring for mental health assistance when necessary.

Step 4: Document

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Step 4: Document ...

- Document advance care planning discussion
- Document completion of advance directive

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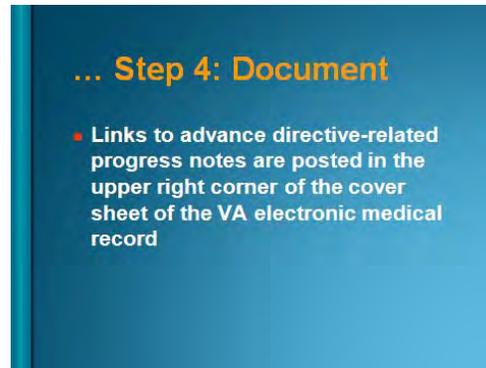
... Step 4: Document ...

- VA progress note titles
 - advance directive – used when the patient completes advance directive
 - advance directive discussion – used when there is a discussion but no advance directive is completed
 - addendum – used to note progress associated with existing directive

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... Step 4: Document ...

- VA recognizes:
 - VA Form 10-0137, “VA Advance Directive: Durable Power of Attorney for Health Care and Living Will”
 - state-authorized advance directive
 - DoD Advance Medical Directive
- Documents may be scanned into the VA electronic medical record



Formalize the directives

Once the Veteran has come to some decisions, it is crucial for the clinician to review the advance directive with the Veteran and surrogate. The goal of this is to confirm the content and check for and help correct any inconsistencies and misunderstandings. After a final review is complete, ask the Veteran to confirm his or her wishes by signing the directive. Reassure the Veteran that the document can be changed as his or her wishes change. Although any statement of a Veteran's wishes, written or verbal, can be considered an advance directive and should be respected by the clinician, a formal, written document signed by the Veteran has special status within VA and can help avoid ambiguity.^{18,19}

Enter the directives into the medical record

VA electronic health record (CPRS) has specific notes for recording advance directives.

The “**Advance Directive**” note title is used to document the entry of an advance directive document into the Veteran's record (either scanned or completed electronically). This title must be used only to document the filing of an advance directive.

The “**Advance Directive Discussion**” note title is used to document an advance care planning discussion between the clinician and Veteran. Discussion about an advance directive that is already in the health record may be documented either with a note titled “Advance Directive Discussion,” or in an addendum to the “Advance Directive” note associated with the subject directive.

To provide further information about their treatment goals, specific treatment preferences, etc., Veterans may attach one or more additional page(s), each of which must be initialed and dated, to VA Form 10-1037. This may consist of blank sheets on which Veterans write what they wish or pages from existing documents. To ensure that the document filed in the Veteran's record is complete, VA Form 10-1037 and any supplemental pages must be scanned (or filed) together, to create a single document.

It is also useful for the health care provider to ensure that the surrogate decision maker’s contact information is correct in the CPRS system and readily available. This offers

reassurance to the Veteran and helps ensure the involvement of the surrogate in eventual decision making.²⁰

Change the plan of care

Once preferences have been documented, the health care provider may need to change the plan of care and put certain procedures in place to ensure that the Veteran's preferences are followed. For Veterans who wish to remain at home and not be taken to an emergency department or hospitalized again, appropriate alternative arrangements, including referral to a home hospice agency, provision of appropriate medications, and instructions detailing how to handle symptoms and crises may be needed. In states in which they are legal, help the patient complete an out-of-hospital order form (such as the Physicians Orders for Life-Sustaining Treatments, or POLST, or Medical Orders for Life-Sustaining Treatments or MOLST).²¹ Practical suggestions may be helpful. Consider recommending that Veterans post telephone numbers by the home telephone to call in an emergency, e.g., the hospice nurse on call, or numbers not to call, e.g., 911.

Distribute the directive

It is important that a copy of the advance directive and related treatment plans be available wherever the Veteran may receive care. CPRS makes the record available in any VA facility. However, many Veterans receive some of their medical care in a non-VA facility or may go to a non-VA provider in an emergency. Provide the original advance directive and copies of related treatment plans/orders to the Veteran, and as per the Veteran's direction, provide copies to surrogate decision makers, family members, and all health care providers as appropriate. VA Form 10-0137, *VA Advance Directive: Living Will and Durable Power of Attorney for Health Care*, is honored at all VA medical centers. However, it may not be honored at non-VA community hospitals, according to their policies. If Veterans utilize both VA and community hospitals, then a state-specific advance directive should also be distributed, with the permission of the Veteran, along with VA forms.

Step 5: Revisit

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Step 5: Revisit

- Who
- When
- Where
- What

Preferences may change over time. Revisit Veterans' advance care planning preferences at regular intervals (at least every 3 years) or when there is a change in health status of the Veteran or surrogate. Any changes in preferences warrant discussion to allow the Veteran to reassess and to ensure that the medical provider and surrogate decision maker fully understand the new wishes. In addition, the appointed surrogate decision maker may become ill, incapacitated or even die. In these instances it is important to work with the Veteran to select an alternate.

Challenges in advance care planning

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Challenges in advance care planning

- Avoidance
- Failing to clarify Veteran preferences
- Focusing discussion too narrowly
- Ignoring Veterans who are communication-impaired
- Assuming the content of the advance directive

It is important to understand the perspective and wishes of all who are present at the time advance care planning takes place: the Veteran, the family, and any other caregivers. Advance care planning is a framework to foster communication between the Veteran, family, and staff, and is a process that fosters personal resolution for the Veteran, preparedness for the surrogate, and effective teamwork for the professionals.

Below are listed the five major challenges to successful completion of the advance care planning process, each of which can derail the process.

Challenges

Avoidance

Do not avoid advance care planning. Too often, situations occur and decisions are made without the benefit of advance care planning. It is easy to forget the central role of the Veteran and the importance of the surrogate in planning for a time in which the Veteran is no longer able to make health care decisions. Involve both early and often.^{22,23,24} If possible, include the surrogate decision maker(s) in the initial discussions with the Veteran.^{25,26,27}

Failing to clarify Veteran preferences

Vague statements can be misleading. Be sure to clarify Veteran preferences if they do not seem clear to you or to the surrogate. For instance, Veterans who make statements such as “I never want to be kept alive on a machine” should be asked to clarify whether their

wishes would change if their condition were readily reversible, or if their prognosis were unclear.^{28,29,30}

Focusing discussion too narrowly

Avoid isolated do-not-resuscitate (DNR) discussions; they often create chaotic emotions and thoughts in Veterans who have to imagine imminent death to make the decision. A clinician’s decision that a discussion about resuscitation is needed is usually an indication that decisions about other life-sustaining treatments should be considered in the context of a range of scenarios.^{31,32,33,34} It is important to be sure that the Veteran understands the medical condition, prognosis, risks and benefits of treatment options considered in advance care planning. It is important to reassure Veterans and their families that decisions to forego some treatment will not lead to neglect and/or less attention to usual care.

Ignoring patients who are communication-impaired

Even Veterans who are communication-impaired may still may be able to participate in advance care planning. As long as the Veteran has capacity to make health care decisions, talk to him or her. A communication-impaired Veteran may still be able to express wishes and complete advance care planning documents.

Assuming the content of the advance directive

Sometimes health care providers assume that they know what is stated in an advance directive. This is a mistake. Even if you have read an “Advance Directive” progress note summarizing the contents, read the original document. Advance directives may indicate preferences for a full scope of treatment, comfort care, or a wide range of specific preferences, and must be read and understood.^{35,36,37} Having knowledge of the contents of the advance directive will help in discussing with the Veteran any changes that may be desired.

Summary

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Advance care planning should be a routine part of standard medical care that is integrated into clinical encounters by all members of the health care team. Formally, it can be thought of as a stepwise approach, to include the appropriate introduction of the topic, structured discussions covering potential scenarios, documentation of preferences, and periodic review and update of the directives that can inform the proper application of the Veteran's wishes when needed. Less formally, the process fosters personal resolution for the Veteran facing serious, life-limiting illness, preparedness for the surrogate, and effective teamwork for the professionals. A number of critical factors contribute to a successful process and outcome, particularly guidance of and participation by the clinicians and family/surrogate participation.

As Veterans approach the end of their lives, they have a last chance to finish their business, create final memories, give final gifts, and say their goodbyes. With appropriate assistance, considerable planning can be accomplished around many of these issues. The five-step model for eliciting, documenting, and reviewing advance directives can be used to guide these decision-making processes and document patient choices. As these important tasks may be more than individual clinicians can handle, multiple other members of the interdisciplinary team can help Veterans and families explore, understand, and document the Veteran's preferences and prepare for a time when the Veteran is no longer capable of making health care decisions.

Key take-home points

1. Make a partnership with the Veteran and the family caregiver; draw them into the interdisciplinary team to foster their active participation in the care plan and developing their advance directive.
2. Conduct advance care planning conversations as a part of routine care.
3. Emphasize that advance care planning is a process and not a document.
4. Advance care planning does not need to be done in one session. It can be started at one appointment or encounter and revisited at a later time.
5. Review advance care planning documents upon a change in the patient's condition to be sure they continue to reflect the patient's preferences.
6. Keep in mind that advance directives are different from life-sustaining treatment plans or medical orders to provide or limit life-sustaining treatment. Advance directives are written by patients to help the patient's family and health care team understand their preferences for how they would want to be treated under hypothetical future circumstances if they were to lose the capacity to speak for themselves. Life-sustaining treatment plans with associated orders are written by health care providers and direct the patient's treatment for their current circumstances.

Appendix

Examples of advance care planning language

Linda Jones, a 45-year-old Gulf War era Veteran in good health, has come in for a routine examination.

Getting started

“Linda, I’d like to talk with you about something I try to discuss with all of my patients. It’s called advance care planning. In fact, I feel that this is such an important topic that I have done this myself, with my own health care provider. Are you familiar with advance care planning?”

“I also like to ask my patients if they have someone that they would like to identify to act on their behalf in the event that they are unable to express their own wishes. This person could be a relative or a friend. Is there someone whom you would want to be part of our discussion and whom you might want to have act on your behalf if you were unable to speak for yourself?”

“Most people can identify the person or persons that they would like to have make decisions for them if they were too ill to speak for themselves. It is important we understand who you would prefer to be your spokesperson if you could not speak for yourself.”

“Since these are important and difficult decisions that your family and loved ones might have to make if you were unable to speak for yourself, it is wise to record your preferences for care in an advance directive and discuss this with other health care providers and the surrogate(s) that you choose.”

“Advance care planning will help both of us to understand your values and preferences for health care if you were to become critically ill. Eventually, you may put your choices into a written document that I would make part of your medial record. We call this document an advance directive, and it would only be used if you were to lose the capacity to make decisions on your own, either temporarily or permanently...”

“Would you like to talk further about the kind of care you would want to have if you were no longer able to express your own wishes?”

After a change in health status (such as relapse of cancer, stroke or decline in function for other reasons), after allowing time to adjust to the new reality

“Ms. Jones, you have had some changes in your health since we completed your advance care plans. People sometimes change their wishes, so let’s review the wishes you wrote down before.”

“Now that you have been diagnosed with heart failure, we need to consider the situations that your heart failure can cause; that way you can be confident we will do what you want. Recently when you were in the hospital for your heart failure there were times when it was difficult for you to think and speak clearly. Are there particular things about your health, medical problems, past treatment or treatment received by other friends or family that you would like to discuss? Are there particular things that you worry about or frighten you? People sometimes think about circumstances they have seen or heard about. Do you ever think about such circumstances?”

If the patient seems unsure of decisions

“Your choices have changed since the last time we reviewed your advance directive. If there are some things you aren’t sure about, rather than writing down preferences about them you have the option of relying on [name of surrogate] to decide what he/she thinks would be in your best interests when the time comes and all the details of the situation are available. Would you rather handle it that way?”

“For the remaining decisions, about which you are clear and firm, would you like [proxy/family member] to stick closely to them, or would you prefer to give him/her room to make changes if he/she thinks your best interests would be better served by a different decision?”

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