ELNEC- For Veterans

END-OF-LIFE NURSING EDUCATION CONSORTIUM

Palliative Care For Veterans

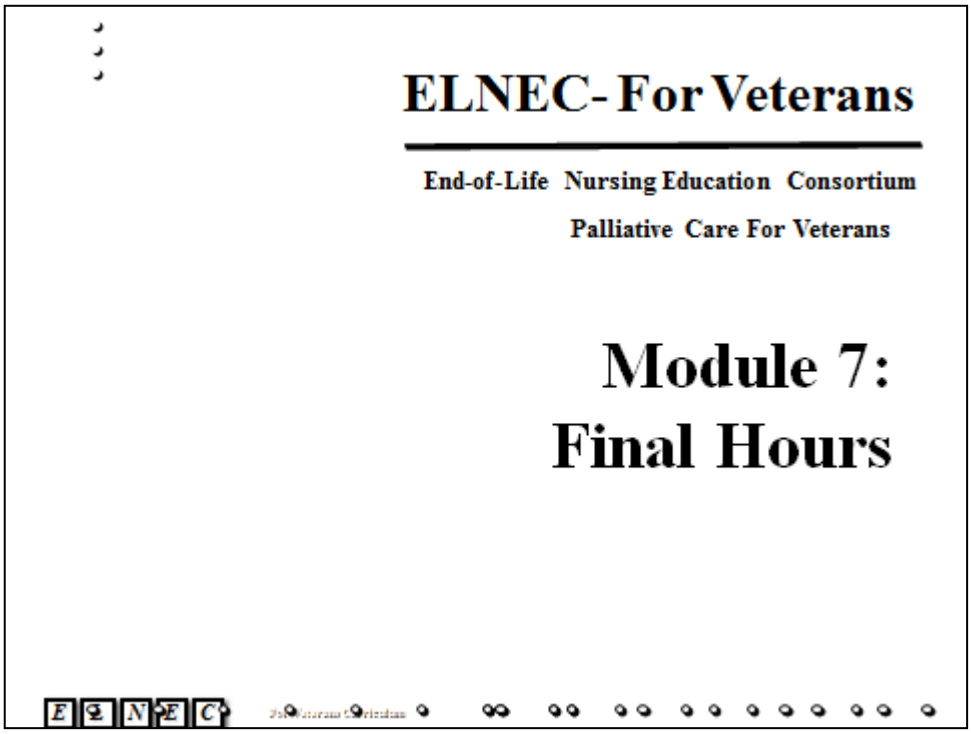
FACULTY GUIDE

Module 7
Final Hours

The End-of-Life Nursing Education Consortium (ELNEC – For Veterans train-the-trainer program and curriculum was developed by the National ELNEC Project Team, a partnership between the City of Hope (Betty R. Ferrell, PhD, RN, MA, FPCN, FAAN, Principal Investigator) in collaboration with the American Association of Colleges of Nursing (Pam Malloy, MN, RN, FPCN, FAAN, Co-Investigator). Curriculum development and 6 national ELNEC-For Veterans train-the-trainer courses were generously funded by the US Department of Veterans Affairs (2009-2012).

Module 7: Final Hours
Faculty Outline

Slide 1



This module focuses on care leading up to and the actual time of death, emphasizing the preparation necessary to insure the best care at this critical event in the trajectory of illness.

- The actual time of death creates unique issues beyond those encountered during the course of illness.

- Care at this time demands attention to physical, psychological, social and spiritual needs of Veterans across life's span and the special needs of their families.

- Nurses and other members of the healthcare team must work together to orchestrate a dignified death for all Veterans.

- Nurses who work with Veterans will be exposed to death during their entire career including care for:
  - Veterans who die suddenly (i.e. accidents, heart attacks, etc.) including those who commit suicide
  - Veterans who are diagnosed with six months or less to live (i.e., cancer, etc.)

- Veterans who die from debilitating chronic illnesses (e.g., diabetes, cardiac disease, COPD, dementia .)

- National Consensus Project: Domain 7: Care of the Imminently Dying Patient. Dying is an individualized, personal experience and is a physical, psychological, social and spiritual event. Planning and consulting with the interdisciplinary team is vital (NCP, 2013).

- Family members who witness the last days, hours and minutes of their loved one's life will remember the death for as long as they live. Nurses have a unique role in collaborating with the interdisciplinary team to make every effort to ensure that Veterans die with dignity, honor, and peace.

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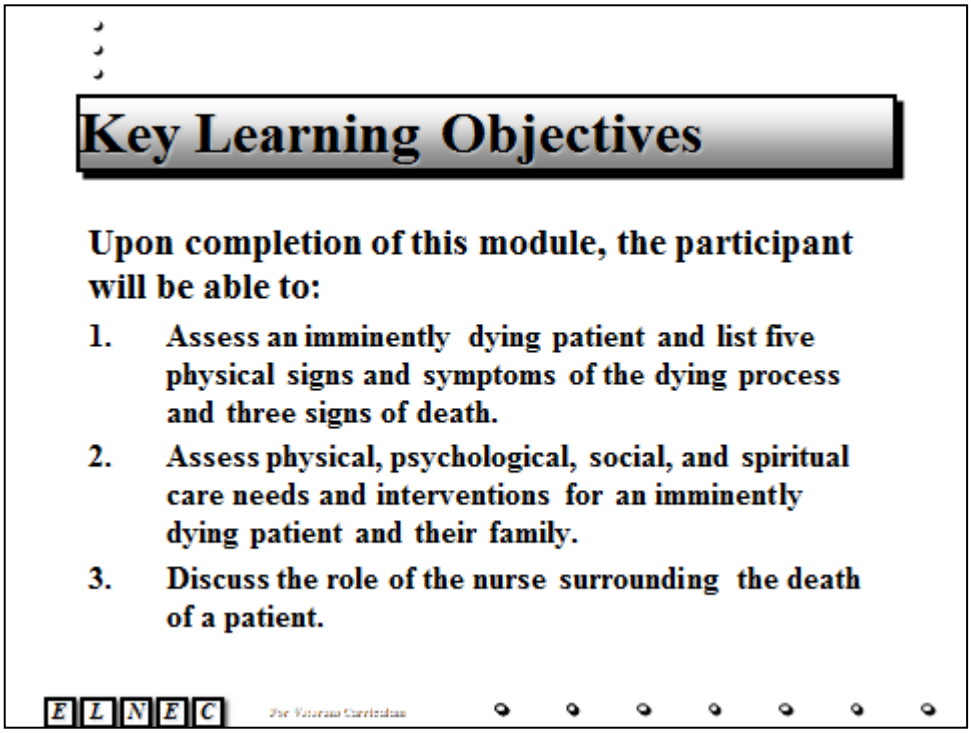
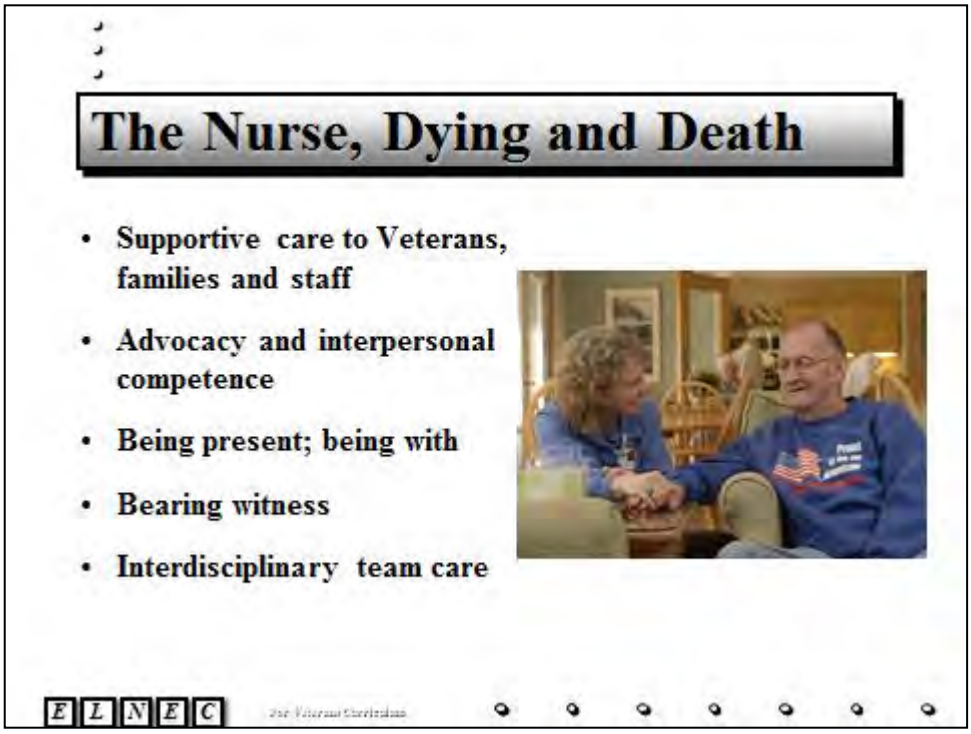


Key Learning Objectives

Upon completion of this module, the participant will be able to:

1. Assess an imminently dying patient and list five physical signs and symptoms of the dying process and three signs of death.
2. Assess physical, psychological, social, and spiritual care needs and interventions for an imminently dying patient and their family.
3. Discuss the role of the nurse in caring for patients in the period surrounding death.

Slide 3



- Most nurses probably have more "real" exposure to death than any other health care professionals.

  "I need your help. I cannot do this alone. I know that when you come to see me, you think of me as some other 'poor patient' who will soon succumb to his terminal illness. You have seen people like me all too frequently, I am sure. I have tried to be a good man, good husband, good father, good son. May you see me as more then just my disease. I have never been on this road before, so I don't always know how to respond. What's the proper etiquette for dying? Please know that I wish I could live longer, that I could fight harder against this disease. I am fearful of dying, of pain, and of prolonged suffering. Will you help me, will you listen to me, and will you advocate for me when I can not advocate for myself so that I will not have to suffer needlessly?" (Personal written communication between a nurse and patient)

- The final hours to days of a Veteran's life may be the most significant moments for the Veteran and family as they prepare for death, say goodbye, and complete end-of-life closure tasks.

- The nurse, in the role as advocate/companion/professional caregiver/educator/supporter, is often the one to facilitate a dignified, comfortable death that honors Veterans/family choices, no matter where the setting of death occurs (home, nursing home, hospice, in-patient settings) (Berry & Griffie, 2015).

- Interpersonal competence includes:
  - Empathy (putting oneself in another's place),
  - Unconditional positive regard (nonjudgmental acceptance),
  - Genuineness (trustworthiness, openness),
  - Attention to detail (critical thinking).

- The nurse must be comfortable with "being with" and "bearing witness" with the dying Veteran and family.

- Care of the dying must be interdisciplinary. Nurses collaborate closely with physicians and all team members to provide care at this sensitive time.

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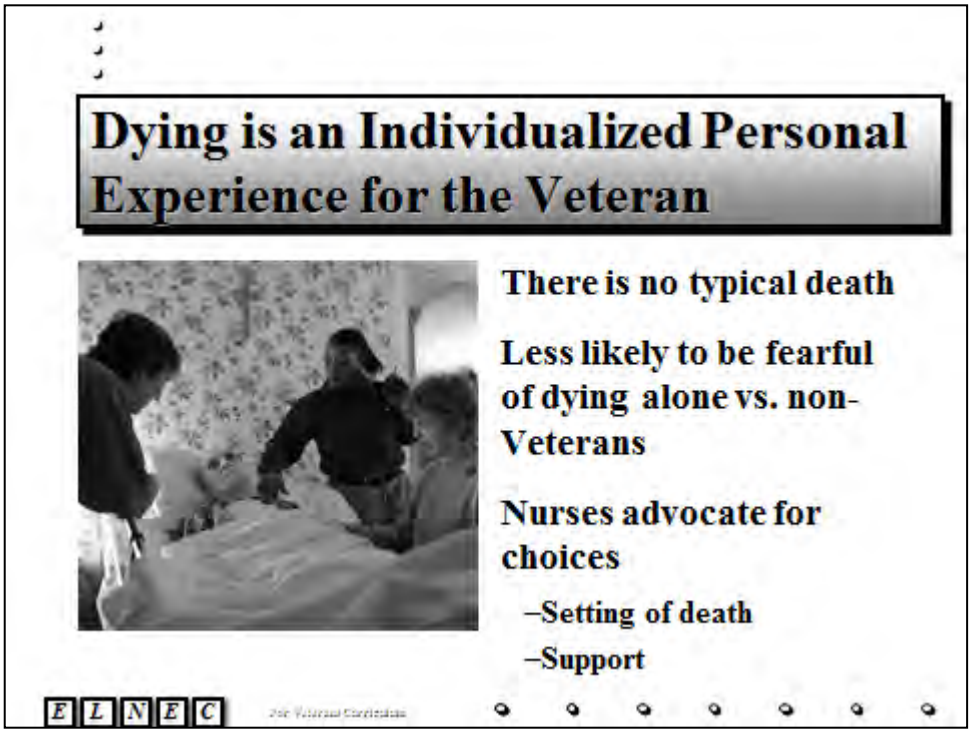

- There is no typical death. Though much has been written about the "culture" of the VA, it is important not to generalize and stereotype Veterans. Instead it is vital to recognize and honor the Veteran's individual preferences. Those preferences always supersede group norms (Duffy et al., 2006).

  Each person dies
  In their own way,
  Own time,
  With their own culture,
  With their own belief system and values,
  With unique relationships with family, friends, colleagues.

- In 2006, the Nebraska End-of-Life Survey was sent to Veterans and non-Veterans throughout the state of Nebraska. This study showed that Veterans do have preferences for specific end-of-life care and they are somewhat different from non-Veterans (Freeman & Berger, 2009). For example, a question on the survey asked, "How afraid are you of dying alone?"
  - Veteran's responses: 43% expressed no fear of dying alone whereas only 19% of non-Veterans expressed no fear of dying alone.
  - Due to military training and possible viewing of death in war time, Veterans may have thought about and witnessed death more frequently than non-Veterans.

- Like many non-Veterans, Veterans often know where they want to die, who they want near them when they die, and how they want to die. Nurses need to advocate for Veteran/family choices in relation to:
  - Where, with whom, and how they die. The nurse, in collaboration with an interdisciplinary team, advocates for Veteran/family choice by providing optimal end-of-life care in any practice setting.
  - Open and honest communication with the Veteran/family provides education and support at the end of life.

Exercise - Stop and Consider

A Special Focus on Caring for Vets at the End of Their Lives.
On May 26, 2015 NPR (National Public Radio) initiated "Back at Base".
Listen to the story of Mark Goodwin at Madigan Army Medical Center, Tacoma, Washington and how palliative care supported him during his final days (4:07 minutes). Retrieved March 8, 2016 from
http://www.npr.org/2015/05/26/408765335/a-special-focus-on-caring-for-vets-at-the-end-of-their-lives

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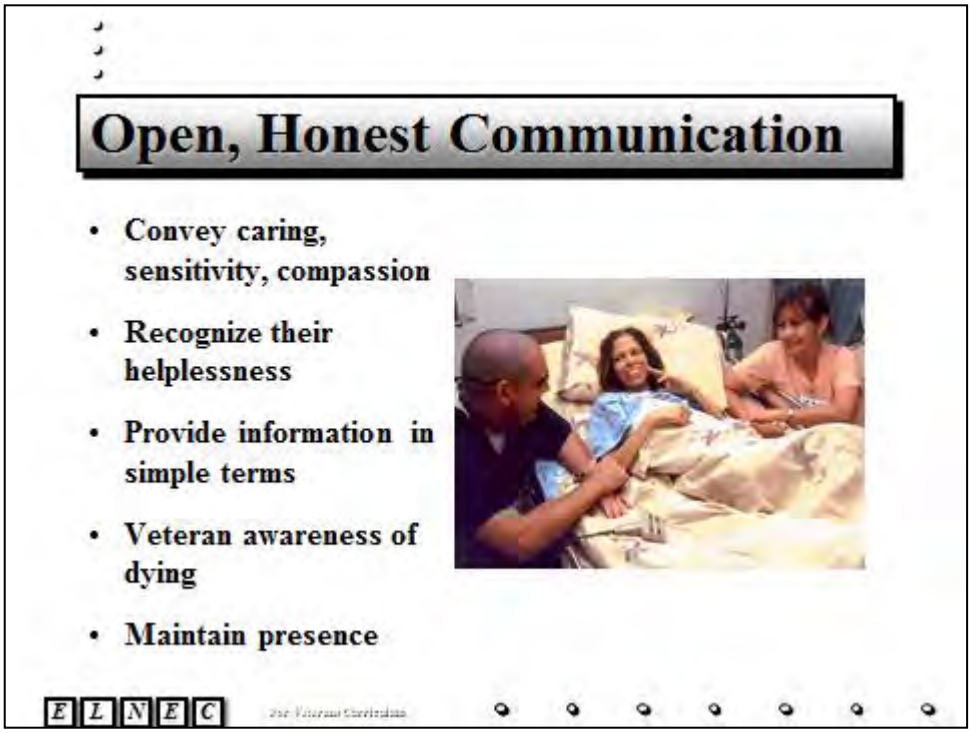

- Amidst all of the "tasks" of work, don't forget to take the time to communicate. Open, honest communication is vital as death approaches.

- The team should be open and honest to promote trust and informed decision-making. In all communication, convey caring, nurturing, sensitivity, and compassion.

- Many people want to be in control throughout their lives, including the time of death but as illness progresses and death nears, feelings of helplessness are common.. By recognizing their helplessness, and helping to mitigate it we affirm our skill and compassion.
  - For example, asking the following questions can be helpful: "It can be hard to wait for death to come," or "It's tough to realize we are not in control of all aspects of our life".
  - Many times, anger accompanies the helplessness and assisting them with recognizing the relationship between the two can be helpful. "Sometimes Veterans say that feeling helpless makes them angry. It has to be hard for a soldier to learn how to surrender, to let go" (Grassman, 2009).

- Provide information in simple, uncomplicated terms.
  - Avoid medical jargon and keep explanations simple.
  - Family members may be tired, have difficulty concentrating, and be focusing on the present and not the future. You may need to answer the same questions, provide the same information repeatedly as Veterans/families may be in crisis and unable to retain some information.

- The Veteran may have a greater awareness of dying than those around him/her:
  - If a Veteran asks if he/she is dying, be honest.
  - Encourage open and honest communication between Veteran and family.
- If the family is fearful of the Veteran knowing he/she is dying, address these concerns and fears:
  - Educate the family that the patient may already know he/she is dying.
  - Open and honest communication is vital.

- Maintain presence:
  - Ask about the family's hopes and help them identify strategies to achieve these hopes.
  - Provide companionship, active listening, and simple presence.

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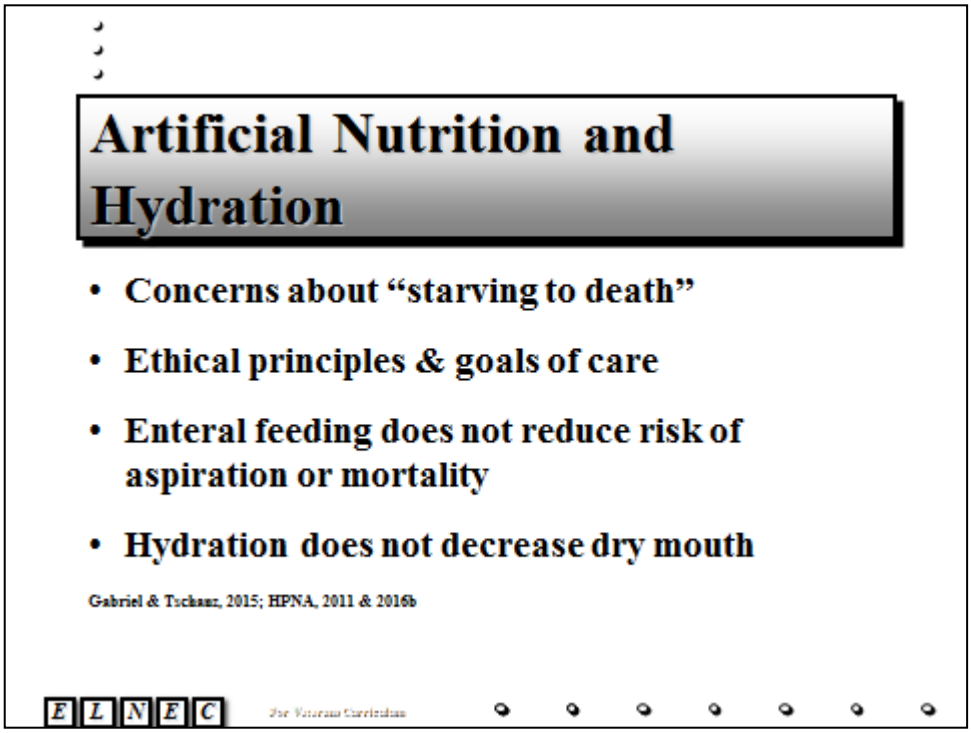


- The family may be concerned that the Veteran will "starve to death." Our society is one where nutrition and hydration are equated with caring and nurturing.

- Studies suggest that enteral feeding tubes, such as percutaneous endoscopic gastrostomy (PEG), do not reduce the risk of aspiration pneumonia or mortality.

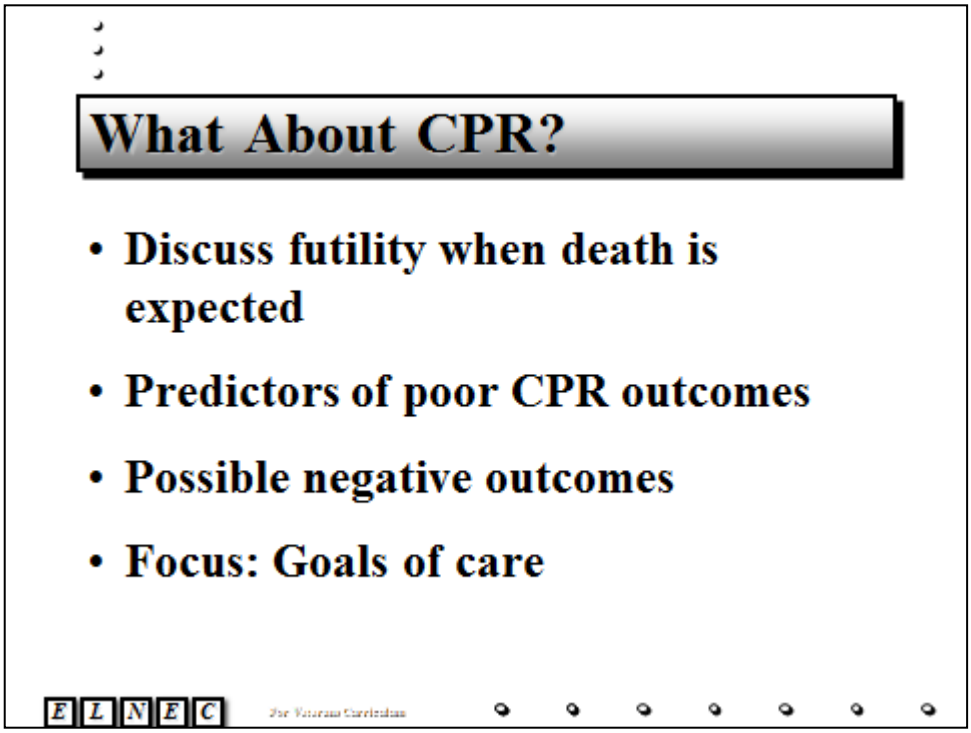
- Family members watching their loved one lose weight and muscle can cause great anxiety. Families need much support during this time.

- The ethical principles of autonomy, beneficience, nonmaleficience and the patient's goals of care help guide choices regarding the use of artificial nutrition and hydration (Gabriel & Tschanz, 2015). Regarding hydration, there is little evidence that increasing fluids decreases dry mouth. Other "pros" and "cons" of dehydration include (HPNA, 2011 & 2016b):
  - Pros of dehydration:
    - Increased production of ketones, which result in sleepiness and euphoria; decreased urinary output,
    - Decreased GI fluid resulting in decreased nausea/vomiting and decreased abdominal distention,
    - Edematous layer around tumor may shrink (if tumor present),
    - Increased opioid peptide production, resulting in increased endorphin levels and natural occurring analgesia,
    - Decreased gastric stimulation, resulting in a lack of hunger,

  - Hypernatremia and uremia, resulting in clouding of sensorium,
  - Decreased lung secretions.
- Cons of dehydration:
  - Potential for "dry mouth" (use ice chips, mouth care),
  - Feeding symbolic of nurturing,
  - Appearance of abandoning the patient,
  - Feeding considered "basic" nursing care.

Remember: The ethical principles of autonomy, beneficience, and nonmaleficience should always be remembered when withholding nutrition and hydration.

Slide 7



- It is important that Veterans and their families communicate about choices regarding cardiopulmonary resuscitation (CPR), especially when death is expected from a terminal illness (Berry & Griffie, 2015).

- Predictors of the burdens of CPR and poor outcomes include patients with:
  - Advanced terminal illnesses
  - Dementia
  - Poor functional status who must depend on others for meeting their everyday basic needs

- Possible negative outcomes from CPR include:
  - Fractured ribs
  - Punctured lung
  - Possible brain damage
  - Permanent vegetative state

Note: Goals of care should always focus on benefits, burdens and risks. Futile options should never be offered to Veterans and their families.

Exercise - Stop and Consider:
- How do you discuss goals of care with Veterans? Their families? The interdisciplinary team?

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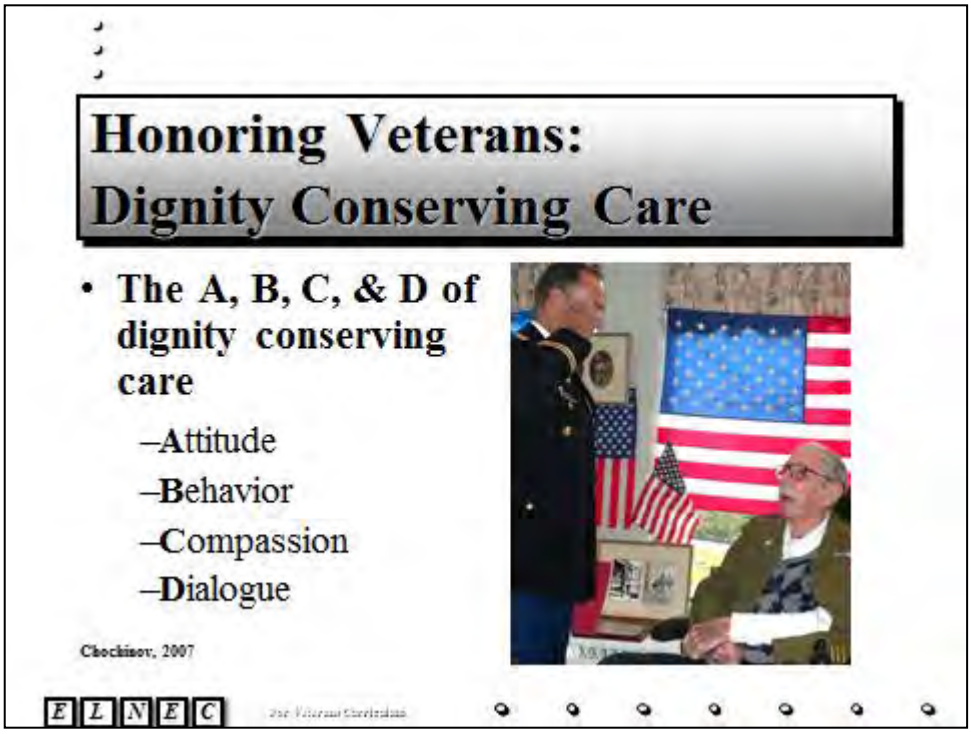

- Just as we always emphasize the importance of the "A,B,C" rule (airway, breathing, and circulation) in clinical settings, the mnemonic A, B, C, & D of *dignity conserving care* (attitude; behavior; compassion; & dialogue) can remind all healthcare providers about the importance of caring for and about patients (Chochinov, 2007). This is particularly important at the end of life--one last opportunity to honor and provide dignified care.

- **Attitude:** As healthcare professionals, it is important that we examine our own attitudes and assumptions toward patients. Think about these questions:
  - How would I be feeling if I were in this patient's situation?
  - Have I checked whether my assumptions are accurate?
  - Am I aware how my attitude towards the patient may be affecting him/her?
  - Actions: Make these questions a conscious part of your reflection on the care of each patient. Review these questions in case studies and clinical teaching; create a culture where acknowledgement and discussion of these types of issues become standard.

- **Behavior:** Professional behavior must always include respect and kindness to each patient. A lack of curative options should not justify a lack of ongoing patient contact. Actions:
  - Make sure the patient knows that he/she has your full attention
  - Provide privacy when patient wants to discuss personal issues
  - When speaking with patient, be seated and at eye-level
  - Repeat explanations prn

- Ask patient if they have further questions, reminding them that there will be further opportunities to respond as they arise.

- **Compassion:** A deep awareness of the suffering AND the wish to relieve it is vital. Compassion is felt, it is more than intellectual appreciation. Actions:
  - Know the personal stories that accompany illness
  - Provide an understanding look
  - Give a gentle touch on the shoulder, arm, hand
  - Acknowledge the person beyond their illness (either spoken or unspoken).

- **Dialogue:** Acknowledges that the person is more than the disease and recognizes the emotional impact that accompanies the disease. Actions:
  - Openly communicating with patients, "This must be frightening for you."
  - "I can only imagine what you must be going through."
  - "It is natural to feel overwhelmed at this time."
  - "What do I need to know about you so I can take the best care of you?"
  - "What are you the most concerned about today?"
  - "Who/what else will be affected by what is happening with your health?"
  - "Who should be here to support you?" (i.e. friends, family, spiritual/religious support groups, etc).
  - "Who else should we get to support you?" (i.e. psychosocial services, support groups, chaplaincy, etc) (Chochinov, 2007).

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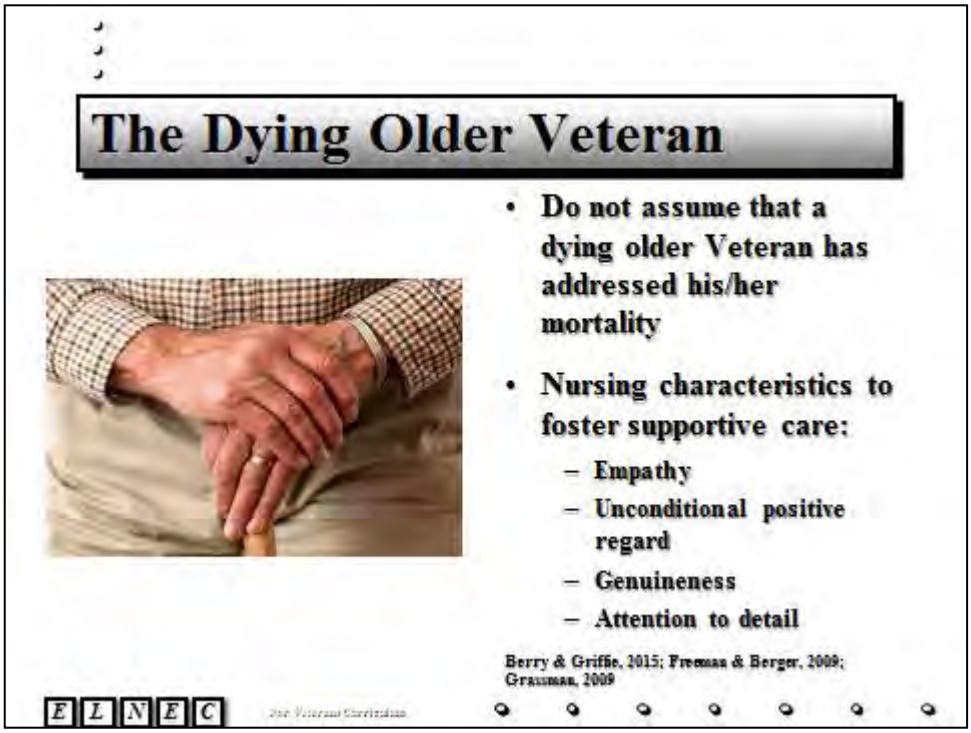

- Do not assume that the dying older adult has addressed his/her own mortality prior to their impending death.
  - Though many older adults may deny fearing death and state that they accept it as an inevitable part of life, they still have concerns about quality of life and effect that their illness has on their family (Freeman & Berger, 2009).
  - Combat Veterans' deaths may be further complicated by traumatic memories or paralyzing guilt, depending on the extent to which they were able to integrate and heal traumatic or guilt-inducing memories (Grassman, 2009). PTSD may trigger intrusion symptoms, avoidance behaviors, negative cognition, increased arousal and distress (Grassman, 2015).

- During the final hours, nurses may not know all of the circumstances and "unfinished business" of the Veteran. Thus, establishing and maintaining meaningful, helpful and therapeutic relationships are of utmost importance for both the Veteran and family members or significant other(s). Nursing characteristics to foster supportive care include (Berry & Griffie, 2015):
  - Empathy: putting aside your own personal bias and putting yourself in the other person's place
  - Unconditional positive regard: warm, nonjudgmental feeling towards others, nonjudgmental acceptance
  - Genuineness: convey trustworthiness and openness.
  - Attention to detail: think critically about patient care needs without making assumptions recognizing how his/her attitudes and actions are being interpreted by others.

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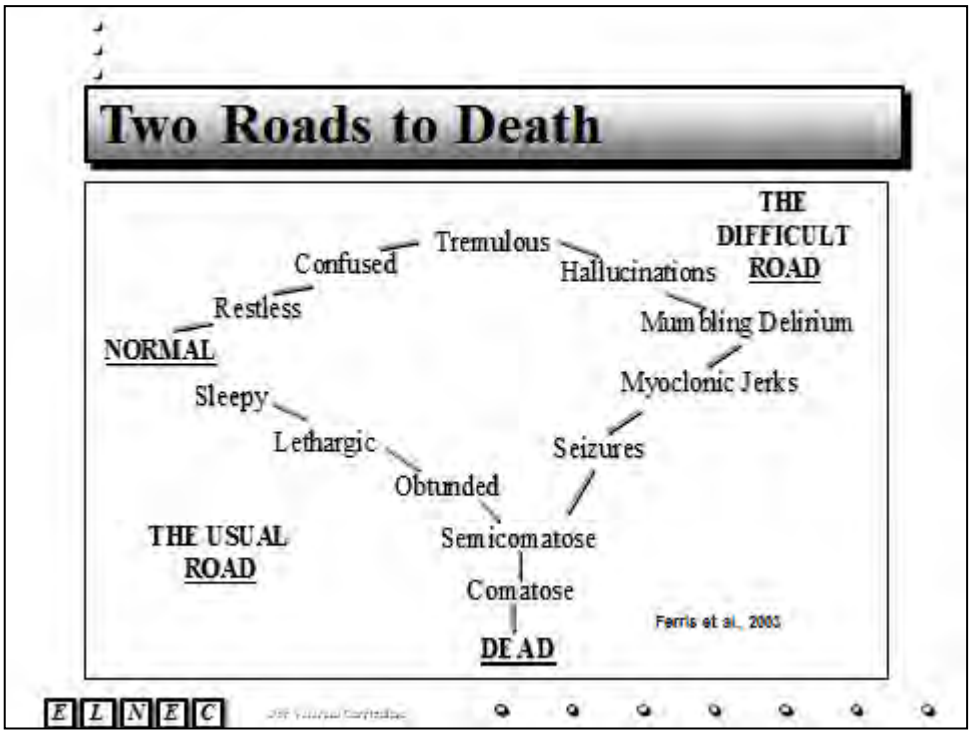

- It is vital that nurses know and understand the signs, symptoms, and nursing interventions for the imminently dying. This allows the nurse to communicate accurately to the interdisciplinary team, the Veteran, and family.

- Remember that :
  - No one can predict the exact time of death.
  - However, some patients seem to instinctively know when death will occur.
  - Prognosis is affected by the disease, patient's will to live, desire/choice to wait for special event (e.g. birthday, holiday, etc) and/or completion of life closure goals.

- Signs and symptoms of the dying process only serve as a guideline.

- Not all signs and symptoms necessarily occur in sequence.

- Assess for causes of symptoms other than the dying process.

- Most patients experience the dying process as a natural slowing down of physical and mental processes:
  - Usual road—sedation, lethargy and gradual obtundation leading to a comatose state and death.
  - For some, the road may be more difficult, including confusion and restlessness, delirium, myoclonus, seizures, and eventually, death (Ferris et al., 2003).

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- Psychological and emotional considerations are important for nurses to assess throughout the final hours (Berry & Griffe, 2015):
  - Fear of the dying process
  - Fear of abandonment
  - Fear of the unknown
  - Nearing death awareness
  - Withdrawal

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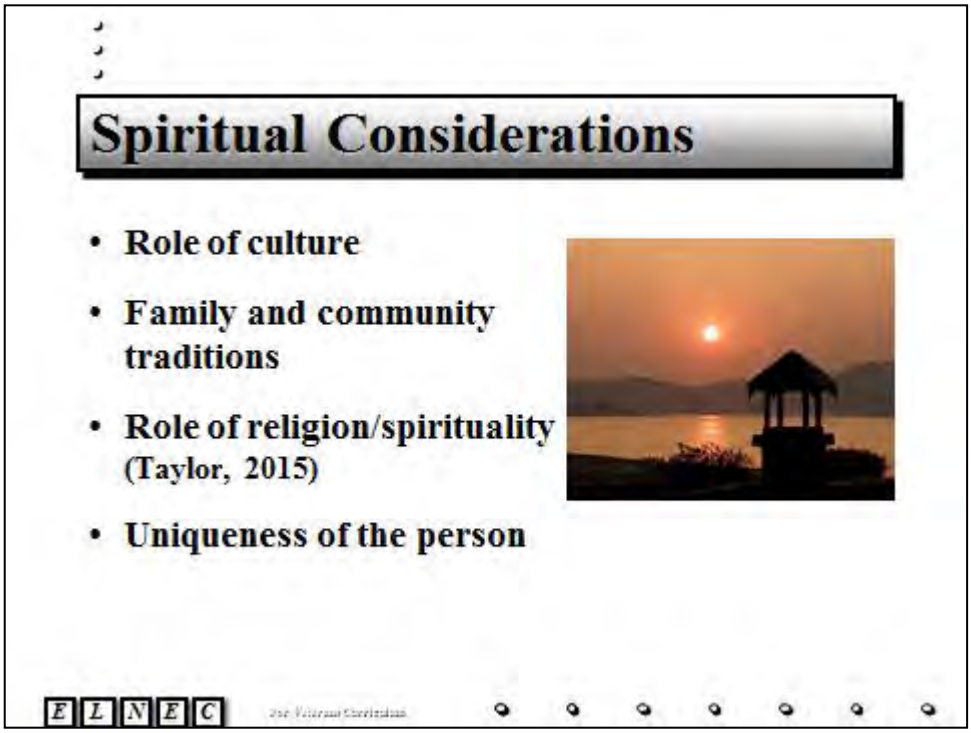

- Be aware of culture and family or community traditions as factors in promoting a "good death"

- What is the role of religion or spirituality for this patient/family? Do they have a spiritual advisor/leader? If so, who is it? Ask patient/family if they would like for you to contact him/her.
  - Encourage family members to bring in favorite hymns on CD, scriptures, symbols (e.g. rosary) so patient can experience these through different senses (hearing, seeing, touching) (Taylor, 2015).

- The key to effective integration of spirituality and healthcare is learning to listen.

- Know that each person is a culture of one—understand their "uniqueness."
  - As healthcare providers, know your own "uniqueness"—your own culture affects the way you receive messages from others.
  - Understand that each person has a unique set of spiritual beliefs or values (they see illness and death with different meanings).

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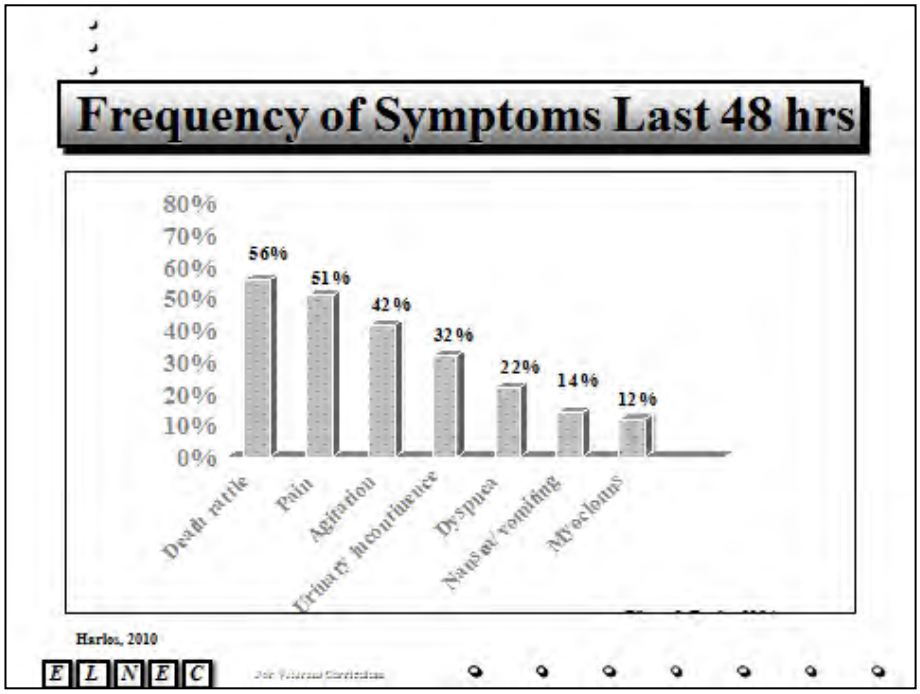

- Many symptoms are frequently seen in the last 48 hours of life. The symptoms listed in this graph occurred in at least 30% of 200 actively dying patients with the following frequency (Harlos, 2010):
  - Noise and moist breathing or death rattle (56%)
  - Pain (51%)
  - Restlessness and agitation (42%)
  - Urinary incontinence (32%)

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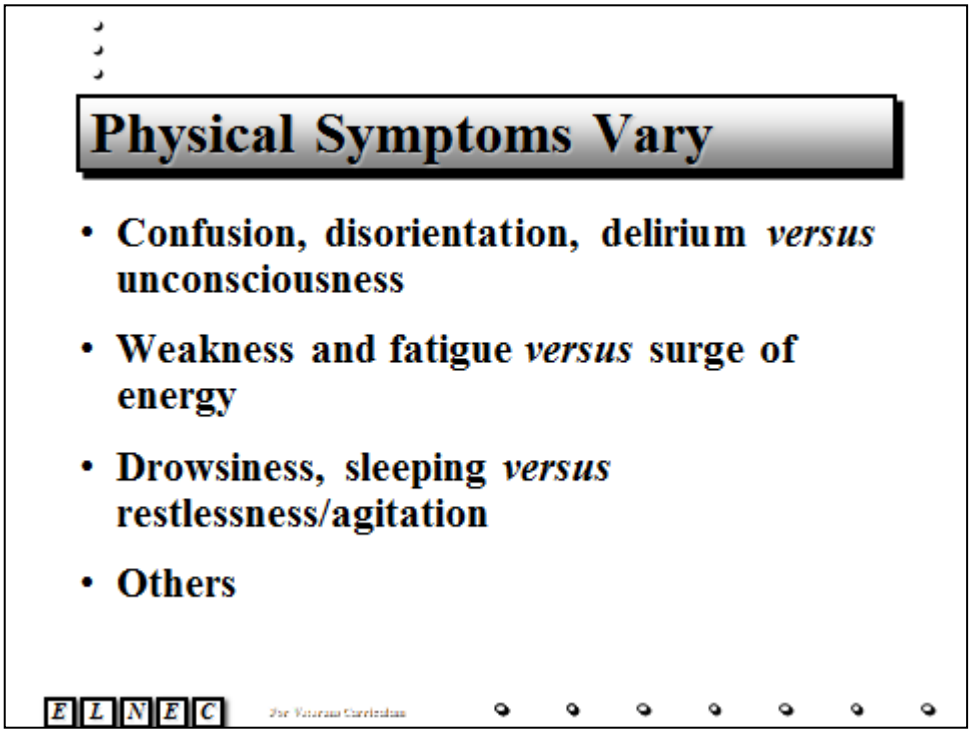

- Physical signs and symptoms associated with dying may occur months, weeks, days, or hours before death.
  - One patient may be confused, disoriented and delirious, while another patient may be unconscious.
  - One patient may state he/she is weak and fatigued, while another experiences a surge of energy.
  - One patient may be drowsy and sleeping most of the day and night, while another experiences restlessness and agitation.

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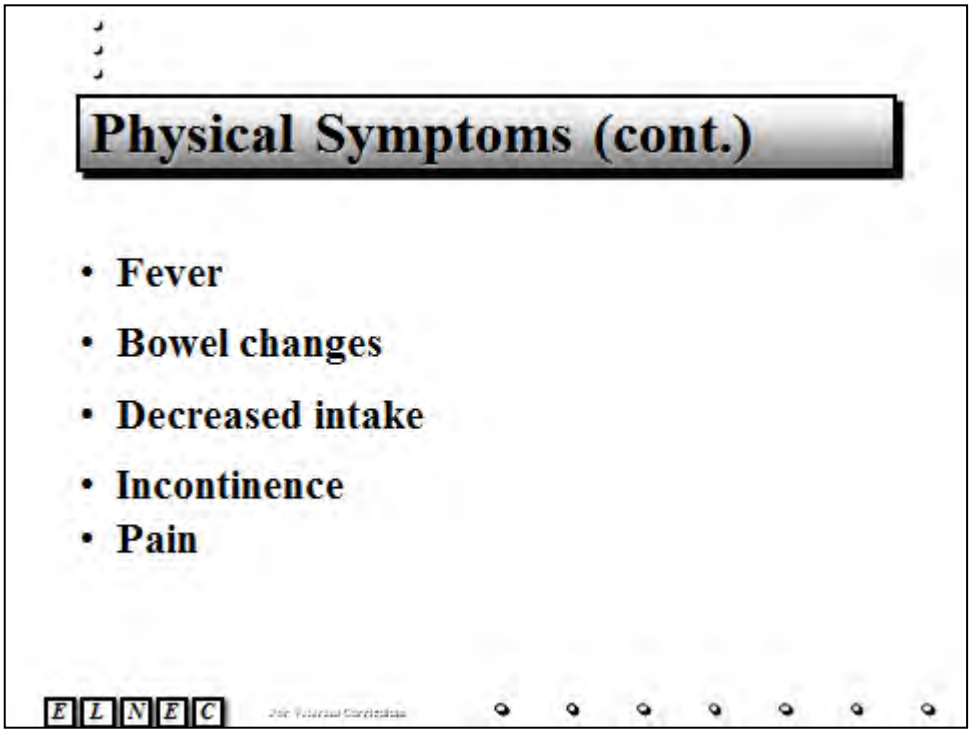

- Other physical considerations to assess as a patient nears the time of impending death include:
  - Fever: Fever may be due to an infection or dehydration—keep patient's goal of care in mind when treating or not treating fever.
  - Bowel changes:
    - As patients begin to have a lack of interest in food and water, bowel changes will occur.
    - If on opioids, continue to preventively treat constipation, though patient may be eating very little/nothing.
  - Decreased intake: Attributed to lack of desire to eat/drink, inability to swallow, mouth ulcers, etc.
  - Incontinence: Assess for this and keep patient dry in order to prevent skin breakdown.
  - Pain (refer to next slide):

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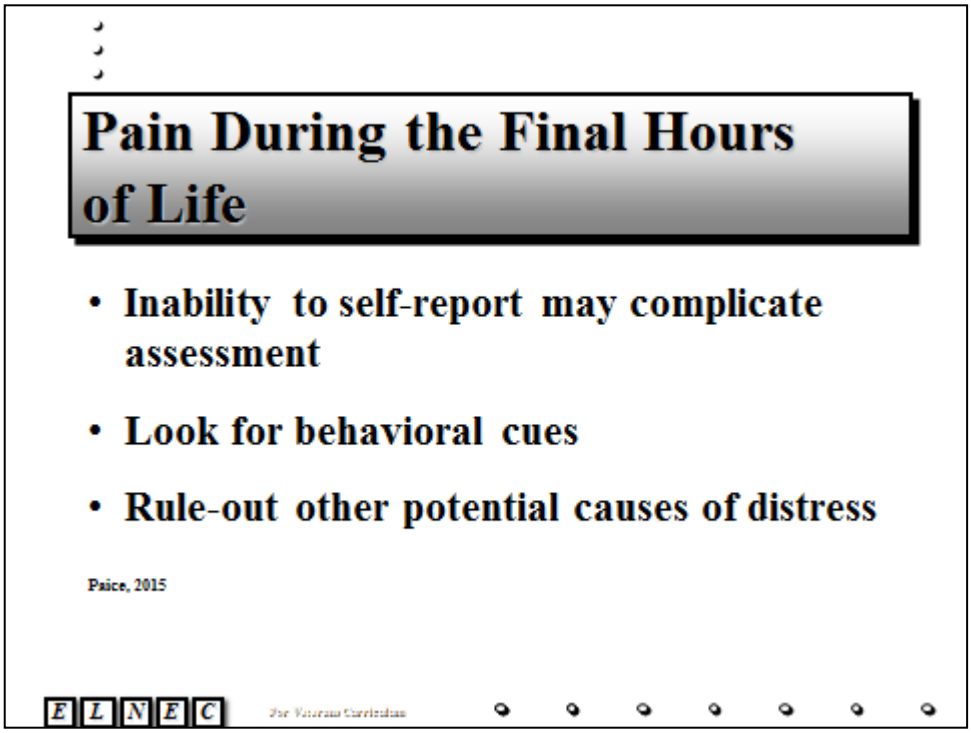

- Diminished consciousness may make pain assessment complicated.

- When unable to report pain, look for the following behavioral cues:
  - Furrowed brow,
  - Stiffened body posture.

- If the patient did not previously have pain, but now appears to be in pain, rule out other potential causes of distress such as:
  - Constipation
  - Delirium (Close & Long, 2012)
  - Damage to skin as a result of immobility (check bony prominences)
  - Mucositis (especially if patient is neutropenic).

Note: Refer to Module 2: Pain for further information.

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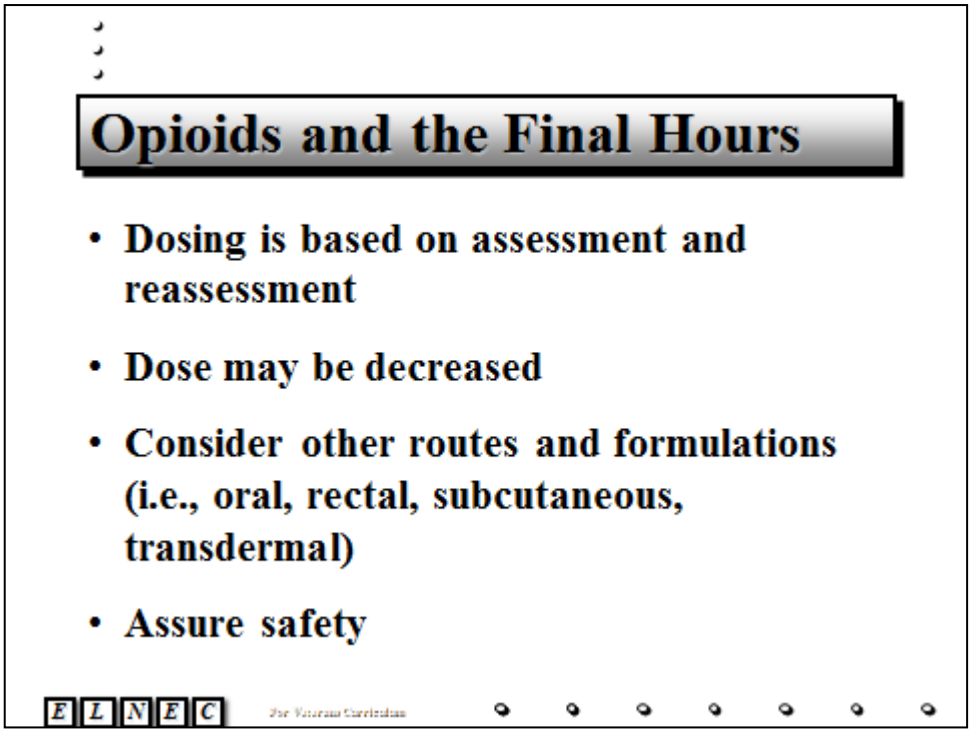

- As with all phases of pain treatment, the timing, route, and dose of opioids and other pain medications during the last hours of life should be based upon appropriate assessment and reassessment (Paice, 2015).

- There is a lack of evidence that opioid administration shortens patients' lives. According to the Hospice and Palliative Nurses Association position statement, *The ethics of opiate use within palliative care* (HPNA, 2013) "… there is no convincing scientific evidence that administering opioids using established guidelines, even in very high doses, accelerates death. Numerous clinical studies demonstrate no significant association among opioid use, respiratory depression, and shortened survival. Respiratory depression and other changes in breathing are part of the dying process and are more likely to result from disease and multi-system organ failure than from opioids." Moreover, "the administration of opioids to alleviate pain at the end of life is consistent with widely accepted ethical and legal principles". (HPNA, 2013).

Note: The dose of opioid needed to produce relief may be decreased during the final hours of life. This may be due to several factors, but decreased renal function is prominent. Renal function is altered due to decreased perfusion of the kidneys as well as the reduced volume of fluid as patients take in fewer liquids. The reduction in protein stores allows remaining fluid to enter peripheral tissues rather than remain in the vasculature. This changing renal status alters the clearance of opioids and other drugs, allowing more of the drug (and metabolites) to remain in the plasma for longer time

periods. Never abruptly discontinue an opioid (or benzodiazepine) as the patient can experience severe withdrawal, even if cognitively impaired or unresponsive.

The oral route for drug administration is possible even in the last hours of life. In one study, researchers reported that 60% of patients in hospice were able to swallow until a few hours before death, another 25% required a dose or two of opioid by suppository, and only 15% required injection (Harlos, 2010).

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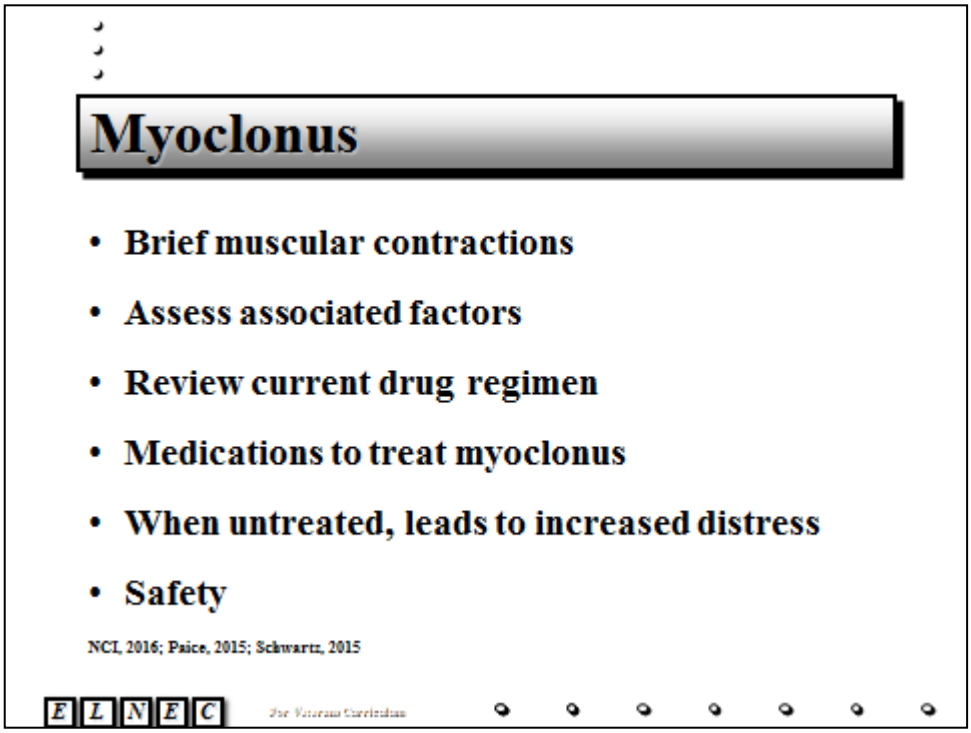

- Myoclonus is a series of brief muscular contractions that are irregular in amplitude of contraction and rhythm (Schwartz, 2015). It is less common than other EOL signs and symptoms, occurring in about 10% of patients, but it may be distressing to patients and families.

- Myoclonus or myoclonic jerking is associated with multiple factors, including:
  - High-dose opioids (i.e. morphine, meperidine)
  - Neuroleptics
  - Metoclopramide
  - Withdrawal from barbiturates, benzodiazepines, anticonvulsants, alcohol
  - Metabolite accumulation
  - Cerebral edema
  - Hypoxia
  - Multi-organ system failure (especially renal and hepatic)

- Review the current drug regimen to ascertain interactions and contributing factors. Opioids are the most common medications that are associated with myoclonus, (NCI, 2016) . If an opioid is suspected, consider opioid rotation (NCI, 2016).

- Evidence for the effectiveness of any specific pharmacologic agent for myoclonus is weak (Stone P., & Minton O., 2010; Stone et al, 2011) but most frequently includes benzodiazepines such as:
  - Clonazepam
  - Diazepam

- Lorazapam
- Midozolam

- Several other medications for myoclonus that have been described in the literature (mostly case reports) including gabapentin and other anticonvulsants, dantrolene, and haloperidol. (Stone & Minton, 2011) Some reports also support the use of hydration to manage myoclonus (NCI, 2016)

- Untreated myoclonus can lead to increased pain, fatigue and other distressing symptoms. Thus, treatment is essential (Pasero & McCaffery, 2011; Schwartz, 2015).

- Safety is of utmost concern. Ambulation may not be possible. At the end of life, assure the bed rails are padded. Assure that pain continues to be managed.

Note: For a patient with rapidly impending death, the healthcare provider may choose to treat the myoclonus rather than switching opioids in the final hours of life (NCI, 2016).

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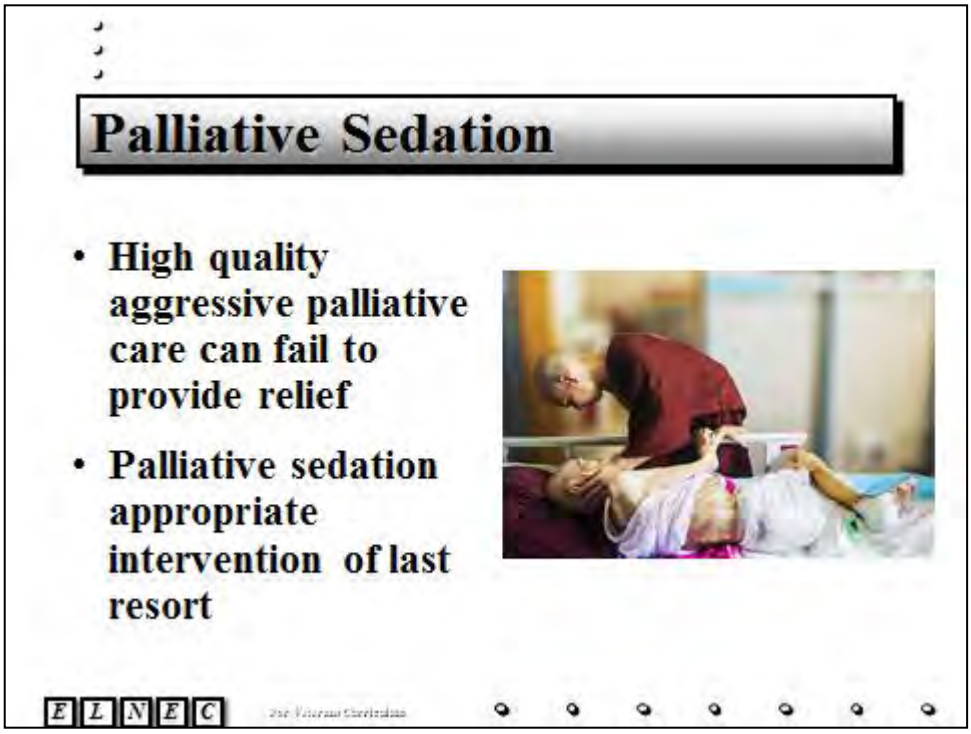

- The official statement from the National VA center for Ethics states that for purposes of this analysis, the National Ethics Committee defines palliative sedation as the administration of nonopioid drugs to sedate a terminally ill patient to unconsciousness as an intervention of last resort to treat severe, refractory pain or other clinical symptoms that have not been relieved by aggressive, symptom-specific palliation.
  - However, for some patients even high quality aggressive palliative care fails to provide relief. For patients suffering from severe pain, dyspnea, vomiting, or other intrusive symptoms that prove refractory to treatment, there is a consensus that palliative sedation is an appropriate intervention of last resort.

- According to the AAHPM consensus, Palliative sedation (PS), as defined in this statement, is the intentional lowering of awareness towards, and including, unconsciousness for patients with severe and refractory symptoms.

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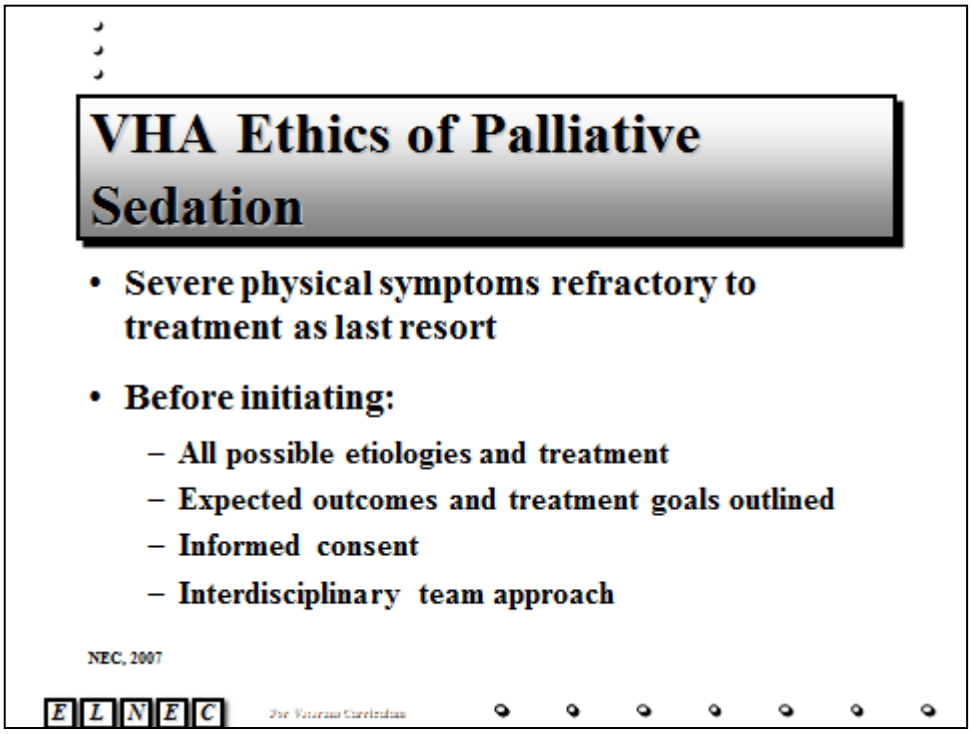

- For terminally ill Veterans suffering from severe symptoms, a National Ethics Committee report recommends that VA adopt policy that: (1) Permits the administration of palliative sedation (by definition, as a last resort) only: (a) when severe pain or other clinical symptoms (e.g., dyspnea, nausea and vomiting, agitated delirium) is/are not ameliorated by aggressive symptom-specific interventions that are tolerable to the patient; (b) for patients who have entered the final stages of the dying process and who have a DNR order; (c) with the signed informed consent of the patient, or surrogate if the patient lacks decision-making capacity, as required by VA policy for treatments or procedures involving general anesthesia.

Note: Additional reading on palliative sedation is available from the American Academy of Hospice and Palliative Medicine and the Hospice and Palliative Nurses Association (AAHPM, 2014; HPNA, 2016a)
For further information about the National Ethics Committee (NEC) Report on the Ethics of Palliative Sedation for Veterans (last retrieved February 25, 2016) at http://www.ethics.va.gov/docs/necrpts/NEC_Report_20060301_The_Ethics_of_Palliative_Sedation.pdf

Exercise - Stop and Consider:
In the past month, have you had a Veteran that underwent palliative sedation? If so, what were the circumstances that palliative sedation was necessitated?

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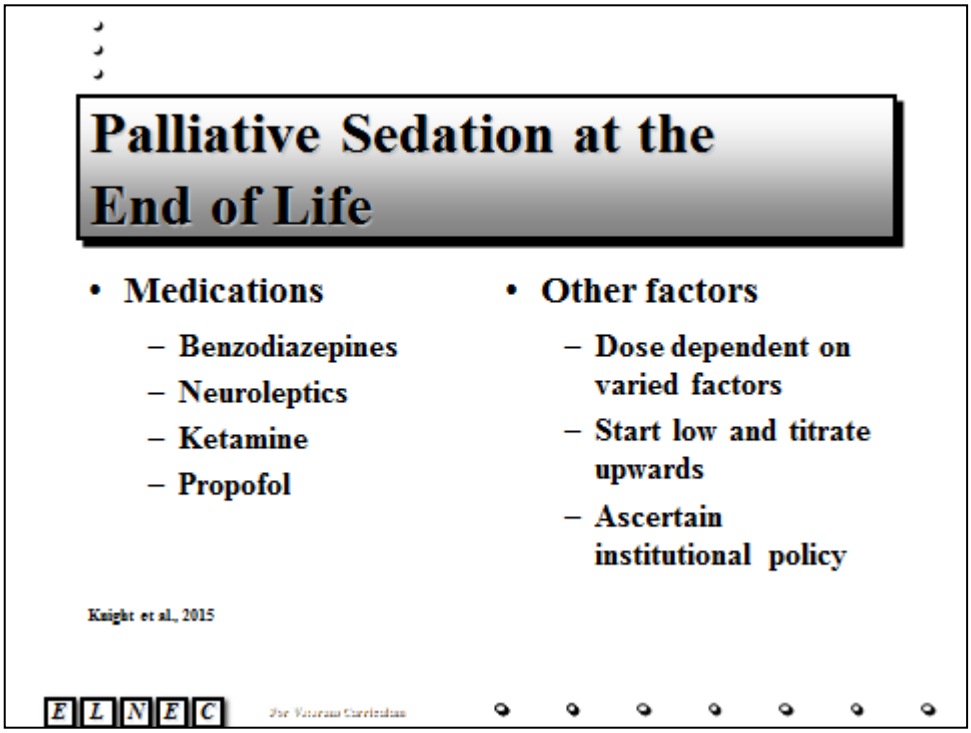

- Medications used for palliative sedation include:
  - ➢ Benzodiazepines, including lorazepam and midazolam may be used, either as an intravenous or a subcutaneous infusion.
  - ➢ Neuroleptics, such as haloperidol (monitor for extrapyramidal side effects) or chlorpromazine (more sedating than haloperidol), may be added to treat myoclonus and induce sedation. Haloperidol is used for delirium and can be combined with opioids and sedatives to manage acute agitation (Knight et al., 2015).
  - ➢ Ketamine, parenteral or oral, may be used for refractory pain at the end of life. It is effective for neuropathic pain. Adverse effects are hallucinations, dysphoria, nightmares and excess salivation with medications used to counteract these effects. Additional considerations such as decreasing long-acting opioid, may apply (Paice, 2015).
  - ➢ Propofol (Diprivan®), another anesthetic agent used during invasive procedures, can be given as an intravenous infusion with boluses as needed. It is useful as a sedative for ICU patients (Knight et al., 2015). Propofol is not an analgesic.

- In general, the medication is started as a low dose and titrated upward. Dose ranges are variable and dependent upon the patient's weight, renal and liver status, state of hydration, concurrent medication use, and other variables (Knight et al., 2015).

- The nurse should determine whether administration of these compounds is consistent with institutional policies and, if not, pursue modification or exemption for units where death is frequent (HPNA, 2016a). Emotional support of the family is imperative.

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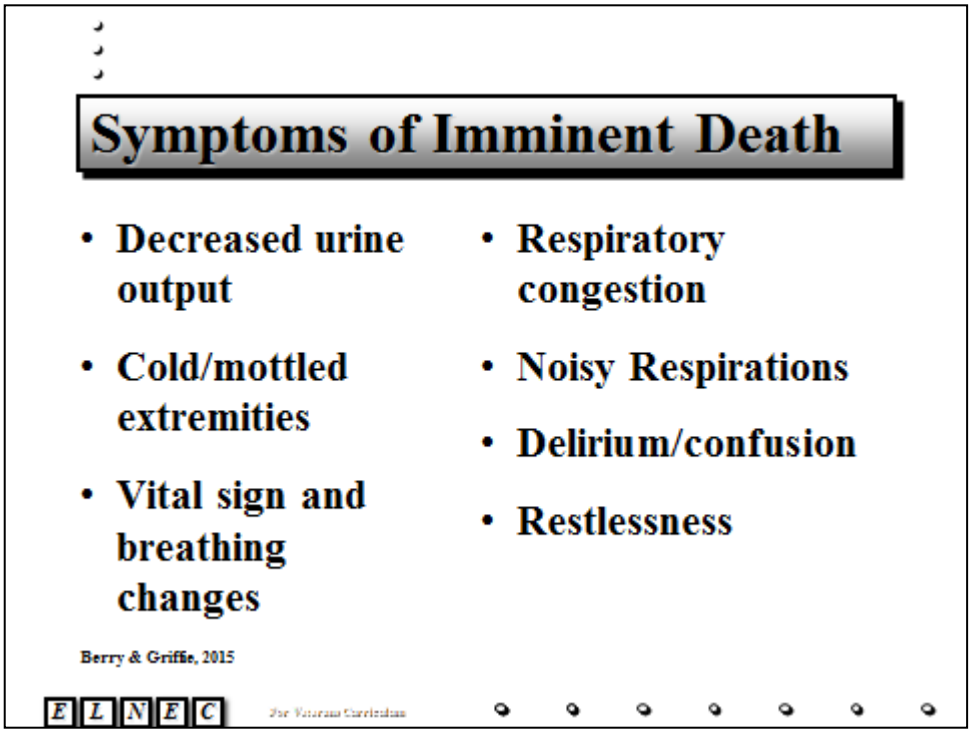

- Not all signs/symptoms of imminent death will occur with every person or in the following sequence (Berry & Griffie, 2015):
  - Decreased urine output
  - Cold and mottled extremities
  - Vital sign and breathing changes
  - Noisy breathing and respiratory congestion with rattling secretions is often called the "death rattle" (Wee & Hillier, 2010).
    - Educate family and caregivers that this is due to the patient being unable to clear throat
    - Elevate the head of the bed/change position
    - Avoid suctioning, as this is uncomfortable and decreases oxygen intake
  - Delirium/confusion or restlessness

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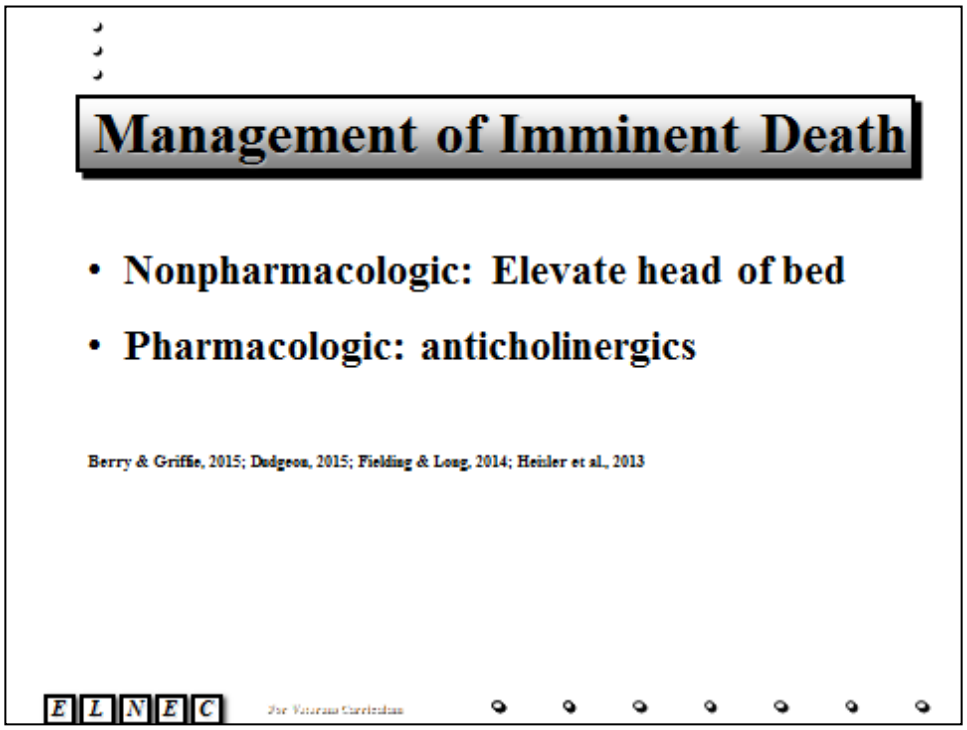

- Management of imminent death symptoms include (Berry & Griffie,2015):
  - Nonpharmacologic: Elevate head of bed to support the airway and breathing.
  - Treatment for terminal secretions:
    - Ascertain if the patient appears to be uncomfortable or if it may be the nursing staff or family members who become distressed with the sounds of noisy respirations. Consider all nonpharmacological interventions, education, and emotional support to team members and family prior to pharmacologic interventions (Fielding & Long, 2014; Heisler et al., 2013).
    - Consider anticholinergic drugs to dry secretions, if distressing for the patient, such as a scopolamine patch or infusion, atropine, or other agents: glycopyrrolate, oxybutynin, or hyoscine.
    - Reduce (to <500ml/24 hrs) or withhold parenteral fluids or enteral feeding, as the fluids may be contributing to the rattling secretions (Harlos, 2010).
  - As death becomes imminent, patients who have an implantable cardioverter defibrillator (ICD) may choose to have them deactivated/turned off. This will allow no interference from the device at the time of death. For those who have accepted their impending death, this provides them with peace of mind that as they are dying, the ICD will not activate (Berry & Griffie, 2015).

Note: for additional information see HPNA Position statement: Withholding and withdrawing life-sustaining therapies. Retrieved March 16, 2016 from http://hpna.advancingexpertcare.org/wp-content/uploads/2015/08/Withholding-and-or-Withdrawing-Life-Sustaining-Therapies.pdf and
Hospice and Palliative Nurses Association (2012). *Patient /family teaching sheet*. *Final days.* Retrieved December 26, 2015 from:
http://hpna.advancingexpertcare.org/education/patient-family-teaching-sheets

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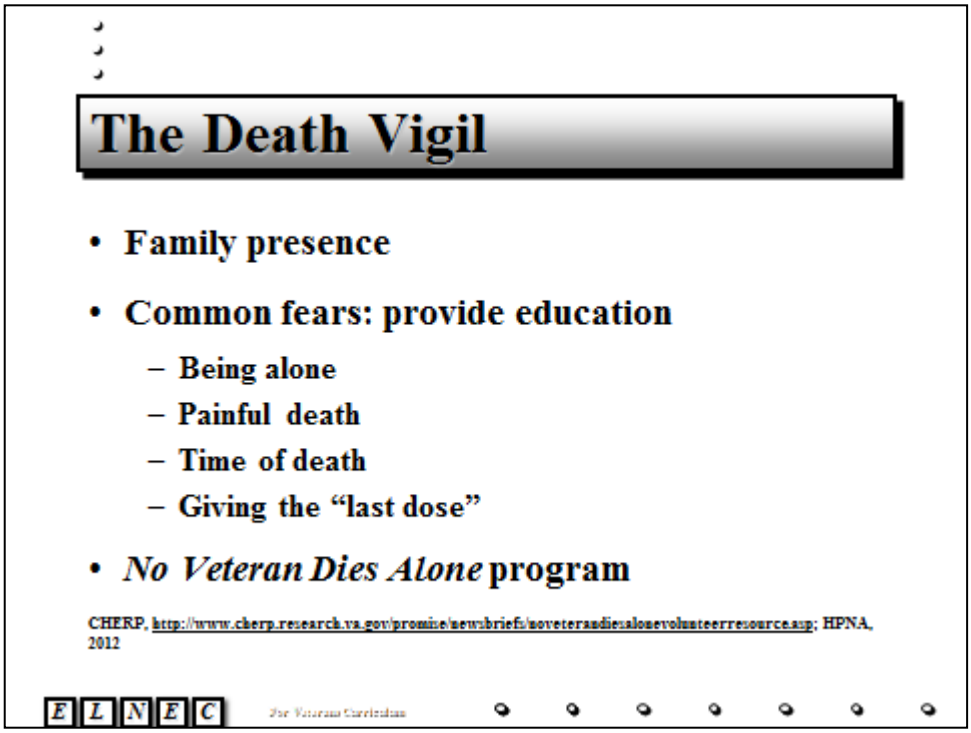

- The death vigil is difficult and may last for hours or days. Nurses play a key role in meeting the needs of both the dying Veteran and his/her family.

- Family will often want to be constantly at the bedside during the hours to days before death.
  - In some situations, however, they may be uncomfortable at the bedside due to fears or other personal reasons.
  - It is important to explore family preferences for a bedside vigil, address fears, and provide education and support for the family during a vigil (HPNA, 2012).

- Common fears:
  - Fear of being alone with the patient when he/she dies.
  - Fear that the patient will have a painful death and/or they will have to watch the patient suffer.
  - Fear that they will not know if the patient has died.
  - Fear of giving the "last dose" of pain medication and causing death.

- The *No Veteran Dies Alone* program is a volunteer effort in the VA, sponsored by a VA-wide team of hospice and palliative care employees who have created various resources, including a comprehensive tool kit, orientation guide and other materials for hospice volunteers. These tools and resources have been designed to support volunteers who provide presence, support and reassurance at the bedside when friends and family of the Veteran cannot be there at the end of life. For additional information see the Center Health Equity Research and Promotion (CHERP) at the

VA, retrieved April 19, 2016 from http://www.cherp.research.va.gov/promise/newsbriefs/noveterandiesalonevolunteerresource.asp.
No Veteran Dies Alone training manual can be downloaded from https://www.wehonorveterans.org/sites/default/files/public/No_Veteran_Dies_Alone.pdf.

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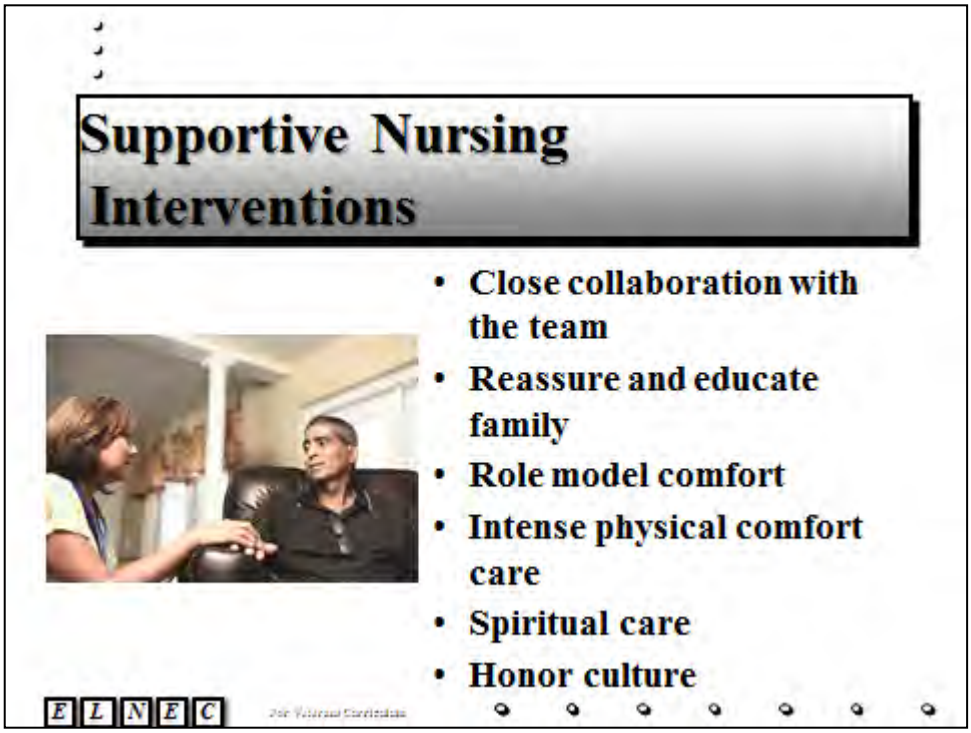

"Personhood can be maintained in a palliative care program that aims to satisfy the primary self, social self, and inner self with meaningful connections" (Long, 2009).

- To calm family fears, the nurse should increase support and care to the patient and family by:
  - Close collaboration with the physician and increasing the presence of all disciplines including social workers, nurse's aides, volunteers, and pastoral care. Seek increased presence from family members, friends, and church groups.
  - Reassure the family that the patient will be kept as comfortable as possible. Educate the family on the signs and symptoms of the dying process, signs and symptoms of death, what they should do if they suspect the patient has died and to call the nurse for any questions or concerns they may have at any time.
  - Role modeling comfort care is an effective way to educate family members about care needs.
  - Intense physical comfort care including mouth care, turning and positioning, pain and symptom management.
  - Provide spiritual care.
  - Honor culture.

Exercise - Stop and Consider:

- What do you and your staff do to assist Veterans and their families during the "death vigil?"

- How do you orchestrate not only physical care, but also psychological, social, and spiritual care during this difficult time?
- What are areas that you and your institution do well during this time?
- What are areas that could be improved?

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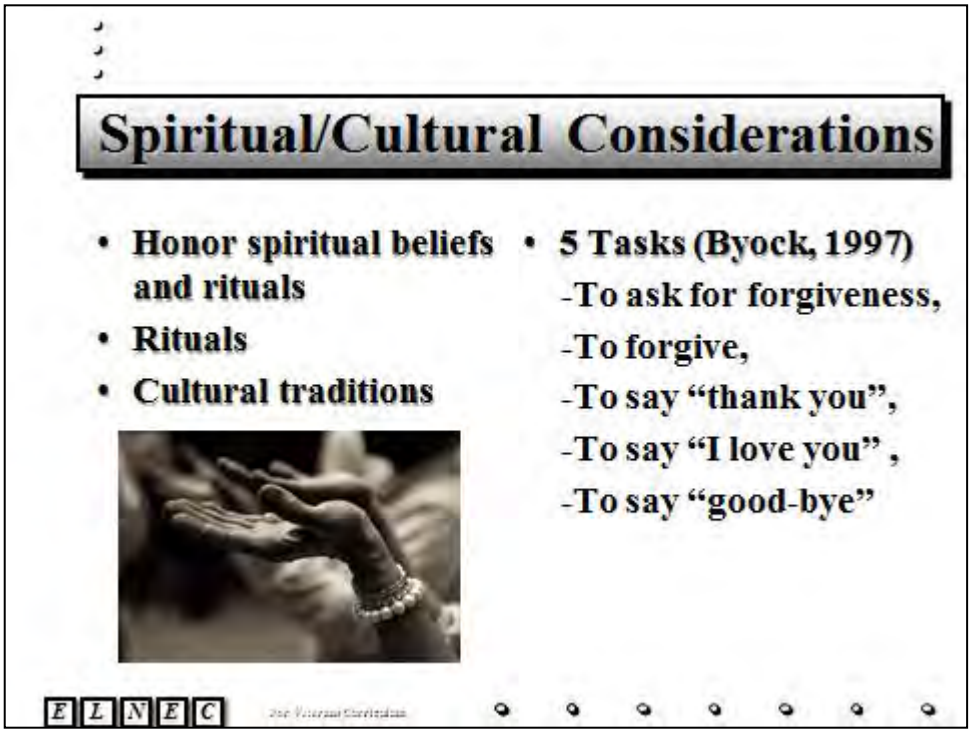

- Remember to honor spiritual beliefs and rituals.

- Provide intensive spiritual comfort through presence, prayer, rites, and rituals.

- Honor cultural beliefs, traditions, rites, and rituals (i.e., Military has its own burial traditions and rites).

- Consider coaching families about the five "tasks" that may serve as parting words (Byock, 1997):
  - To ask for forgiveness,
  - To forgive,
  - To say "thank you",
  - To say "I love you" ,
  - To say "good-bye"

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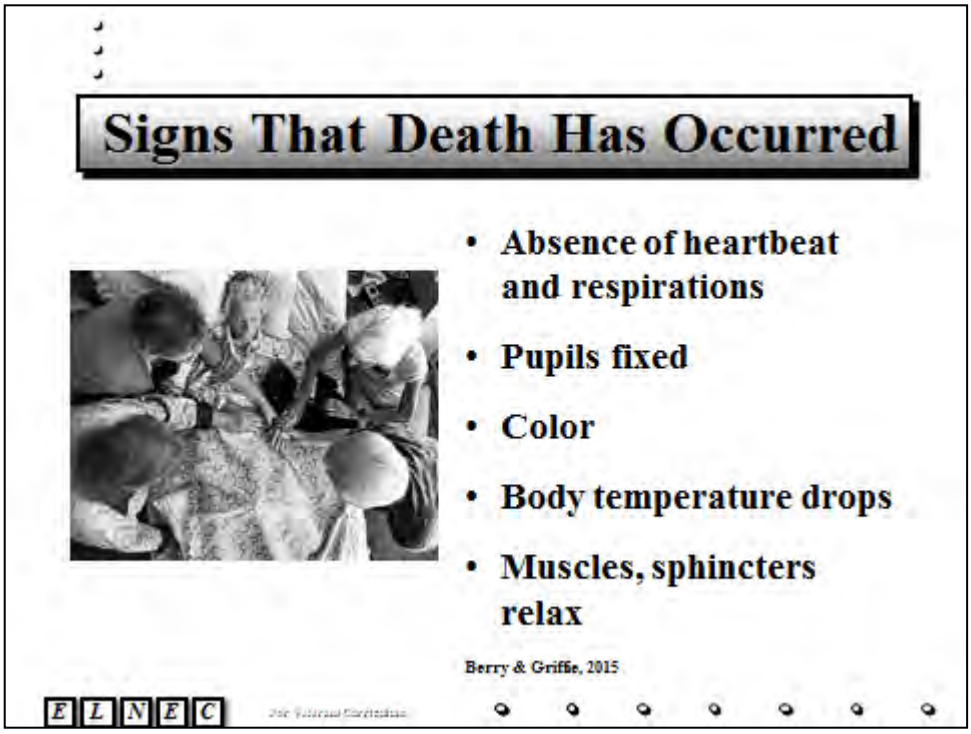

- There are many different signs and symptoms that death has occurred (Berry & Griffie, 2015):
  - Absence of heart beat, respirations
  - Pupils fixed
  - Change in skin color (pale, waxen as blood settles)
  - Body temperature drops
  - Muscles, sphincters relax (release of stool and urine, eyes may remain open, jaw may fall open)

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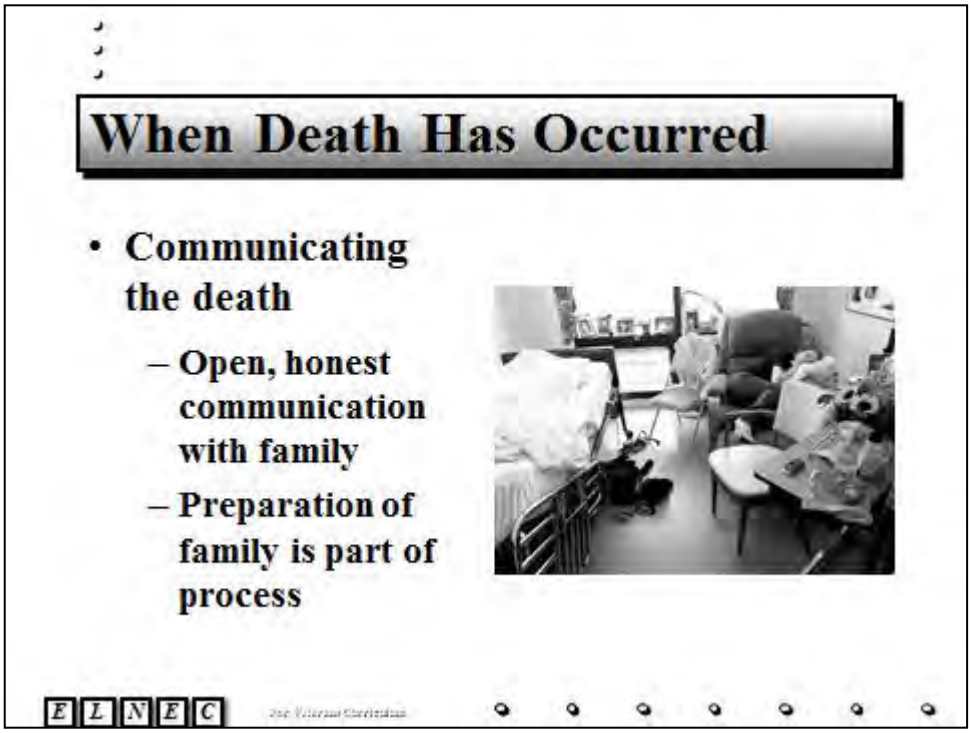

- Telling the family that their loved one has died should be done with sensitivity.
  - Be open, honest in communication, and provide small amounts of information at a time, at the family's level of understanding.
  - The news of the death may be easier if the family was prepared in advance and experienced anticipatory grief (Refer to Module 7 – Loss, Grief, Bereavement for additional information).
  - Information about the death may need to be repeated due to the family feeling overwhelmed or shocked by the actual death.

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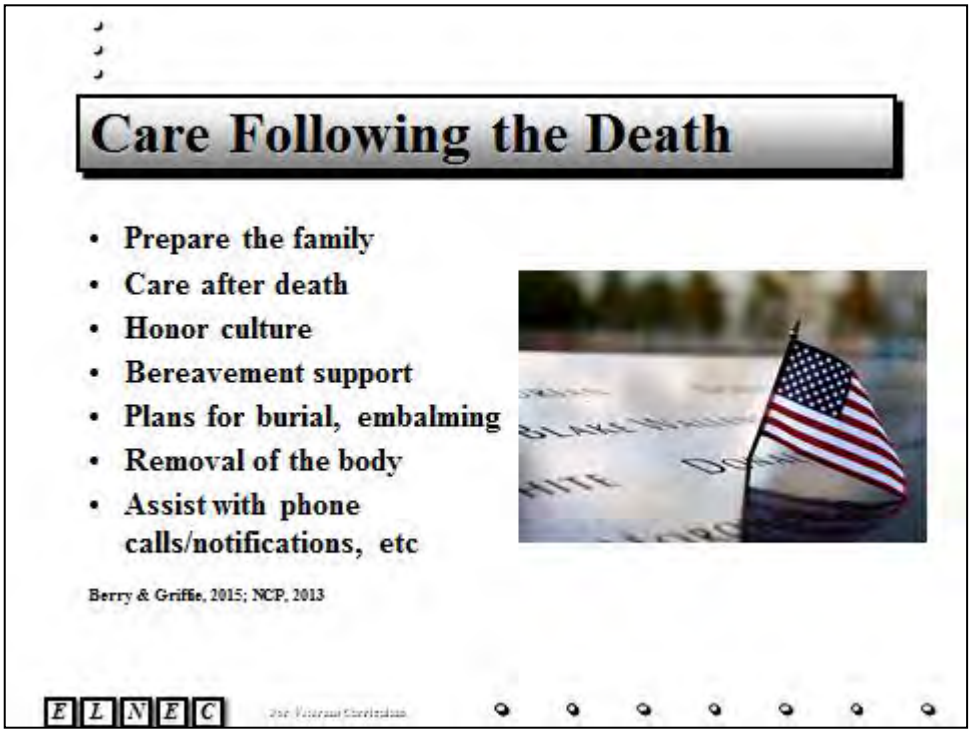

- Once a death has occurred, a postdeath bereavement plan is activated. A member of the interdisciplinary team should be assigned to the family during the postdeath period to assist with religious practices, funeral arrangements, and burial planning (NCP, 2013).

- Care following the death takes time and sensitivity in regards to not only the deceased, but also the family members (Berry & Griffie, 2015; NCP 2013).
  - Prepare the family: Following the death and pronouncement, family members may feel numb and confused about what to do next. In a quiet and private place, the nurse should explain the process/procedures for care of the body immediately following the death.
  - Care after death:
    - Following the death in any setting, medical supplies, equipment, tubes such as catheters, IVs, etc. should be removed from the room immediately. (Note: An exception would be instances where such tubes would need to be left in place until a medical examiner/coroner approves removal of such devices or appliance). The goal is to provide a more personal closure experience for the family, leaving the family with memories of the deceased as a loved one rather than as a patient.
    - Bathing, dressing and positioning body shows respect and provides dignity for the Veteran and family. (Note: For some families who have chosen cremation and/or no funeral/memorial services, this may be the last time they can physically touch/be with the deceased). Place dressings on leaking wounds, diaper as needed for incontinence. Position the body in proper alignment,

place dentures in mouth. Ask the family if they would like to assist with bathing/dressing. Ask the family if they have preferences in clothing for the deceased and/or preferences in care of the body.

- ♦ Autopsy is a part of Veteran's benefit package (no charge); so someone needs to discuss this at some point.

- ➢ Remember to honor culture: Some culture practices dictate the care of the body after death, and who should provide that care. Assess, honor and advocate for cultural practices.
- ➢ Initiate bereavement support (follow your institutions' policy).
- ➢ Time with the body, removal of the body, and attending to family needs are further opportunities for nurses to care for grieving families.
- ➢ Discuss with the family about plans for burial/embalming. Provide as much time as needed for the family to say goodbye and let go. Rigor mortis occurs 2 to 6 hours after death. Be aware that, if the body is turned at this time, air may escape lungs and those present may hear a sighing sound similar to breathing. Alert the family to this possibility. If the family has planned for burial, embalming is best done within 12 hours of death. For information about burial in a VA National Cemetery, go to: http://www.cem.va.gov/index.asp (last retrieved February 26, 2016)
- ➢ Removal of body: The nurse should be aware of cultural considerations. Many VAMCs have ceremonies when bodies of Veterans are removed from the hospital, using flags/flag quilts to transport the body to the morgue or funeral home. In some cultures, time with the body may need to be extended beyond a few hours to days. The body should not be removed until the family is ready, and viewing along with closure needs met. During the physical removal, treat the body with dignity and respect, covering exposed body parts. Covering or uncovering the face during removal should be based on family choice. Physical removal may be dictated by cultural considerations. In most settings, the funeral home will require a time of death, social security number, diagnosis, physician, and survivor contact.
- ➢ Assistance with phone calls and notifications: Assist with notifying family members, physician(s), co-workers, or other involved health care agencies, as needed.

Exercise - Stop and Consider:

Does your hospital have a protocol for honoring a Veteran after death? If so, share with the group. Examples of what other VAMC's do to honor a Veteran after he/she dies includes:

- ➢ Escorting the body to the morgue, with an American flag draped over the body.
- ➢ Placing an American flag on the bed of a Veteran who died (for up to 2 hours after the death). This provides an opportunity for staff and other hospitalized Veterans to come into the room and remember their fellow Veteran.
- ➢ Some VAMC's may play "Taps" over the speaker-system of the VAMC after a Veteran has died.

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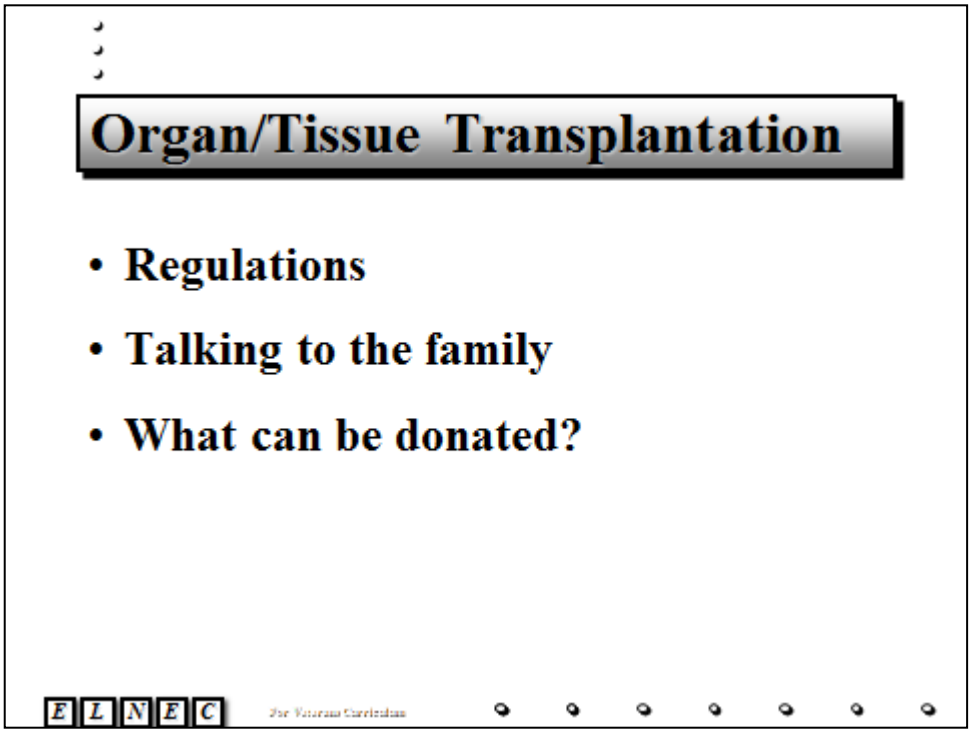

- If the patient is an organ donor, follow procedures as planned and in accordance with the state, setting guidelines, policies and/or procedures.
- Regulations: Federal law (Public Law 99-509; Section 9318) and Medicare regulations mandate that hospitals give surviving family members the chance to authorize donation of their family member's organs and tissues (IOM, 2006; Organdonor.gov, n.d.). Staff working in hospital settings must notify their state Organ Procurement Organization (OPO) when decisions about ventilator withdrawal are being considered (Campbell & Gorman, 2015).
- Talk to the family about organ/tissue transplantation (Caplan, 2008). Healthcare providers should be specifically trained for having these conversations):
  - Most families are receptive to the requests for donation.
  - Many feel consolation in helping others, despite their own loss.
- Common questions from potential donor's family:
  - Do we have to pay for the cost of organ donation? No. The donor's family neither pays for, nor receives payment for organ and tissue donation. The transplant recipient's health insurance policy, Medicare, or Medicaid usually covers the cost of transplant.
  - Will organ donation disfigure my loved one's body? No. Donation does not change the appearance of the body. Organs are removed surgically in a routine operation. It does not interfere with having a funeral, including open casket services.

- Can only hearts be donated? No. Organs and tissues that can be donated include: Corneas, the middle ear, skin, heart valves, bone, veins, cartilage, tendons, and ligaments can be stored in tissue banks and used to restore sight, cover burns, repair hearts, replace veins, and mend damaged connective tissue and cartilage in recipients.

Note: For more information, go to the U.S. Department of Health and Human Services "Organdonor.gov" website retrieved March 16, 2016 from http://www.organdonor.gov

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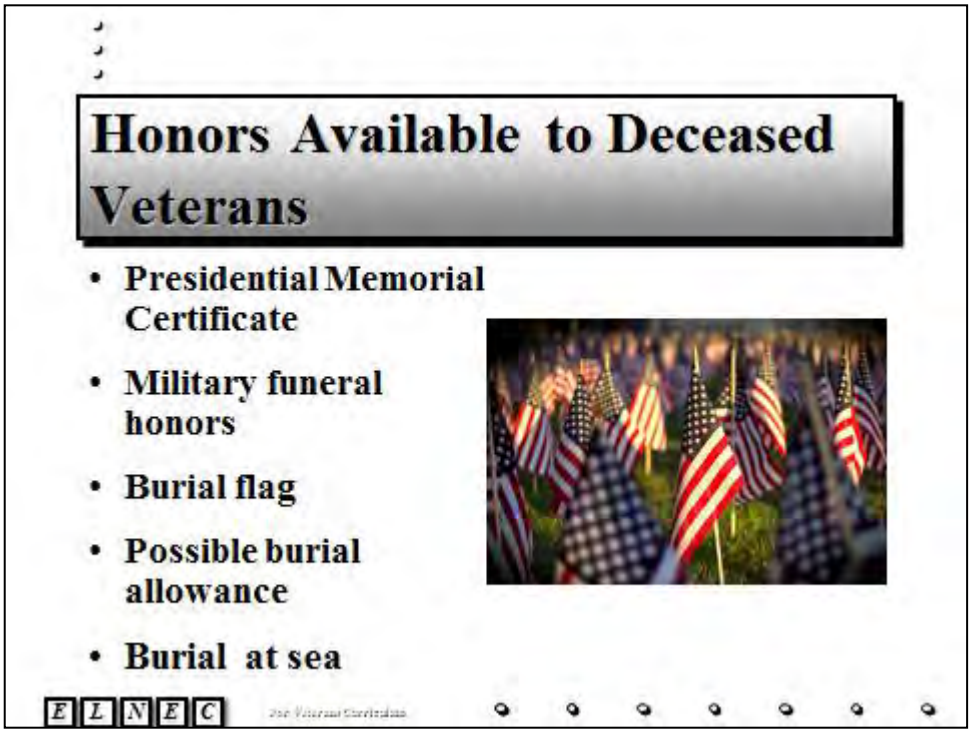

Remember that……

- A Presidential Memorial Certificate (PMC) may be given to family members of a deceased Veteran. PMC is an engraved paper certificate, signed by the current President, to honor the memory of honorably discharged deceased Veterans. For more information, go to: http://www.cem.va.gov/pmc.asp (last retrieved February 25, 2016) and to obtain the application http://www.va.gov/vaforms/va/pdf/VA40-0247.pdf (last retrieved February 25, 2016)

- Military funeral honors are available. The Department of Defense (DOD) is responsible for providing military funeral honors. "Honoring Those Who Served" is the title of the DOD program for providing dignified military funeral honors to Veterans who have defended our nation. For more information, go to: http://www.cem.va.gov/military_funeral_honors.asp (last retrieved March 8, 2016).

- Burial flags are provided, at no cost, to drape the casket or accompany the urn of a deceased Veteran who served honorably in the U. S. Armed Forces. It is furnished to honor the memory of a Veteran's military service to his or her country. For more information, go to: http://www.cem.va.gov/burial_benefits/burial_flags.asp (last retrieved February March 8, 2016).

- Burial allowance benefits may be available in certain circumstances from the Veterans Benefits Administration. For more information, go to: http://www.cem.va.gov/bbene/benvba.asp (last retrieved February 25, 2016).

- The US Navy offers a sea burial program free of charge for members of the uniformed services, retirees/Veterans who were honorably discharged from any branch of service, dependant family members of active duty personnel, retirees, and uniformed service Veterans. Both cremated and non-cremated remains can be buried at sea by the Navy. Family members are not allowed to attend service. For more information go to: http://www.seaservices.com/veterans.htm (last retrieved February 26, 2016).

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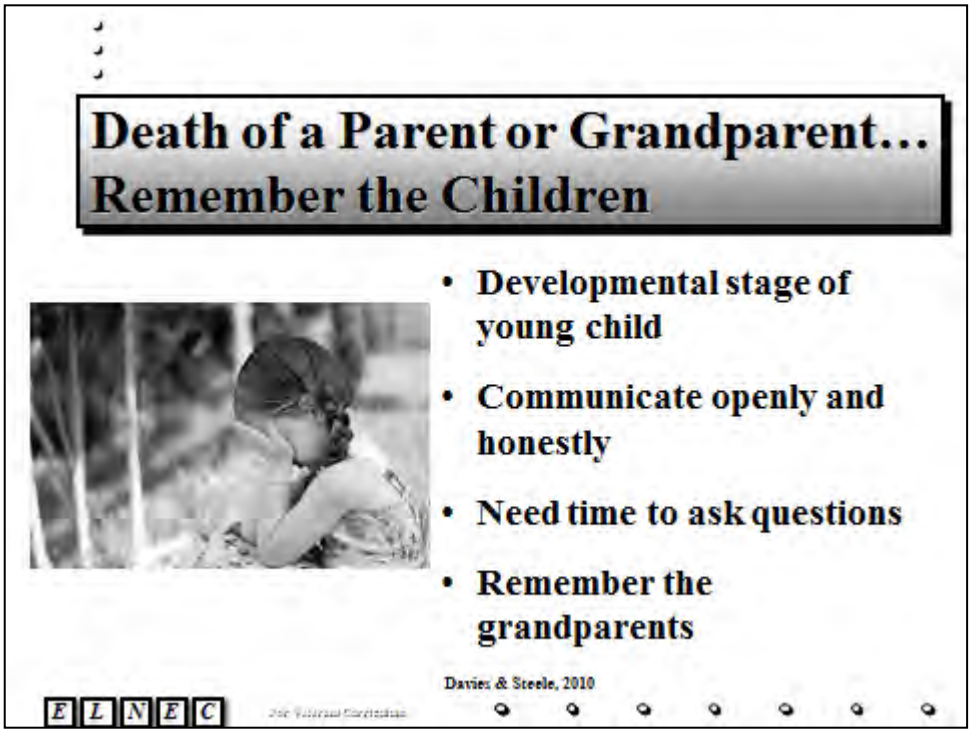

- The death of a parent or grandparent can be traumatizing for a child, no matter their age. Members of the interdisciplinary team must be cognizant of the needs of young children upon the death of one of their parents or grandparents (Steele & Davies, 2015).

- Conversation should be geared to the developmental stage of the child and should be communicated with openness and honesty.

- Give time for information to be processed by a child and give opportunities for the child to ask questions. The answers should be in terms that the child can comprehend. Note: The more a child, young or old, has been involved in the care during the terminal phase of their parents' or grandparents' life and in the activities that follow the death, the better able the child will be to cope with the bereavement.

- Adult children may grieve the loss of the physical and emotional strength that their parent always was to them. Adult children usually have many other roles (i.e. working full-time, caring for their own children, maintaining chores around the house, etc) and may feel guilty for not being able to spend enough time with their ill parent.

- Remember grandparents when an adult child is dying. They experience double grief, as they watch their grandchildren suffer the loss of a parent, and then as they (the parents of the deceased) experience the grief of losing a child of their own.

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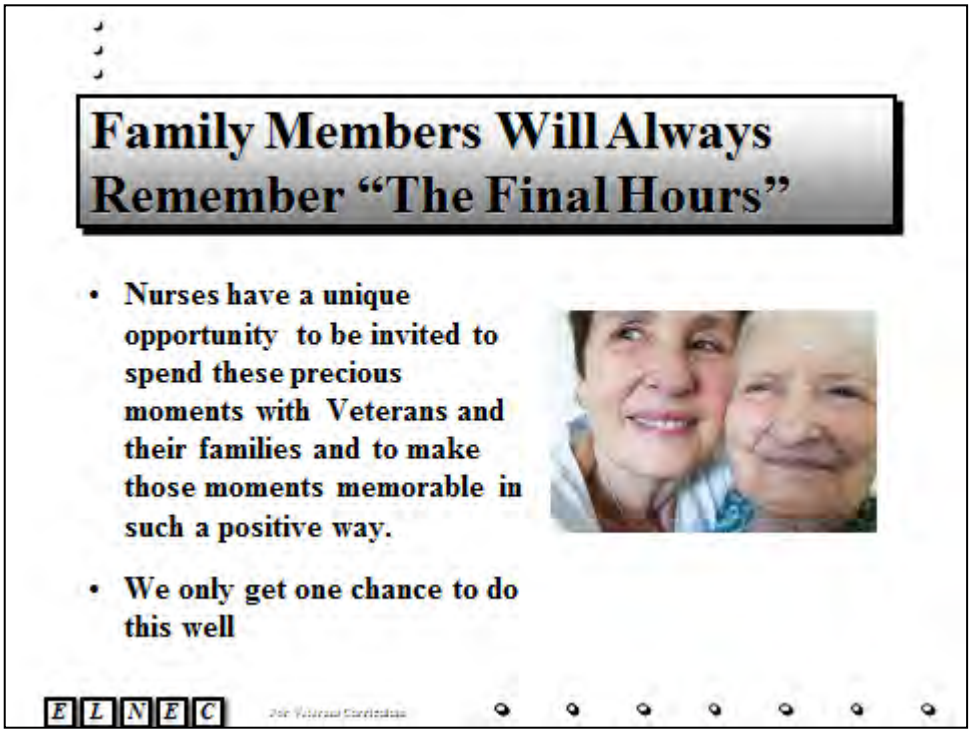

- Nurses have a unique opportunity to be invited to witness the last moments of a Veteran's life. They have the privilege to "be present", and to prevent suffering by assessing and managing symptoms. Nurses communicate with other members of the healthcare team and orchestrate care that is needed. We only get one chance to do this well. Family members who witnessed the death of their loved one will remember those last moments the rest of their lives.

- A post-death bereavement plan should always be initiated. An interdisciplinary team member should be assigned to the family in the post-death period to assist with religious practices, funeral arrangements, and burial planning (NCP, 2013).

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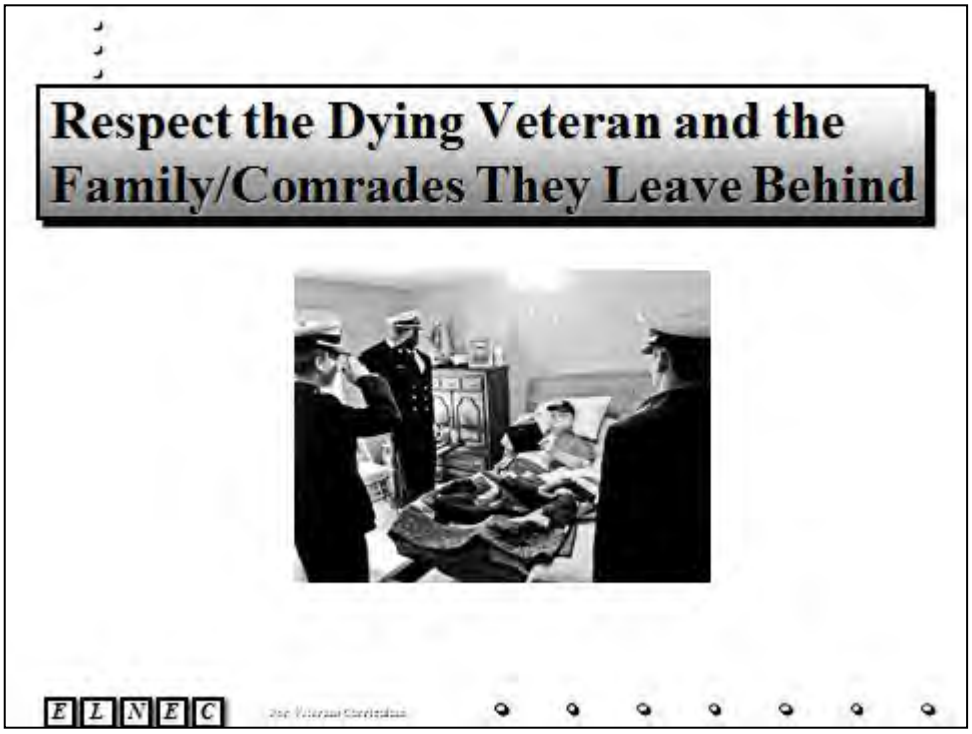

- Providing compassionate, dignified care to Veterans is a way to say "thank-you" for their dedicated military service.

- Nurses have a unique role of being with Veterans in the last moments of their lives. They have the opportunity to assist the family in witnessing a "good" death. Families will always remember those last moments.

- Nurses (Dahlin, 2015):
  - Provide excellent physical assessment skills
  - Manage those physical symptoms
  - Tend to the psychological, emotional, social and spiritual needs
  - Honor the family's culture
  - Prepare them for the death
  - Communicate with other interdisciplinary team members as needed
  - Listen
  - Provide a presence
  - "Bear witness"

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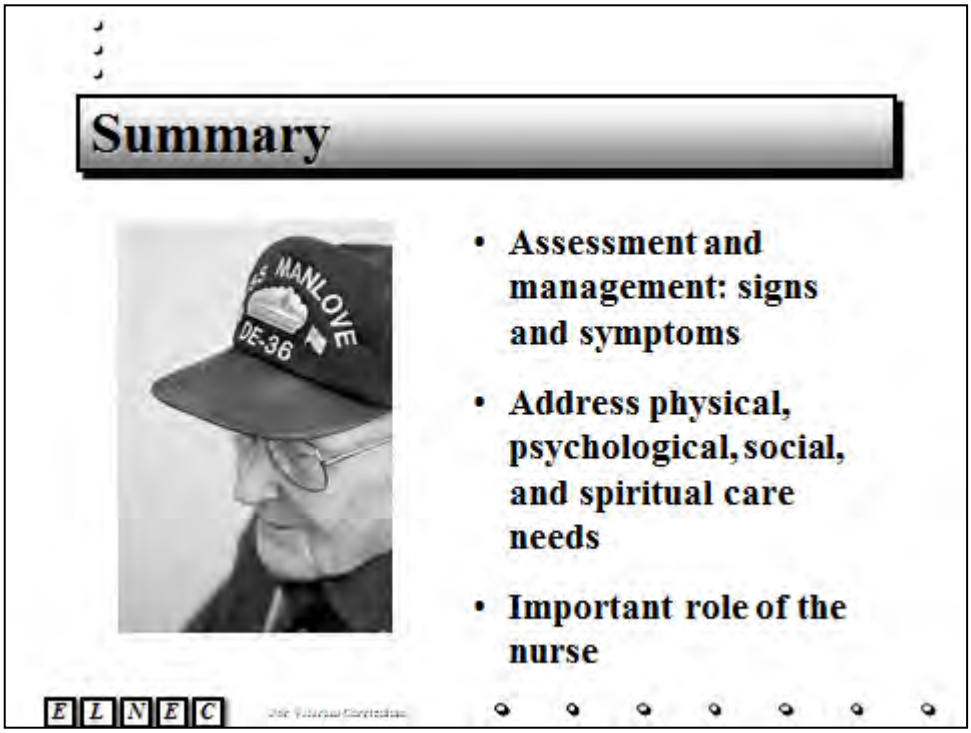

At the beginning of this ELNEC training program, in Module 1, you were reminded of the quote that is at the entrance to the Department of Veterans Affairs office in Washington, DC—"…*to care for him who shall have borne the battle and for his widow, and his orphan*." This quote was taken from the 2nd inaugural address of President Abraham Lincoln, March 4, 1865. He himself, being in the shadow of his own death, spoke these words so that for generations to come, Americans would remember and be committed to compassionately care for those who so bravely gave of themselves to preserve the freedoms that we all hold today.

Due to torrential rains in the previous days, thousands of spectators stood in mud and flood waters at the US Capitol to hear President Lincoln give his 2nd inaugural address. Though there were many barriers to getting there, people came to witness the inauguration, because they knew it was important and that their country was at a cross-road. Now, more than 150 years later, Americans are at a different cross-road…they have the opportunity to seek compassionate and dignified palliative care—care that reflects and honors life to the very end. This is important. Veterans and their families need to be aware of this specialized care. As is expected, there is always much well-deserved celebration when a new life comes into this world. Yet, so often, people leave this world with great anguish, pain, and suffering. Life should end peacefully, with great care to orchestrate a celebration of life. Instead of fighting a battle of pain and suffering, Veterans should spend their last days reminiscing, saying "I love you," and addressing spiritual needs. Many do, but we still have a long road ahead to improve end-of-life care in this country.

What a wonderful time to be a nurse! We have medications, technology, and treatments that can treat pain, alleviate suffering, and decrease life-threatening symptoms. Nurses have been educated to communicate well, to listen, to be present, and to bear witness—we must do this! Despite nursing shortages, financial concerns, and lack of dedicated on-the-job educational time, nurses must rise to the occasion. Palliative care is what nurses do best. It's about the caring, the empathy, and the advocating. Nurses have a unique opportunity to work with Veterans and their families during their most vulnerable time. Though many of you will return to your institution and "stand in mud and flood waters," and attempt to overcome many barriers, the attention must be on the Veteran—that is who we support and advocate for. So, now it is your turn, along with your interdisciplinary colleagues, to take up the fight and to provide exemplary care to every Veteran in this country. Everyday, you have the opportunity to carry out this mission of "caring for him who has borne the battle…." This is OUR privilege and honor!