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Module 13 trainer’s notes

Principal message

Clinicians need to be able to face requests for hastened death with confidence that they have competent, well-thought-out responses.

Module overview

This module focuses on the skills that clinicians need to respond compassionately to a patient’s request to help end his or her life prematurely. This module does not endorse Physician-Assisted Suicide (PAS), or discuss the arguments for or against PAS. This module does not endorse euthanasia, or discuss the arguments for or against euthanasia.

The vast majority of requests for PAS or euthanasia are made by patients who have a partial understanding of their process of dying and are seeking ways to control that process. They may have expectations or fears as to the dying process, depression, moral distress, or they may be dealing with such overwhelming misery that they see only one way to relieve their suffering.

To respond effectively, clinicians must understand the reasons why Veterans ask for PAS, assess the root causes underlying the request, openly state their commitment to the Veteran’s care, address the Veteran’s sources of suffering (physical, psychological, social, and spiritual), educate the Veteran about legal alternatives, and seek support and counsel from IntegratedEthics consultants and Regional Counsel if needed.

For information on the legal history of PAS in the United States, see page 4 of the module.

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 for participants to introduce themselves.

The suggested timing for each part of this module is:

<table>
<thead>
<tr>
<th>Part</th>
<th>Timing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>2-3 minutes</td>
</tr>
<tr>
<td>Trigger tape &amp; discussion</td>
<td>5-7 minutes</td>
</tr>
</tbody>
</table>
Presentation  
40 minutes
Summary  
2-3 minutes
Total  
49-53 minutes

3. **Number of slides: 29**

4. **Preparing your presentation**

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

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

5. **Preparing a handout**

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 13**

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 dealing with requests for physician-assisted suicide 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. Ask participants to not get caught up in the pros and cons of the debate, but to stay with the content of the syllabus.

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

J.W. is a 40 year-old Veteran of Desert Storm. Since discharge from the Army he has completed his education and became an attorney in a newly formed legal firm. One year ago he was diagnosed with chondrosarcoma of the right knee and underwent right above knee amputation with adjuvant chemotherapy. The expense of treatment and the difficulty of working due to his illness and treatment have lead to financial difficulty for himself and his employer. This week, follow-up scans revealed probable metastases to both lungs. Physically, he is doing better than expected but is suffering from depression. He has declined mental health care services and has tried but not tolerated two different antidepressants. He fears “losing control of his mind” and the ability to care for himself.

He wants a way to avoid the fate he fears, and he asks the clinician whether there are any ways to “end things.”

An additional case can be found in the accompanying trigger tape. The case on the trigger tape portrays a patient with AIDS who asks his clinician for assisted suicide.

Discussion

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

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

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

**Setting limits to discussion time**

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

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

**5. Present the material**

**Recommended style: Interactive lecture**

An interactive lecture will permit you to engage your audience, yet cover the material within 45 to 60 minutes. First, provide an overview of issues. Then, use the case to illustrate each step in the protocol for responding to requests for hastened death. Be prepared to deal with misconceptions from participants in your audience about the issues and the alternatives.

**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. Start by presenting an overview of the issues. Then, use and expand on the case to discuss each step in the protocol for responding to requests for hastened death. Use a flipchart or overhead projector to capture the major discussion points. Use the discussion to interweave the key take-home points.

**Alternative style 2: Role-play**

If you feel comfortable directing a role-play exercise and leading the subsequent discussion, this technique can illustrate to participants the complexity, yet importance, of a protocol for responding to requests for hastened death. Note, however, that this method allows more inclusions of participants’ potentially polarized positions, so be prepared to help them keep their focus on diagnoses of root causes and helpful responses.

Start the session by summarizing the issues and the suggested protocol, 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 elaborate on the case from the trigger tape.

Ask participants to divide into clinician, 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 clinicians, ‘2s’ they are patients, and ‘3s’ they are observers. Circulate among the groups and help redirect interactions as need be.

After 10 to 15 minutes, stop the assessment and invite the small groups to discuss their experience among themselves. Ask the patient to comment on the questions and how they made him or her feel. Ask the clinician to comment on the substance of the answers and on his or her feelings. Ask the observer to comment on 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 clinicians, 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. Clinicians must respect decisions to accept or decline life-sustaining treatment when made by Veterans with decision-making capacity or by surrogates acting on their behalf.

2. Clinicians have an obligation to relieve pain and suffering, preserve the dignity of Veterans who are approaching the end of life, assure continuity of care, and avoid abandoning Veterans in their care.

3. Requests for assistance with suicide or for euthanasia should not be construed by the clinicians as an indictment of their medical practice and expertise, but rather part of the range of normal reactions that Veterans experience in the face of suffering caused by illness, loss of function, and fears about the future.

4. A request for physician-assisted suicide may be the first expression of unrelieved suffering.

5. Clinical depression occurs frequently and is underdiagnosed, undertreated, and a frequent motivator for requests to hasten death. Many symptoms of depression, e.g., fatigue, generalized weakness, anorexia, sleep disturbance, and diminished libido may be caused by illness or treatment. Directly asking the Veteran if they are experiencing depression and assessing for hopelessness has been shown to be a valuable method of screening for depression in this population.

6. Emotional and coping responses to life-threatening illness may include a strong sense of shame, feelings of not being wanted, and/or inability to cope.
7. Many Veterans are fearful about what the future will be like (pain and other symptoms, loss of control/independence, abandonment, loneliness, indignity, loss of self-image, being a burden).

8. Therapeutic alternatives to hastened death may include decisions by the Veteran to forgo life-sustaining treatment and/or intentionally decline oral intake.

9. Proportionate palliative sedation may be needed to adequately address intractable symptoms that are not be adequately controlled by aggressive, skilled, interdisciplinary palliative care.

10. Don’t address requests for physician-assisted suicide in isolation – consult with trusted colleagues early. Hospice and palliative care clinicians are familiar with the fears and suffering that cause Veterans to request hastened death.

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

Euthanasia and assisted suicide are strictly prohibited within Veterans Health Administration (VHA). However, Veterans may still suffer in ways that lead to their requests for hastened death. Consistent with this prohibition and VHA’s mission, this module provides a framework for responding compassionately to Veterans’ requests for hastened death and providing therapeutic alternatives to the suffering that might lead to these inquiries.

The vast majority of requests for hastened death are made by individuals who are seeking ways to control the dying process. They may have expectations or fears of the dying process, depression, existential distress, or they may be dealing with such overwhelming misery that they see only one way to relieve their suffering. To respond effectively, clinicians must understand the reasons why Veterans ask for hastened death, assess the root causes underlying the request, openly state their commitment to the Veteran’s care, address the Veteran’s sources of suffering (physical, psychological, social, and spiritual), educate the Veteran about therapeutic alternatives, and seek support and counsel from IntegratedEthics consultants and Regional Counsel, if needed.

Objectives

After studying this module, clinicians will be able to:

- define euthanasia and physician-assisted suicide (PAS);
- describe the current legal status of euthanasia and PAS;
- identify root causes of suffering that prompt Veteran requests for hastened death; and
- use a 6-step protocol for responding to requests for hastened death.

**Clinical case**

Slide 3

J.W. is a 40-year-old Veteran of Desert Storm. Since discharge from the Army he has completed his education and became an attorney in a newly formed legal firm. One year ago he was diagnosed with chondrosarcoma of the right knee and underwent right above knee amputation with adjuvant chemotherapy. The expense of treatment and the difficulty of working due to his illness and treatment have lead to financial difficulty for himself and his employer. This week, follow-up scans revealed probable metastases to both lungs. Physically, he is doing better than expected but is suffering from depression. He has declined mental health care services and has tried but not tolerated two different antidepressants. He fears “losing control of his mind” and the ability to care for himself. He wants a way to avoid the fate he fears, and he asks the clinician whether there are any ways to “end things.”

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

**Introduction**

Requests to end a patient’s suffering by deliberately causing death have likely occurred since the beginning of medicine. Patient requests for assistance in suicide are relatively common.\(^1\,^2\) A national survey of physicians who care for terminally ill patients found that more than 18% had been asked by a patient at least once to assist in suicide and over 11% had been asked to give a lethal injection.\(^2\)

Physical symptoms such as pain, dyspnea, and fatigue are common in Veterans with cancer and advanced stages of serious illness.\(^3\,^4\,^5\,^6\,^7\) The same is true for the syndrome of depression. Physical pain, dependency on others, and depression are all associated with consideration of euthanasia or physician-assisted suicide by patients.\(^8\,^9\) While concerns
about pain are common among people who are seriously ill, studies have found that pain was not the dominant factor motivating people to seek or carry out assisted suicide. Clinical depression and hopelessness have both been associated with the desire for a hastened death among patients with cancer. Issues of dependence on others and loss of autonomy have contributed to the suicides of terminally ill cancer patients who were receiving palliative care. A survey of Oregon nurses and social workers who cared for hospice patients found that a desire to control the circumstances of death was an important factor in the decision of these patients to die by legally prescribed medication. Similarly, loss of control, being dependent on others, and being a burden were the most frequently perceived causes of patients requesting assistance with suicide in a survey of Washington state physicians.

This module presents an approach for responding compassionately and competently to such requests. The focus is not on the debate about whether clinicians should be allowed to assist Veterans who request hastened death, but rather on the practical steps that a clinician can take to assess the Veteran’s request, begin to address its root causes, and ensure optimum quality of care.

**Why Veterans ask for hastened death**

Slide 4

This module considers requests for assisted suicide and for euthanasia as examples of requests for hastened death. Requests by a Veteran for hastened death can be startling and emotionally difficult for clinicians. A Veteran’s expression of a wish to die can be interpreted by the clinician a personal failure to provide adequate care. However hard for the clinician to hear, it is essential for such requests to be understood as invitations for communication and seen as therapeutic opportunities. The courage it takes for an ill and vulnerable person to make such a request of his or her clinician is, in itself, evidence of the Veteran’s trust and opens the door to deeper conversation.

Veterans with advanced, incurable illness may experience “total pain” that has physical, emotional, social, and spiritual dimensions. Suffering may be accompanied by a sense of impending disintegration of the person and a loss of meaning and purpose in life. Social suffering can derive from a sense of being a burden to one’s family or society.
Veterans ask clinicians about hastened death for a variety of reasons. Some Veterans may approach clinicians with the intent of ‘thinking out loud’ about their current and future condition. Others may raise the question based on lifelong values. For some, a request for hastened death is a sign that unmet needs have built up to an intolerable level. For all Veterans, the request for hastened death should prompt the clinician to assess the reasons for it. Veterans make requests for many different reasons that may arise from physical, psychological, social, or spiritual suffering, or practical concerns. Each person will have a unique set of needs and reasons why he or she would like to hasten death. In many surveys of patients’ reasons, unrelieved psychosocial and mental suffering is the most common stimulus for requests. Studies have documented that patients who are depressed are more likely to have made serious inquiries about hastened death or euthanasia. Fear of future suffering, loss of control, indignity, or being a burden are also prominent reasons for requests.

Physical suffering, including pain, is a less frequent motivator than loss of independence and a desire to control the circumstances of death. Research conducted in Oregon, where PAS is legal, revealed that patients requesting PAS cited physical pain as a motivator 43% of the time and loss of independence and desire to control circumstances of death 57% and 54% of the time. Nonetheless, the contribution of physical pain is important because it is often treatable (see EPEC for Veterans Module 4: Pain Management).

The fear of being a burden and loss of independence are important correlates of a desire for hastened death, and for many Veterans are more distressing than physical symptoms.

**The definition of euthanasia and physician-assisted suicide**

Both euthanasia and assisted suicide involve deliberate actions to end a person’s life. The difference is that:

- in **euthanasia**, someone other than the patient administers the lethal agent to the patient; and
- in **assisted suicide**, the patient administers the lethal agent to him/herself with the assistance of someone else who provides the agent.
Physician-assisted suicide (or provider-assisted suicide) occurs when a physician [or other health care provider] knowingly facilitates a patient's death by providing the necessary means and/or information to enable the patient to perform the life-ending act (e.g., the physician provides sleeping pills and information about the lethal dose, while aware that the patient may commit suicide).

Euthanasia and assisted suicide are distinguished from the actions below, both of which are necessary and routine aspects of high quality end-of-life care:

- administration of agents with the intent to alleviate a patient’s pain and suffering but without the intent to cause the patient’s death, and

- withholding or withdrawal of life-sustaining treatments that are inconsistent with the patient’s preferences or that are inconsistent with agreed-upon goals of care for the patient.

The legal status of euthanasia and physician-assisted suicide

In 1997, the U.S. Supreme Court recognized that there is no federal constitutional right to physician-assisted suicide but did affirm that state legislatures may choose to legalize it.\(^{21}\) The same 1997 U.S. Supreme Court ruling supported the right of all Americans to receive quality palliative care, and prohibited states from obstructing the provision of adequate palliative care, specifically for the alleviation of pain and other physical symptoms of
people facing death. As of 2010, Oregon, Washington and Montana were the only states that have voted to legalize PAS. Euthanasia is illegal in every state.

Both euthanasia and physician-assisted suicide are strictly prohibited throughout Veterans Health Administration (VHA). No practitioner functioning within his or her scope of duty for VHA may participate in fulfilling requests for 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.

Veterans who are citizens of the states in which PAS is legal may decide to seek treatment from a non-VA provider to have PAS as an option. The health care records of a Veteran belong to the Veteran and release of information to providers outside the VHA at the legal request of the Veteran should not be hindered even if the information might be used to certify that a Veteran is eligible to request PAS. Clinicians in VHA who practice in states where PAS has been legalized should seek the advice of their own facility, VISN, and Regional Counsel regarding the appropriateness of completing forms or certificates that attest to the diagnosis and prognosis of a particular Veteran if this certification could be used to apply for PAS.

**Professional competence**

As many clinicians are likely to receive a request for hastened death, every clinician must be capable of dealing with these difficult requests in a way that responds to the needs and expectations of the Veteran and offers the best possible care that is medically appropriate, ethical, and legal.

The ability to respond to requests for hastened death with realistic alternatives requires a working knowledge of all aspects of palliative care. The clinician must follow usual standards for communication, know how to provide aggressive symptom control and supportive care, and be skilled at approaches to life sustaining interventions (see EPEC for Veterans Module 3: Delivering Difficult News; EPEC for Veterans Module 4: Pain Management; EPEC for Veterans Module 5: Psychological Symptoms; and EPEC for Veterans Module 10: Life-Sustaining Treatments). A clinician will want to be aware of the legal issues described in EPEC for Veterans Plenary 2: Legal Issues.

The multidimensional suffering of advanced illness is best addressed by interdisciplinary approaches to care. Hospice and palliative care programs can respond in skillful ways, often identifying ways of lessening the burden and enabling families to care well and with love without losing their own wellbeing in the process. Veterans who request hastened death may not be in a formal hospice or palliative care program and so these approaches are relevant for clinicians who care for Veterans in all settings.
Any request for hastened death should be taken seriously. Response should be immediate and compassionate. The six following steps can be identified for responding to such requests:

- clarify the request;
- assess the underlying reasons of the request;
- affirm your commitment to care for the Veteran and family;
- address the root causes of the request;
- educate the Veteran and family and discuss therapeutic alternatives to PAS; and
- consult with colleagues.

While each step will be discussed in this module in sequence, as with other clinical protocols, these steps should flexibly integrate into actual care. Depending on the particular case, some steps may be implicit or accomplished in a few words, while others may be complex and require considerable time to respond.
When a Veteran first raises the issue of hastened death, it is necessary to clarify what is meant. Initial questions to clarify the request should be as open-ended and neutral as possible. Examples include:

- “What do you mean by ‘help me die’?”
- “What makes you ask that?”
- “What do you think is going to happen?” and
- “What are you hoping for?”

During the course of the questioning, it is particularly important to learn whether the Veteran is imagining future symptoms or other conditions that are either unlikely or easily preventable.

As you listen to the answers, use the therapeutic approach of empathic listening. Avoid endorsing the request for PAS. Avoid responding to the Veteran’s concerns in a way that confirms the Veteran’s perception that his or her life is worthless. Similarly, avoid reacting to the request by immediately rejecting the concept out of hand as this will often serve to close rather than open any further discussion. Remember that empathizing is not the same thing as agreeing.

Some people assume that if there is a routine treatment available for a condition that threatens their life, they have little choice other than to accept it, as if doing less than everything to prolong life is tantamount to suicide. By making it clear that it is legally and ethically permissible to decline treatments – even antibiotics for infection and feeding tubes and hydration – and allow a natural death to occur, Veterans may be satisfied that their life will not be prolonged against their wishes.²⁶

Sometimes, Veterans will use statements, such as, “I hope you’ll help me die when it’s time” or “Please promise not to let me suffer,” as if to test the clinician’s willingness to talk about their fears of unrelieved suffering during the dying process. It is important to understand whether they are actually referring to physician-assisted suicide, euthanasia, or adequate analgesia. For many, their request is to be assured of a way to escape suffering if it becomes unbearable. Such Veterans are commonly reassured to learn that
good palliative care extends to whatever treatments are necessary to alleviate physical distress. At the same time, Veterans may need assurance that effective symptom management is not a euphemism for euthanasia, but rather good medical care for a serious medical problem.

When a Veteran asks for hastened death, listen carefully to the nature of the request. Ask open-ended questions in a calm and nonjudgmental manner to elicit specific information about the request that is being made and the underlying causes for it. Review with the Veteran their goals of care and how the request for hastened death relates to these articulated goals. While some clinicians fear that talking about suicide or hastened death will increase the likelihood that the Veterans will act, this fear has not been substantiated. An open discussion is more likely to reduce the intensity of the request.

**Personal biases vs. therapeutic listening**

To respond effectively to the needs of the Veteran, the clinician must be aware of his or her own biases and the potential for countertransference. If the idea of suicide is offensive to the clinician, the Veteran may feel his or her disapproval and worry about abandonment. Conversely, if the clinician feels it would be best for everyone if the Veteran were to die soon then the Veteran may sense this.

Be open to the possibility that your personal reactions to the Veteran’s suffering may give insight into his or her experience. For example, if the clinician feels weighed down by meeting with the Veteran, perhaps the Veteran is depressed.

In making the request, the Veteran is opening a door for communication. The therapeutic response to requests for assisted suicide or euthanasia begins with listening. Possibly because listening involves little outward motion, to the casual observer it seems passive, and its value as an active therapeutic intervention is often unrecognized.

In actuality, the clinician’s ability to listen and commitment to stay involved are the main components of an effective response. The therapeutic power of listening must not be underestimated. Confronted with a request to hasten death, many times the critical early intervention consists of listening to a Veteran’s fears, acknowledging the Veteran’s suffering coupled with the clinician’s firm commitment to remain involved, continuing to try new ways to improve the Veteran’s quality of life, and supporting the Veteran and family during this difficult time.

The clinician-Veteran relationship is the most powerful therapeutic resource to bring to suffering. By carefully assessing and effectively treating pain and other symptoms a Veteran’s confidence in their clinician’s knowledge and skills is reaffirmed. The sources of suffering at the end of life are complex with physical, psychological, social and existential components. These complex problems are best addressed by an interdisciplinary team approach. The clinician that a Veteran may approach regarding hastened death may be any one or more members of the palliative care team. Exploring a Veteran’s suffering and fears engenders confidence in the clinician’s and the
interdisciplinary team’s compassion and willingness to be there in the hard times that may lie ahead.

**Step 2: Assess the underlying reasons of the request**

A request for PAS may indicate a failure to address the full scope of a Veteran’s needs. Focus on all four dimensions of physical, psychological, social, and spiritual suffering as well as practical concerns.

**Physical suffering**

Many physical symptoms may accompany advanced illness. These may include pain, breathlessness, anorexia/cachexia, weakness/fatigue, nausea/vomiting, constipation, dehydration, edema, incontinence, loss of function, sleep deprivation, etc. Their presence, particularly if they are unmanaged for long periods, can increase suffering. Approaches to the assessment of physical symptoms are covered in EPEC for Veterans Module 7: Comprehensive Whole Patient Assessment. The management of pain is discussed in EPEC for Veterans Module 4: Pain Management. The management of other common physical symptoms is discussed in EPEC for Veterans Module 6: Non-pain Symptoms.

**Psychosocial suffering and practical concerns**

Psychosocial suffering may include feelings of not being wanted, and difficulty coping. Adjustment to the loss of previous function, independence, control, and/or self-image may be difficult. Each change may lead to tensions within relationships that further increase isolation and misery.

Worries about practical matters, e.g., who the caregivers will be, how domestic chores will be done, who will care for dependents and pets, can create distress. If support is not forthcoming or is insufficient, suffering may ensue or increase. Approaches to the assessment of psychosocial issues and practical concerns are covered in EPEC for Veterans Module 7: Comprehensive Whole Patient Assessment.
Clinical depression

Among all the psychological possibilities, give particular consideration to the possibility of clinical depression or anxiety, as research indicates correlation between requests and these conditions.\textsuperscript{13,18} Clinical depression occurs frequently and is both underdiagnosed and undertreated in Veterans near the end of life. It can be a source of intense mental suffering and a barrier to completing life closure.

Despite its prevalence among people with serious illness,\textsuperscript{30} clinical depression may go unrecognized, undiagnosed, and untreated by health care professionals. Diagnosis of depression is more challenging in Veterans with advanced illness, since the physical symptoms typically associated with depression, e.g., changes in appetite, weight, energy level, libido, or sleeping frequently occur as a result of their illness. Health care professionals more readily diagnose depression when patients exhibit outward manifestations, such as crying and sad affect.\textsuperscript{31}

Studies have shown that the screening question, “Do you feel depressed most of the time?” is highly sensitive and specific in the terminally ill.\textsuperscript{32} Feelings of pervasive helplessness, hopelessness, and worthlessness are not normal. Do not assume they are situational and leave them unattended. Chronic mental illness, PTSD, and history of (or ongoing) substance use disorder are often causes of additional suffering in Veterans. Mental health providers are an integral part of the interdisciplinary team working with Veterans struggling to bear their suffering resulting from illness and increasing debility and dependency (see EPEC for Veterans Module 5: Psychological Symptoms and EPEC for Veterans Module 8: Psychosocial Issues in Veterans).

Spiritual suffering

The prospect of dying may evoke seemingly irresolvable existential concerns that are then experienced as suffering. As illness advances and disability increases, the Veteran’s sense of his or her meaning, value, and purpose in life may all come into question. If there is a sense of abandonment or punishment by God, the comfort and strength that faith and religious beliefs often bring may be eroded and anger may ensue.\textsuperscript{33} Approaches to the assessment of spiritual issues are covered in EPEC for Veterans Module 7: Comprehensive Whole Patient Assessment.

Fears for the future

Often a person’s suffering is rooted in fears of the future; the person can tolerate the current situation but worries what will happen if things get worse.\textsuperscript{16} In addition to current concerns, many people who ask for hastened death are fearful about what the future will be like. They may worry about pain and other symptoms, loss of control or independence, abandonment, loneliness, indignity, loss of self-image, and being a burden to others. Many may have witnessed suboptimal care in others that fuels their fears and fantasies.
When evaluating the Veteran’s psychological and social issues, explore fears about his or her future.

It may be possible to diminish an acutely anxious Veteran’s distress and improve the Veteran’s sense of control by drawing attention to the present moment in which their discomfort is tolerable, if only barely, and by emphasizing that life is a series of present moments. The future-based nature of most suffering allows clinicians to inform and affirm for Veterans that there is always something they can do to decrease the severity of pain or other symptoms and support Veterans and families through these difficult times. Outlining some specific steps that can be taken if pain or other symptoms worsen can be reassuring for Veterans and their loved ones.

Direct questions may be adequate to assess a Veteran’s fears. If not, discussing a series of scenarios and preferences, as is done during advance care planning, may be helpful. When personal values and goals of care are being discussed, clarify the things the person most wants to avoid. This may help to preempt unrealistic fears.

**Step 3: Affirm your commitment to care for the Veteran**

Veterans facing the end of life may have fears of abandonment. They may feel vulnerable to their family, friends, or clinicians not being there for them when they are in most in need, or will feel that they are a burden. Listen to and acknowledge expressed feelings and fears. Make a commitment to help find solutions to the issues of concern, both current and anticipated. Reinforce that you want to continue to be the Veteran’s clinician throughout the entire course of the illness. Explore options to allay immediate concerns and fears.

As a request for hastened death affects everyone who is close to the Veteran, a commitment to the Veteran also affirms a commitment to the family and those close to the Veteran, including other caregivers.
Step 4: Address the root causes of the request

This section provides a general framework for addressing some of the potential root causes for a request for hastened death in each dimension of suffering. Start by discussing the Veteran’s health care goals and preferences, explaining palliative care approaches and services, and describing the legal alternatives to hastened death. Remember that some Veterans may not trust either an individual health care clinician or the VHA or other health care system to meet their needs. If possible, it helps to discuss this lack of trust with the Veteran at the outset, so that the issues can be understood, if not dealt with, early on (see EPEC for Veterans Module 2: Advance Care Planning; EPEC for Veterans Module 7: Comprehensive Whole Patient Assessment; and EPEC for Veterans Module 1: Goals of Care).

Address physical suffering

Veterans with life-threatening illnesses have many unaddressed physical issues. If left unmanaged for long periods, each can add considerably to a Veteran’s sense of suffering. Each symptom needs to be pursued aggressively and successful management often requires extensive and careful thought and trials of different therapies until symptoms are brought under control. For further information on pain, see EPEC for Veterans Module 4: Pain Management. For other physical symptoms, see EPEC for Veterans Modules 6a-6c.
Function is critical to maintaining independence. Physiatrists, nurses, and physical and occupational therapists may be helpful and knowledgeable about the exercises and aids that can be used to optimize and maintain function and to ensure safety.

Sexuality and intimacy are integral aspects of each one of us, particularly through touch and the closeness to partners and family members we cherish. Illness and disfigurement may change the way people are able to interact. To establish individual desires and tensions, facilitate discussions between partners and key family members. Help them to look for alternatives that may be comforting.

**Address psychological suffering**

As psychological suffering leads to many of the requests for hastened death, its management warrants considerable attention. Start by assessing and managing any depression, anxiety, or delirium aggressively (see EPEC for Veterans Module 5: Psychological Symptoms).

As each Veteran’s emotional response to illness can be profound and coping responses varied, they will require careful exploration in a positive and understanding way. Supportive counseling, which involves active listening and acknowledgment of the Veteran’s feelings, may be woven into general care, or it may be provided more intensively through dedicated individual or group counseling. Social workers and chaplains trained in supportive counseling can provide considerable assistance. Referral to trained counselors, psychologists, or psychiatrists may be required if the issues are complex and/or the risks high.

People can be helped to see their physical dependence as a consequence of their illness, rather than as a personal failing. Clinicians can foster a sense of dignity by the manner in which care is provided. In coming to know the Veteran as a person, the clinician acknowledges their uniqueness and inherent worth.

One way to do this is to explore what the Veteran is hoping for. Cure of illness may be one hope, but there may also be more specific hopes that Veterans have – seeing a specific person, being outside if possible, going home. Therefore, if hope were to reside solely in avoiding death, ultimately all hope would be lost. In practice, it is often possible for people who are approaching the end of life to reframe hope, discovering meaningful
opportunities that still exist. Clinicians can assist Veterans in identifying achievable goals, such as participating in meaningful events, engaging in life review, completing personal affairs and relationships, and feeling prepared to leave this life.

**Address social suffering, practical concerns**

Stresses and conflicts in the social or practical aspects of a person’s life can have profound effects on his or her will to live. Serious illness disrupts plans and sometimes derails long-held aspirations. While it is essential for clinicians to affirm their commitment to suffering Veterans, they need not shoulder these responsibilities alone.

Express interest and inquire in detail about this aspect of the Veteran’s life. Consider the following questions:

- What is the Veteran’s family situation? Does he or she live with someone? Are family members supportive? Are there unresolved issues?
- How is the Veteran’s financial situation? Is health insurance available and sufficient?
- Are legal affairs in order? Does the Veteran have a living will, a power of attorney for health care, a power of attorney for business affairs, and a will?
- Where would the Veteran like to receive care? Who is there to help? Who will the caregivers be? Is there tension over the caregiving role for either party?
• Who attends to domestic chores such as cooking, cleaning, shopping, banking, and/or bill payments? and

• Are there any dependents the Veteran cares for, or pets? Who will care for them if the Veteran is not able to?

**Address spiritual suffering**

The spiritual dimension of human experience is often challenged in the face of a life-threatening illness. Each person has a sense of meaning and purpose to his or her life, and a sense of where he or she fits into the grand scheme of things. This may have a religious orientation or may be expressed through a more personal sense of spirituality. Nevertheless, the transcendental dimension is critical to explore when a Veteran requests hastened death.

Helping Veterans to establish or reestablish a sense of meaning and purpose is often fundamental to the relief of spiritual suffering. Encouraging them to reminisce with family and friends and assisting with life closure, gift giving, and the creation of legacies may also be helpful.

Some more traditionally medicine-focused clinicians (such as physicians and nurses) feel comfortable dealing with spiritual suffering. Others feel inexperienced and out of their depth. As these issues are critical and may be very time consuming, a skilled hospice chaplain or a psychiatrist or psychologist skilled in end-of-life care may bring considerable support to both the Veteran and the clinician.

Engagement of the Veteran’s own faith community should be encouraged if the Veteran would find this comforting. Many community clergy have training and experience in caring for members of their congregations at end-of-life. While it would be ideal if the needed skills came from the Veteran’s own pastor, do not assume that all members of the clergy are equally comfortable with the care of people with advanced life-threatening illness. Like clinicians, many have not received adequate training in chaplaincy issues and may be ill-equipped to deal with the profound conflicts surrounding requests for physician-assisted suicide or euthanasia. If appropriate and consistent with Veteran’s preferences the palliative care interdisciplinary team and the chaplain in particular can support the Veteran’s community clergy to support the Veteran.
Address fears

Fear of loss of control

The autonomy and control that each one of us has over our lives and affairs is central to our personhood. For many, independence is profoundly challenged by illness that is debilitating and deprives them of mastery or control over their day-to-day activities and their sense of future.

This fear of losing control may be further heightened by fears that their expectations and needs won’t be addressed, or fears that people will do things to them that they don’t want, e.g., forced feeding, invasive procedures, life-sustaining therapies.

The specific issues that are most important for each person to control are unique to that individual. They may include things such as the ability to choose day-to-day activities and experiences that are meaningful, choices for therapies, settings of care, caregivers, etc.

All clinicians can be instrumental in helping the Veteran to continue to realize as much control as possible, given the changes in function that are likely to occur. This may take unusual flexibility on the part of the clinician and the health care team. Educate and help the Veteran plan for aspects of medical care that are under his or her control, e.g., the ability to accept or decline any medical intervention, life-sustaining treatment, etc.

Encourage the Veteran to select personal advocates and surrogate decision makers, prepare advance directives, and plan for death. This planning can include funeral plans, wills, and disposing of personal belongings after death. Teach family members and
caregivers alternate approaches to caregiving that optimize the Veteran’s participation in decision making, i.e., instead of “doing without asking,” encourage family and caregivers to “ask before doing.”

**Fear of future pain and other symptoms**

While Veterans may find current symptoms acceptable, they frequently fear a future where symptoms will be out of control and unbearable. Reassure the Veteran that almost all symptoms can be controlled well. Ensure that Veterans and families know that pain ordinarily does not get suddenly worse as death approaches. Help them to understand the difference between pain and terminal delirium, particularly if they have known someone else who had a difficult death. As many Veterans fear adverse effects of medications, particularly drowsiness and confusion, discuss their management should they occur.

The possibility of palliative sedation, should pain or other symptoms be unbearable for the Veteran and unmanageable by experts, may be explored with the Veteran and family. Some Veterans and families will find the possibility reassuring; others will not want to consider it.

Most importantly, during all of these discussions, make a commitment to keep working to manage the symptoms until they are satisfactorily controlled. This is a critical piece for Veterans who may fear being told, “I’m sorry, there’s nothing more we can do.”

**Fear of being a burden**

One of the things people fear most about a life-threatening illness is the prospect of being a burden to others. This is connected with the fear of losing control, particularly as our culture generally does not value being dependent on others.

Try to determine how and why the Veteran believes they are or will be a burden to their family. If there are caregiving issues, facilitate a discussion between the Veteran and family. In many cases, families are willing and eager to care for the Veteran, and their desires simply remain unspoken. If Veterans and families are worried that family members will not have enough skill to provide adequate care, suggest home hospice care. One of the fundamental goals of the home hospice team is to help educate, train, and supplement the family in the care of the Veteran. Alternate care settings can be arranged.
as a backup if care at home does not go as planned. Home hospice agencies must make provisions for brief periods of respite care if it is needed. If there are financial issues, help the Veteran find information and resources that may help—many people are unaware of the services available.

Social workers in VA can help the Veteran, family and clinicians tap into a number of unique sources. Programs such as Aides and Attendance, Home Maker, Home Health Aides and Adult Day Care (see EPEC for Veterans Plenary 3: Caring for Veterans in VA Settings and Beyond) are all examples of noninstitutional care in the community that some Veterans may be eligible for to help supplement family caregivers and reduce the real and perceived burden on family. It is important to look into these options early on since there may be an application and certification process that takes time.

**Fear of indignity**

Dignity is a complex construct. Veterans may fear the loss of their dignity. While there is an intrinsic sense of dignity that some would argue cannot be taken from any human being, there is also an attributed sense of dignity, the value or worth we attribute to ourselves or to others, which serious illness and death often call into question.41,42 This attributed sense of dignity may include elements of being dependent, having lost control, being a burden, being embarrassed, and it is important to explore what it means to the particular individual.43,44

Once the issues are clear, explore approaches to caring and resources that can help to maintain dignity. Ensure that the Veteran, where possible, participates in decision making. Veterans have served their country in times of peace and conflict and are due our respect and honor. Remembering to thank the Veteran for their service and emphasizing the commitment of the interdisciplinary team as well as VA and the country to supporting the Veteran now in their time of need is a meaningful way to bring reciprocity to the relationship of caregiver and caregiving. Ensure that family members and caregivers know how to approach and address these issues. Ensure that everyone has permission for their roles and each task that they will do. Reassure the Veteran that he or she has dignity in your eyes.
Fear of abandonment

For some Veterans, their worst possible fear is abandonment—by families, their friends, their physicians, or other health care professionals. This fear can be heightened by the realization that others are having difficulties coping with the illness and the changes it brings, or the role of being a caregiver.

Explore this fear in detail with the Veteran and family in a family conference. Try to establish how realistic the Veteran’s concerns may be. If tensions seem high or there are indications that family and friends are not coping, a meeting with everyone may be helpful to assess the situation. If caregiving is becoming onerous, offer a respite or an alternate setting for care. As appropriate, try to connect families to available supports in the community, particularly those provided by the interdisciplinary teams available through hospice and palliative care programs.

Above all, when addressing fear of abandonment, the clinician must be able to honestly reassure the Veteran about his or her plans for being involved in ongoing care. This will involve being clear about what one can do as a clinician and how the interdisciplinary team will be a part of care.

Step 5: Educate the Veteran about alternatives to hastened death

In most cases if the underlying cause for suffering are adequately addressed the request for hastened death will be withdrawn. In those rare cases were the request persist it may
be appropriate to explore the scenarios discussed in Step 5 while continuing to work to address the suffering and distress is leading to the request.

**Therapeutic alternatives**

Veterans may not be aware of the therapeutic alternatives available to them instead of hastened death. This may be particularly true if they have not participated in discussions to clearly define their goals of care and treatment priorities. As part of the process of discussion, planning, and decision-making, the clinicians should consider discussing the 3 following therapeutic alternatives to hastened death:

**Refusal of interventions/treatment**

The treating clinician should explain to Veterans that they have the right to consent to, decline, or withdraw any intervention, e.g., surgery, chemotherapy, pacemakers, ventilators, resuscitation, medications including antibiotics, IV fluids, or settings of care (e.g., hospitalization) if any of them seem too burdensome (see EPEC for Veterans Module 10: Life-Sustaining Treatments). They should also be reassured that their choices to decline particular therapies will not affect their ability to receive high-quality end-of-life care.

**Intentional decision to not take food or drink by mouth**

People with advanced disease often lose appetite and/or thirst. In addition, a competent individual can decide not to eat or drink. Based on the principle of respect for patient autonomy, force-feeding is not acceptable.

Veterans who decline oral intake should be reassured that their physical symptoms will continue to be assessed and addressed. The Veteran and family should also be informed that patients who discontinue oral intake do not routinely have worsening of symptoms as a result of that decision. In fact, forced feeding frequently contributes to nausea, vomiting, edema, and worsening pulmonary congestion and dyspnea without benefit. A detailed discussion of the natural history of anorexia at end-of-life and the appropriate management of symptoms should they occur will usually allay fears and reduce anxiety considerably (see EPEC for Veterans Module 11: Last Hours of Living).
As fluids and food are central to many rituals and socialization, and culturally ingrained, family and caregivers will need education and support if a Veteran decides to cease oral intake. Encourage family members and caregivers to have food and water available so that the Veteran can take something by mouth, if desired. Discuss the potential for anger and resentment to result if the Veteran is badgered or forced to eat or drink. Above all, recognize the desire and need of family members to give care and refocus them on activities that will be beneficial to everyone.

**Palliative sedation**

For the rare person with unbearable and unmanageable pain, or other intractable symptoms, which is approaching the last hours or days of his or her life, the induction and maintenance of a state of sedation may be the only remaining option for symptom management. Sedation in the imminently dying Veteran for the purpose of relieving unremitting symptoms should only be considered a treatment of last resort; after all other options have failed.45,46,47

The administration of palliative sedation is only an appropriate option to consider:

- when severe pain or other clinical symptoms (e.g., dyspnea, nausea and vomiting, agitated delirium) is/are not ameliorated by aggressive symptom-specific interventions that are tolerable to the Veteran;
- for Veterans who have entered the final stages of the dying process and who have a DNR order;
• with the signed informed consent of the Veteran, or surrogate if the Veteran lacks decision-making capacity, as required by VA policy for treatments or procedures involving general anesthesia;

• with the participation of a health care professional with appropriate expertise in palliative care and the administration of palliative sedation;

• with appropriate monitoring to assure adequate symptom management while avoiding untoward drug effects; or

• with referral for ethics consultation if ethical concerns are raised by the Veteran, family, or staff.

If the Veteran and family find the option acceptable and the Veteran chooses to receive palliative sedation, intermittent or continuous intravenous or subcutaneous infusions of lorazepam, propofol, or barbiturates have been used successfully to induce sedation and reduce awareness. This has been described as proportionate palliative sedation where the minimum amount of sedation necessarily to relieve refractory symptoms is used. In some Veterans the sedation may need to be titrated up to maintain symptom control. Infrequently, palliative sedation with an endpoint of unconsciousness is necessary due to intractable symptoms.

Opioids are not recommended if the primary goal is to induce sedation. However, if the person has been in pain, opioids should be continued so that the sedated person will not experience pain. Follow standard opioid dosing guidelines and alter doses if renal clearance decreases and signs of opioid toxicity are of concern (see EPEC for Veterans Module 4: Pain Management; EPEC for Veterans Module 10: Life-Sustaining Treatments; and EPEC for Veterans Module 11: Last Hours of Living).

In discussing palliative sedation with Veterans, it is important to be explicit in your language. Veterans who have survived in combat situations may have seen other soldiers who have been gravely injured receive pain medication but not immediate transport to medical care as part of the triage process. Veterans learned that the wounded would be evacuated with the most critical but survivable injuries first, then those with less life-threatening injuries and only then those with severe injury who are triaged to have non-survivable injury. These soldiers often received analgesia on the battle field administered by the medic. Veterans may relate their own terminal illness to this triage process and if the diseases is not survivable that they could get “the shot” of medication analogous to what they thought they had witnessed in battle.
Step 6: Consult with colleagues

Requests for hastened death are some of the most challenging situations clinicians face. In such circumstances, the support and advice from colleagues and peers is critical. Unfortunately, it is in these situations that clinicians may hesitate to involve someone else. There may be several reasons for such reluctance related to their own professional and/or personal experience with patients, friends, and family who have considered the option of hastened death in the face of suffering at the end of life. Others may have the conviction that it is not appropriate to talk about death. A few may be reluctant to discuss requests for physician-assisted suicide or euthanasia because of the legal implications of the situation.48

As requests for hastened death can have considerable personal, ethical, and legal ramifications, they should not be dealt with in isolation, but rather with the support and input of trusted colleagues or advisors and the Integrated Ethics Consultation Service at your facility. Physicians may also find considerable support from nurses, social workers, chaplains, and other members of the interdisciplinary team who are involved in the Veteran’s care.

Summary

A request for physician-assisted suicide or euthanasia indicates unrelieved suffering. This module has presented a practical approach for clinicians to use to respond to such requests. The clinician needs to treat all requests seriously and compassionately, look for
the root causes of the request, and work with the Veteran and others to relieve those root causes. Existing therapeutic options for symptom control and comfort can provide alternatives for most if not all Veterans who persist in their request for hastened death.

**Key take-home points**

1. Clinicians must respect decisions to accept or decline life-sustaining treatment when made by Veterans with decision-making capacity or by surrogates acting on their behalf.

2. Clinicians have an obligation to relieve pain and suffering, preserve the dignity of Veterans who are approaching the end of life, assure continuity of care, and avoid abandoning Veterans in their care.

3. Requests for assistance with suicide or for euthanasia should not be construed by the clinicians as an indictment of their medical practice and expertise, but rather part of the range of normal reactions that Veterans experience in the face of suffering caused by illness, loss of function, and fears about the future.

4. A request for physician-assisted suicide may be the first expression of unrelieved suffering.

5. Clinical depression occurs frequently and is underdiagnosed, undertreated, and a frequent motivator for requests to hasten death. Many symptoms of depression, e.g., fatigue, generalized weakness, anorexia, sleep disturbance, and diminished libido may be caused by illness or treatment. Directly asking the Veteran if they are experiencing depression and assessing for hopelessness has been shown to be a valuable method of screening for depression in this population.

6. Emotional and coping responses to life-threatening illness may include a strong sense of shame, feelings of not being wanted, and/or inability to cope.

7. Many Veterans are fearful about what the future will be like (pain and other symptoms, loss of control/independence, abandonment, loneliness, indignity, loss of self-image, being a burden).

8. Therapeutic alternatives to hastened death may include decisions by the Veteran to forgo life-sustaining treatment and/or intentionally decline oral intake.

9. Proportionate palliative sedation may be needed to adequately address intractable symptoms that are not be adequately controlled by aggressive, skilled, interdisciplinary palliative care.

10. Don’t address requests for physician-assisted suicide in isolation – consult with trusted colleagues early. Hospice and palliative care clinicians are familiar with the fears and suffering that cause Veterans to request hastened death.
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