

# **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 with updates undertaken by Carma Erickson-Hurt, DNP, LCDR, USN, RET. Curriculum development and national ELNEC-For Veterans train-the-trainer courses were generously funded by the US Department of Veterans Affairs (original courses and ongoing updates spanning 2009-2023).

Slide 1



## **ELNEC- For Veterans**

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**End-of-Life Nursing Education Consortium**

**Palliative Care For Veterans**

# **Module 7: Final Hours**

*“Life is pleasant. Death is peaceful. It’s the TRANSITION that’s troublesome.”*  
Isaac Asimov (1920–1992)

- Dying is a physical, psychological, social, cultural, and spiritual event, so planning and consulting with the interdisciplinary team is vital.
- 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 making sure that patients die with dignity and great peace.
- This module is divided into three sections:
  - Section I: Preparing for a good death
  - Section II: Frequent symptoms associated with imminent death
  - Section III: Bereavement Care

### Teaching Tip

Have participants write/discuss about a recent death. What went well? What did not go well? What might they have done differently in the care of the patient and their loved ones?

**Key Learning Objectives**

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

- 1. Assess an imminently dying Veteran and list five physical signs and symptoms of the dying process.**
- 2. Assess physical, psychological, social, and spiritual care needs and interventions for an imminently dying Veteran and their family.**
- 3. Discuss the role of the palliative nurse surrounding the death of a Veteran.**

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# NCP Guidelines

- **Domain 7: Care of the Patient Nearing the End of Life**
  - **Care provided to patients and their families near the end of life, with emphasis on the days leading up to and just after the death of the patient.**
  - **Comprehensive assessment & management of pain and other physical symptoms.**
  - **Assessment & management of social, spiritual, psychological, and cultural aspects of care as the patient nears death.**
  - **IDT provides appropriate education to the patient, family and/or other caregivers about what to expect near and immediately following the patient's death.**

NCP, 2018



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National Consensus Project (NCP) Guidelines (NCP, 2018):

- **Domain 7: Care of the Patient Nearing the End of Life**
  - **Interdisciplinary Team:** The IDT includes professionals with training in end-of-life care, including assessment and management of symptoms, communicating with patients and families about signs and symptoms of approaching death, transitions of care, and grief and bereavement. The IDT has established structures and processes to ensure appropriate care for patients and families when the end of life is imminent.
  - **Screening and Assessment:** The IDT assesses physical, psychological, social, and spiritual needs, as well as patient- and family preferences for setting of care, treatment decisions, and wishes during and immediately following death. Discussions with the family focus on honoring patient wishes and attending to family fears and concerns about the end of life. The IDT prepares and supports family caregivers throughout the dying process, taking into account the spiritual and cultural background and preferences of the patient and family.
  - **Treatment Prior to Death:** In collaboration with the patient and family and other clinicians, the IDT develops, implements, and updates (as needed) a care plan to anticipate, prevent, and treat physical, psychological, social, and spiritual symptoms. The care plan addresses the focus on end-of-life care and treatments to

- meet the physical, emotional, social, and spiritual needs of patients and families. All treatment is provided in a culturally and developmentally appropriate manner.
- *Treatment During the Dying Process and Immediately After Death:* During the dying process, patient and family needs are respected and supported. Post-death care is delivered in a manner that honors patient and family cultural and spiritual beliefs, values, and practices.
  - *Bereavement:* Bereavement support is available to the family and care team, either directly or through referral. The IDT identifies or provides resources, including grief counseling, spiritual support, or peer support, specific to the assessed needs. Prepared in advance of the patient’s death, the bereavement care plan is activated after the death of the patient and addresses immediate and longer-term needs.

**Module 1 Suggested Supplemental Teaching Material:**

Table 1 (in Module 1 Supplemental Teaching Materials): National Consensus Project Domains and Corresponding National Quality Forum Preferred Practices



**Section I:**  
**Preparing for a Good Death**

- **The important role of the nurse**
- **Hydration?**
- **Resuscitation?**
- **Hasten death request?**
- ***A Good Death* video:**  
<https://vimeopro.com/reliaslearning/el nec/video/129463027>

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- A good death generally does not occur without thoughtful planning and anticipation. Nurses are invited to spend final days and moments with Veterans and families during this difficult, yet sacred time.
- This section will give you the resources to help plan a good death for a Veteran, as you respect his/her wishes.

**Suggested Video:**

*Testimonial Video: A Good Death* Accessed from:

<https://vimeopro.com/reliaslearning/el nec/video/129463027>

**Discussion Questions post viewing video:**

1. What were the main concepts shared in this video about a good death
2. Do you consider it a privilege to care for people in their last days/moments of life?
3. Do you believe these experiences help you to grow professionally?

**Module 8 Suggested Supplemental Teaching Materials:**

Table 1: Physical Signs, Symptoms and Interventions of the Actively Dying

Table 2: Psychosocial and Spiritual Signs, Symptoms and Interventions of the Actively Dying

Figure 1: Hierarchy of the Dying Person's Needs

**Preparing for Death**

- **Everyone dies**
- **Advance care planning**
- **Advance directive —view:**  
<https://www.youtube.com/watch?v=iTxv-20ULwQ>
- **Recognizing the transition to active dying**
- **Care for the dying**
- **Post death care**

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- Approximately 60% of all Americans have one or more chronic illnesses. Nearly 40% of adults have two or more chronic illnesses. Seven out of ten causes of death are from chronic illness. People dying today may have been sick for many years with multiple co-morbidities. They have suffered and their families are exhausted, and in some cases, financially broke (CDC, 2022).
- Advance care planning is important as it lays out a blueprint of the Veteran’s preferences regarding end-of-life care. Advance care planning can:
  - Increase likelihood that Veterans receive care consistent with their wishes
  - Decrease healthcare costs
  - Improve quality of life
  - Improve bereavement outcomes

**NOTE:**

The VA honors all types of legal Advance Directives, including forms from another state, Department of Defense or VA. The VA form contains more detail than most other forms and allows the option to attach additional documents.

Forms such as MOLST/POLST (Medical orders for life sustaining therapies) and *Five Wishes™* forms and others help spur discussion (for further information on these



documents, go to <https://polst.org/>; ; <https://molst.org/> ; <https://www.fivewishes.org/>  
Accessed June 27, 2022

- ANA position statements support the role of the nurse in initiating and supporting these discussions and decisions (ANA, 2016 & 2019).
- For those living with serious, life-threatening illness, recognizing approaching death allows the Veteran, family, and care team to prepare for the actively dying phase.
- When a Veteran's death is imminent, nurses should be committed to:
  - Providing expert symptom management
  - Knowing and respecting the Veteran's culture
  - Preparing the family for what to expect, as death is approaching
  - Anticipating and notifying other interprofessional team members that may be needed (i.e., social worker, chaplain, child life specialist, etc.).
- Planning for and providing care after death includes death pronouncement, care of the body, burial plans, bereavement care.

**Suggested Video:**


*Who Will Speak For You?:* <https://www.youtube.com/watch?v=iTxv-20ULwQ>  
(Accessed June 27, 2022)

**Note:** For information on the VA and Advance Care planning see the VA Making Decisions: Advance Care Planning  
[https://www.va.gov/geriatrics/pages/advance\\_care\\_planning\\_topics.asp](https://www.va.gov/geriatrics/pages/advance_care_planning_topics.asp) (Accessed July 28, 2022)

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## The Nurse, Dying and Death

- **Nurses provide support to staff, Veterans/families**
- **Interpersonal competence**
- **Being present**
- **“Bearing witness”**
- **Interprofessional care**



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- Most nurses probably have more “real” exposure to death than any other healthcare professional.
  - The final days before a Veteran dies are significant moments for a Veteran and family, as they prepare for death, say goodbye, and complete end-of-life closure tasks.
  - The nurse, in the role as advocate/ /professional caregiver/educator/supporter, is often the professional who is most able to facilitate a dignified, comfortable death that honors Veteran/family choices, no matter where the setting of death occurs.
- Interpersonal competence includes (Berry & Griffie, 2019):
  - 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 orchestrated in an interprofessional way. Nurses collaborate closely with physicians, chaplains, social workers, and all team members to provide care at this poignant time.
- **NOTE:** Be prepared for the “rhythm of care” to change (i.e. Assessing vital signs? Recording intake/output? Evaluating daily weights? Collecting laboratory specimens?). Are these benefits or burdens?

## **Describe a Recent Death You Have Observed**

- **What went well?**
  - **Were the Veteran's and family's wishes honored??**
  - **Describe any cultural traditions that were honored.**
  - **Was pain controlled, as well as other symptoms??**
  - **Was interdisciplinary care evident??**
- **What could have been improved??**
  - **What issue(s) could have been prevented?**
  - **Are there policies/procedures that need to be developed to provide better direction?**

## Open, Honest Communication

- **Convey caring, sensitivity, compassion**
- **Provide information in simple terms**
- **Veteran awareness of dying**
- **Maintain presence**



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- Open, honest communication fosters trust and informed decision-making.
- In all communication, convey caring, nurturing, sensitivity, and compassion.
- Elicit Veteran and family understanding of condition/prognosis.
  - Veterans may have a greater awareness of dying than those around them.
  - If Veteran asks if they are dying, explore the question. What makes you ask now? Has something changed for you?
  - Encourage open and honest communication between Veteran and family.
  - If the family is reluctant to address death with the Veteran, address these concerns and fears:
    - Educate the family that the Veteran may already know he/she is dying.
    - Preparing for death leads to better bereavement outcomes.
- Provide information in simple, uncomplicated terms.
  - Avoid overloading or overwhelming with too much medical jargon.
  - Provide simple answers to questions in accordance with Veteran/family understanding/readiness for responses.

- Information and understanding make for better choices and fewer regrets: options, benefits/burdens, outcomes.
- Family members may be tired, have difficulty concentrating, and be focused on the present and not the future.
  - May need to answer same questions, provide the same information repeatedly, as Veterans/families may be in crisis and unable to retain some information.
- Maintain presence.
  - Address patient's/family's hopes.
  - Do not destroy hope: what are you hoping for? If that is not possible, what else would you hope for? Use "I wish", "I worry", I "wonder" statements from Module 4 Communication.
  - Provide presence: be available, listen, reflect, and connect.
  - Provide assurance that someone will be available during the dying process.



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## Dying is an Individualized Personal Experience for the Veteran



- **There is no typical death**
- **Veteran preferences**
- **Nurses advocate for choices**
  - Setting of death
  - Support
- **Psychological and emotional considerations**

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- There is no typical death. 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
- When Veterans are aware that they are dying, they usually know where they want to die, with whom they want to 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.
- Psychological and emotional considerations (Berry & Griffie, 2019):
  - Fear of the dying process
  - Fear of abandonment

- Fear of the unknown
- Nearing death awareness
- Withdrawal
  
- 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).

# Medically Administered Nutrition & Hydration

- **Perceptions of “starving to death”**
- **Hydration does not decrease “dry mouth”**
- **Arguments for and against hydration**

HPNA, 2020; Lanz et al., 2019; Prince-Paul & Daly, 2019

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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, yet regarding hydration, there is little evidence that increasing fluids decreases dry mouth and may further discomfort. As the Veteran approaches death and becomes less aware, the perception of thirst and hunger may be diminished (Lanz et al., 2019; Prince-Paul & Daly, 2019).
- Arguments for and against medically administered nutrition and hydration are listed below (HPNA, 2020; Lanz et al., 2019; Ramirez & Dahlin, 2022):
  - **Arguments for medically administered nutrition and hydration:**
    - Dehydration can lead to prerenal azotemia (elevation of blood urea nitrogen [BUN] and serum creatinine levels. This can lead to accumulation of drug metabolites, such as opioids that can cause delirium, myoclonus, and seizures. For some patients, hydration can reverse these symptoms, and increase energy while reducing fatigue, which can improve comfort.
    - There is no scientific evidence that providing fluids prolong the dying process.
    - Family and others want to know that they have “done everything.” While there is no medical value, this can ease the family’s anxiety at the time of death.
    - Essential in some cultures

- **Arguments against medically administered nutrition and hydration:**
  - Parenteral fluids may prolong dying and may be uncomfortable for the Veteran.
  - With less urine, there is less need to void/use catheters.
  - With less gastrointestinal fluid, there may be less diarrhea and nausea/vomiting.
  - With fewer secretions from the respiratory tract, there may be less cough/pulmonary edema.
  - Edema or ascites may be reduced if patient is dehydrated.
  - Dehydration may be a natural anesthetic to ease the dying process.
  - Does not prevent or reduce aspiration

A presentation slide with a dark blue background and a white title bar. The title bar contains the text "What are the Cultural and Ethical Implications of Withholding Nutrition & Fluids?". Below the title bar, there is a list of bullet points. At the bottom of the slide, there is a logo for "ELNEC For Veterans Curriculum" and a citation: "Lanz et al., 2019; Prince-Paul & Daly, 2019".

## What are the Cultural and Ethical Implications of Withholding Nutrition & Fluids?

- **In most cultures, food is used for not only nutritional purposes, but also social engagement**
- **When a patient is no longer interested/able to eat/drink, this can cause great angst to the family**
- **Maintain three ethical principles**
  - **Autonomy**
  - **Beneficence**
  - **Nonmaleficence**

Lanz et al., 2019;  
Prince-Paul & Daly,  
2019

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- Culture influences the death experience. It affects how people view death- their distress or peace with it. It affects social customs (i.e., care of body after death and mourning rituals). It affects how people talk about death. It can strain or enhance relationships between caregivers and patients/families.
- It affects decision making. For families to see their loved one no longer wanting or being able to eat or drink can be extremely distressing. Listening to Veterans and their families is critical during this time. This is another outward sign that the Veteran is close to death. Be aware of any cultural traditions that may be important at this time (Lanz et al., 2019; Prince-Paul & Daly, 2019).
- It is important that nurses remember three ethical principles during this time (Lanz et al., 2019):
  - **Autonomy:** The Veteran, family/surrogate decision maker's right to self-determination. They have the right to determine whether to accept or reject these interventions, based on their own beliefs and values.
  - **Beneficence:** "To do good." To act in the interest of the Veteran.
  - **Nonmaleficence:** "To bring no harm." To respect the wishes of the Veteran/family/surrogate decision maker, to bring no further suffering, and to weigh benefits versus burdens.

**Suggested Supplemental Teaching Material:**

Figure 3: HPNA Position Statement (2021): Withholding and/or Withdrawing Life  
Sustaining Therapies




## Resuscitation

- **No advance planning**
- **Unrealistic beliefs regarding survival**
- **Family presence during resuscitation**

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- Veterans, family members, and the public may have unrealistic beliefs about survival after resuscitation, based upon favorable survival portrayed in the media.
- In cases of sudden death, or where advance care planning did not take place, cardiopulmonary resuscitation may be instituted.
- Outcomes after resuscitation within a hospital-setting are poor. Survival to hospital discharge has been reported to range from 0% to 40%, with most larger studies reporting survival to discharge at approximately 20%. (Anderson, et al., 2019).
- What about family presence during resuscitation? While it may be controversial in some institutions, evidence is continuing to mount that shows family presence during resuscitation and invasive procedures is beneficial to patients and their families (Guzzetta & the AACN Clinical Resources Task Force, 2016).
  - Positive results on psychological variables.
  - No interference with medical efforts or increases on health providers' stress.
  - No result in medicolegal conflicts.



## Cardiac Devices

- **Discontinuing cardiac devices**
  - **Pacemakers**
  - **Cardiac resynchronization therapy (CRT)**
  - **Implantable Cardiac Defibrillators (ICDs)**
  - **Extracorporeal membrane Oxygenation (ECMO)**
  - **Left Ventricular Assist Devices (LVADs)**

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- **Discontinuing Cardiac Devices**
  - **Pacemakers and Cardiac Resynchronization Therapy (CRT-P) Devices**
    - Pacemaker and CRT helps symptoms
    - Deactivation of pacemaker not necessary in most cases
    - If patient dependent, deactivation will cause imminent death
    - May worsen symptoms of heart failure (fatigue, SOB, dizziness)
  - **Implantable Cardiac Defibrillators (ICDs) and CRT-Defibrillator**
    - At end of life arrhythmias activate causing unnecessary shocks and suffering and deactivation should occur for this reason
    - Discussions about deactivation should be had at time of implantation and regularly afterward, during change in clinical status
    - All nurses need to know resources for deactivation
  - **Extracorporeal Membrane Oxygenation in Adults (ECMO) or Left Ventricular Assist Devices (LVADs)**
    - Discontinuation if prognosis poor (e.g., anoxic brain injury) or poor quality of life even if not at end of life
    - Preventive symptom control for discontinuation.

- Optimally discussions regarding deactivation of cardiac assist devices have been held at the time of implantation, although this is often neglected. Pacemakers or cardiac resynchronization therapy (CRT-P) without defibrillator functions are generally not deactivated at the end of life, and doing so may worsen symptoms of heart failure, such as fatigue, dyspnea and dizziness. Discontinuing CRT-D and implantable cardioverter defibrillators (ICD) will preclude Veterans from suffering painful shocks during arrhythmias. Nurses caring for those at end of life, regardless of setting, must be aware of resources for deactivation.
- Discontinuing ECMO or LVADs generally occur after catastrophic complications of either (e.g., anoxia, stroke, multisystem organ failure), when treatment may no longer be consistent with goals of care. Careful preparation of the Veteran and family is necessary, along with aggressive symptom prevention and management. Consultation with experts is essential.

For further information on these, go to:

- *FAST FACTS #111*: Cardiac pacemakers at end of life (2017). <https://www.mypcnow.org/fast-fact/cardiac-pacemakers-at-end-of-life/>
- *FAST FACTS #112*: Implantable cardioverter defibrillators at end of life (2017). <https://www.mypcnow.org/fast-fact/implantable-cardioverter-defibrillators-at-end-of-life/>
- *FAST FACTS #269*: Deactivation of a left ventricular assist device at the end-of-life. (2015). <https://www.mypcnow.org/fast-fact/deactivation-of-a-left-ventricular-assist-device-at-the-end-of-life/>
- *FAST FACTS #339*: Extracorporeal membrane oxygenation in adults (2017). <https://www.mypcnow.org/fast-fact/extracorporeal-membrane-oxygenation-in-adults/>

All accessed June 27, 2022

## Discontinuing Inotropes

- **Inotropes increase cardiac contractility and cardiac output**
- **Discontinuing may cause abrupt onset of severe heart failure symptom**
- **Preload Veterans with pain and symptom medications**
- **Many home hospices will not accept inotrope dependent patients**
- **If enrollment in hospice is planned, coordination with cardiologist is needed**

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- Discontinuing Inotropes
  - Inotropes increase cardiac contractility and cardiac output (e.g., milrinone, dopamine, dobutamine)
  - Discontinuing these agents may cause abrupt onset of severe heart failure symptom
  - Preload patients with pain and symptom medications as perfusion will be poor once these drugs are stopped
  - Many home hospices will not accept inotrope dependent patients
  - If enrollment in hospice is planned, coordination with cardiologist is needed
- Inotropes, such as milrinone, dobutamine and dopamine, are used to treat heart failure with reduced ejection fraction. They increase cardiac contractility to improve cardiac output, relieving symptoms of heart failure. However, over time, transitions in goals of care may lead some patients to request discontinuation of these therapies. Preloading the patient with opioids for pain and shortness of breath is warranted prior to stopping the drugs as perfusion will be significantly limited.
  - For additional information:  
Fast facts #283 Use of Home Inotropes in Patients Near the End-of-Life.  
<https://www.mypcnow.org/fast-fact/use-of-home-inotropes-in-patients-near-the-end-of-life/> Accessed July 21, 2022



## Withdrawing/Discontinuing Mechanical Ventilation

- **Noninvasive mechanical ventilation**
  - Continuous positive airway pressure (CPAP)
  - Bilevel positive airway pressure (BiPAP)
- **Invasive mechanical ventilation**
- **Withdrawing or discontinuing treatments**



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- Withdrawing/Discontinuing Mechanical Ventilation
  - Noninvasive mechanical ventilation
    - Continuous positive airway pressure (CPAP)
    - Bilevel positive airway pressure (BiPAP)
  - Invasive mechanical ventilation
  - Withdrawal or Discontinuing Treatments
    - Advance preparation
    - Pre-medicate
    - Two methods - Immediate extubation or terminal weaning
- When mechanical ventilation therapy is no longer consistent with goals of care, these therapies may be discontinued after discussions with patients and family members. Noninvasive mechanical ventilation, such as continuous positive airway pressure (CPAP) or bilevel positive airway pressure (BiPAP), requires pre-medication with an opioid for dyspnea, and gradual weaning of oxygen prior to removing the mask. Strategies for withdrawing or discontinuing mechanical ventilation include immediate (also called terminal) extubation or terminal weaning. Each institution should have protocols in place to guide clinicians. (Campbell, 2019)

For more specific information:

FAST FACTS #33 Ventilator Withdrawal Protocol (2015).

<https://www.mypcnw.org/fast-fact/ventilator-withdrawal-protocol/> Accessed June 27, 2022

FAST FACTS #34 Symptom Control for Ventilator Withdrawal in the Dying Patient (2015). <https://www.mypcnw.org/fast-fact/symptom-control-for-ventilator-withdrawal-in-the-dying-patient/> Accessed June 27, 2022

FAST FACTS #35 Information for Patients and Families about Ventilator Withdrawal (2015). <https://www.mypcnw.org/fast-fact/information-for-patients-and-families-about-ventilator-withdrawal/> Accessed June 27, 2022



## Discontinuation of Dialysis

- **When should dialysis be discontinued?**
  - **When burdens outweigh benefits and/or,**
  - **When dialysis is no longer prolonging life or only prolonging death**

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### **Benefits and Burdens of Dialysis:**

- Today, over 550,000 Americans are on dialysis (National Kidney Foundation, 2022). Those at risk for renal disease are older adults (60 years of age and older), with multiple comorbidities (obesity, hypertension, heart disease), and those from marginalized communities (e.g., Black/African Americans, Hispanics or Latinos, Asian Americans or Pacific Islanders and American Indians or Alaska Natives). After one year of treatment, people on dialysis have a 15-20% mortality rate with a 5-year survival rate under 50%. Those over the age of 80 years are the fastest-growing segment of the dialysis population with a 46% mortality rate in the first year of dialysis. (University of California San Francisco; The Kidney Project, 2022; <https://pharm.ucsf.edu/kidney/need/statistics#:~:text=After%20one%20year%20of%20treatment,about%2080%25%20after%205%20years.>) Accessed June 27, 2022.
- When should dialysis be discontinued?
  - When burdens of dialysis outweigh the benefits and/or,
  - When dialysis is no longer prolonging life or only prolonging death.

- The most common reason for discontinuing dialysis is poor quality of life (i.e. pain; burden of multiple symptoms; acute complications such as infection; technical problems with dialysis; dementia; stroke; and cancer).
- Assessing symptom burden, along with psychological symptoms are vital considerations in making the decision to discontinue dialysis. These Veterans struggle often with depression, changes in body image, sexual dysfunction, loss of control, irritability, and dependency issues, as well as with numerous physical symptoms.
- When Veterans make their own decisions, stopping dialysis can be an opportunity to take control. They usually have a few days before uremic symptoms begin. They can generally eat favorite, formerly forbidden foods. They have opportunities to say good-bye to loved ones, to say “I love you,” “I forgive you.” This allows a Veteran to maintain some sense of control over his/her life and the dying process.
  - When does death occur after dialysis discontinuation? Generally, within 8–12 days.
  - Those with comorbidities may die sooner.
  - Those who can make some urine will live longer.
  - Generally, Veterans discontinuing dialysis die within one month from the accumulation of toxins, including potassium, and other factors due to comorbidities.
  - Last days/hours are characterized by hypersomnolence followed by coma.
- Use of medications to control frequent symptoms (i.e. pain, delirium, dyspnea, nausea, itching) (Davison & Rosielle, 2015):
  - Morphine should be avoided due to its metabolite morphine-3-glucuronide, which increases in kidney failure, putting the Veteran at risk for myoclonus, seizures, and hyperalgesia.
  - Fentanyl or methadone are better choices; methadone excreted through feces rather than kidneys.
  - Use hydromorphone and oxycodone with caution.
  - Benzodiazepines can be used to treat myoclonus.
  - Opioids and other medications can be given in liquid/elixir form (sublingually or buccally-although most absorbed through gastrointestinal tract, except for methadone and fentanyl), if Veteran is obtunded.
  - Haloperidol, clonazepam, or lorazepam can be used if agitation is observed, as long as the dose is not dependent on renal function.
  - Anticholinergics and opioids can be useful to reduce oral secretions and improve dyspnea, respectively.
  - Nitroglycerin paste may be used for systemic vasodilatation due to pulmonary edema.
  - Haloperidol can be used for nausea, a common effect of uremia.
  - Benzodiazepines and diphenhydramine can be used for itching, caused by uremia. Lanolin-based or capsaicin creams can also be used.

## Organ/Tissue Donation

- **Regulations**
- **Talking to the family about organ/tissue transplantation**
- **What can be donated?**

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- In 2021, 41,354 organ transplants were performed in the US, primarily kidney, liver and heart transplants. During that same year, 13,861 people became deceased donors, an increase of 10% over the previous year. (UNOS, 2022; US Dept of Health & Human Services, 2021).
- If the Veteran is an organ donor, follow procedures as planned and in accordance with the state, setting guidelines, policies and/or procedures.
  - Regulations <https://www.organdonor.gov/awareness/organizations/local-opo.html>:
    - Federal law (Public Law 99-5-9; Section 9318) and Medicare regulations mandate that hospitals must give surviving family members the chance to authorize donation of their family member's organs and tissues. This conversation is to be done by the local Organ Procurement Organization [OPO] only. Health care professionals are not permitted to discuss this (Berry & Griffie, 2019).
  - Only the OPO talks with the family about organ/tissue donation (**NOTE:** These are individuals through the OPO which coordinate the donation process and also provide bereavement support for donor families). OPOs are certified by the

- Centers for Medicare and Medicaid Services [CMS] and abide by CMS regulations:
- 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.
    - **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.
  - 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. For more information, go to [www.organdonor.gov](http://www.organdonor.gov); <https://www.organdonor.gov/statistics-stories/statistics.html#glance> (US Dept. of Health and Human Services, 2021) Accessed June 28, 2022.
  - For more information on the **VA National Transplant program**: <https://www.va.gov/health/services/transplant/>

## Requests For Medical Aid in Dying

- **Intervention to cause death more immediately than if illness took its natural course**
- **Statement made by Veteran**
  - **Progressive incurable illness**
  - **Judgment not impaired**
  - **Medication administered by Veteran**
- **Nurses needs to assess**
  - **Context for the request for medical aid in dying**
  - **Veteran's decisional capacity and understanding**
  - **Veteran's goals of care**
- **Nurses to provide support and comfort**
- **VA Policy**

ANA, 2019

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- It is not uncommon for patients to ask their healthcare professional to help hasten their death. The request may come because they have persistent symptoms that prolong suffering, loss of control, anxiety about the future, and fear of being a physical and financial burden to their loved ones. Though this request can cause healthcare providers angst, it is an opportunity to be aware of the patient's suffering and to look at all ways to provide better assessment and care (Quill & Arnold, 2015 & 2016).
- The American Nurses Association (ANA) states that nurses are ethically prohibited from administering medical aid in dying medication(s) to patients as this act is in direct violation of Code of Ethics for Nurses with Interpretive Statements (ANA, 2015; herein referred to as The Code), the ethical traditions and goals of the profession, and its covenant with society. However, nurses must be comfortable supporting patients with end-of-life conversations, advocating optimized palliative and hospice care services, and know about aid in dying laws and how those affect practice. In the process of assessing the context of the medical aid in dying request, the nurse has an obligation to provide humane, comprehensive, and compassionate care and comfort that respects the rights and choices of patients who request medical aid in dying (ANA, 2019).

- Clarify what is being asked (Ramirez et al., 2019)
  - Explore motivations.
  - Explore alternatives to address issues raised:
    - Symptom management,
  - Psychosocial counseling.
  - Assure non-judgmental commitment to care.
  - Openly discuss patient's request with others to eliminate secrecy.
  - Seek interdisciplinary support, as you care for the patient.
  
- The VA follows Federal law therefore they are guided by the **Assisted Suicide Funding Restriction Act of 1997** which prohibits the use of appropriated funds to provide or pay for any health care item or service or health benefit coverage for the purpose of causing, or assisting to cause, the death of any individual. (H.R. 1003, 1997). State Veteran homes and VA facilities have policies in place and it is best to know what your state facility specific policy is. It is possible that a Veteran choosing this option may have to be discharge home or to another facility.
  
- **NOTE:** Important nursing codes & position statements, and references:
  - American Nurses Association (ANA). (2015). *Code of ethics for nurses with interpretive statements*, 3<sup>rd</sup> edition. Silver Spring, MD: American Nurses Association.
  - American Nurses Association (ANA). (2017). *Position statement: nutrition and hydration at the end of life*. Accessed June 21, 2022 from: <https://www.nursingworld.org/practice-policy/nursing-excellence/official-position-statements/>
  - American Nurses Association (ANA). (2016). *Position statement: nurses' roles and responsibilities in providing care and support at the end of life*. Accessed June 21, 2022 from: <https://www.nursingworld.org/practice-policy/nursing-excellence/official-position-statements/>
  - American Nurses Association (ANA). (2019). *Position statement: the nurse's role when a patient requests aid in dying*. Accessed June 21, 2022 from: <https://www.nursingworld.org/practice-policy/nursing-excellence/official-position-statements/>
  - Hospice and Palliative Nursing Association (HPNA). (2017a). *Position statement: guidelines for the role of the registered nurse and advanced practice registered nurse when hastened death is requested*. Accessed June 21, 2022 from: <http://advancingexpertcare.org/position-statements/>
  - Hospice and Palliative Nursing Association (HPNA). (2017b). *Position statement: physician assisted death (PAD)/physician assisted suicide (PAS)*. Accessed June 21, 2022 from: <http://advancingexpertcare.org/position-statements/>
  - Quill, T., & Arnold, R.M. (2016). *Fast Facts and Concepts #159: responding to a request for hastening death*. Accessed June 21, 2022 from <https://www.mypcnw.org/fast-facts>

- Ramirez, C., Fundalinski, K., Knudson, J., & Himberger, J. (2019). Palliative care and requests for assistance in dying. In B.R. Ferrell and J.A. Paice (Eds.) *Oxford textbook of palliative nursing*, 5<sup>th</sup> edition (Chapter 71, pp. 837-843). New York: Oxford University Press.



## Psychosocial Changes

- **We only die once**
  - **Fear of dying**
  - **Feelings of loss**
  - **At end of life, Veteran may be more introspective**


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- People only die once, and so they do not have experience in this event. It is not unusual for people to experience fear, worry about being abandoned, and be anxious about uncontrolled pain and suffering – both physical and existential. Veterans experience great losses, including body parts, dignity, control, self-esteem, etc. Towards the end of life, patients may choose to be more introspective, focusing on maintaining a sense of self, finding meaning in life, and pursuing ways of leaving a legacy.

**Module 6 Suggested Supplemental Teaching Material:**

Figure 1: Hierarchy of the Dying Person's Needs

# Spiritual Considerations When Death is Imminent



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SPIRITUAL CONSIDERATIONS (Rosa, 2019; Taylor, 2019)

- Many Veterans/family members may have an increased focus on spiritual issues at this time of impending/imminent death.
- Be aware of culture (e.g., religiosity, spirituality). Remember that nurses play a key role in orchestrating this care with the interdisciplinary team, in an effort to honor spiritual and cultural beliefs, traditions, rites, and rituals (Cormack et al., 2019). Spirituality is an important component of one’s identity and quality of life. Religious practices and beliefs may be a part of one’s spirituality. So be aware of traditions and rituals that are sacred to the patient and family. Are they seeking meaning of this experience? Do they express hope and/or despair?
- What is the role of “religion” for this Veteran/family? Do they have a spiritual advisor/leader? If so, who is it? Ask Veteran/family if they would like for you to contact him/her.
- Provide spiritual comfort through presence, prayer, rites, and rituals.

- Encourage family members to bring in favorite hymns, scriptures, symbols (e.g., rosary) so Veteran can experience these through different senses (hearing, seeing, touching).
- Remember to contact your pastoral care department, chaplains, priests, rabbis, imams, etc. as directed by the Veteran and/or family. Also, be aware of your staff, who witness suffering, moral distress, and other stresses related to caring for so many seriously ill patients. They may need this care, too.
- Consider coaching families about the five “tasks” that may serve as parting words:
  - To ask forgiveness
  - To forgive
  - To say “thank you”
  - To say “I love you”
  - To say good-bye (Byock, 1997)

**Module 8 Suggested Supplemental Teaching Material:**

Table 2: Psychosocial and Spiritual Signs, Symptoms and Interventions of the Actively Dying

**\*This Concludes Section I**

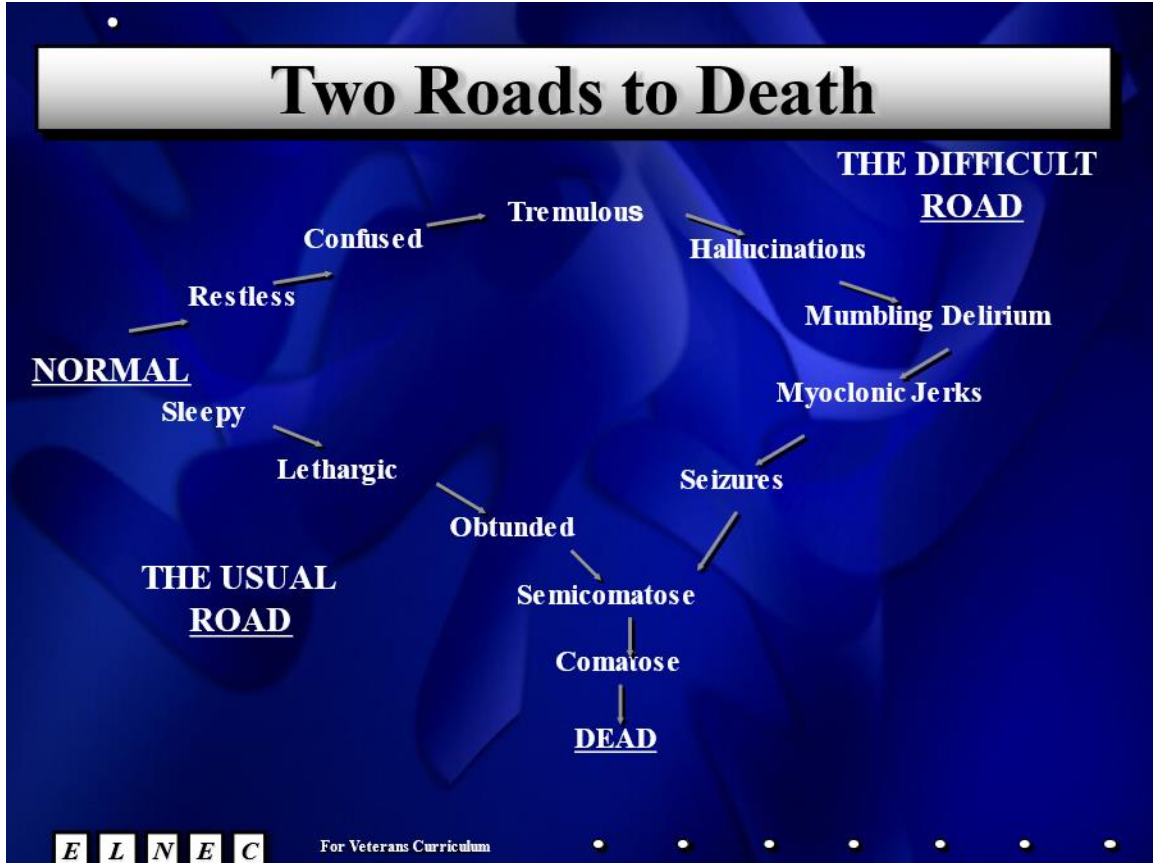
## Section II: Frequent Symptoms Associated with Imminent Death



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- Nurses must be educated to effectively assess and manage symptoms associated with imminent death. Interdisciplinary communication during this phase is critical.



- Transitioning from living with to dying of:
  - Acute or progressive physiological changes related to disease progression
  - Declining function and performance status
  - Increasing number and severity of symptom
  - Increase use of healthcare resources
  - Need for more informal caregiving
  - Determine prognosis
    - No one can predict the exact time of death.
    - Some Veterans seem to instinctively know when death will occur.
    - Prognosis is affected by the disease, Veteran’s will to live, desire/choice to wait for special event (e.g., birthday, holiday, etc.), and/or completion of life closure goals.
    - Understanding prognosis often influences Veteran and family decision-making
    - Most Veterans 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.
- Signs, symptoms, and nursing interventions for the imminently dying patient (Berry & Griffie, 2019).
  - 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.

**Module 8 Suggested Supplemental Teaching Material:**

Table 1: Physical Signs, Symptoms, and Interventions of the Actively Dying



## Physical Symptoms Vary

- **Confusion, disorientation, delirium vs. unconsciousness**
- **Weakness and fatigue vs. surge of energy**
- **Drowsiness, sleeping vs. restlessness/agitation**
- **Physical considerations:**
  - **Fever**
  - **Bowel changes**
  - **Incontinence**
  - **Decreased intake**

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- Physical signs and symptoms associated with dying may occur months, weeks, days, or hours before death.
- Physical considerations may vary and be paradoxical when death is imminent.
  - One Veteran may be confused, disoriented and delirious, while another patient may be unconscious.
  - One Veteran may state they are weak and fatigued, while another describes a surge of energy.
  - One Veteran may be drowsy and sleeping most of the day and night, while another experiences restlessness and agitation.
- Other physical considerations to assess as the Veteran nears the time of impending death include:
  - **Fever:** Fever may be due to an infection or dehydration. Keep the Veteran's goal of care in mind when treating or not treating fever.
  - **Bowel Changes:** As Veterans begin to have a lack of interest in food and water, bowel changes will occur. If on opioids, continue to treat for constipation, though Veteran may be eating very little/nothing.
  - **Incontinence:** Assess and keep Veteran dry in order to prevent skin breakdown.

- **Decreased intake:** lack of desire to eat/drink, inability to swallow, mouth ulcers, etc.
- Pain (refer to next slide)

**NOTE:** The nurse plays a significant role in ANTICIPATING all of these symptoms. Symptoms should be prevented when at all possible and assessed/managed impeccably when not prevented. In addition, the nurse provides education to family members about assessments and treatments.

**Module 8 Suggested Supplemental Teaching Material:**

Figure 2: Nearing Death Awareness

## Most Common Symptoms in Final Days/Weeks of Life

- **Dyspnea**
- **Pain**
- **Noisy breathing/respiratory congestion**

Berry & Griffie, 2019

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- Symptom assessment and management are critical during the final days, hours, and moments of life. The nurse plays a major role in this care. In a systematic review of signs and symptoms of impending death in the last 2 weeks of life, the following symptoms were noted the most frequently (Berry & Griffie, 2019):
  - Dyspnea (56.7%)
  - Pain (52.4%)
  - Noisy breathing/respiratory congestion (51.4%)
- **Dyspnea (56.7%):** In advanced illness, one should treat this symptom while assessing whether or not to treat the underlying cause. This would include treating infections or management of tumor progression. Symptom relief is the primary objective of care when the causes are no longer reversible. See Module 3: Symptom Management for assessment and management of dyspnea.
- **Pain (52.4%):** Frequent assessment of pain is critical in individuals with serious illness. “When pain cannot be prevented, relief is imperative” (Paice, 2016). Diminished consciousness may make pain assessment complicated. When Veterans are unable to report pain, consider:
  - Behavioral cues such as grimacing, posturing
  - Proxy report

- Previous pain issues
- If the Veteran did not previously have pain, but now appears to be in pain, or seems to have changes in pain behaviors, rule out other potential causes of distress such as:
  - Constipation
  - Delirium
  - Decubitus ulcer(s) (check bony prominences)
  - Mucositis (especially if patient is neutropenic)
  - Extreme headache (especially if thrombocytopenic)
  - Opioid toxicity if increasing analgesic use

**NOTE:**

Remember that physical and spiritual pain, coupled with psychosocial suffering, are all components of “total pain.”

- Refer to the American Society for Pain Management Nursing and Hospice and Palliative Nurses Association position statement: *Pain management at the end of life* (Coyne et al., 2018), accessed June 28, 2022 from: <http://www.aspmn.org/Documents/Position%20Statements/Pain%20Management%20at%20the%20End%20of%20Life%202017.pdf>
- Herr, K., Coyne, P.J., Ely, E., Gélinas, C., & Manworren, R.C.B. (2019). Pain assessment in the patient unable to self-report: clinical practice recommendations in support of the ASPMN 2019 position statement. *Pain Management Nursing*, 20(5), 404-417. doi: 10.1016/j.pmn.2019.07.005
- See Module 2: Pain Management for further information about assessing and managing pain.
- **Noisy breathing/respiratory congestion (51.4%):** also known as the “death rattle,” is a distressing and frightening symptom for those involved in the Veteran’s terminal care.
  - For Veterans who are alert, their noisy respirations can cause them to become agitated and fearful of suffocating.
  - Terminal secretions occur as the Veteran approaches and death and can no longer clear the secretions by coughing or swallowing. Most Veterans will die within 48 hours after developing terminal secretions (Donesky, 2019).
  - Assessment includes determining if causes (e.g., pulmonary embolism, myocardial infarction, fluid overload, pneumonia, etc.). of the terminal secretions /respiratory congestion can be treated.
  - Symptom management Symptom management should focus on the underlying cause if appropriate to the disease/prognosis and Veteran/family wishes.
  - Pharmacological interventions include the use of anticholinergics as the primary mode of treatment.
    - Scopolamine patch, starting with one (1.5 mg) and increasing by one patch daily. If at three patches the patient is without relief, begin an infusion of 50 mcg/hr. and titrate hourly to a maximum of 200 mcg/hr.

- Scopolamine subcutaneous 20 mcg given four times daily was found to reduce terminal secretions in a randomized trial comparing it with placebo. (van Esch, et al., 2021)
- Atropine (0.4 mg), either IV or SQ can be used, but this may cause tachycardia.
- Nonpharmacological interventions include:
  - Attempt to reposition the Veteran (either on their side or semi-prone to assist with any postural drainage).
  - Keep head of bed elevated.
  - Suctioning is generally not recommended, as it can increase agitation and distress in the Veteran.
  - Reduce fluid intake.
- Support the Veteran and family
  - Using the term “death rattle” can be a frightening term to hear. Some have suggested using the term “respiratory congestion” to describe this phenomenon to Veterans/family.
  - Be honest with families and let them know that this can occur before death, so that families caring for their loved one at home will know what may be available to relieve this symptom.
  - If at home, the family should be instructed to contact hospice or the palliative care team about this, so they can treat accordingly (Donesky, 2019).

## Other Symptoms to be Aware of Near the End of Life

- **Delirium**
- **Myoclonus**



Burhenn, 2016; Schwartz, 2019

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- **Delirium:** Delirium is frequently overlooked or misdiagnosed and yet is seen in 3%-45% of palliative care patients. For inpatients, delirium can be seen in 59%-88% in the weeks or hours before death
  - Good assessment and proactive management are critical. Review history, current medications, and perform a thorough physical exam are key to assessment. Triggers and flashbacks may complicate peaceful dying in the Veteran with PTSD (Grassman, 2017).
  - Delirium can be a prognostic indicator of impending death (Burhenn, 2016).
  - As you consult with the interdisciplinary team, keep the Veteran's goals of care in mind as you work to develop management strategies.
  - See Module 3: Symptom Management for more information on assessing and managing delirium.
- **Myoclonus:** Or myoclonic jerking, is associated with multiple factors:
  - High-dose opioids (e.g., morphine, fentanyl, methadone, meperidine, and transdermal fentanyl), neuroleptics, and metoclopramide.
  - Discontinue any medications that may be causing myoclonus.



- Assess for withdrawal from barbiturates, benzodiazepines, anticonvulsants, and alcohol.
- Be aware of certain conditions such as cerebral edema, hypoxia, multi-organ system failure(s), and dementia.
- The primary treatment for myoclonus is opioid rotation, especially if the Veteran is on high doses of an opioid and has poor renal function.
- Consider a preservative-free solution as the preservatives and antioxidants in high doses of opioid infusion may lead to adverse effects.
- Other treatments include use of benzodiazepines. Clonazepam is the most frequently used and most effective. Untreated myoclonus can progress to seizures. Treatment is essential (Schwartz, 2019).

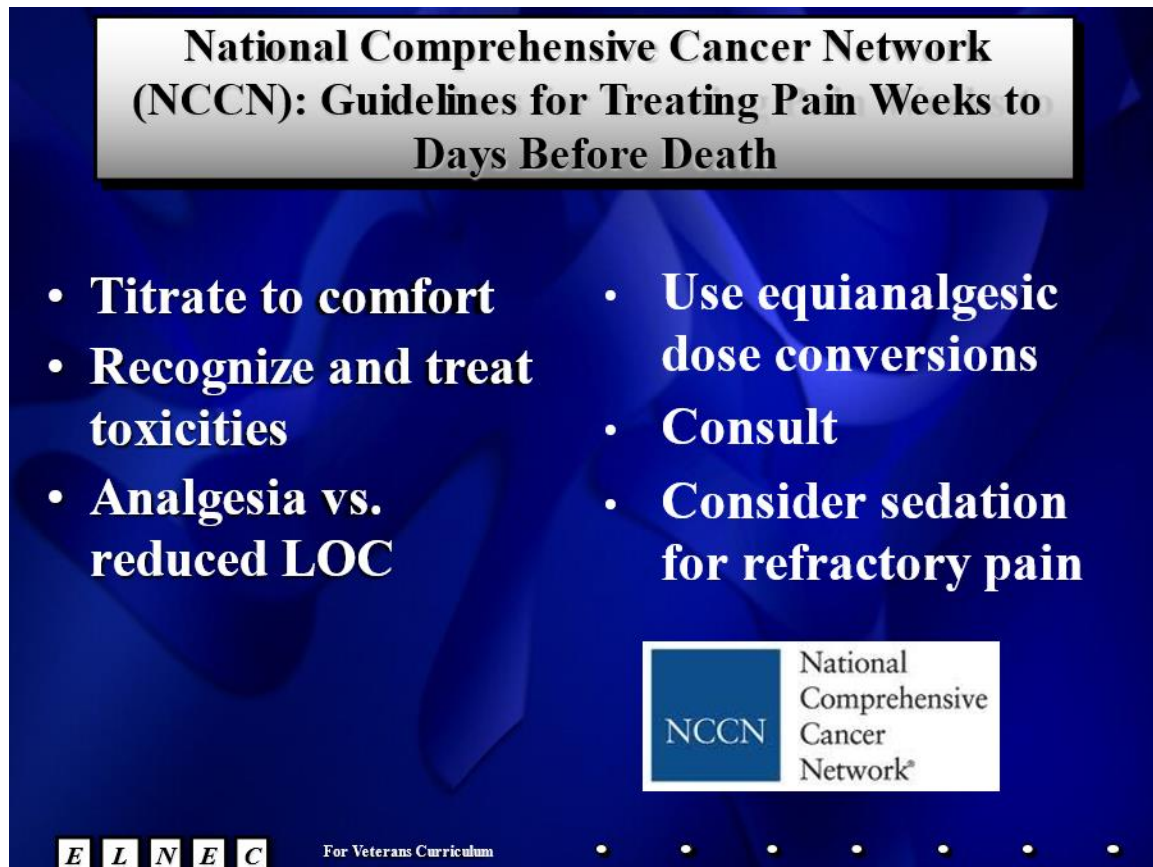
## Use of Opioids in the Final Days/Hours

- **Dosing of opioids given during last hours based on appropriate assessment and reassessment.**
- **Dose may be decreased or increased**
- **Consider other routes:**
  - **Oral**
  - **Rectal**
  - **Subcutaneous**
  - **Transdermal**

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- As with all phases of pain treatment, the dose of opioids given during the last hours of life should be based upon appropriate assessment and reassessment.
- Many professionals often believe that opioid doses require extensive escalation during the last hours of life and fear that providing these doses will result in hastening death. Several studies indicate that for the majority of patients during the last 24 hours of life, the opioid doses remained low. For patients who did require significant increases, their survival was no different than patients who remained on stable dosing (Paice, 2019).
- **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. (Lacey, 2021).



**National Comprehensive Cancer Network (NCCN): Guidelines for Treating Pain Weeks to Days Before Death**

- **Titrate to comfort**
- **Recognize and treat toxicities**
- **Analgesia vs. reduced LOC**
- **Use equianalgesic dose conversions**
- **Consult**
- **Consider sedation for refractory pain**

 National Comprehensive Cancer Network®

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- The National Comprehensive Cancer Network (NCCN) has developed guidelines for treating pain in patients who have weeks to days before death. These guidelines include:
  - Dose of opioid should not be reduced solely for a decrease in blood pressure, respirations, and/or level of consciousness.
  - Analgesics therapy should be maintained and titrated to optimal comfort.
  - Opioid-induced neurotoxicities (e.g., myoclonus, hyperalgesia, etc.) should be recognized immediately.
  - If the opioid must be reduced, it should be decreased by  $\leq 50\%/24$  hours to prevent withdrawal from the opioid and/or for the patient to experience unnecessary pain and suffering. “Do not administer opioid antagonist” (NCCN, 2022).
  - Listen to the patient and hear his/her preference. Balance analgesia against the possibility of reduced level of consciousness.
  - Modify routes of administration (e.g., oral, IV, rectal, subcutaneous, sublingual, transmucosal, and transdermal). Be knowledgeable about equianalgesic dose conversions.
  - Collaborate and consult with a pain/palliative care specialist.
  - For refractory pain, consider sedation.

## Sedation for Uncontrolled Symptoms or Palliative Sedation

### Consider:

- All possible etiologies and treatments
- Education of Veteran/ family regarding goals and outcomes
- Interprofessional team approach
- Medications

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- The goal of Sedation for Uncontrolled Symptoms or Controlled sedation (also known as palliative) is to relieve intractable symptoms—*not* to hasten death.
- **What is a refractory/intractable symptom?** A refractory symptom, one for which total sedation may be appropriate, has the following three attributes (Salacz & Weissman, 2015a & 2015b):
  - Aggressive efforts short of sedation fail to provide relief.
  - Additional invasive/non-invasive treatments are incapable of providing relief.
  - Additional therapies are associated with excessive/unacceptable morbidity, or are unlikely to provide relief within a reasonable time frame
- Before initiating Sedation for uncontrolled symptoms, several actions must take place (HPNA, 2016a):
  - All possible etiologies and treatments for the intractable pain or other symptoms have been considered and ruled out.
  - The Veteran or his/her surrogate should be instructed regarding the expected outcomes and treatment goals of this approach.
  - Informed consent should be obtained.

- Interprofessional team meetings are critical in planning this approach. Consultation should take place with another healthcare provider or team with expertise in initiating sedation at the end of life to ensure that this is the only rational treatment option.
- Medications used for controlled sedation:
  - Aggressively increasing the existing opioid regimen may be sufficient for some Veterans. (Paice, 2019).
  - Benzodiazepines, including lorazepam, midazolam (most commonly used because of its rapid onset of 60 seconds) or neuroleptics, such as haloperidol (unreliable for complete sedation) or chlorpromazine, may be added to treat myoclonus and induce sedation (Banerjee & Freeman, 2019).
  - **Ketamine** can be used for severe neuropathic pain and can be effective as an opioid sparing agent (Paice, 2017). Ketamine may cause vivid dreams and hallucinations, and excessive salivation. Haloperidol can be used in the treatment of hallucinations and scopolamine, may be used for excessive salivation
  - In rare cases, **propofol**, another anesthetic agent used during invasive procedures, can be given as an intravenous infusion with boluses as needed. While it has excellent sedative and hypnotic properties, propofol has little or no analgesic properties. Therefore, **do not discontinue opioids, as withdrawal may occur and pain would return** (Paice, 2019).
  - 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; HPNA, 2017c). Emotional support of the family is imperative.

## Symptoms of Imminent Death

- **Decreased urine output**
- **Cold and mottled extremities**
- **Vital sign and breathing changes**
- **Delirium / confusion**
- **Restlessness**

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- Not all signs/symptoms of imminent death will occur with every person or in the following sequence (Berry & Griffie, 2019):
  - Decreased urine output
  - Cold and mottled extremities
  - Vital sign and breathing changes
  - Delirium/confusion
  - Restlessness

**Suggested Supplemental Teaching Material:**

- Figure 1: Hierarchy of the Dying Person's Needs



# The Death Vigil

- **Family presence**
- **Common fears**
- **Opportunities for nurses**



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- The death vigil:
  - Family will often want to be 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.
- Attention to family concerns (Weissman, 2014):
  - Does my loved one have pain? How would I know?
  - Are we starving him/her by not feeding and/or administering IVs?
  - How many more minutes/hours/days do we have?
  - Should I call in other family members/friends who live far away?
  - Should I leave or stay at the bedside?
  - Can they hear me?
  - Giving the “last dose” of pain medication and causing death (in home setting)
  - What do we do after our loved one dies?
- This is a wonderful opportunity for nurses to do important work during this difficult time:
  - Keep in mind the goals of care
  - Assess and treat symptoms

- Communication with the interdisciplinary team
- Document
- Provide frequent oral and skin care
- Support families: Be present, listen, and bear witness

**\*This Concludes Section II**

**Section III: Bereavement Care**



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The slide features a dark blue background with a subtle pattern of hands. At the top, a white banner with a black border contains the text "Section III: Bereavement Care" in a bold, black, serif font. Below this banner is a central rectangular image of a white dove in flight, wings spread wide, against a bright blue sky with scattered white clouds. At the bottom of the slide, the acronym "E L N E C" is displayed in white letters on a black background, followed by the text "For Veterans Curriculum" in a smaller white font. To the right of this text are several small white dots.

## Care Following Death

- **Communication with the family**
- **Prepare family for next steps**
- **Technical tasks**



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- Care following the death takes time and sensitivity in regard to not only the deceased, but also the family members.
- Prepare the family prior to the death.
- After the death, prepare the family for the process which depends on setting (home vs. acute care vs. facility)
  - 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:
  - Removal of tubes, medical supplies and equipment:
    - 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 if the death was a coroner's case, where such tubes would need to be left in place until a coroner approves removal of tubes/equipment, etc.

- 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.
- Place dressings on leaking wounds, incontinence pad as needed for incontinence.
- Position the body in proper alignment, place dentures in mouth.
- Discuss plans for burial/cremation.
- Provide as much time as needed for the family to say good-bye.

## Care and Respect of the Body

- **Reflects importance and value of the Veteran**
- **Respect family rituals**
- **Allow family to provide physical care**
  - **Comb hair**
  - **Wash face/body**
  - **Hold hand, kiss, hug**

Berry & Griffie , 2019


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- Once the Veteran dies, the actions of the nurse should show not only excellent care of the body, but also exhibit respect (Berry & Griffie, 2019).
  - During this time, family members should be invited to talk and reminisce about their family member who died. This can help them begin to work through their grief.
- Before the Veteran died, the nurse has already spoken with the family to find out what traditions/rituals are important to them at this time.
  - Every effort should be made to honor requests that allow the family to grieve in accordance with their religion, cultural mores, etc.
- If a Veteran dies in the hospital, there is usually a sense of getting the room “cleared” as soon as possible, so another patient can be admitted. But, the nurse needs to advocate for the family at this time and make arrangements such that the family does not feel rushed.
- If the Veteran dies at home, the family may want their loved one’s body to remain in the home, until other family and friends can arrive.

- If the body is to be embalmed, this is generally best done within 12 hours after death. If the body is not going to be embalmed, the body can, in most cases, remain in the home for approximately 24 hours, before further decomposition and odor production occur. State laws vary on the amount of time a body can remain in the home.
- Family may want to take pictures, cut a lock of hair, etc. after their loved one dies.
  - Families should be encouraged to be as involved, as they would like to be in regard to care of their loved one's body.
  - Some family members will want to comb their loved one's hair, wash his/her face, hold his/her hand, kiss him/her, crawl into the bed with him/her and hold him/her.
- Families should be supported in these various ways of saying "good-bye."



# The Pause



*A Pause* is a brief acknowledgment of the patient's humanity just after death has been declared

Providence Health Care, Spokane, WA

[https://www.youtube.com/watch?v= HVXM2YhZ2A](https://www.youtube.com/watch?v=HVXM2YhZ2A) (2:16 min)

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## Pause

- As health care providers who have been in attendance at the death of a patient, we witness one of the most profound moments in a person's life. Unfortunately, the need to continue to provide care to our other patients takes us away from the patient who just died, before we have had a chance to either acknowledge the patient's humanity or the care we provided for the patient.

### **Suggested Video:**

*The Pause:* [https://www.youtube.com/watch?v= HVXM2YhZ2A](https://www.youtube.com/watch?v=HVXM2YhZ2A)

- The Pause has three simple parts:
  - One person in the room simply says something like, "Let's take a pause to honor the death of this patient, who was someone's brother (father, mother, son, partner, parent, etc.)."
  - In addition, healthcare professionals recognize their own contribution with a statement such as, "We all worked to provide the best care possible for this patient and should acknowledge that care."
  - Lastly, everyone simply stands silently at the bedside for 30 seconds or so (to reflect or as a moment of silence) before going to care for other patients.

**Final Salute**

- **Watch video of the Final Salute at Dublin VA**

**[https://www.youtube.com/watch?v=VRbHRRJeFjg&ab\\_channel=TheTelegraph](https://www.youtube.com/watch?v=VRbHRRJeFjg&ab_channel=TheTelegraph)**

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The above video link shows what may occur when a veteran dies at some VA hospitals. The body is placed on a gurney and is draped with the flag. As the body and family are led out of the hospital room to the exit, a ceremonial exit takes place. Health care workers, staff and, especially, their fellow Veterans come to the doors of their rooms. Civilians stand with their hands on their hearts. Veterans give the military salute, standing if they are able.

# Military Burial

## Burial in National Cemetery



## Burial at sea



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- Military veterans may choose to be buried in a national cemetery.
  - Cremated remains are buried or inurned in national cemeteries in the same manner and with the same honors as casketed remains.
  - If a Veteran chooses to be buried in a national cemetery their spouse and eligible dependents may also be buried with the Veteran. The name of the spouse will be inscribed on the Veteran's headstone, at no cost to the family. Eligible spouses and dependents may be buried, even if they predecease the Veteran.
- Some Veterans may choose a burial at sea.
  - This program is run through the U. S. Navy mortuary affairs not the VA.
  - The burial is performed on United States Navy vessels. The ceremony is performed while the ship is deployed. Therefore, family members are not allowed to be present. The commanding officer of the ship assigned to perform the ceremony will notify the family of the date, time, and longitude and latitude once the 1 service has been completed.

- The average amount of time, for burial at sea, is 12 to 18 months, once the remains/cremains are received at the port of embarkation.

**VA information on burial at sea:**

<https://www.va.gov/burials-memorials/eligibility/burial-at-sea/>

**U.S. Navy mortuary affairs**

<https://www.mynavyhr.navy.mil/Support-Services/Casualty/Mortuary-Services/Burial-at-Sea/>

## Honors Available to Deceased Veterans

- **Presidential Memorial Certificate**
- **Military funeral honors**
- **Burial flag**
- **Possible burial allowance**



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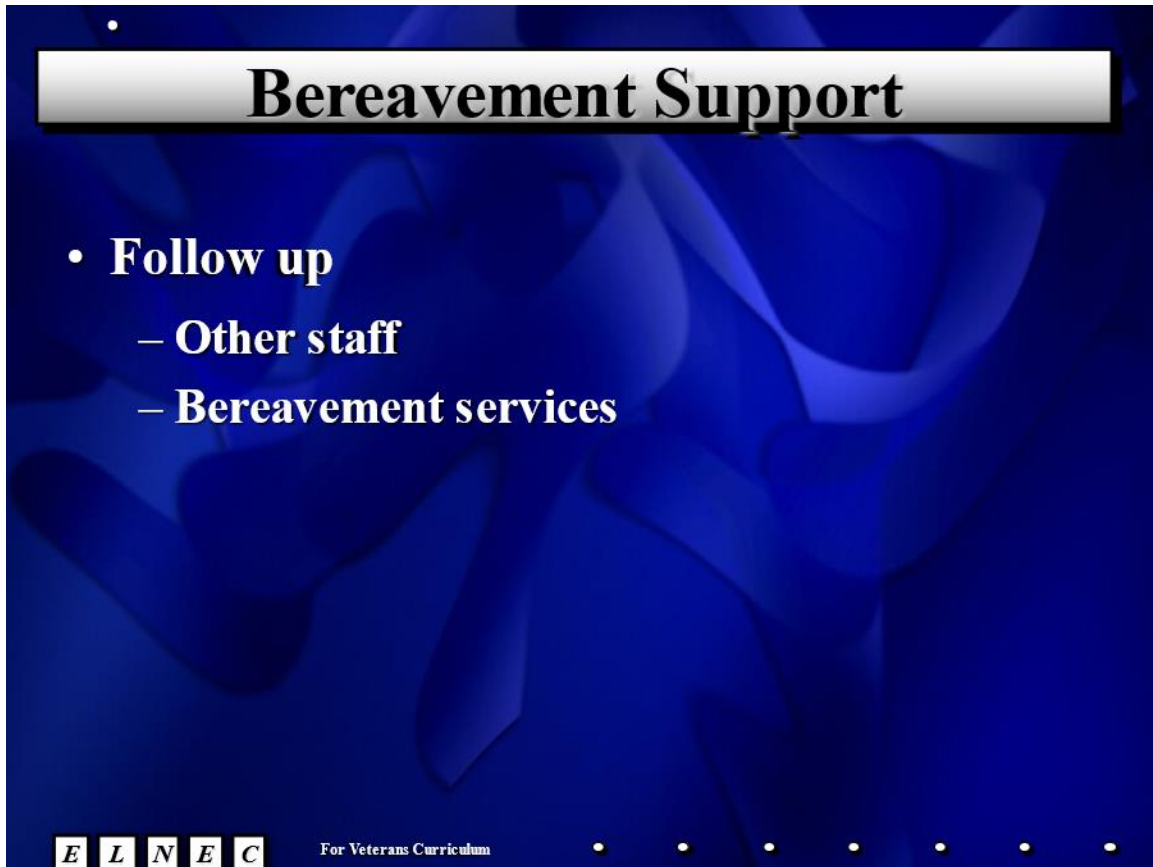
- A Presidential Memorial Certificate (PMC) is an engraved paper certificate that honors the memory of honorably discharged deceased Veterans who are eligible for burial in a national cemetery. Next of kin, other relatives, and friends may request PMCs and there is no time limit for requesting the certificate(s)
- A military funeral and honors at national cemeteries include a committal service, reading to accompany the burial if the family chooses, burial flag and military funeral honors requested by funeral directors on behalf of family and provided by DoD (uniformed persons, Taps, rifle detail, color guard) (WHV, 2022)
- Burial allowance may be available
  - The burial allowance for a non-service-connected death is \$300, and \$2,000 for a death connected to military service.
  - VA will pay up to \$796 toward burial and funeral expenses for deaths (if hospitalized by VA at time of death), or \$300 toward burial and funeral expenses (if not hospitalized by VA at time of death), and a \$796 plot-interment allowance (if not buried in a national cemetery).



Burial benefits: <https://www.benefits.va.gov/compensation/claims-special-burial.asp#:~:text=Service%2Drelated%20Death,the%20deceased%20may%20be%20reimbursed.>

Helpful Video for Veterans and families on VA death benefits:  
<https://youtu.be/c3hsIEj6Hpo>

We honor Veterans Burial benefits links:  
<https://www.wehonorveterans.org/benefits/burial-benefits/>



**Bereavement Support**

- **Follow up**
  - **Other staff**
  - **Bereavement services**

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- Bereavement support
  - Follow-up bereavement support through phone calls, cards, attending funeral/memorial service, and visits are helpful for the family and nurse's closure with the deceased.
  - If possible, nurses/social workers/chaplains should notify units where the Veteran had long and/or frequent admissions. Staff nurses on these units often need support and feel sad, and have the need to grieve the loss of the Veteran.
  - For survivors in need of continued bereavement support, refer to community bereavement resources including hospice, support groups. Survivors may need to know they are not alone and that they will not be abandoned to cope with their grief alone.
  - For further information on bereavement and self-care, review Module 6: Loss, Grief, and Bereavement.

**STOP AND CONSIDER:**

- Does your unit have a list of bereavement services you can offer families?
- Do you have a mechanism where families are sent a card or a follow-up phone call is made 1-2 months after a death? This is a very important opportunity to reach out to families, letting them know you have not forgotten them or their loved one.



## Death of a Parent....Remember the Children

- **Be aware of the developmental stage of the child**
- **Communicate openly and honestly**
- **Children need opportunities to ask questions**
- **Questions should be answered in terms that they can comprehend**

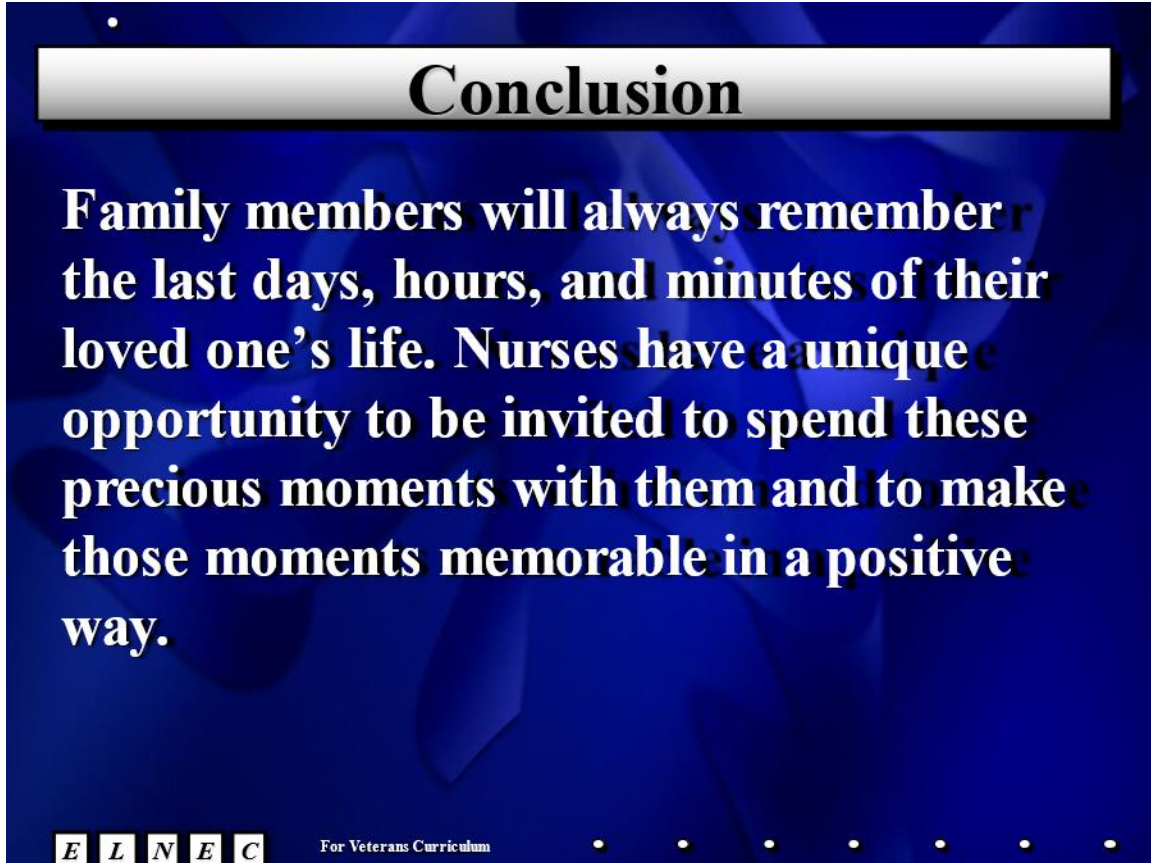
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- The death of a parent can be traumatizing for a child, no matter how old the child is. Members of the interdisciplinary team must be cognizant of the needs of young children, upon the death of one of their parents. Their conversation should be geared 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 parent's 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.** 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.

**NOTE:** All family members should receive a list of bereavement services in their communities. Many are found within hospice services, churches, and other community agencies.



**Conclusion**

**Family members will always remember the last days, hours, and minutes of their loved one's life. Nurses have a unique opportunity to be invited to spend these precious moments with them and to make those moments memorable in a positive way.**

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- 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. As nurses (Carpenter & Berry, 2016):
  - 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 interprofessional team members, as needed;
  - Listen;
  - Provide a presence;
  - “Bear witness.”
- Care of the Veteran and family at the time of approaching death or the time of death entails unique dimensions beyond those seen earlier in terminal illness care.
- Close collaboration of an interprofessional team and recognition of individual Veteran and family needs are essential.