

EPEEC for Veterans

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

Trainer's Guide

Module 10

Life-Sustaining Treatments

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Module 10 trainer's notes

Principal message

Discussion about the withholding and/or withdrawing of life-sustaining treatments is a responsibility clinicians must accept when the circumstances are relevant. Yet, such discussions can be challenging. Learning skills and approaches to the subject in general, and the specific issues of nutrition and hydration can help the clinician approach these situations with confidence and competence.

Module overview

The withholding or withdrawing of life-sustaining therapies is ethically and medically appropriate in many circumstances near the end of life. Clinicians need to develop facility with general aspects of the subject, as well as specific skills and approaches. In this module, general aspects are discussed first. Then, specific applications to artificial nutrition and hydration and withdrawing ventilatory support are presented.

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 collect participants' demographic data and complete the pre-test.

The suggested timing for each part of this module is:

Introduction	2-3 minutes
Trigger tape & discussion	5-7 minutes
Presentation	35 minutes
<u>Summary</u>	<u>2-3 minutes</u>
Total	45-50 minutes

3. Number of slides: 37

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. You may choose not to use all of the slides. By giving a handout, you can refer participants to it for the information you choose not to cover.

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 10**

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 withholding/withdrawing life-sustaining ther-

apy 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 or present 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

M.T. is an 85-year-old Veteran of World War II who experienced a spontaneous intracranial hemorrhage (ICH) into a brain metastasis from known melanoma one week ago. He had surgical evacuation of the hemorrhage and the single metastatic lesion, and has been on mechanical ventilation with limited neurological functioning since the surgery. He currently has a central line infection. Before his ICH, M.T. was actively involved in gardening and the American Legion, and volunteered with Habitat for Humanity. His wife of 62 years is at his bedside daily and is having difficulty coping with her husband's condition.

An additional case can be found in the trigger tape that accompanies this module.

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 the material within 45 to 60 minutes. Use the case from the trigger tape to illustrate key points. You may want to use case experiences of your own as examples. You may want to ask participants for comments and examples during the presentation. However, be careful

that they don't get derailed in such a way as to prevent you from covering the material you want.

Alternative style 1: Case-based

If you have mastered the material and the method, a case-based approach to teaching this module can be very effective. Develop your own case or use the one from the trigger tape. Some trainers may choose not to use slides at all. Rather, present the case and use the participants to lead you through the key elements.

Use a flipchart or overhead projector to capture the major discussion points. Use the discussion to interweave the key take-home points from the syllabus.

Alternative style 2: Role-play

If you feel comfortable directing a role-play exercise and leading the subsequent discussion, this technique can be a valuable way to illustrate to participants the complexity, yet importance, of communication skills in discussing nutrition and hydration issues with cancer patients.

Start the session by summarizing the general approaches to withholding and withdrawing support either by using a few slides or by listing the main issues on a flipchart or overhead projector.

Then, introduce the role-play exercise. Develop your own scenario for the small groups to use, or use the one from the trigger tape. Ensure that all participants are clear about the nature and stage of the patient's life-threatening illness.

Ask participants to divide into physician, patient, and observer groups. One way to do this is to ask them to 'count off' from 1 to 3. Then, tell the '1s' they are physicians, '2s' they are patients, and '3s' they are observers.

After 10 to 15 minutes, stop the role play and invite the small groups to discuss their experience. Ask the patient to comment on the questions and how they made him or her feel. Ask the physician to comment on the substance of the answers and on his or her feelings. Ask the observer to comment on the substance and the nature of the interaction.

After the small group discussion, lead the larger group in a discussion of the results. Ask for feedback first from the physicians, then from the patients, then from the observers. 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. Goals for the Veteran's care and all significant treatment decisions should be the result of collaborative discussions between the Veteran/surrogate, the Veteran's family (if the Veteran chooses to involve them), and appropriate members of the health care team.

2. Treatment decisions should be based on a clear understanding of the Veteran's values and preferences identified early in the course of an illness and reevaluated on an ongoing basis through discussions with the Veteran or surrogate.
3. Veteran or their surrogates may accept or decline any life-sustaining treatment offered (including artificial nutrition and hydration, mechanical ventilation, or cardiopulmonary resuscitation).
4. Withdrawal or withholding of life-sustaining treatment according to the Veteran's preferences is a decision/action that allows the disease to progress on its natural course. It is not a decision or action intended to cause death.
5. The decision to forego one type of life-sustaining treatment (e.g., CPR) should not be presumed to imply a decision to forego other types of life-sustaining treatment (e.g., dialysis).
6. Health care providers have a duty to offer effective palliative care and, if appropriate, to provide medications and other treatments to relieve pain, other physical symptoms, and psychological and spiritual distress near the end of life. This duty includes the provision of palliative therapies, accepted by the Veteran, that may diminish consciousness or potentially shorten life. The appropriate use of palliative therapies does not constitute euthanasia or practitioner-assisted suicide.
7. If the provision of a life-sustaining treatment is not consistent with prevailing medical standards or consistent with the goal of care, it should not be offered. If such a treatment has been requested by Veteran/surrogate, clinicians have an obligation to clarify the reasons behind the decisions not to offer the treatment in question.
8. Clinicians have the obligation to offer treatments that are consistent with the agreed-upon goals of care, even if the likelihood of success is low. Information should be provided to the Veteran/surrogate including the relative benefits, burdens, and alternatives that allows them to make an informed decision to accept or decline the treatment.
9. Health care providers acting within their scope of duty for VHA may not participate in treatments that are contrary to VHA policy, e.g., physician/practitioner-assisted suicide (PAS) or euthanasia. This prohibition applies equally to VHA practitioners in states that have laws permitting PAS, as federal law supersedes state law in this matter.

7. Summarize the discussion

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

8. Post-test/evaluation

Ask the participants to evaluate the session.

Abstract

Slide 1

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Module 10

This module provides guidance for clinicians who discuss life-sustaining treatments with Veterans and families. It presents procedures to facilitate shared decision making such that decisions about the use of life-sustaining treatments are consistent with the goals of care. The clinician is provided with information needed to address common concerns and misconceptions about the use, withholding or withdrawal of these treatments.

Objectives

Slide 2

Objectives ...

- Describe the process for discussing life-sustaining treatment decisions with Veterans and families
- Describe how goals of care influence clinicians' decisions about which life-sustaining treatments to offer or recommend

Slide 3

... Objectives

- Identify information needed by Veterans and families to make informed decisions about accepting, declining, or withdrawing life-sustaining treatments
- Respond appropriately to common concerns and misperceptions regarding the use, withholding, and withdrawal of life-sustaining treatments

After studying this module, clinicians will be able to:

- describe the process for discussing life-sustaining treatment plans with Veterans and families;

- describe how the goals of care influence clinicians’ decisions about which life-sustaining treatments to offer or recommend;
- identify information needed by Veterans and families to make informed decisions about accepting, declining, or withdrawing life-sustaining treatments; and
- respond appropriately to common concerns and misconceptions regarding the use, withholding, and withdrawal of life-sustaining treatments.

Clinical case

Slide 4



M.T. is an 85-year-old Veteran of World War II who experienced a spontaneous intracranial hemorrhage (ICH) into a brain metastasis from known melanoma one week ago. He had surgical evacuation of the hemorrhage and the single metastatic lesion, and has been on mechanical ventilation with limited neurological functioning since the surgery. He currently has a central line infection. Before his ICH, M.T. was actively involved in gardening and the American Legion, and volunteered with Habitat for Humanity. His wife of 62 years is at his bedside daily and is having difficulty coping with her husband's condition.

An additional case can be found in the trigger tape that accompanies this module.

Introduction

Slide 5





Over the last 40 years, legal and ethical precedent has established that patients with decision-making capacity or their surrogates (if the patient lacks capacity) have the right to consent to or decline any recommended treatment or procedure, including life-sustaining treatments. For a review of some of the precedent-setting cases, see **Appendix A** at the end of this module. Related discussions appear in EPEC for Veterans Plenary 2: Legal Issues.

Impediments to good care at the end of life include poor communication, lack of clarity about the goals of care, misconceptions about legal and ethical issues, and unfamiliarity with the practical aspects of implementing a decision. Over the last 15 years, studies have described inadequacies in a number of aspects of end-of-life care. For example, the SUPPORT study found that only 47% of physicians knew when their patients preferred to avoid CPR, and for 50% of conscious patients who died in the hospital, family members reported moderate to severe pain at least half the time. Many of the study subjects were found to have undergone some form of invasive medical treatment against their previously stated wishes.¹

A number of efforts have been made to address these problems. The Portable Orders for Life-Sustaining Treatment (POLST) project has championed state legislation allowing the use of portable medical orders for specified treatments.² State-authorized portable orders are specialized forms or identifiers (e.g., DNAR bracelets or necklaces) authorized by state law that translate a patient’s preferences with regard to specific end-of-life treatment decisions into portable medical orders.² Portable orders are designed to be easily recognizable and understandable by first responders and other health care personnel outside of a medical facility and to travel with the patient wherever the patient is transported. VHA Handbook 1004.04, “State-Authorized Portable Orders,” recognizes these documents as a way of helping to ensure that a Veteran’s documented orders regarding life-sustaining treatments are known and honored by caregivers across care settings within and outside VA. VA clinicians should provide portable orders or identifiers for Veterans who desire them and reside in states that authorize them, and should enter corresponding orders when Veterans with portable orders or identifiers are admitted to a VA facility. For a listing of VHA policies and initiatives related to life-sustaining treatment decisions, see **Appendix B**.

Along with this, increasing emphasis has been placed on the importance of shared decision making that assesses the goals of care for patients and their families.^{3,4} This approach recognizes that much of medical care is provided on the basis of unspoken assumptions about the appropriate goals of care, and aims to better align the care that is provided with each individual Veteran's values and preferences. One Veteran may want their health care focused on cure or life extension while another may have comfort as a primary goal. Life-sustaining treatments are not desired by all Veterans. One of the primary aims of shared decision making in end-of-life care is to specify the goals of care that will guide treatment decisions.

Slide 7



Discussions about Veterans' values and preferences for life-sustaining treatment and goals of care should take place with all Veterans who have a serious, life-limiting condition, and may take place at several points in time: as a part of routine outpatient care, during an acute care admission, after a significant change in condition, or any time the Veteran or surrogate indicates a desire to discuss life-sustaining treatment.

In EPEC for Veterans Module 1: Goals of Care, the clinician is provided with a protocol for establishing agreed-upon goals of care while incorporating evidence-based communication practices for enhancing trust, reducing distress, and improving Veteran understanding of his/her medical condition and potential treatments. Once goals for the Veteran's care are clarified, the clinician should recommend treatment options that are consistent with those goals then engage in shared decision making with the Veteran or surrogate to establish and confirm a plan of care.

This module presents guidance for successful facilitation of decision-making about life-sustaining treatments. The clinician must facilitate informed decision making by presenting appropriate information about interventions and their risks and benefits in the context of the Veteran's illness, and clarifying the relationship between the goals of care and the treatment options. The clinician must also address misconceptions about the use, withholding, and withdrawal of life-sustaining treatments.

Facilitating life-sustaining treatment decisions

Life-sustaining treatment decisions are best guided by the goals of care

Slide 8

Life-sustaining treatment decisions

- Guided by the goals of care
- Use protocol for goals of care conversation (see EPEC for Veterans Module 1: Goals of Care)
- Can be difficult for Veterans and families to discuss
- Provide support, follow-up

There are a variety of life-sustaining treatments that might be considered by an individual Veteran or surrogate. These include but are not limited to: cardiopulmonary resuscitation (CPR), mechanical ventilation, surgery, dialysis, blood transfusions or administration of blood products, artificial nutrition and hydration, antibiotics, and future hospital or intensive care unit admissions. Decisions about these treatments are best made when considering whether those treatments will or will not help achieve the goals of care. This section provides a brief overview of the steps to conducting a discussion about goals of care, and expands on the portions related to life-sustaining treatment decisions. For more detailed information about the other steps in the goals of care conversation, see EPEC for Veterans Module 1: Goals of Care.

Discussions about life-sustaining treatments are among the most difficult conversations for Veterans and their families to have, particularly when it is not clear to them whether a life-sustaining treatment should be accepted or declined. If the clinician does not know the Veteran well, prior to discussing goals of care or life-sustaining treatment decisions, information should be solicited about the Veteran as an individual, including values, characteristics, and priorities. The clinician should use appropriate communication strategies, including eliciting concerns and responding to verbal and nonverbal signs of distress, and enlist other members of the treatment team (e.g., chaplains, social workers, nurses) to follow up with the Veterans about issues causing emotional or spiritual distress.^{5,6}

Who should establish the Veteran’s life-sustaining treatment plans?

Discussions about life-sustaining treatment plans may involve the Veteran, the surrogate (if the Veteran does not have decision-making capacity), or both, along with others the Veteran or surrogate desire to be present. Life-sustaining treatment plans should be

generated through a process of shared decision making between the clinician and the Veteran or, if the Veteran lacks decision-making capacity, the Veteran’s authorized surrogate.

Patients are presumed to have decision-making capacity unless an appropriate clinical evaluation determines that patient lacks decision-making capacity, the patient is a minor, or the patient has been ruled incompetent by a court. For patients who lack decision-making capacity, practitioners must follow VHA policy for surrogate identification.

Slide 9



Surrogate decision making

When the Veteran lacks decision-making capacity, decisions about life-sustaining treatment plans must be made on the basis of one of two standards.

First, the *substituted judgment standard* is to be used by surrogate decision makers who have specific knowledge of the Veteran’s values and wishes pertaining to health care choices. This standard requires that the surrogate decides based on what the Veteran would have wanted if the Veteran were capable of expressing those preferences. That decision may not necessarily coincide with what the surrogate and health care team otherwise would consider optimal for the Veteran.

Second, the *best interest standard* is used to guide health care decisions when the Veteran’s specific values and wishes are unknown. The surrogate, together with the health care team uses this standard to determine the optimal outcomes for Veterans and the interventions most likely to produce them. In making that determination the Veteran’s cultural, ethnic, and religious perspectives must be taken into account, if known.

Life-sustaining treatment plans for Veterans who lack capacity and have no surrogate

Veterans have the right to limit unwanted life-sustaining treatments, including having those treatments withheld or withdrawn, even if this action results in death. In order to ensure health care decisions are consistent with the Veteran’s values and wishes or best interests, there is a special process that must be followed when considering the life-sustaining treatment plan for a Veteran who lacks decision-making capacity and has no surrogate. Implementation of decisions to limit life-sustaining treatments, including

withholding or withdrawal, must follow the procedures set out in VHA policy, which include review by a multidisciplinary committee appointed by the Facility Director.

Establishing a life-sustaining treatment plan

Slide 10



Establishing a life-sustaining treatment plan should be done within the context of a discussion about goals of care. This protocol incorporates the steps outlined in EPEC for Veterans Module 1: Goals of Care, and includes information specific to discussing life-sustaining treatment plans with Veterans and their families.

Step 1: Confirm a shared understanding of the Veteran's medical condition

Elicit the Veteran's and family's understanding of the Veteran's condition and expected course of the illness using the Ask-Tell-Ask strategy, in which you bracket information you provide with questions to be sure you are giving the information that is most helpful. Elicit concerns about what may happen in the future, clarify misperceptions and provide information that is missing.

Step 2: Explore the Veteran's personal goals for health care

Explore whether goals are achievable. Listen for perceptions of the relationship between the disease and symptoms. For example, the statement, "I would like see if we can get him to eat so he would get stronger," may reflect the need to review reasons for the Veteran's weakness. Examples of things a clinician might say include:

- "Given how you are feeling and what we know about the status of your heart failure, tell me your goals for your health care."
- "Now that we have reviewed your dad's condition, tell me your goals for his health care."

Sometimes the team "goals" can be overly abstract. It may help to use phrases such as "what is most important to you for your care?"

Step 3: Negotiate goals of care

If a Veteran expresses a goal that is unrealistic but not unusual for someone to hope for when facing life-limiting illness, align with his hope and note that you would provide the treatment that would accomplish that goal if you could. For example:

- “I want your tumor to stop growing, too. I wish there was a treatment available that could make that happen.”

The “I wish” statement implies that the desired goal is not possible while maintaining allegiance with the Veteran.

There may be goals that you believe are achievable and consistent with the Veteran’s values that the Veteran or surrogate did not mention, either because they forgot or did not know such goals were possible. Give information about what is possible, and ask whether those goals would be desirable to the Veteran.

Give a summary of the agreed-upon goals and ask for confirmation. For example:

- “From what I understand, you would like to live as long as possible, and you are willing to do what it takes to accomplish that, except experience severe nausea. If a treatment causes severe nausea, you do not want it. Did I understand you correctly?”

Step 4: Recommend treatments consistent with the goals of care

Slide 11



Once goals of care for the Veteran have been agreed upon, recommend treatments that will help accomplish the goals of care. Sometimes the discussion is about whether to start a particular treatment, and sometimes it is about whether to continue or stop a treatment that has already been initiated. Life-sustaining treatments that are clearly inconsistent with the goals of care or have no chance of success (e.g., organ transplant in a Veteran who is requesting palliative care only) should not be offered. The treatment may be desired by the Veteran or family, and it is important to provide clear information about why the treatment is not being offered or recommended.

Clinicians usually have biases about whether some treatments are “worth it” for Veterans with life-limiting illnesses. Clinicians need to be aware of these biases, and remember

that each individual has the right to pursue more aggressive care despite the risks even if the odds of success are low or less aggressive care even if the odds of success are high. Veterans with different goals of care than the clinician would have in the same situation are not “in denial” but rather are selecting treatment options according to their personal preferences, which are mediated by personality, cultural and religious values, concerns for the impact on the family, and willingness to take risks.

Treatments to manage disease and/or symptoms

Recommend treatments for disease and/or symptom management and explain how treatments you are recommending will help accomplish the agreed-upon goals.

- “Based on your goal to be as comfortable as possible, I would recommend a treatment plan which includes adjusting your medications to get better control of pain, nausea, and constipation. I would also recommend a medication to help you sleep, and a different mattress that may help you be more comfortable. I am also recommending that the social worker and chaplain meet with you regularly to provide the support you need and help you feel more emotionally comfortable.”

If the goal is for the Veteran to live longer, recommend any treatments that may be effective in doing so. If there are no potentially effective disease management options, tell the Veteran that you wish you had effective options to offer, and cannot in good conscience give the Veteran something that will not help meet the goals and may actually cause harm. Your empathy is critical when there are no potentially effective disease management options. Note the Veteran’s admirable strength of determination (or the family’s obvious love for the Veteran), and empathize with the frustration and sense of loss that comes when there are no more potentially effective disease-management treatments available.

Life-sustaining treatments

Recommend life-sustaining treatments according to whether they will or will not, with any reasonable likelihood, contribute toward efforts to meet the agreed-upon goals of care. Veterans and families are ill-served if clinicians believe they are honoring the principle of autonomy by offering all possible therapies from which Veterans and families can choose, as if from a menu in a restaurant. The clinician has the responsibility to recommend for or against life-sustaining treatments, explain the relationship of those recommendations to the goals of care, and to provide enough information for the Veteran or surrogate to make informed decisions among treatments that are offered.

Discuss specific treatments in language that the Veteran and family will understand. Give information in small pieces. Reinforce the context in which the decisions will apply. Stop frequently to check for reactions, ask for questions, and clarify misunderstandings.

Step 5: Establish a plan

Slide 12

... Establishing a life-sustaining treatment plan

5. Establish a plan and confirm it with the Veteran

- make shared decisions based goals of care
- summarize goals and decisions
- write orders to start, stop, or continue treatments
- document and disseminate the plan
- revisit goals and plans over time

The final step is to establish a plan and confirm it with the Veteran. The clinician should facilitate shared decision making about treatments, and then provide a summary of the decisions that have been made to confirm shared understanding and agreement. Documentation of all life-sustaining treatment discussions is important for the Veteran and family as it can provide a guide of decisions made at various points in time. The clinician is responsible for documenting the discussion, including goals of care and treatment plans, and writing associated orders in the Veteran’s medical record. Veterans and families may change their goals and treatment preferences depending on circumstances. Make a plan to reassess goals of care in light of the response to treatment and the Veteran’s condition and preferences. The next steps may be as simple as planning to discuss the subject again at the next visit, or convening a meeting the next day to assess the degree to which the Veteran has responded to life-sustaining interventions.

Specific examples of life-sustaining treatments

Slide 13

Specific examples of life-sustaining treatments

Life-Sustaining Treatments

- CPR
- Mechanical ventilation
- Artificially-administered hydration
- Artificially-administered nutrition
- Dialysis
- Transfusions
- Antibiotics
- Implanted cardiac defibrillator
- Hospitalization
- ICU care
- Surgery

A number of treatments are generally considered life-sustaining. Some but not others may be useful in reaching the goals of care at any given point in the course of an illness.

Cardiopulmonary Resuscitation (CPR)

Slide 14

Cardiopulmonary resuscitation ...

- Default action for every patient in cardiopulmonary arrest, unless:
 - DNAR order
 - provider has pronounced the patient dead
 - patient manifests obvious signs of death such as rigor mortis, exsanguination

Unlike most other interventions, cardiopulmonary resuscitation (CPR) may be performed without consent or initiating orders. CPR must be initiated immediately and/or a code team summoned for every Veteran found to be in cardiopulmonary arrest, except when a Do Not Attempt Resuscitation (DNAR) order is in effect, a provider has pronounced the Veteran dead, or the Veteran manifests rigor mortis, dependent livedo, exsanguination, or other obvious signs of death. Withholding CPR can only be done with the consent of the Veteran or, if the Veteran lacks decision-making capacity, the Veteran’s surrogate, and this decision is documented through a DNAR order. By using the phrase “do not attempt resuscitation” rather than “do not resuscitate,” VA is acknowledging the evidence that resuscitation attempts are often unsuccessful.

Slide 15

... Cardiopulmonary resuscitation

- Discuss in context of the goals of care
- Provide information about probability of success relative to those with similar conditions
- The decision to forego CPR does not presume a decision to forego other life-sustaining treatments

The use or withholding of CPR in the event of cardiopulmonary arrest should always be discussed in the context of the goals of care conversation and the development of the overall plan of care. Engaging in a discussion that focuses only on CPR and DNAR status may leave the Veteran and family confused and anxious.

Patients are often unable to name all the components of CPR, and often overestimate the likelihood of its success. Evidence suggests that when provided with information about actual probability of survival following CPR, approximately half of patients who initially opt for CPR change their minds.⁷ It is very important to provide information about CPR in the context of the Veteran’s illness. The following conversation might be appropriate, for example, for a Veteran with widely metastatic cancer.

- “CPR is an emergency procedure used to restart a person’s heart and lungs when they stop. It involves physical intervention by repeatedly pushing on the chest and breathing with mask and bag ventilation. CPR is generally continued with advanced life support that includes electrical shocks to the heart, putting a breathing tube into the lungs, and injecting medication into the veins. In some situations, such as (example - in a person with a heart rhythm problem which causes their heart to stop), CPR may be successful in restarting the heartbeat and breathing.

When people have a serious life-limiting illness such as (examples – advanced cancer, advanced dementia, advanced lung disease), CPR very rarely works to restart the heartbeat and breathing, and just causes harm to the body. Even if CPR works to restart the heart, the person may never wake up or fully return to the way they were before.

I would not recommend it for you, and I would recommend entering a Do Not Attempt Resuscitation order. If you agree, I’d like to go ahead and write that order because it’s consistent with your goal to stay as comfortable as possible rather than prolonging life. Is that OK with you?”

The decision to forgo one type of life-sustaining treatment (e.g., CPR) should not be presumed to imply a decision to forgo other types of life-sustaining treatment (e.g., dialysis). For example, some Veterans want all other medical interventions to reverse disease and sustain life but do not want resuscitation attempts if their heart stops. Reassure the Veteran and family that care will continue to be provided to help the Veteran meet the goals of care regardless of his or her decision about resuscitation. Provide examples of interventions that are or will be done for the Veteran.

- “If you were short of breath we would use oxygen, breathing treatments and other medicine to help you feel better. If you were in pain we would work to get the pain under control by adjusting your medicines, including some that can be applied under the tongue or through a patch . . .”

Family members who want to “do everything” for their loved one may believe that foregoing CPR is tantamount to devaluing the Veteran. Emphasize that everyone involved—Veteran, family, clinician, health care team—wants to do everything possible to achieve the health and well-being of the Veteran. CPR is but one medical treatment that may or may not help to achieve goals related to the Veteran’s care.

For inpatients, if the Veteran or surrogate chooses to withhold resuscitation attempts in the event of cardiopulmonary arrest, the clinician should write a Do Not Attempt Resuscitation (DNAR) order. For outpatients, an order to withhold resuscitation can be written as part of state-authorized portable orders. See VHA Handbook 1004.04, “State-Authorized Portable Orders” in **Appendix B**.

Unfortunately, palliative care clinicians sometimes give the impression that the treatment team’s goal is to “get the DNAR order.” Repeatedly approaching the Veteran or family when they are not in favor of a DNAR order is inappropriate, unproductive, and sends the wrong message about the priorities of the health care team.

So-called “slow codes,” “chemical-only,” “partial codes,” or “walk don’t run codes” codes are prohibited in VHA. These clinical euphemisms intended to override the Veteran or family’s decision for the Veteran to receive CPR are not ethically justifiable in the practice of medicine.⁸

Mechanical ventilation

Slide 16

Mechanical ventilation

- Trial may be useful for patients with advanced lung or cardiac disease
- Define endpoints
- Use of ACLS without airway support (intubation and mechanical ventilation) is not appropriate – cannot have DNI but no DNAR

Some Veterans would want mechanical ventilation to continue indefinitely, while others would want mechanical ventilation only temporarily, while still others would never want a ventilator used, even if the machine could prolong their lives. CPAP and BiPAP are noninvasive forms of mechanical ventilation and are sometimes used before or after a trial of mechanical ventilation. Although many Veterans benefit from brief or intermittent periods of noninvasive ventilatory support, others may find the treatment distressing and uncomfortable and discussions regarding withdrawal of this treatment may be patterned on the process discussed here. A time-limited trial of a few days on a ventilator before making a final decision to discontinue may be warranted. Goals, with specific measures of success, and a timeline for reevaluation should be clearly specified.

Before making a decision, Veterans and surrogates should be informed of the possible benefits of mechanical ventilation, such as keeping the Veteran alive as long as possible, or for a goal such as birth of a grandchild or another important milestone, and the potential burdens, including discomfort, the potential need for sedation, the inability to talk, or a tracheotomy for longer periods of use.

If the use of a ventilator is not consistent with the agreed-upon goals of care but the Veteran or family is requesting its use, it may be an indication of fear of death or loss. Be sensitive to and explore the underlying emotions associated with the request, directly expressing empathy and your wish that there were treatments that could reverse the Veteran’s condition and save his or her life. It may be helpful to provide information about what happens if a Veteran goes on a ventilator but cannot be weaned due to the

irreversible nature of the disease, and that a ventilator may simply prolong death rather than save someone's life.

After mechanical ventilation has been initiated, the Veteran or surrogate can decide to discontinue its use if it is no longer consistent with the goals of care. A protocol for withdrawing a ventilator in a manner which provides for the Veteran's comfort and for the needs of the family is found in **Appendix D**.

Protocol for withdrawal of mechanical ventilation

Slide 17



For many Veterans supported by mechanical ventilation at the end of life, death occurs after a decision that the goals of care are not achievable by continuing the treatment. Compassionate extubation is appropriate when the Veteran or surrogate decides that the burden of continued intubation and mechanical ventilation is greater than any expected benefits, and/or continued use is not congruent with the Veteran's previously expressed values or wishes. The withdrawal of mechanical ventilation may pose a complex set of emotionally charged issues for the Veteran, the family, and the treatment team. In many hospitals, palliative care teams assist with family conferences regarding the continued use of mechanical ventilation and the withdrawal of this treatment. Careful preparation of the Veteran and family as well as plans to insure prevention and/or relief of distressing symptoms around the time of extubation are paramount.

The purpose of this section is to describe an approach that can guide clinicians through such an encounter. While there are no tested protocols, if you are uncertain, seek the assistance of experienced colleagues and other health care professionals to help in the process.

Preparing the family

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Preparing the family

- Describe the procedure in clear, simple terms
- Assure that the Veteran's comfort is of primary concern
- Prepare them for possible symptoms and treatments
- Explain how the family can show love and support

Ideally, members of the family will be involved in the decision regarding ventilator withdrawal. They will need to understand the procedure and be reassured about their roles. Since the result of ventilator withdrawal is unpredictable, it is also important for the clinician to prepare the family for the range of outcomes that might occur.

The clinician should not assume that the family knows what treatment withdrawal means or what to expect. The clinician should describe the procedure in clear, simple terms and elicit questions. Assure the family that the Veteran's comfort is of primary concern. Explain that breathlessness may occur, but that it can be managed. Confirm that you will have medication available to manage any discomfort. Assure them that involuntary moving or gasping does not reflect suffering if the Veteran is properly sedated or in a coma.

Explain how the family can show love and support through touch, wiping of the Veteran's forehead, holding a hand and talking to him or her. Encourage family to make arrangements for special music or rituals that may be important to them. Ask the family what other concerns they have. Explain that there is always some uncertainty as to what will happen after the ventilator is withdrawn. Some Veterans die within several minutes, whereas others may live for longer periods. Caution the family that, although death is expected, it is not certain.

If the Veteran has the ability to listen and understand, this information should be shared with the Veteran as well.

Documentation and communication

Slide 19



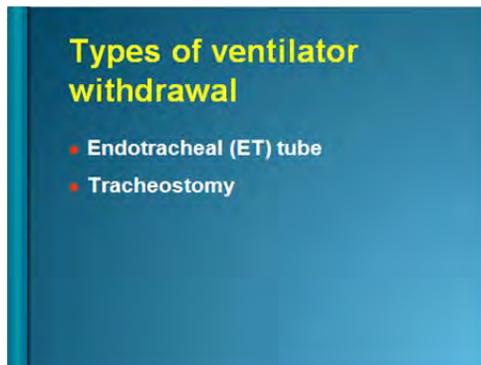
Documentation & communication

- Reach agreement with family about when to proceed with withdrawal
- Communicate with team members, discuss the care plan
- Document decisions, issues, plans in the medical record

In addition to fulfilling all the requirements of informed consent in a good decision-making process, there should be discussion and agreement with the Veteran, if he or she has decision-making capacity, and the family about when to discontinue the ventilator. In addition nurses, respiratory therapists and all professional staff on the unit should understand this development, and have the opportunity to discuss the plan of care. Document issues, clinical findings, and the care plan in the Veteran’s medical record.

Types of ventilator withdrawal

Slide 20



Types of ventilator withdrawal

- Endotracheal (ET) tube
- Tracheostomy

Removal of ventilation in Veterans with an endotracheal (ET) tube

Immediate extubation is the removal of the endotracheal tube with medications, oxygen via open face mask or nasal prongs as appropriate, and titration of treatments to the Veteran’s comfort.

“Terminal weaning” and/or leaving the endotracheal tube in place at the time of removal from mechanical ventilation are not appropriate forms of compassionate discontinuation of mechanical ventilation for Veterans at end-of-life.

Some providers have advocated a “terminal wean,” i.e., turning ventilatory support down in a stepwise fashion that may or may not ultimately result in removal of the endotracheal tube. However, stepwise weaning is not endorsed as the slow, stepwise hypercarbia induce a physiologic sense of suffocation for the Veteran.

Others have suggested that removing the ventilator but leaving the endotracheal tube in place to maintain the airway. This may be uncomfortable for the Veteran and disturbing for the family and is also not recommended.

Removal of ventilation in Veterans with a tracheostomy

Many Veterans who have been on mechanical ventilation for more than 2 weeks before the decision to withdrawal mechanical ventilation is made have had a tracheotomy placed due to concerns of complications of prolonged oral intubation. Removal of the ventilator in a Veteran with a tracheostomy is the same as with extubation except that the tracheostomy is left in place. Tracheostomy care should include supplemental oxygen and humidity via tracheostomy collar and cleaning and suctioning for comfort. If a Veteran has a longer than expected survival after the withdrawal of ventilator support and is awake then a tracheostomy button may be tried to allow the Veteran to speak if possible.

Medications for symptom prevention and management

Slide 21



Breathlessness

Opioids (such as morphine) are the most effective medications for relieving the sense of breathlessness. They work through both central and peripheral mechanisms of action. Concerns about unintended secondary effects, such as shortened life, are exaggerated, particularly if established dosing guidelines are followed. Palliative treatment protocols must be proportionately calibrated to existing symptoms. Dosage levels should not be titrated upward on a schedule, but in response to symptoms (i.e., when the current dose provides inadequate relief) to achieve comfort. Increasing the dose with the intent of hastening death constitutes euthanasia, which is strictly prohibited. Oxygen is helpful to correct hypoxemia, but not necessarily breathlessness (see EPEC for Veterans Module 6c: Dyspnea).

Anxiety

Benzodiazepines such as lorazepam and others are the most effective anxiolytic drugs in this setting and can be used in combination with opioids for effective management of severe breathlessness.

Secretions

In Veterans who are intubated and having significant secretions, two antisecretory medications are recommended: scopolamine and glycopyrolate. When there are no or minimal secretions, these medications do not need to be used. The usual starting dose of scopolamine is 100 mcg IV or SC. This can be followed by a continuous infusion of 100-200 mcg/hr IV or SC. The usual starting doses of glycopyrolate is 200 mcg SC. This can be followed by a continuous infusion of 50 mcg/hr SC.

Protocol for ventilator withdrawal

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Protocol for ventilator withdrawal ...

- Determine desired degree of consciousness
- Bolus 2-20 mg morphine IV, then continuous infusion
- Bolus 1-2 mg lorazepam IV, then continuous infusion
- Titrate to degree of consciousness, comfort

Step 1

This protocol should be performed as a team, with a preintervention discussion of medications and roles. It should be clear who will be tending to the Veteran and who will be tending to the family. If the Veteran is conscious, determine if he or she would like to remain conscious as the ventilator is withdrawn. This will determine the endpoints for initial medication and guide the use of additional medication during the procedure. If the Veteran wishes to remain awake, institute opioids and benzodiazepines at low doses. Make plans to intervene if severe breathlessness or discomfort ensues after extubation. Determine, with the Veteran and family, how and when you would decide to titrate to an endpoint of sedation.

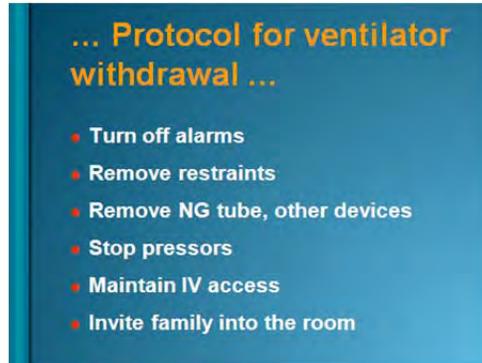
Before withdrawing the ventilator, ensure that the Veteran is comfortable. If he or she is naive to opioids and benzodiazepines, start by giving a bolus dose of 2 to 4 mg of morphine IV to prevent breathlessness. Also, give a bolus dose of 1 to 2 mg of lorazepam IV. Titrate these medications to minimize anxiety and achieve the desired state of comfort and sedation. If these medications have been in use routinely and pharmacologic tolerance has developed, higher doses will be required. There is no need to increase the doses once comfort and the desired level of sedation have been achieved.

In planning for ventilator withdrawal, a skilled clinician must reevaluate the Veteran's situation, anticipate potential discomfort and institute appropriate medical and nonmedical measures in advance to prevent these symptoms from occurring. The

clinicians should have medication immediately available at the bedside so that it can be rapidly titrated to the level appropriate to ensure the Veteran’s comfort.

Step 2

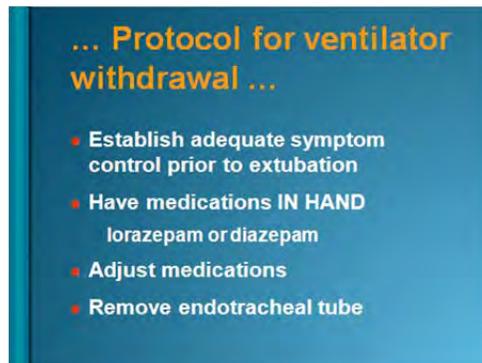
Slide 23



Ensure that all monitors and alarms in the room are turned off, and that staff members are assigned to override any alarms that cannot be turned off in advance. Remove all restraints. Before the family comes into the room, remove NG tube and any other unnecessary devices that may be crowding the bedside. At this point, invite the family into the room to be with the Veteran. Some family members may choose to be in the room during the extubation process while others family members may choose to wait outside and come into the room after the tube is removed and the Veteran is comfortable. Maintain intravenous access for administration of palliative medications.

Step 3

Slide 24



Establish adequate symptom control prior to extubation (see “Symptom Prevention and Management” above). The clinician should have a syringe of a sedating medication (e.g., morphine and lorazepam) at hand to use in case distressing tachypnea or other symptoms occur.

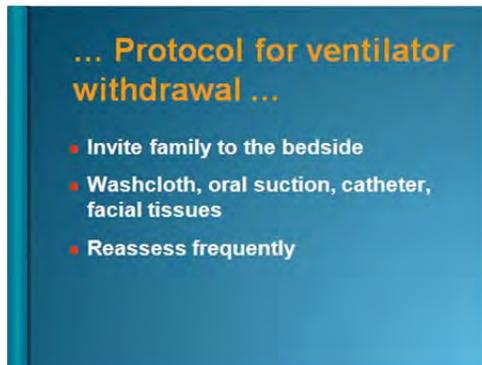
Adjust opioids and benzodiazepines to relieve distress before proceeding to remove the ventilator. If the Veteran appears comfortable, prepare to remove the endotracheal tube. When ready to proceed, first deflate the endotracheal (ET) tube cuff. If possible, someone should be assigned to silence the ventilator alarm, turn off the ventilator, and move it out

of the way. Once the cuff is deflated, remove the ET tube under a clean towel which collects most of the secretions and keep the ET tube covered with the towel. If oropharyngeal secretions are excessive, suction them away and if anticipated or persistent then use scopolamine and/or glycopyrolate to reduce this problem.

If distress ensues once the ventilator is withdrawn, aggressive procedures for symptom control should be implemented. Consider using morphine, 2 to 4 mg IV push q 10 min, and/or lorazepam, 1 to 2 mg IV push q 10 min, until distress is relieved. When it becomes clear that a Veteran will need very frequent dosing for comfort, begin a continuous infusion of morphine and/or lorazepam according to usual procedures (bolus and titration of infusion for comfort). The doses recommended here are for Veterans who were not previously taking anxiolytic medication or opioids.

Step 4

Slide 25



The family can now come forward to a loved one whose face is no longer encumbered by medical devices. A washcloth and oral suction catheter should be available. The family and the staff should have tissues for extra secretions and for tears. The family should be encouraged to hold the Veteran's hand and provide assurances to their loved one. Counsel the family that the prognosis off of the ventilator is rarely predictable and may range from minutes to hours to days.

If the Veteran dies at the time of extubation or soon after, accommodating the need to "say goodbye" to their loved one in the ICU setting is appropriate. Many Veterans may survive for some time, hours to days, after extubation. In this situation it is appropriate to transfer the Veteran to a private room in the hospital or the palliative care or hospice unit as available. Doing so can improve the Veteran's and family's comfort and allow the family to stay with the Veteran if so desired.

Step 5

Slide 26

... Protocol for ventilator withdrawal

- After the patient dies
 - talk with family and staff
 - provide acute grief support
- Offer bereavement support to family members
 - follow up to ensure that they are coping adequately

After the Veteran dies, there is no need to rush anyone. Encourage the family to spend as much time at the bedside as they require. Provide acute grief support.

Once they are ready to leave, provide the family with the clinician's name and phone number and encourage them to call if they have any questions. Offer follow-up bereavement support. See EPEC for Veterans Module 11: Last Hours of Living for details about caring for the Veteran during this period.

Artificially administered hydration

Slide 27

Artificially-administered hydration

- Factors influencing decisions are complex
- Consider goals, symptom burden, impact on family of withholding, burdens of maintaining access
- Address misconceptions of family, Veteran

Reduced oral intake is common at the end of life. Factors influencing decisions to use artificially administered hydration are complex and controversial, and there are arguments on either side of the debate. The clinician should have a complete understanding of the pathophysiology of dehydration and the role of artificially administered fluids in Veterans with end-stage disease; this information is covered in **Appendix D**.

Some problems associated with dehydration (e.g., confusion, restlessness, prerenal failure resulting in opioid metabolite accumulation and associated delirium, myoclonus and potentially seizures) can be alleviated or prevented by parenteral hydration. On the other hand, artificially administered enteral fluids can increase nausea and vomiting, and both parenteral and enteral fluids may increase respiratory tract secretions and thereby worsen cough and pulmonary edema, increase the need to void and use catheters, increase ascites, and decrease Veteran comfort and mobility. Decisions about whether to

recommend artificially-administered hydration should be made based on goals of care, symptom burden, family distress about withholding it, and the burden to the Veteran and caregivers of maintaining the route of administration.

The Veteran and family should be informed about the risks and benefits of using artificially administered hydration. They should be informed that attempts to improve one symptom may result in others as a result of greater fluid burden and that even with hydration the targeted symptom may not respond if caused by a different problem. If time-limited trials using intravenous hydration are a reasonable option, provide the Veteran and family with clear information about the goal, the timeline for reevaluation of success, and associated problems (e.g., clot formation, local skin irritation, local or systemic bacterial infections). Subcutaneous infusion (i.e., hypodermoclysis) offers some advantages over IV hydration, including better patient mobility and ease of use in home settings. Placement of nasogastric and gastrostomy tubes is generally not indicated in the last few weeks of life.

If the Veteran is close to dying, make sure the family knows that a dry mouth may not improve with intravenous fluids. Relief is much more likely to occur with attention to mouth care and oral lubricants (see EPEC for Veterans Module 11: Last Hours of Living). The family may need to be informed that urine output normally declines in a Veteran who is dying; it is not just an indicator of dehydration.

Artificially administered nutrition

Slide 28



Nutrition is essential for life and has a symbolic value to families who want to provide care to their loved ones. It is natural for families to expect that someone who does not eat will experience hunger and associated suffering, and for families to want to do something to reverse it.⁹ Family members and clinicians often feel helpless in the face of advanced chronic and terminal illness, and advocacy for artificial nutrition or hydration may be a response to this feeling.

However, at the end of life, many Veterans do not experience hunger or thirst, and weight loss is due more to the progression of disease than to inadequate nutrition.

Because limited oral intake is so often a concern of Veterans and their families, it is very important for clinicians to understand the pathophysiology of weight loss and anorexia,

and the role of artificial nutrition in these states for Veterans at the end of life, provided in detail in **Appendix E**.

Provision of artificial nutrients for Veterans with advanced cancer has not been found to improve quality of life or survival.¹⁰ Although the evidence is somewhat mixed and studies do suggest benefit in certain populations, providing nutrients is often not medically beneficial in Veterans with serious, life-limiting illnesses. Tube feeding may be helpful in prolonging life for patients with amyotrophic lateral sclerosis, some patients with HIV, and those with good functional status and proximal gastrointestinal obstruction or who are receiving chemotherapy/radiation therapy to the proximal GI tract. A Dobhoff tube (nasogastric feeding tube) may be useful for evaluation of new-onset fatigue and anorexia.

If artificially administered nutrition may help achieve the goals of care, treatment should be offered along with information about the potential benefits and risks (e.g., artificial fluids and nutrition may make edema, ascites, pulmonary and other secretions, and dyspnea worse, particularly if there is significant hypoalbuminemia). As with a trial of any life-sustaining treatment, it should be clearly stated at the outset what the measures of success will be. “Tolerating” the feeding is not a very satisfying endpoint. Reasonable endpoints for the use of artificial nutrition and hydration in a dying Veteran are whether the Veteran feels stronger or is able to resume eating after two weeks.

If it is determined that tube feedings would not serve to meet the goals of care, provide reassurance that oral intake will be facilitated as the Veteran desires, and that the Veteran will be able to take in what his body is able to accept and use.

It may be necessary to address misperceptions about lack of appetite and diminished intake, and help the Veteran and family members understand that loss of appetite and thirst is a natural part of the dying process. Listen for cues like:

- “I don’t want him to starve to death.”
- “We can’t just let her not eat anything.”

These statements may indicate a belief that lack of appetite and reduced oral intake is causing the Veteran’s level of disability, and if only the Veteran got more fluids and nutrition, he or she would be stronger. Use clear, simple language to help the Veteran and family focus on the true causes of the situation, for example:

- “The lung disease is taking all of your strength.”
- “The fact that your heart is so weak is what is causing you to lose your appetite and feel so fatigued.”
- “People who are dying of cancer often reduce the amount they take in near the end. Most don’t feel hungry, and giving them more nutrition doesn’t help slow down or reverse the dying process and doesn’t help them feel better.”

Clinicians should let family members know that if the dying Veteran is not hungry, artificial fluids and hydration will not help him or her feel better. Badgering the Veteran to eat or drink will only increase tension and may cause the Veteran to become angry, depressed, or withdrawn if he or she cannot comply.

Religious teachings about certain treatments such as artificial hydration and nutrition may shape a Veteran or family’s understanding of what constitutes appropriate care. For example, for some Orthodox Jews, food and fluids must always be provided. Within other branches of Judaism, artificial feeding or hydration is understood as an extraordinary measure that need not be provided if it is incompatible with the goals of care.¹¹

The Roman Catholic tradition has a long and evolving teaching distinguishing between treatments that are proportionate or disproportionate to the preservation of life.¹² When questions or concerns are raised regarding particular religious teachings on life-sustaining treatments, providers may want to engage leaders or teachers of the specific faith traditions for clarification.

Discussions and decisions about the use of artificial nutrition and hydration are always challenging. Some of the important risks include the concern that attempts to improve one symptom may result in others as a result of greater fluid burden, and that even with hydration the targeted symptom may not respond. Benefits may include improving renal function to clear drug metabolites that may be causing symptoms such as delirium. A structured approach guided by the goals of care is needed to address the cultural and emotional implications of decisions about artificial hydration and nutrition for the Veteran, family, and clinician.

Information about artificially-administered nutrition and hydration for Veterans and families is found in **Appendix F**.

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Helping with the need to give care

- Identify emotions and the need to “do something”
- Identify other ways of caring
- Teach skills to cope with emotions, engage with the patient

Family members have a need to provide nurturance to their loved one which is often frustrated when eating and drinking are not possible for the Veteran in the same way as in the past. Clinicians have a responsibility to help the family find other ways to demonstrate their caring. As part of the discussion about goals of care and treatments options, clinicians should identify the emotional need that is met by providing food and

water, particularly for families and other health professionals, rather than simply addressing issues of artificial hydration and nutrition. Teach them the skills they need to feel helpful rather than helpless. Examples include:

- planning social interactions that don't center on meals – read, watch movies, or look at photo albums together;
- participating in mouth care;
- massaging the extremities or feet;
- reminiscing and telling stories;
- holding their hand; and
- recognizing that eating is now for pleasure but not for sustenance.

Teach Veterans that they can better cope with their desire to provide nurturance to the Veteran by reminding themselves that eating is now for pleasure rather than sustenance, and the loss of appetite and thirst can help protect their loved one from unwanted effects when the body cannot process food or fluids.

Dialysis

Slide 30

Dialysis

- Dialysis is generally not indicated for patients whose primary goal is comfort
- For patients who have been on dialysis, stopping is considered when dialysis is only prolonging death when the complications outweigh the life-prolonging benefits

Dialysis is a life-sustaining and life-prolonging treatment that is generally not indicated for Veterans whose primary goal is comfort. When Veterans who have been on dialysis develop a life-limiting illness, goals of care discussions should include consideration of whether dialysis is helping to meet those goals. Stopping dialysis is often appropriate when dialysis is only serving to prolong suffering, or when the complications of dialysis outweigh the life-prolonging benefits.

For Veterans who request withdrawal of dialysis and are not otherwise near death, it is important for the clinician to assess for treatable factors that may be contributing to that desire (e.g., inadequately treated depression or pain, existential suffering, concern about being a burden, difficulties with dialysis itself). Offer to treat those concerns and offer a trial to see if the Veteran's quality of life can be improved.

For Veterans whose goals of care are not met by dialysis, provide information about the process of withdrawal and what the Veteran and family can expect. Information should

include survival following withdrawal (8-14 days, rarely can be many weeks), the likelihood of progressive encephalopathy, and the treatments for possible symptoms (e.g., pain, shortness of breath, anxiety/restlessness, nausea, edema, restless legs, muscle cramps, and pruritus).¹³ If the Veteran or surrogate is fully informed and the decision to stop dialysis is consistent with the Veteran's values and the goals of care, the decision should be honored.

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Transfusions

Recommendations about whether to continue ongoing transfusions or to initiate treatment should be made according to whether they are likely to help achieve the goals of care. For example, although transfusions of red blood cells can treat symptoms associated with anemia in Veterans at the end of life (especially fatigue and dyspnea) there are risks including allergic reactions and those associated with fluid overloading. Transfusions should only be recommended when the likely outcome will serve the agreed-upon goals.

Antibiotics

It is not unusual for Veterans at the end stage of their disease to develop signs of an infection, such as pneumonia, and it may be reasonable to consider it a sign of a terminal event and recommend withholding antibiotic treatment. If an infection is likely to cause significant symptoms or a rapid clinical response to the antibiotic could be expected, such as with an infected catheter, central line or stent, or cellulitis or urinary tract infection, treatment with antibiotics may be appropriate. Decisions about the use of antibiotics should be discussed with the Veteran and family in light of the goals of care.

Implantable cardiac defibrillators (ICDs)

ICDs are usually implanted in the upper chest; they monitor cardiac rhythm and deliver shocks when abnormal, rapid rhythms are detected. Most patients experience these shocks as painful, and therefore ICDs are inconsistent with purely palliative goals of care. ICDs can also serve a cardiac pacing function by increasing the heart rate when slow heart rhythms are identified, which can promote comfort by preventing symptoms of heart failure that can occur with a slow rhythm.

Turning off the ICD should be recommended when its use is no longer consistent with the goals of care. If antiarrhythmic medications have been withdrawn, turning off the device will help the Veteran avoid frequent shocks. Turning off the device should be recommended when the Veteran has a DNAR order or when death is imminent. Be sure the Veteran and family are aware that deactivating the ICD means that it will no longer provide a shock in the event of an arrhythmia, and that turning off the device will not be painful and will not directly cause death. If the decision is made to turn off the device, the physician who implanted should be consulted to assist with deactivation.¹⁴

Hospitalization/ICU Care/Surgery

Some Veterans may wish to place specific restrictions on the type of care they receive. For example, some may wish never to be hospitalized, never to be transferred to an intensive care unit, or never to receive surgery, even if these measures are necessary to ensure comfort. Orders may be written to carry out these wishes.

Common concerns about life-sustaining treatments

Slide 32

Common concerns ...

- Is the provider legally required to “do everything”?
- Are clinicians required to provide treatment that they consider futile?
- Can a clinician decline to participate in care that violates his or her conscience?
- Can the use of large doses of pain or sedative medications to relieve symptoms constitute euthanasia?

Slide 33

... Common concerns

- Is withdrawal or withholding of artificial hydration and nutrition or a ventilator a form of euthanasia or physician / practitioner-assisted suicide (PAS)?
- Are VA practitioners allowed to participate in euthanasia or physician / practitioner-assisted suicide (PAS)?

There are several common concerns about end-of-life care and the use, withholding and withdrawal of life-sustaining treatments. These may be concerns of Veterans, family members, and/or clinicians.

Are clinicians legally required to provide all life-sustaining measures possible?

No. Clinicians are required to provide care that will accomplish goals of care within the bounds of accepted medical practice. Even when a treatment might prolong life (e.g.,

intravenous antibiotics for pneumonia), Veterans have the right to refuse these treatments, and the clinician has an obligation to respect the Veteran's wishes.

Are clinicians required to provide treatment that they consider futile?

Because "futility" is not an objective determination, but one whose meaning depends on the particular goal being sought, there has been a distinct trend toward resolving conflicts about futility through a procedural approach that emphasizes the effectiveness, benefits, and burdens of a treatment relative to goals of care.^{15,16} Accordingly, concerns about the futility of treatment in the course of a Veteran's end-of-life care should be handled on a case-by-case basis to assess whether the proposed treatment will be effective in meeting the goals of care and therefore will be beneficial to the Veteran, or whether the benefits of the treatment are outweighed by its risks.¹⁷

Situations involving true medical futility are rare. More often than not, the question of futility comes up when there is moral distress coupled with miscommunication and conflict. Potential sources of conflict include the following: the clinician or surrogate may not be making decisions that are consistent with the Veteran's stated preferences or acting in the Veteran's best interests; there may be misunderstandings over prognosis; there may be personal factors such as distrust or guilt; and/or there may be differences in values. When agreement cannot be reached between the health care team and the Veteran/surrogate, a fair process for conflict resolution is recommended. This process should include discussions about the Veteran's preferences and values, a review of the relationship between the potential treatment and the goals of care, and a discussion of the risks and benefits of the treatment. If the conflict persists, an ethics consultation should be requested.

Can a clinician decline to participate in care that violates his or her conscience?

Yes, a health care professional who concludes as a matter of conscience that he or she is unable to comply with the wishes of the Veteran may request to decline to participate in the withholding or withdrawal of life-sustaining treatment. The obligation of nonabandonment requires that the clinician or medical director facilitate the transfer of responsibility for that aspect of the Veteran's care to another health care professional of comparable skill and competency who is willing to accept it. If conflict arises over the transfer of care, the matter should be referred to the ethics consultation service.

Can the use of large doses of pain or sedative medications to relieve symptoms of pain, breathlessness, or other symptoms constitute euthanasia?

The intent of the clinician and the means used to accomplish the intent are important. Opioids for pain, sedatives for restlessness, and other treatments to control symptoms are not euthanasia when accepted dosing guidelines for palliating the Veteran's symptoms are followed. Palliative treatment alleviates symptoms; it does not intentionally cause death. Even very large doses of opioids or other drugs are both permitted and appropriate, if the intent is to and the doses are titrated for the relief of the Veteran's symptoms.

Is withdrawal or withholding of artificial hydration and nutrition or a ventilator a form of euthanasia or physician/practitioner-assisted suicide (PAS)?

No. There is consensus in law and ethics that a Veteran (or authorized surrogate) has a right to refuse treatment, and that the action of withholding or withdrawing treatment consistent with the Veteran’s wishes is not euthanasia (the direct administration of a lethal agent to a Veteran with the intent to mercifully end the Veteran’s life) or physician/practitioner-assisted suicide (intentionally providing the Veteran the necessary means to facilitate suicide, e.g., a prescription for barbiturates for the purpose of enabling the Veteran to perform a life-ending act).

Are VA practitioners allowed to participate in euthanasia or physician/practitioner-assisted suicide (PAS)?

No. The practice of euthanasia and PAS are strictly prohibited. No practitioner functioning within his or her scope of duty for VHA may participate in any aspect or process related to euthanasia or PAS. This prohibition applies equally to practitioners in states that have laws permitting PAS, as federal law supersedes state law in this matter. VHA practitioners confronted with requests for hastened death should explore and attempt to resolve the circumstances that may have led the Veteran to consider ending their life, such as depression, unrelieved suffering, or unpalliated symptoms. For more information, please refer to EPEC for Veterans Module 13: Responding to Requests to Hasten Death.

Summary

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This module has addressed the role of the clinician in facilitating shared decision making about life-sustaining treatment plans and in the implementation of those decisions. The importance of discussing life-sustaining treatment decisions with Veterans and families in the context of a conversation about the goals of care, and with compassion and understanding for the difficulties of these choices, should not be underestimated. A ventilator may be a powerful symbol of us “keeping someone alive” and so its discontinuation can be very challenging to discuss. Food and water are widely held symbols of nurturance and caring, so withholding artificial nutrition and hydration may

be easily misperceived as neglect by the Veteran, family, or other professional and volunteer caregivers.

Reasonable clinicians may disagree about the extent to which specific treatment preferences ought to be discussed, if such treatment will not help achieve the overall goals. It is well established that if a treatment has no chance of achieving its intended benefit, it need not be offered. However, since the chance for benefit is rarely absolutely zero, and since discussion of treatment decisions is favored by Veterans and builds trust, an approach to discussing these decisions should be part of the skill set of the clinician. In approaching all treatment decisions, the discussion and identification of the goals of care should precede the establishment of a treatment plan.

Key take-home points

1. Goals for the Veteran's care and all significant treatment decisions should be the result of collaborative discussions between the Veteran/surrogate, the Veteran's family (if the Veteran chooses to involve them), and appropriate members of the health care team.
2. Treatment decisions should be based on a clear understanding of the Veteran's values and preferences identified early in the course of an illness and reevaluated on an ongoing basis through discussions with the Veteran or surrogate.
3. Veteran or their surrogates may accept or decline any life-sustaining treatment offered (including artificial nutrition and hydration, mechanical ventilation, or cardiopulmonary resuscitation).
4. Withdrawal or withholding of life-sustaining treatment according to the Veteran's preferences is a decision/action that allows the disease to progress on its natural course. It is not a decision or action intended to cause death.
5. The decision to forego one type of life-sustaining treatment (e.g., CPR) should not be presumed to imply a decision to forego other types of life-sustaining treatment (e.g., dialysis).
6. Health care providers have a duty to offer effective palliative care and, if appropriate, to provide medications and other treatments to relieve pain, other physical symptoms, and psychological and spiritual distress near the end of life. This duty includes the provision of palliative therapies, accepted by the Veteran, that may diminish consciousness or potentially shorten life. The appropriate use of palliative therapies does not constitute euthanasia or practitioner-assisted suicide.
7. If the provision of a life-sustaining treatment is not consistent with prevailing medical standards or consistent with the goal of care, it should not be offered. If such a treatment has been requested by Veteran/surrogate, clinicians have an obligation to clarify the reasons behind the decisions not to offer the treatment in question.

8. Clinicians have the obligation to offer treatments that are consistent with the agreed-upon goals of care, even if the likelihood of success is low. Information should be provided to the Veteran/surrogate including the relative benefits, burdens, and alternatives that allows them to make an informed decision to accept or decline the treatment.
9. Health care providers acting within their scope of duty for VHA may not participate in treatments that are contrary to VHA policy, e.g., physician/practitioner-assisted suicide (PAS) or euthanasia. This prohibition applies equally to VHA practitioners in states that have laws permitting PAS, as federal law supersedes state law in this matter.

Appendix A: Legal Precedents

Karen Ann Quinlan (1976)

The Quinlan case established the right of terminally ill and permanently unconscious patients to have life-sustaining medical treatment withheld or withdrawn. Karen Ann Quinlan had a respiratory arrest and was initially resuscitated, only to remain in a persistent vegetative state.¹⁸ Her father, as her legal guardian, and her mother asked that the ventilator keeping her alive be discontinued and that she be allowed to die naturally. The hospital and her doctors initially refused, stating that removing life-sustaining treatment was the equivalent of murder and they felt they had an inherent duty to protect life and specifically to keep Ms. Quinlan alive. The New Jersey Supreme Court ruled in favor of Karen Quinlan's parents thereby establishing a legal precedent for legally recognized surrogates to make decisions based on patients' wishes about foregoing treatment.

Nancy Cruzan (1990)

Nancy Beth Cruzan sustained a cardiac arrest after a car accident in 1983.¹⁹ She was subsequently in a persistent vegetative state and was placed on artificial nutrition and hydration to sustain her life. Based on the previously-stated wishes of Cruzan, her parents sought to have the artificial feeding and hydration equipment removed. The case was decided in favor of the Cruzans by the U.S. Supreme Court. The decision affirmed that on the basis of patient autonomy, patients or their surrogates may refuse unwanted medical treatment, including artificially delivered food and water. This and other precedent-setting cases have established a unanimous consensus on the legal and ethical right of competent patients, or incompetent patients through a surrogate, to refuse life-sustaining treatments.²⁰ In 1990, the year of the *Cruzan* decision, Congress enacted the Patient Self-Determination Act (PSDA) requiring health care institutions to provide patients with information about their right to make an advance directive.

Terri Schiavo (2005)

Terri Schiavo was in a persistent vegetative state following a cardiac arrest in 1990.^{21,22} In 1998, her husband, who was her legal guardian, petitioned the court to authorize the removal of Ms. Schiavo's percutaneous endoscopic gastrostomy (PEG) which was providing nutrition and hydration. Ms. Schiavo's parents and siblings did not agree with the decision and attempted to have Mr. Schiavo removed as the surrogate decision maker. The courts found no cause to remove him from this role. Although the case became a lightning rod in debates about right-to-die/right-to-life, the court decisions in this case upheld the patient's rights previously established in Quinlan and Cruzan.²³ The 6-year

battle over who had authority to be the surrogate decision-maker for Ms. Schiavo created greater awareness of the importance of advance directives, including durable power of attorney for health care designations.

Appendix B: VHA Policies and Initiatives Related to End-of-Life Care

The Veterans Health Administration has established a number of initiatives, including policy and procedures related to our commitment to honor Veterans' end-of-life preferences, consistent with law and ethics. These include:

- IntegratedEthics, a VA-wide systems-focused model to promote and improve ethical practices in health care, addresses ethical practices in end-of-life care as one of its core domains (see <http://www.ethics.va.gov/integratedethics/index.asp>).
- Informed Consent for Clinical Treatments & Procedures (VHA Handbook 1004.01). This handbook establishes procedures for surrogate identification and for the withdrawal and withholding of life-sustaining treatments for patients who lack both decision making capacity and a surrogate (see <http://www.ethics.va.gov/activities/policy.asp>).
- Advance Care Planning and Management of Advance Directives (VHA Handbook 1004.02; see <http://www.ethics.va.gov/activities/policy.asp>).
- Do Not Resuscitate (DNAR) Protocols within the Department of Veterans Affairs (VHA Handbook 1004.3; see <http://www.ethics.va.gov/activities/policy.asp>).
- State-Authorized Portable Orders (VHA Handbook 1004.04). This Handbook establishes procedures for writing and implementing state-authorized portable orders regarding life-sustaining treatment in VHA (see <http://www.ethics.va.gov/activities/policy.asp>).
- Comprehensive End of Life Care Initiative. The purpose of this multipronged initiative is to ensure that hospice and palliative care services are reliably accessible at all VA facilities and to build an infrastructure for long-term sustainability of high quality end-of-life care.

Appendix C: Pathophysiology of weight loss, anorexia, and dehydration, and the role of artificial nutrition and fluids in these states

Weight loss

Weight loss is a common feature and an independent poor prognostic sign in cancer and many other chronic illnesses near the end-of-life.²⁴ Various mechanisms have been proposed including decreased caloric intake, increased metabolic rate, specific nutritional or vitamin deficiencies, and disordered or futile metabolic pathways.

Anorexia

The causes of anorexia are numerous.²⁵ The consequences of anorexia depend on the composition of what continues to be ingested. The Veteran who takes in no calories develops ketosis as fats and proteins are metabolized to an energy source

Dehydration

The conventional evidence base for dehydration comes from the study of normal individuals and those with reversible conditions causing the dehydration. It is divided into *hyponatremic dehydration* (where salt loss exceeds water loss), *hypernatremic dehydration* (where water loss exceeds salt loss), and *mixed dehydration*, where salt and water loss are balanced. Diuretics, vomiting, diarrhea, osmotic diuresis, adrenal insufficiency, edema, ascites, fever, laxatives, and postobstructive diuresis may all contribute to dehydration. Most Veterans at the end of life without a confounding etiology usually have a mixed pattern.

Symptoms of dehydration differ between those who are ambulatory and those who are bedbound. Whereas an otherwise healthy person will experience reversal of severe thirst, fatigue, or malaise with rehydration, a seriously ill person will not. There is no evidence that IV fluids relieve thirst in Veterans with advanced cancer. The same is true for fluids given via an enteral feeding tube. In contrast, stopping medications with anticholinergic side effects and administering good mouth care has been shown to relieve thirst.^{26,27,28,29,30}

Artificial nutrition and hydration

Since advanced illness is frequently accompanied by a loss of appetite and diminished caloric intake, the hypothesis that the provision of nutrients, either enterally or parenterally, would improve quality of life or survival has been repeatedly tested over the past 30 years.³¹ Unfortunately, except in limited circumstances for clearly defined subsets of Veterans, the hypothesis has not been supported.⁵

In cancer, there is no evidence that artificial nutrition alone improves functional ability or energy, relieves fatigue, or improves survival or symptom control (except hunger) if it is

cancer that is responsible for the anorexia and weight loss.^{32,33,34,35,36,37,38,39,40,41} Although the evidence base regarding artificial nutrition in other chronic medical illness and end-organ failure at the end of life is not as robust as for cancer, evidence to support benefit is lacking. For example, tube feeding in Veterans with advanced dementia does not have a demonstrated benefit in terms of survival or other important clinical parameters.^{42,43,44}

Natural administration of nutrition and hydration (i.e., food and drink provided by hand, spoon, cup, or straw) is generally considered to be basic care and not a life-sustaining treatment. This includes bringing food to the mouth even if the Veteran is too weak to do so, and giving special attention to appearance, color, smell, and consistency to make food appetizing. There is also a general presumption that the potential benefits of oral nutrition and hydration outweigh the risks. Nonetheless, as part of the normal dying process, many Veterans nearing the end of life gradually lose the desire to eat and choose to stop eating and/or drinking. Veterans with decision-making capacity have the right to refuse to eat or drink and should not be force-fed. In the case of Veterans who have lost decision-making capacity, the health care team must make reasonable attempts to provide the Veteran with oral nutrition and hydration unless one of the following conditions apply: 1) the Veteran had voluntarily stopped eating and drinking prior to losing decision-making capacity; 2) the Veteran repeatedly resists attempts to provide oral nutrition and hydration; or 3) the Veteran cannot effectively swallow food and fluids (e.g., the Veteran repeatedly chokes or gags).

Administration of nutrition by an alternate route is indicated if the Veteran desires food but cannot eat (i.e., when there is a neurological abnormality affecting swallowing or an obstructing esophageal cancer).⁴⁵ The gastrointestinal tract should always be the route of intake if it is functional.

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Enteral nutrition

Enteral nutrition is a way to provide food through a tube placed in the nose, the stomach, or the small intestine. A tube in the nose is called a nasogastric tube or nasoenteral tube. A tube that goes through the skin into the stomach is called a gastrostomy or percutaneous endoscopic gastrostomy (PEG). A tube into the small intestine is called a jejunostomy or percutaneous endoscopic jejunostomy (PEJ) tube.

Two reasons are commonly cited for instituting enteral nutrition in Veterans with cancer or other chronic illnesses near the end of life: to improve weakness and fatigue, and to prevent the Veteran from “starving to death.” These reasons are often cited by Veterans and families as well as clinicians. Veterans, families, and some clinicians may erroneously believe that the Veteran is weak because he or she is not eating and that if the Veteran does not eat, he or she will die.

Contrary to these beliefs, there is no evidence that enteral nutrition improves energy level, survival, or quality of life in the Veteran with progressive cancer. With the exception of Veterans with a mechanical reason for not being able to eat (e.g., an obstructing cancer or stroke involving deglutition), cancer patients who report anorexia and cachexia do so for a number of complex reasons. If the cancer cannot be reversed, the pathophysiology underlying the causes of cancer cachexia and anorexia is not reversible.

No study has demonstrated improved outcome of enteral feeding over oral feeding alone. In contrast to original expectations, percutaneous endoscopic gastrostomy (PEG) tubes increase the risk for aspiration rather than reduce it. Enteral feeding tubes may also be associated with infection, obstruction, edema and ascites. The use of feeding tubes is associated with increased mortality. Overall, complications from PEG tubes may be as high as 35%.^{46,47} Reviews of enteral and parenteral nutrition in most chronic illnesses at the end of life found that most studies have failed to demonstrate a benefit and complications and suffering associated with nonvolitional feeding can be great.⁴⁸ Prospective, randomized controlled trials have failed to demonstrate that nutritional support alone improves morbidity, mortality, or duration of hospitalization for the majority of cancer patients with incurable and progressive disease.^{49,50}

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Parenteral nutrition

- TPN
- Central line
- No benefit in routine perioperative, ICU settings
- Benefit in prolonged GI tract toxicity
- Benefit in absence of GI tract function in otherwise healthy patient (short gut)

Parenteral nutrition

Parenteral nutrition (often referred to as TPN – “total parenteral nutrition”) is concentrated nutrition delivered intravenously through a central line. The weight of evidence has shown no general benefit for parenteral nutrition in patients with advanced cancer.³³ Parenteral nutrition has been shown to be of benefit in the limited circumstances where the gastrointestinal tract suffers prolonged toxicity (e.g., bone marrow transplants), or in the perioperative setting where there is preexisting malnutrition.⁵¹ A meta-analysis suggests that patients with cancer who receive parenteral nutrition may have shorter

survival than patients who do not, and the use of TPN in terminally ill cancer patients has generally not been shown to improve quality of life or survival.^{52,53,54}

The role of TPN in the setting of chronic life-limiting illness and end-stage organ failure is not as extensively studied as the role of TPN in cancer. However, many of the caveats for benefit and risk related to TPN are true for patients dying from other illnesses.

Review of the literature, consultation with knowledgeable colleagues as it relates to the burden and benefit of parenteral feedings, and understanding the goals of care and the Veteran's preferences for treatment allows the clinician to provide wise counsel and recommendations related to parenteral nutrition. If treatment is instituted, a time-limited trial is an effective way to routinely evaluate if the treatment is still appropriate.

Parenteral nutrition should be discontinued if it is ineffective and/or contributing to suffering.

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Parenteral hydration

- Intravenous
- Subcutaneous (hypodermoclysis)
equally efficacious, less risk, less skill,
less cost
- Does not relieve dry mouth

Parenteral hydration

One of the most common treatments associated with medical care is an intravenous infusion of fluids. The desired outcome is the maintenance of fluid and electrolyte balance when the Veteran is temporarily unable to drink adequate volumes. At the end of life, intravenous infusion of fluids is no longer a bridge to recovery. The complications of intravenous fluids include, edema, pulmonary congestions, worsening ascites, and the pain and distress involved with starting and maintaining an intravenous line. If a trial of parenteral fluids is appropriate then the administration of isotonic fluids subcutaneously (hypodermoclysis) may be considered. Hypodermoclysis is an underutilized, equally efficacious way to administer fluids without the risks of intravenous access (infection, clot, bleeding) or the skills needed to locate a vein.

Appendix D: Information for Veterans/families about artificial fluids and nutrition

When are artificial fluids and nutrition most appropriate?

If you have a temporary condition that prevents swallowing, artificial fluids and nutrition can be provided until you recover.

What is involved in the procedure?

An intravenous catheter may be placed in a vein in the skin for fluids or sometimes nutrition.

Alternatively, a plastic tube called a nasogastric tube (NG tube) may be placed through the nose, down the throat, and into the stomach. It is approximately 1/8 inch in diameter. This can only be left in temporarily.

If feeding by this route, a more permanent feeding tube may be placed into the wall of the stomach (PEG tube or G tube).

What happens if artificial fluids and nutrition are not administered?

If a person is unable to take any food or fluids due to illness, he or she will eventually fall into a state much like a deep sleep. This process will take 1 to 3 weeks.

Before entering the deep sleep, he or she will normally not experience any hunger or thirst after the first several days.

For a person who has an advanced illness, giving artificial hydration and nutrition will usually not prolong life.

What are the benefits of a feeding tube or IV fluids?

A feeding tube may reduce hunger in someone who is hungry, but cannot swallow.

Intravenous fluids may reduce some symptoms, such as delirium.

What are the burdens of a feeding tube?

Feeding tubes are associated with significant risk. Around 30% of patients have signs of the liquid entering the lungs (aspiration). This aspiration of fluid can cause coughing, pneumonia, and shortness of breath.

Feeding tubes may feel uncomfortable. They can block the stomach, causing pain, nausea, and vomiting.

Tubes for food and fluids may become infected.

Physical restraints are occasionally needed so the patient won't remove the tube.

Appendix E: Resources for Veterans and Families

National Hospice and Palliative Care Organization (NHPCO) Website:

<http://www.nhpc.org> Phone: 1-800-658-8898

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