EPEC for Veterans

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

Trainer's Guide

Module 11

Last Hours of Living

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Contact EPEC by E-mail at info@epec.net, or

EPEC®

750 N. Lake Shore Drive, Suite 601

Chicago, IL 60611

USA

Phone: +1 (312) 503-EPEC (3732)

Fax: +1 (312) 503-4355

Module 11 trainer's notes

Principal message

The last hours of living can be some of the most important, both for patient and for family. Managed well, they can lead to smooth passage and healthy grief and bereavement.

Module overview

Clinical competence, willingness to educate, and calm, empathic reassurance are critical to helping Veterans and their families in the last hours of living. Clinical issues that commonly arise in the last hours of living include the management and discussion of feeding and hydration, changes in consciousness, and the management of symptoms such as delirium, pain, breathlessness, and secretions. Management principles are the same at home or in a VA health care facility. However, death in a VA Medical Center (VAMC) or VA Community Living Center (CLC) requires accommodations to assure privacy, cultural observances, and communication that may not be customary. In anticipation of a Veteran dying, inform the family and other professionals about what to do and what to expect.

Preparing for a presentation

1. Assess the needs of your audience

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

2. Presentation timing

The suggested timing for each part of this module is:

Introduction	2-3 minutes
Trigger video & discussion	5-7 minutes
Presentation	40 minutes
Summary	2-3 minutes
Total	49-53 minutes

3. Number of slides: 30

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 aloud 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 11**

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 learning how to manage the last hours of living.

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 video or present the clinical case

After reviewing the objectives for the session, show the trigger video 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

A.F. is a 79-year-old Veteran with metastatic prostate cancer living at home, and cared for by his daughter with the help of a home hospice program. He developed aspiration pneumonia, and it was treated with oral antibiotics. Advance care planning indicates he does not want to go to the hospital under any circumstances, and oral antibiotics were an intermediate level of care. The Veteran and his daughter agree that if he gets better, he may have some quality of time left. But if he doesn't, A.F. says he is "ready to go." His VA clinician makes a joint home visit with the home hospice nurse in order to assess changes in mental status.

An additional case is available on the EPEC Trigger video DVD. It depicts a granddaughter caring for her grandmother at home who is dying. She is visited by a hospice nurse and hospice physician.

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 granddaughter 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 clinician address the granddaughter'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 video or how 'real' the players seemed. If the participants don't like something that was said or done in the trigger video, ask them how they would do it themselves.

Setting limits to discussion time

Limit discussion of each scene of the trigger video 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 of A.F. and her daughter to illustrate key points. You may want to use case examples of your own. You may ask the participants for examples and comments. But be careful that the discussion doesn't derail your overall goals to cover the material.

Alternative style: 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 domains and elements of comprehensive end-of-life care during the last hours.

Then use the case from the trigger video, the case from the start of the module or another you have prepared. Ask the participants about their response to the scenario. What do they think is happening? What do they expect will happen next? Major issues to illustrate are that the patient is dying, both the patient and her family need care, and multiple medical issues are likely to arise in the next few hours to days.

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.

6. Key take-home points

1. Advance preparation and education of professional, family, and volunteer caregivers are essential. They should also be knowledgeable about the potential time left, signs and symptoms of the dying process, and their potential management. The clinicians need to help family members understand that what they see may be different from what the Veteran is experiencing.
2. The physiologic changes of dying are complex. To control each symptom effectively, clinicians need to have an understanding of its cause, underlying pathophysiology, and the appropriate pharmacology to use.

3. Most Veterans lose their appetite and reduce food intake long before they reach the last hours of their lives. Anorexia may be protective.
4. Moaning, groaning, and grimacing accompanying agitation and restlessness are frequently misinterpreted as pain. Terminal delirium may be occurring. While a trial of opioids may be beneficial in the Veteran who is difficult to assess, benzodiazepines or sedating neuroleptics may be needed to manage terminal delirium. Benzodiazepines may cause paradoxical exciting effects; these Veterans require neuroleptic medications to control their delirium.
5. Secretions from the tracheobronchial tree frequently accumulate. Scopolamine or glycopyrrolate will effectively reduce the production of saliva and other secretions.

7. Summarize the discussion

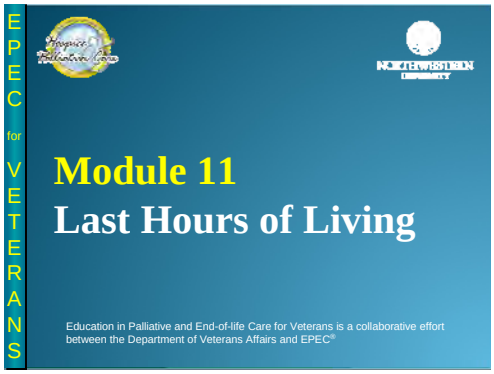
Briefly review each part of the presentation. Recap 2 or 3 of the most important points that were discussed.

8. Post-test/evaluation

Ask the participants to evaluate the session.

Abstract

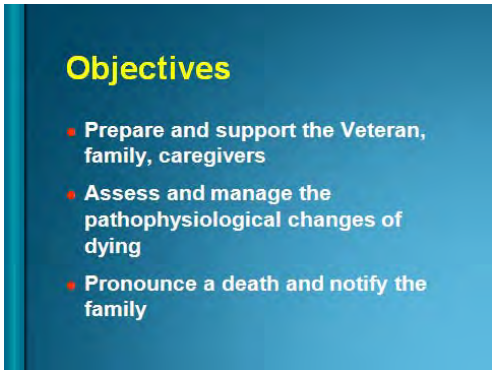
Slide 1



Clinical competence, willingness to educate and calm, and empathic reassurance are critical to helping Veterans and their families in the last hours of living. Clinical issues that commonly arise in the last hours of living include the management and discussion of feeding and hydration, changes in consciousness, and the management of symptoms such as delirium, pain, breathlessness, and excessive secretions. Management principles are the same at home or in a VA facility. However, death in a VA Medical Center (VAMC) or VA Community Living Center (CLC) requires accommodations to ensure privacy, cultural observances, and communication that may not be customary.

Objectives

Slide 2



After studying this module, clinicians will be able to:

- assist families to prepare for the last hours of life;
- assess and manage the pathophysiologic changes of dying; and
- pronounce a death and notify the family.

Clinical case

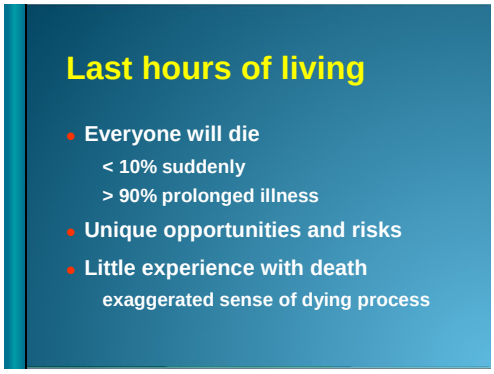
Slide 3

A.F. is a 79-year-old Veteran with metastatic prostate cancer who is at home, cared for by his daughter with the help of a home hospice program. He developed aspiration pneumonia, and it was treated with oral antibiotics. Advance care planning indicates he does not want to go to the hospital under any circumstances. The Veteran and his daughter agree that if he gets better, he may have some quality time left. But if he doesn't, A.F. had said that he is "ready to go." He is now minimally responsive. His VA clinician makes a joint home visit with the home hospice nurse in order to assess changes in mental status.

An additional case is available on the EPEC Trigger Tape DVD.

Introduction

Slide 4



Virtually all clinicians will participate in the care of dying Veterans and their families during their careers. Of all patients who die, only a few (<10%) die suddenly and unexpectedly. Most (>90%) die after a long period of illness with gradual deterioration until an active dying phase at the end.[1] We do not have these data for VA, but it is likely that the proportions are similar. Care provided during those last hours and days can have profound effects, not just on the Veteran but on all who participate.

Most clinicians have little or no formal training in managing the dying process or death. Families usually have even less experience or knowledge. Based on media dramatization

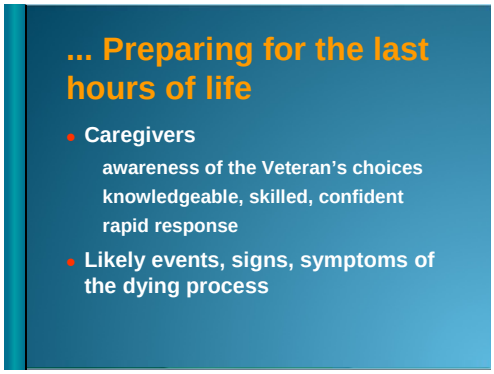
and vivid imaginations, many people may have developed an exaggerated sense of what dying and death are like.

This module first summarizes the physiologic changes that occur as Veterans are dying and approaches to the management of associated symptoms. It will then discuss care at the time of death for the Veteran's family. Loss, grief, and bereavement are covered in EPEC for Veterans Module 12: Loss, Grief and Bereavement.

Preparing for the last hours of life

Slide 5

Slide 6



During the last hours of their lives, most Veterans require skilled care around the clock. This can be provided in any setting as long as the professional, family, and volunteer caregivers are appropriately prepared and supported throughout the process. The environment must allow family and friends access to their loved one at any time, without disturbing others and should be conducive to privacy and intimacy. Medications, equipment, and supplies need to be available in anticipation of problems, whether the Veteran is at home, a VA medical center (VAMC), or a community living center (CLC).

As the Veteran's condition and the family's ability to cope can change frequently, both must be reassessed regularly and the plan of care modified as needed. Changes in the Veteran's condition can occur suddenly and unexpectedly, so caregivers must be able to respond quickly. This is particularly important when the Veteran is at home, if unnecessary travel to an Emergency Department or readmission to the hospital is to be avoided.

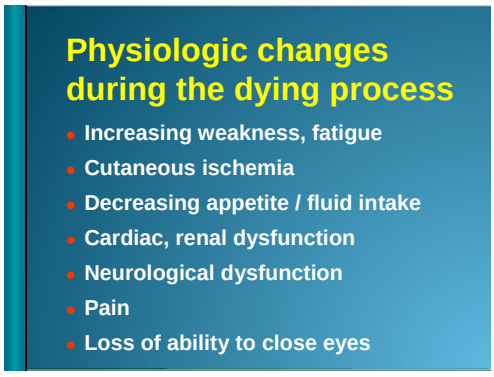
If the last hours of a Veteran's life are to be as rewarding as possible, advance preparation and education of professional, family, and volunteer caregivers is essential, whether the Veteran is at home, in acute care or CLC, a hospice or palliative care unit, etc. Everyone who participates must be aware of the Veteran's health status, his or her goals for care, advance directives, and the proxy for decision making. They should also be knowledgeable about the potential time course, signs, and symptoms of the dying process, and their potential management. If family members and caregivers feel confident and prepared, the experience can be a time of final gift giving. If unprepared and unsupported, they may spend excessive energy worrying about how to handle the next event. If things do not go as hoped for, family members may live with frustration, worry, fear, or guilt that they did something wrong or caused the Veteran's death.

Although we often sense that death will either come quickly over minutes or be protracted over days to weeks, it is not possible to predict when death will occur with precision. Some Veterans may appear to wait for someone to visit, or for an important event such as a birthday or a special holiday, and then die soon afterward. Others experience unexplained improvements and live longer than expected. A few seem to decide to die and do so very quickly.

While it is possible to give families or professional caregivers a general idea of how long the Veteran might live, always advise them about the inherent unpredictability of the moment of death. It is generally best to discuss prognosis, even in the final hours and days, in ranges of times. In this way, saying things such as, "I think it may be over the next hours to day or two," is preferable to saying, "I think it will be about 12 hours." Communication about prognosis is further discussed in EPEC for Veterans Module 3: Communicating Difficult News. The overall goal is to give families an accurate time frame while recognizing the uncertainty at the individual level.

Physiologic changes and symptom management

Slide 7



There are a variety of physiologic changes that occur in the last hours and days of life. Each can be alarming if it is not understood. The most common issues are summarized in **Table 1** and the text that follows. To effectively manage each syndrome or symptom, clinicians need to have an understanding of its cause, underlying pathophysiology, and

the appropriate medications to use in management. It is important for clinicians to understand each of these changes so that they can in turn educate family members about this process.

Table 1: Changes during the dying process

Change	Manifest by/Signs
Fatigue, weakness	Decreasing function Inability to move around bed Inability to lift head off pillow
Cutaneous ischemia	Erythema over bony prominences Skin breakdown and pressure ulcers
Decreasing appetite/ food intake, wasting	Anorexia Poor intake Aspiration, asphyxiation Weight loss (muscle & fat), notable in temples
Decreasing fluid intake, dehydration	Poor intake Aspiration Peripheral edema due to hypoalbuminemia Dehydration, dry mucous membranes/conjunctiva
Cardiac dysfunction, renal failure	Tachycardia Hypertension followed by hypotension Peripheral cooling Peripheral and central cyanosis Mottling of the skin Dark urine Oliguria, anuria
Loss of sphincter control	Incontinence of urine or bowels Maceration of skin Perineal candidiasis
Pain	Facial grimacing Tension in forehead; between eyebrows
Loss of ability to close eyes	Eyelids not closed Whites of eyes showing
Neurological dysfunction, including:	
Decreasing level of consciousness	Increasing drowsiness and difficulty awakening Unresponsive to verbal or tactile stimuli
Terminal delirium	Early signs of cognitive failure (e.g., day-night reversal) Agitation, restlessness Purposeless, repetitive movements Moaning, groaning
Respiratory dysfunction	Change in respiratory rate—increasing first, then slowing Decreasing tidal volume Abnormal breathing patterns—apnea, Cheyne-Stokes respirations, agonal breaths
Loss of ability to swallow	Dysphagia

	Coughing, choking Loss of gag reflex Buildup of oral and tracheal secretions Gurgling
Rare, unexpected events:	
Bursts of energy just before death occurs, the “golden glow” or the “active day” Aspiration, asphyxiation	

Weakness/fatigue

Slide 8

Weakness and fatigue usually increase as the Veteran approaches the time of death. It is likely that the Veteran will not be able to move around in the bed or raise his or her head.[2] Joints may become uncomfortable if they are not moved.[3] Continuous pressure on the same area of skin, particularly over bony prominences, can increase the risk of skin ischemia and pain.[4] As the Veteran approaches death, providing adequate cushioning on the bed will lessen the need for uncomfortable turning. At the end of life, fatigue need not be resisted and most treatments to alleviate it can be discontinued (see EPEC for Veterans Module 6b: Constitutional Symptoms).

Cutaneous ischemia

Veterans who are too fatigued to move and have joint position fatigue may require passive movement of their joints every few hours. To minimize the risk of pressure ulcer formation, turn the Veteran from side to side every 2 hours and protect areas of bony prominence with hydrocolloid dressings and special supports. Avoid “donuts” as they can worsen areas of breakdown by compressing blood flow circumferentially around the compromised area. A draw sheet can assist caregivers to turn the Veteran and minimize pain and shearing forces to the skin. If turning is painful, consider a pressure-reducing surface, e.g., an air mattress or airbed. Or consider pretreating with pain medications. As the Veteran approaches death, the need for turning lessens as the risk of skin breakdown becomes less important. A candid discussion with a Veteran’s family about these issues is important.

Intermittent massage before and after turning, particularly to areas of contact, can both be comforting and reduce the risk of skin breakdown by improving circulation and shifting edema. Avoid massaging areas of nonblanching erythema or actual skin breakdown.

Decreasing appetite/food intake

Slide 9

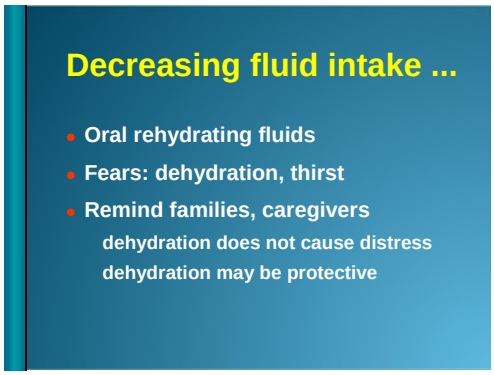
Most dying patients lose their appetite.[5] Unfortunately, families and professional caregivers may interpret cessation of eating as "giving in" or "starving to death." Yet studies demonstrate that parenteral or enteral feeding of patients near death neither improves symptom control nor lengthens life.[6,7,8,9,10]

Clinicians can help families to understand that loss of appetite is normal at this stage. Remind them that the Veteran is not hungry, that food either is not appealing or may be nauseating, that the Veteran would likely eat if he or she could, that the Veteran's body is unable to absorb and use nutrients, and that clenching of teeth may be a way for the Veteran to express his/her desire not to eat.

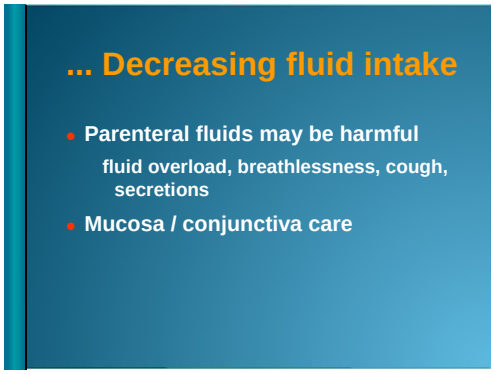
Whatever the degree of acceptance of these facts, it is important for clinicians to help families and other caregivers realize that food pushed upon the unwilling Veteran may cause problems such as aspiration (see EPEC for Veterans Module 10: Life-Sustaining Treatments). Above all, help family members to find alternate ways to nurture and care for the Veteran so that they can continue to participate and feel valued during the dying process. Examples include sitting with the Veteran, listening to music, reminiscing.

Decreasing fluid intake, dehydration

Slide 10



Slide 11



In addition to decreasing food intake, dying patients also stop drinking.[11] This may heighten families' distress as they worry that the dehydrated Veteran will suffer, particularly if he or she becomes thirsty. Most experts feel that dehydration in the last hours of living does not cause distress.[12,13,14] In addition, patients who are able to communicate during this time and do appear clinically dehydrated, do not generally report that it is uncomfortable. This can be reassuring information for families.

Low blood pressure or a weak pulse is part of the dying process and not necessarily an indication of dehydration. Veterans who are not able to be upright generally do not get light-headed or dizzy. Veterans with peripheral edema or ascites have excess body water and salt and are not dehydrated.

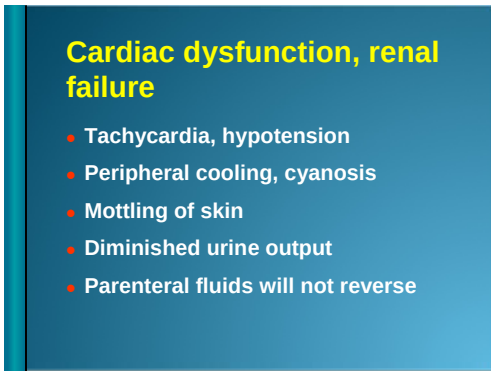
Parenteral fluids, given either intravenously or subcutaneously using hypodermoclysis, are sometimes considered, particularly when a goal is to reverse delirium or increase alertness.[15] In certain clinical situations, a brief trial of parenteral fluids may be warranted. However, parenteral fluids may have adverse effects that are not commonly considered. Intravenous lines can be cumbersome and difficult to maintain. Changing the site of the IV can be painful, particularly when the Veteran is cachectic or has no discernible veins. Excess parenteral fluids can lead to fluid overload with consequent peripheral or pulmonary edema, worsened breathlessness, cough, and secretions, particularly if there is significant hypoalbuminemia.

Mucosal/conjunctival care

To maintain Veterans' comfort and minimize the sense of thirst, even in the face of dehydration, maintain moisture on mucosal membranes with meticulous oral, nasal, and conjunctival hygiene.[16] Moisten and clean oral mucosa every 15 to 30 minutes with either baking soda mouthwash (1 teaspoon salt, 1 teaspoon baking soda, 1 quart tepid water) or an artificial saliva preparation to minimize the sense of thirst and avoid bad odors or tastes and painful cracking. Treat oral candidiasis with topical nystatin or systemic fluconazole if the Veteran is able to swallow. Coat the lips and anterior nasal mucosa with a thin layer of petroleum jelly to reduce evaporation. If eyelids are not closed, moisten conjunctiva with an ophthalmic lubricating gel every 3 to 4 hours, or artificial tears (saline solution).

Cardiac dysfunction, renal failure

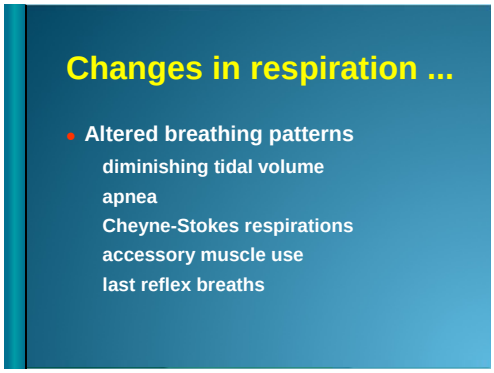
Slide 12



As cardiac output and intravascular volume decrease near the end of life, there will be evidence of diminished peripheral blood perfusion. Tachycardia, hypotension, peripheral cooling, peripheral and central cyanosis, and mottling of the skin (livedo reticularis) are expected. Venous blood may pool along dependent skin surfaces. Urine output falls as perfusion of the kidneys diminishes. Oliguria or anuria usually ensue. Parenteral fluids will not reverse this circulatory shut down.[17]

Respiratory dysfunction

Slide 13



Slide 14

Changes in a dying Veteran's breathing pattern may be indicative of significant neurologic compromise.[18,19,20] Breaths may become very shallow and frequent with a diminishing tidal volume. Periods of apnea and/or Cheyne-Stokes pattern respirations may develop. Accessory respiratory muscle use may become prominent.

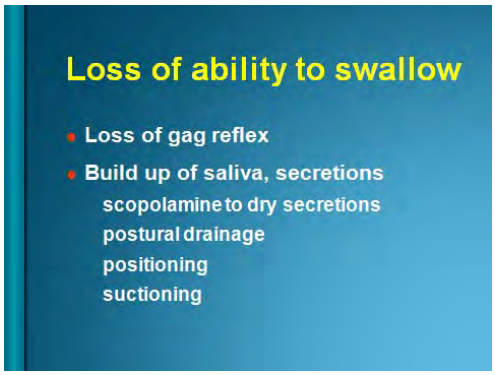
Families and clinicians frequently find changes in breathing patterns to be some of the most distressing signs of impending death. Many fear that the comatose Veteran will experience a sense of suffocation. Knowledge that the unresponsive Veteran may not be experiencing breathlessness or "suffocating" may be reassuring for families.

Oxygen is a potent symbol of medical care to families – this may be a good thing or a bad thing depending on the patient. An oxygen mask can lead to a sense of smothering and Veterans may struggle to take them off. Counseling families to use fans and fanning, repositioning and nasal prong oxygen as long as it does not contribute to distress is helpful to many families. Written material about the dying process may augment the personal counsel provided. Low doses of opioids are appropriate to manage possible symptoms of breathlessness (see EPEC for Veterans Module 6c: Dyspnea). If there is accompanying agitation, benzodiazepines are also indicated.

Some clinicians express concern that the use of opioids or benzodiazepines for symptom control near the end of life will hasten death. Consequently, they feel they must invoke the ethical principle of double effect to justify treatment. While it is true that Veterans are more likely to receive higher doses of both opioids and sedatives as they get closer to death, there is no evidence that initiation of treatment or increases in dose of opioids or sedatives is associated with precipitation of death. In fact, the evidence suggests the opposite.[21]

Loss of ability to swallow

Slide 15



Weakness and decreased neurologic function frequently combine to impair the Veteran's ability to swallow. The gag reflex and reflexive clearing of the oropharynx decline and secretions accumulate. These conditions may become more prominent as the Veteran loses consciousness. Buildup of saliva and oropharyngeal secretions may lead to gurgling, crackling, or rattling sounds with each breath.[22] Some have called this the "death rattle" (a term that frequently is disconcerting to families and caregivers).

Once the Veteran is unable to swallow, cease oral intake. Warn families and other clinicians of the risk of aspiration. Scopolamine or glycopyrrolate will effectively reduce the production of saliva and other secretions.[23,24] Common starting doses are the following:

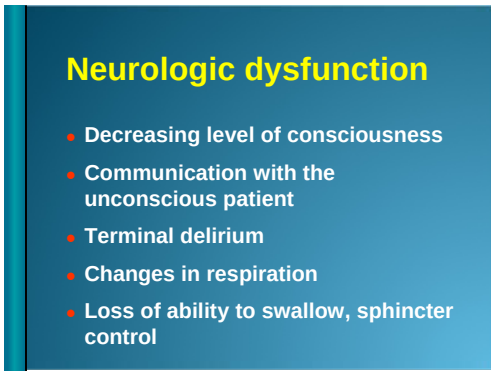
- **Scopolamine** 0.2-0.4 mg SC q 4 h, or 1-3 transdermal patches q 72 h, or 50-200 mcg/hr IV; and
- **Glycopyrrolate** 0.2 mg SC q 4 to 6 hr.

These medications will minimize or eliminate the gurgling and crackling sounds, and may be used prophylactically in the unconscious dying Veteran. Anecdote suggests that the earlier treatment is initiated, the better it works, as larger amounts of secretions in the upper aerodigestive tract are more difficult to eliminate. However, premature use in the Veteran who is still alert may lead to uncomfortable drying of oral and pharyngeal mucosa.

If excessive fluid accumulates in the back of the throat and upper airways, it may need to be cleared by repositioning the Veteran or postural drainage. Turning the Veteran onto one side or into a semi-prone position may reduce gurgling. Oropharyngeal suctioning is not recommended. It is frequently ineffective, as fluids are beyond the reach of the catheter, and may only stimulate an otherwise peaceful Veteran and distress family members who are watching.

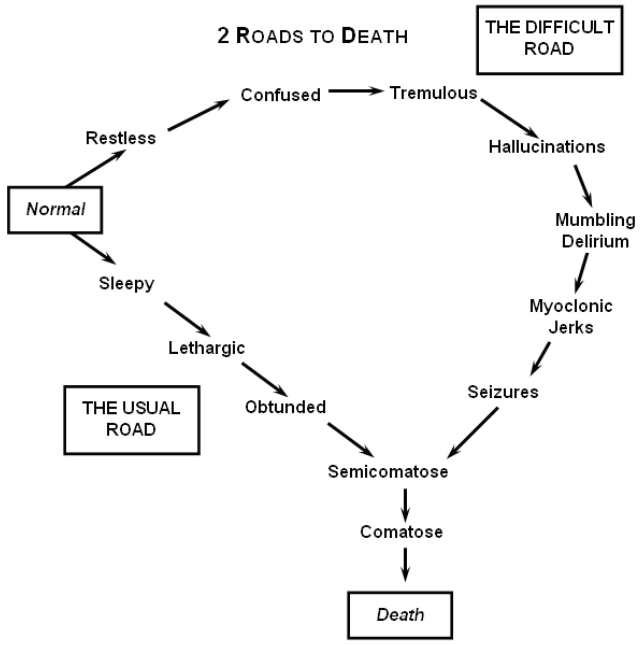
Neurologic dysfunction

Slide 16



The neurologic changes associated with the dying process are the result of multiple concurrent irreversible factors. These changes may manifest themselves in two different patterns that have been described as the "two roads to death" (see **Figure 1** below).[25] Many Veterans with careful symptom management and support follow the "usual road" that presents as a decreasing level of consciousness that leads to coma and death.

Figure 1



As reprinted in: Advance planning. In: Ferris FD, Flannery JS, McNeal HB, Morissette MR, Cameron R, Bally GA, eds. Module 4: Palliative care. In: *A Comprehensive Guide for the Care of Persons with HIV Disease*. Toronto, Ontario: Mount Sinai Hospital and Casey House Hospice Inc; 1995:118-120. Originally published in: Freemon FR. Delirium and organic psychosis. In: *Organic Mental Disease*. Jamaica, NY: SP Medical and Scientific Books; 1981:81-94.

Terminal delirium

Slide 17

An agitated delirium may be the first sign of the "difficult road to death." It frequently presents as confusion, restlessness, and/or agitation, with or without day-night reversal.[26] To the family and clinicians who do not understand it, agitated terminal delirium can be very distressing. Although previous care may have been excellent, if the delirium goes misdiagnosed or unmanaged, family members will likely remember a death "in terrible pain" and may worry that their own death will be the same.

In anticipation of the possibility of terminal delirium, educate and support family and professional caregivers to understand its causes, the finality and irreversibility of the situation, and approaches to its management. It is particularly important that all onlookers understand that what the Veteran experiences may be very different from what they see.

Many Veterans may have emotional and psychological conditions, such as Posttraumatic Stress Disorder (PTSD), that may or may not have been previously diagnosed and that may contribute to agitation and distress at life's end. Also, some Veterans may have spiritual and existential concerns that relate to their time in service or afterwards. Sometimes the Veteran has never shared any of these experiences with family or clinicians. It is important to reflect on how the military experience of the Veteran may impact care in the last hours of living. See EPEC for Veterans Module 8: Psychosocial Issues in Veterans for information on PTSD.

If the Veteran is not assessed to be imminently dying, it may be appropriate to evaluate and try to reverse treatable contributing factors to delirium while at the same time treating the distressing symptoms of delirium. However, if the Veteran is in the last hours of his or her life, the condition is by definition irreversible. Focus on the management of the symptoms associated with the terminal delirium in order to settle the Veteran and the family.[27]

When moaning, groaning, and grimacing accompany the agitation and restlessness, they may be signs of physical pain. While a trial of opioids may be beneficial in the unconscious Veteran who is difficult to assess, clinicians should remember that opioids may accumulate and add to delirium when renal clearance is poor.[28,29] If a trial of increased opioids does not relieve the agitation or increases agitation or precipitating

myoclonic jerks or seizures (rare), then pursue alternate therapies directed at suppressing the symptoms associated with delirium.

Benzodiazepines are used widely to treat terminal delirium as they are anxiolytics, amnestics, skeletal muscle relaxants, and antiepileptics.[30]

Common starting doses are the following:

- **Lorazepam** 1-2 mg as an elixir, or a tablet predissolved in 0.5-1.0 ml of water and administered against the buccal mucosa q 1 h PRN will settle most Veterans with 2 to 10 mg/24 h. It can then be given in divided doses, q 3-4 h, to keep the Veteran settled. Lorazepam 0.5-1 mg can also be administered SC/IV if the oral and buccal route is not available or difficult to tolerate. SC therapy can be used in most individuals and is much less cumbersome and painful then IV.

Benzodiazepines may paradoxically excite some Veterans.[31] These Veterans require neuroleptic medications to control their delirium.

Common starting doses are the following:

- **Haloperidol** 0.5-2.0 mg IV, SC, PR q 1 h PRN (titrated to effect, then nightly to q 6 h to maintain) is also an appropriate treatment for delirium.[32]

If agitated delirium cannot be adequately controlled by lorazepam and haloperidol, barbiturates, midazolam or propofol have been suggested as alternatives for rare situations in which lorazepam and haloperidol are not able to provide adequate sedation to control agitated delirium in the last hours of living.[33,34]

Seizures are rare and can be managed with high doses of benzodiazepines. Lorazepam 2 mg IV/SC is an effective anticonvulsant. Other antiepileptics such as phenytoin IV, fosphenytoin SC, or phenobarbital 60 to 120 mg pr, IV/SC q 10 to 20 min PRN, may become necessary until control is established. Alternatively, carbamezepine PR 200 mg tid to qid can be used.

Communication with the unconscious patient

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Families will frequently find that their decreasing ability to communicate with a dying Veteran is distressing. As many clinicians have observed, the degree of family distress seems to be inversely related to the extent to which advance planning and preparation occurred. The time spent preparing families is likely to be very worthwhile.

While we do not know what unconscious Veterans can actually hear, extrapolation from data from the operating room and "near death" experiences suggests that at times their awareness may be greater than their ability to respond. Given our inability to assess a dying Veteran's comprehension and the distress that talking "over" the Veteran may cause, it is prudent to presume that the unconscious Veteran hears everything. Advise families and clinicians to talk to the Veteran as if he or she were conscious.

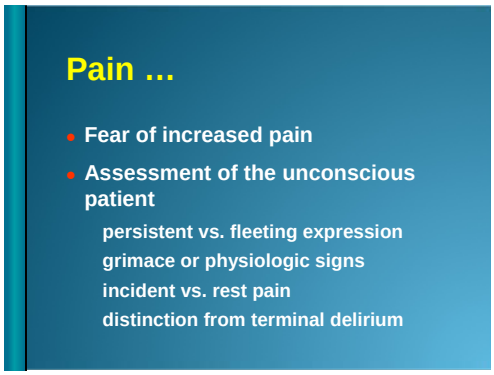
Encourage families to create an environment that is familiar and pleasant. Surround the Veteran with the people, children, pets, objects, music, and sounds that he or she would like. Include the Veteran in everyday conversations. Encourage family members to say the things they need to say. At times, it may seem that a Veteran may be waiting for permission to die. If this is the case, encourage family members to give the Veteran permission to "let go" and die in a manner that feels most comfortable.

As touch can heighten communication, encourage family members to show affection in ways they are used to. Let them know that it is okay to lie beside the Veteran in privacy to maintain as much intimacy as they feel comfortable with.

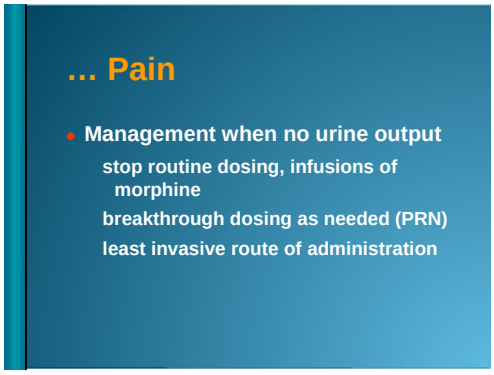
For clinicians modeling talking directly to the Veteran, calm and patient presence is important for families.

Pain

Slide 20



Slide 21



While many people fear that pain will suddenly increase as the Veteran dies, there is no evidence to suggest that this occurs.

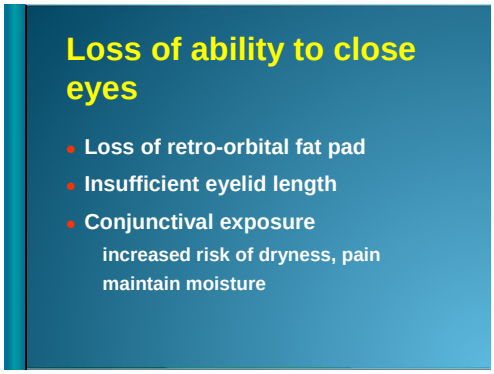
Though difficult to assess, pain in the semiconscious or obtunded Veteran may be associated with grimacing and continuous facial tension, particularly across the forehead and between the eyebrows. It is also important to remember that the Veteran may have specific focus or source of pain but due to delirium or decreased cognition, he is not able to express this. Always note previously painful conditions. A fractured hip or an enlarged liver and bowel obstruction are painful conditions that will continue to be sources of pain. The possibility of pain must also be considered when physiologic signs occur, such as transitory tachycardia that may signal distress. Do not over-diagnose pain when fleeting forehead tension comes and goes with movement or mental activity, e.g., dreams or hallucinations. If the differential diagnosis between pain and delirium is unclear, a trial of a higher dose of opioid may be necessary to judge whether pain is driving the observed behaviors.

Knowledge of opioid pharmacology becomes critical during the last hours of life. The liver conjugates codeine, morphine, oxycodone, and hydromorphone into glucuronides. See EPEC for Veterans Module 4: Pain Management for more information. Some of their metabolites remain active as analgesics until they are renally cleared, particularly morphine. As dying Veterans experience diminished hepatic and renal function and usually become oliguric or anuric, routine dosing or continuous infusions of morphine

may lead to increased serum concentrations of active metabolites, toxicity, and an increased risk of terminal delirium. If there is evidence of worsening delirium, consider discontinuing routine dosing or continuous infusions of morphine. Titrate morphine breakthrough doses to manage expressions suggestive of pain. Consider the use of alternative opioids such as fentanyl or hydromorphone which are less likely to contribute to delirium. Hydromorphone clinically seems less problematic, but also has glucuronides and in animal models can cause problems similar to morphine. Hydromorphone is routinely available in most clinical settings while fentanyl may be more difficult to dose and clinicians may not be as familiar with its use.

Loss of ability to close eyes

Slide 22



Eyes that remain open can be distressing to onlookers unless the condition is understood. Advanced wasting leads to loss of the retro-orbital fat pad, and the orbit falls posteriorly within the orbital socket.[35] This may leave some conjunctiva exposed even when the Veteran is sleeping. If conjunctiva remains exposed, maintain moisture by using ophthalmic lubricants, artificial tears, or saline.[36]

Loss of sphincter control

Slide 23

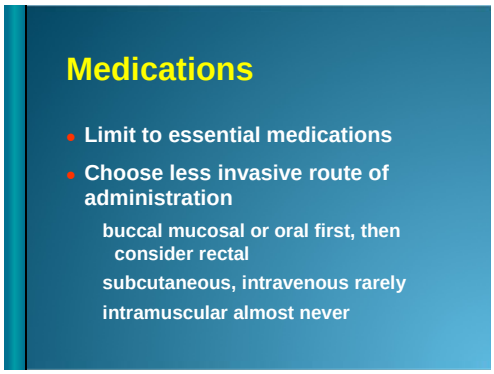
Fatigue and loss of sphincter control in the last hours of life may lead to incontinence of urine and/or stool. Both can be very distressing to Veterans and family members, particularly if they are not warned in advance that these problems may arise. If they occur, attention needs to be paid to cleaning and skin care. A urinary catheter may

minimize the need for frequent changing and cleaning, prevent skin breakdown, and reduce the demand on caregivers. However, it is not always necessary if urine flow is minimal and can be managed with absorbent pads.

In male Veterans, bladder outlet obstruction from prostatic hypertrophy can be exacerbated by opioids and other medications used near the end of life. This can lead to agitation. If available, a bladder scanner to detect urinary retention may be helpful in deciding if agitation is in part due to bladder distention. Since Veterans with delirium may pull out a Foley catheter, if it is placed the burden and benefit need to be assessed carefully. In Veterans with prostatic hypertrophy, one option is to insert the catheter, but to not inflate the balloon. If taped carefully the catheter may stay in place for the time that it will be needed and if the Veteran should pull on it or pull it out he will not have injured himself. If diarrhea is considerable and relentless, a rectal tube may be similarly effective. These may be uncomfortable for the Veteran so the benefit vs. discomfort should be considered.

Medications

Slide 24



As Veterans approach death, reassess the need for each medication and minimize the number that the Veteran is taking. Leave only those medications to manage symptoms such as pain, breathlessness, excess secretions, and terminal delirium. Choose the least invasive route of administration: the buccal mucosa or oral routes first, the subcutaneous or intravenous routes only if necessary, and the intramuscular route almost never. In the outpatient setting buccal and mucosa or oral routes are usually successfully used. In inpatient settings the IV route is often used but may be difficult to maintain and painful to restart. Subcutaneous (SC) therapy is an easy and technologically simple procedure that can ensure reliable access and administration of needed medication. Rectal administration can also be considered, especially if the oral route is not possible.

When death occurs

No matter how well families and clinicians are prepared, they may find the time of death to be challenging. Families, including children, friends, and caregivers may have specific questions for the clinician. Basic information about death may be appropriate (see **Table**

2 below) to share with the family. Many hospices and VA palliative care programs also have handouts for family members about clinical changes near the end of life.[37,38]

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Table 2: Signs that death has occurred

The heart and breathing stop
Pupils become fixed and dilated
Body color becomes pale
Body temperature drops
Muscles and sphincters relax (muscles stiffen 4-6 hours after death as rigor mortis sets in)
Urine and stool may be released
Eyes may remain open
The jaw can fall open

There are no universally applicable rules that govern what happens when a Veteran dies (in any setting). If the Veteran dies an expected death at home there is no need to call for emergency assistance. If a hospice program is involved, have the family call the hospice. If a hospice program is not involved, determine in advance who should be notified. Unless death is unexpected, or malice is suspected, involvement of the medical examiner's office is usually not required (since state and local regulations vary, clinicians will need to familiarize themselves with the regulations in the areas where they practice).

When an expected death occurs, the focus of care shifts from the Veteran to the family, and to those who provided care. Even though the loss has been anticipated for some time, no one will know what it feels like until it actually occurs, and indeed it may take hours, days to weeks, or even months for each person to realize the full effect.

Many experts assert that the time spent with the body immediately after death may help people deal with acute grief.[39,40,41] Those present, including family members, may need the clinician's permission to spend the time to come to terms with the event and say their goodbyes. There is no need to rush, even in the hospital or other care facility. Encourage those who need to touch, hold, and even kiss the Veteran's body as they feel most comfortable. As a visually peaceful and accessible environment may facilitate the acute

grieving process, a few moments spent alone in the room positioning the Veteran's body, disconnecting any lines and machinery, removing catheters, and cleaning up any mess will allow the family closer access to the Veteran's body.[42,43]

Chaplains or other interdisciplinary team members may be instrumental in orchestrating events to facilitate the experience of those present. Those who have not been present for the death may benefit from listening to a recounting of how things went leading up to the death and afterward.

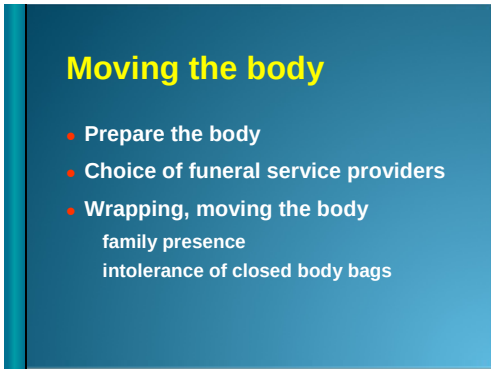
When letting people know about the death, follow the guidelines for communicating bad news. See EPEC for Veterans Module 3: Delivering Difficult News for more information. Try to avoid breaking unexpected news by telephone, as communicating in person provides a much greater opportunity for assessment and support (see next section of this module). If additional visitors arrive, spend a few moments to prepare them for what they are likely to see.

Once family members have had some time to deal with their acute grief reactions and observe their customs and traditions, then preparations for burial or cremation and a funeral or memorial service(s) can begin. Some family members may find it therapeutic to help bathe and prepare the Veteran's body for transfer to the funeral home or the hospital morgue. For many, such rituals will be their final act of direct caring.

A death certificate will have to be completed by a medical provider. Familiarize yourself with the particular issues related to completion of the death certificate in the state(s) in which Veterans you care for live. Depending on the circumstances a home hospice nurse, nursing staff or (in teaching hospitals) resident physicians may pronounce and record the Veteran's death and the death certificate. Care should be taken in completing the death certificate. It is important to note if the Veteran was service-connected, had Agent Orange exposure or other conditions that may affect the benefits available for loved ones. If it is appropriate and related to the death of the Veteran these conditions should be recorded in the cause of death section or in the contributing causes section.

Some Veterans and families may request that an autopsy be performed to determine the cause of death or for legal issues related to compensation claims. If the Veteran has died in a home or non-VA setting he or she can still have an autopsy performed by VAMC. However, if at all possible, this should be discussed earlier so that approval by VAMC is obtained and arrangements on how the body will be transported to VAMC for the autopsy can be made in advance.

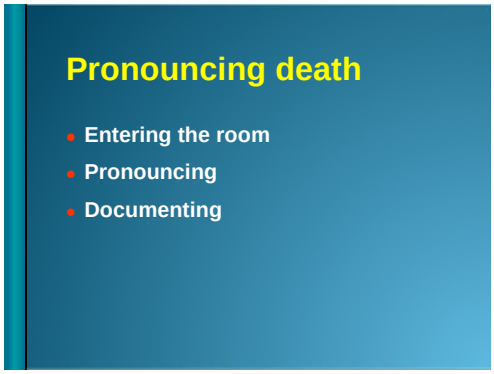
Slide 26



For many families, moving the body is a major confrontation with the reality of the death. Some family members will wish to witness the removal. Others will find it very difficult and will prefer to be elsewhere. Once the body has been removed and family members are settled, clinicians can offer to assist them with some of their immediate tasks. They may notify other clinicians and caregivers that the death has occurred so that services can be stopped and equipment removed. Local regulations governing the handling of medications and waste disposal after a death vary. When family members are ready, professional caregivers can let the family know how to reach them, and then leave them to have some privacy together.

Pronouncing death

Slide 27



In teaching hospitals, resident physicians are typically called to "pronounce" death.[44,45,46,47] In nonteaching settings, the attending physician or nursing staff may be the ones to do it. When a Veteran dies at home with hospice care, it is usually a nurse who confirms the absence of vital signs. Although local regulations differ, if an expected death occurs at home without hospice care and the Veteran has a physician willing to sign a death certificate, then transportation to a hospital for a physician to confirm death is not required.

As an example, consider the following steps that often occur for hospitalized Veterans.

Phone call for a nurse: "Please come; I think the Veteran has died."

- Find out the circumstances of the death- expected or sudden? Is the family present? What is the Veteran's age?

Preparation before you enter the room

- Confirm the details on the circumstances of death. Ask a nurse or other caregiver. Review the chart for important medical (length of illness, cause of death) and family issues (Who is family? What faith? Is there a clergy contact?).
- Find out who has been called. Other physicians? The attending?
- Has an autopsy ever been requested? Do you see a value in requesting an autopsy?
- Has the subject of organ donation been broached? Has the Organ Donor Network been contacted?

In the room

- You may want to ask the nurse or chaplain to accompany you; he/she can give you support and introduce you to the family.
- Introduce yourself (including your relationship to the Veteran) to the family if they are present. Ask each person their name and relationship to the Veteran. Shake hands with each.
- Say something empathic: "I'm sorry for your loss..." or "This must be very difficult for you..."
- Explain what you are there to do. Tell the family they are welcome to stay if they wish, while you examine their loved one.
- Ask what questions the family has. If you cannot answer, contact someone who can.

The pronouncement

- Identify the Veteran. Use the hospital ID tag if available. Note the general appearance of the body.
- Test for response to verbal or tactile stimuli. Overtly painful stimuli are not required.
- Listen for the absence of heart sounds.
- Look and listen for the absence of spontaneous respirations.

- Record the time at which your assessment was completed.

Overall, the physical exam to pronounce death should be brief and focused. The most important part of the interaction is your presence as a clinician for the family.

Documentation in the medical record

Called to pronounce (name); chart findings of physical examination.

- Note date and time of death, and
- Document whether family declines or accepts autopsy; document whether the medical examiner was notified.

Telephone notification

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There will be cases where the people who need to know about the death are not present.[48] In some cases, you may choose to tell someone by phone that the Veteran's condition has "changed," and wait for them to come to the bedside in order to tell the news. Factors to consider in weighing whether or not to break the news over the phone include: whether death was expected, what the anticipated emotional reaction of the person may be, whether the person is alone, whether the person is able to understand, how far away the person is, the availability of transportation for the person, and the time of day (or night). Inevitably, there are times when notification of death by telephone is unavoidable. These situations benefit from a framework such as was discussed in EPEC for Veterans Module 3: Communicating Difficult News. If this is anticipated, prepare for it. Determine who should be called and in what fashion with the following steps:

- **Get the setting right:**
  - Determine the facts before you call. Find a quiet or private area with a telephone. Identify yourself and ask the identity of the person to whom you are talking and their relationship to the Veteran. Ask to speak to the person closest to the Veteran (ideally the health care proxy or the contact person indicated in the chart). Avoid responding to direct questions until you have

verified the identity of the person to whom you are speaking. Ask whether the contact person is alone.

- **Ask what the person understands:**
  - "What have the doctors told you about M's condition?"
- **Provide a "warning shot":**
  - "I'm afraid I have some bad news."
- **Tell the news:**
  - Use clear, direct language without jargon such as, "I'm sorry to have to give you this news, but M just died." Avoid words like expired, passed away, and passed on; they are easily misinterpreted.
- **Respond to emotions:**
  - Listen quietly to the person, and allow enough time for the information to sink in. Elicit questions with a phrase like, "What questions do you have?" Ascertain what support the Veteran's family has. Ask if you can contact anyone for them. Consider other support through the person's community of faith, Red Cross, local police, or other service agencies if it is needed.
- **Conclude with a plan:**
  - If the family chooses to come to see the body, arrange to meet them personally. Provide contact information for the clinician who will meet with them and/or make arrangements.

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Immediately after the death, those who survive will need time to recover. A bereavement card from the clinician and attendance at the Veteran's funeral may be appropriate.[49] Many clinicians consider it a part of their professional duty of care to encourage follow-up visits from bereaved family members in order to assess the severity of their grief reactions and the effectiveness of their coping strategies, and to provide emotional support. Members of the interdisciplinary team can also offer to assist family members in dealing with outstanding practical matters, such as helping to secure documents necessary to redeem insurance, find legal counsel to execute the will and close the estate, find

resources to meet financial obligations, etc. Bereavement care for the family is a standard part of hospice care in the United States. See the EPEC for Veterans Module 12: Loss, Grief, and Bereavement for more information.

Summary

Slide 30

Clinical competence, willingness to educate and calm, and empathic reassurance are critical to helping Veterans and families in the last hours of living. For the majority of dying Veterans, predictable physiologic changes occur. Management principles are the same at home or in a health care institution. However, death in an institution requires accommodations that include ensuring privacy, cultural observances, and communication that may not be customary. In anticipation of the event, it helps to inform the family and other professionals about what to do and what to expect, including matters such as when rigor mortis sets in, and how to call the funeral home, say goodbye, and move the body. Care does not end until the clinicians have helped the family with their grief reactions and helped those with complicated grief to get care. Care at the end of life is an important responsibility, and there is a body of knowledge to guide care.

Key take-home points

1. Advance preparation and education of professional, family, and volunteer caregivers are essential. They should also be knowledgeable about the potential time course, signs and symptoms of the dying process, and their potential management. The clinician needs to help family members understand that what they see may be different from what the Veteran is experiencing.
2. The physiologic changes of dying are complex. To control each symptom effectively, clinicians need to have an understanding of its cause, underlying pathophysiology, and the appropriate pharmacology to use.
3. Most Veterans lose their appetite and reduce food intake long before they reach the last hours of their lives. Anorexia may be protective.
4. Moaning, groaning, and grimacing accompanying agitation and restlessness are frequently misinterpreted as pain. Terminal delirium may be occurring. While a trial

of opioids may be beneficial in the Veteran who is difficult to assess, benzodiazepines or sedating neuroleptics may be needed to manage terminal delirium. Benzodiazepines may cause paradoxical excitatory effects; these Veterans require neuroleptic medications to control their delirium.

5. Secretions from the tracheobronchial tree frequently accumulate. Scopolamine or glycopyrrolate will effectively reduce the production of saliva and other secretions.

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