

# **ELNEC- For Veterans**

END-OF-LIFE NURSING EDUCATION CONSORTIUM

Palliative Care For Veterans

# **FACULTY GUIDE**

## **Module 6 Loss, Grief, and Bereavement**

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**



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

**Palliative Care For Veterans**

# **Module 6: Loss, Grief, and Bereavement Part I: Overview**



*“There is a sacredness in tears. They are not the mark of weakness, but of power. They speak more eloquently than ten thousand tongues. They are the messengers of overwhelming grief, of deep contrition, and of unspeakable love.” ~Washington Irving*

**NOTE TO TRAINERS:**

- This module is divided into three sections:
  - Overview of loss, grief and bereavement from the Veteran’s perspective
  - Factors influencing the grief process for families
  - Factors influencing the grief process experienced by nurses who witness suffering, medical futility, and death all too frequently

**Teaching Tip:**

You may choose to teach this module in its entirety over one hour or in separate sections over 2–3 hours. Be sure to use the case studies, videos, vignettes, and supplemental teaching materials to enhance your presentation.

## Learning Objectives ...

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

- Define loss, grief, bereavement, and mourning.
- Distinguish between anticipatory grief, normal grief, complicated grief and disenfranchised grief.
- Describe eight influences on the grief process.
- Discuss three interventions that may facilitate normal grief.
- Verbalize the issues of grief and loss related to complex or traumatic circumstances.
- Discuss personal death awareness and cumulative loss associated with professional caregiving.
- Identify systems of support for the nurse to cope with death anxiety and loss.



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4. Discuss three interventions that may facilitate normal grief.
5. Verbalize the issues of grief and loss related to complex or traumatic circumstances.
6. Discuss personal death awareness and the cumulative loss associated with professional caregiving.
7. Identify four potential support systems for the nurse to cope with death anxiety and loss.

# NCP Guidelines

- ***Domain 7: Care of the Patient Nearing the End of Life***  
The IDT includes professionals with training in end-of-life care, including assessment and management of ..... grief and bereavement
- ***Domain 3: Psychological and Psychiatric Aspects of Care-*** The IDT... with the knowledge and skills to assess and ....provide emotional support, and address emotional distress and quality of life for patients and families experiencing the expected responses to serious illness [including grief].



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:*
  - Guideline 7.1.1.e: Talking about approaching death with patients and families.
  - Guideline 7.1.1.f: Identifying spiritual concerns related to dying, death, and beliefs about the afterlife.
  - Guideline 7.1.1.g: Facilitating cultural assessments and attending to the cultural aspects of care at the end of life, including cultural rituals and beliefs related to dying, death, or the afterlife.
  - Guideline 7.1.1.h: Supporting legacy building activities, including life review, notes to family and friends, or a video diary.
  - Guideline 7.1.1.i: Planning for post-death care, including funeral planning.
  - Guideline 7.1.1.n: Providing grief and bereavement support
- *Treatment prior to death*
  - Guideline 7.3.8: The IDT provides anticipatory grief support to the family and caregivers.
- *Treatment during the dying process and immediately after death*

- Guideline 7.4.2: Consistent with commitments to the patient and family, the IDT is available to provide support during the dying process.
- *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.
- **Domain 3: Psychological and Psychiatric Aspects of Care**
  - *Global*: Guideline 3.1.3c. Support patients, families, and staff experiencing compassion fatigue, moral distress, grief, loss, and bereavement
  - *Screening and Assessment*: Guideline 3.2.5. The IDT conducts ongoing assessment and reassessment for anticipatory grief, as well as the risk of prolonged grief disorder starting at diagnosis and throughout the illness trajectory
- *Treatment*
  - Guideline 3.3.4 Either directly or through referral, patients and families, including parents, children, and siblings at risk for prolonged grief disorder are provided with services and support based on best practices.
  - Guideline 3.3.5.d. Patient support related to a change in prognosis, anticipatory grief, loss, and emotional responses related to coping with advanced illness and end of life.
  - Guideline 3.3.5.e. Prompt information, resources, or referral to professionals as needed for patients and families at risk for prolonged grief disorder and/or bereavement, intractable depression and anxiety, suicidal ideation, delirium, behavioral disturbances, co-morbid substance use disorder, co-morbid psychiatric diagnoses, and other more complex psychological and/or psychiatric needs.
  - □Guideline 3.3.5.f. Family support related to anticipatory grief, the emotional aspects of caregiving, caregiver burden, or practical needs related to caregiving.

**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

## Sound Familiar?

- **Susan, a single mom Air Force Veteran: Her only son was killed in amotorcycle accident**
- **Joshua and Heather: Joshua is a OEF Army Veteran who committed suicide, Heather is also an Army Veteran**
- **Martin Navy Veteran: Partner died of a heart attack**
- **William a Marine Corps Vietnam Veteran: Wife of 60 years died from complications of diabetes**

## You Know These Stories Well

Nurses witness loss and grief

Many Veterans lose their health

Many Veterans experience changes in body due to serious illness

Many Veterans die - some well and some with difficulty

There are times nurses experience or witness moral distress

How does one process the grief?

## Definitions

- **Loss: Absence of an object, position, ability, or attribute**
- **Grief: Reaction to a loss**
- **Bereavement: Provides dispensation from usual activities for a variable period of time.**
- **Mourning: Refers not so much to the reaction to the loss but rather to the process of integrating the loss into everyday life.**
- **Cultural aspects**

Corless & Meisenhelder, 2019

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- **Loss** is defined as the absence of a possession or future possession, and with this comes the response of grief and the expression of mourning. Losses may occur before the death for the Veteran and significant others, as they anticipate and experience loss of health, changes in relationships and roles, and loss of life (anticipatory grief). After a death, the survivor experiences loss of the loved one. Most losses will trigger mourning and grief, and accompanying feelings, behaviors, and reactions to the loss. Veterans (loss of health, financial security, loss of body part, etc.), family members, and survivors all experience loss.
- **Grief** is the emotional response to a loss. Grief is the individualized and personalized feelings and responses that an individual makes to real, perceived, or anticipated loss (Corless & Meisenhelder, 2019). The feelings associated with grief cannot be felt directly by others, but the reactions to the grief and associated behaviors may be assessed by the nurse. These feelings can include anger, frustration, loneliness, sadness, guilt, regret, peace, etc. Veterans who have had experiences on the battlefield may grieve differently than non-Veterans, due to multiple losses and the horror of war. For many, their military comrades are their family. Some Veterans have witnessed horrors on the battlefield and have learned to be stoic, so they are able to continue with their mission and “fight to the bitter end”. This stoicism can carry over into other areas of the Veteran’s life. Stoicism



can also affect whole family systems. Grief may be hidden by a silent or angry facade (Grassman, 2009 & 2015).

- **Bereavement** provides dispensation from usual activities for a variable period of time. Please see next slide for further information about bereavement. Bereavement comes with certain rituals and obligations (i.e., funeral arrangements, distribution/disposal of the deceased's worldly possessions, and other details outlined in a will, etc.) (Corless & Meisenhelder, 2019).
- **Mourning** is the outward, social expression of a loss/death. How one outwardly expresses a loss may be dictated by cultural norms, customs, and practices including rituals and traditions. It also involves the process by which a bereaved person integrates the loss into his/her ongoing life.
- It is the nurse's responsibility to be aware of the **cultural characteristics** of grief and mourning for Veterans, family members, and survivors they care for. In thinking of culture, remember not only race, ethnicity, etc. but recall the culture of the military and the culture of stoicism that often accompanies it.

Military Culture can influence bereavement care:

- Stoicism may not allow the Veteran to be a gracious receiver of care.
- Death of a loved one can trigger PTSD or activate grief. Those with PTSD do not trust easily or reach out.
- Brotherhood/sisterhood that continues into caring for Veterans as they are dying.
- PTSD/alcohol abuse create multiple families, estrangements, forgiveness/reconciliation issues (Grassman, 2009).

## Overview of Loss, Grief, and Bereavement

- **Veteran, family, and nurse all experience losses**
- **Each person grieves in his/her own way**
- **An interprofessional approach is vital**

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- Loss, grief, and bereavement are experienced by the Veteran, family and nurse and each one experiences grief in their own way:
  - Using their own coping skills
  - In accordance with their own cultural norms, belief systems, faith systems
  - Past and present life experiences related to grief, loss, and bereavement
  - America is a death-denying society. As such, Americans often deny the need to express grief and feel the pain that accompanies a loss.
  - Expressing grief and experiencing the loss are beneficial to psychological healing.
- Nurses must utilize the interprofessional team approach (social workers, chaplains, volunteers, grief and bereavement counselors, psychiatric physicians and APRNs) to facilitate the Veteran's and survivor's grief process. Each discipline can contribute its unique expertise to the bereavement plan of care.

### **Module 7 Suggested Supplemental Teaching Materials:**

Table 3: Stages & Tasks of Grief

Figure 2: Loss Exercise

# Inconvenient Interruptions: Effects of Serious Illness on the Veteran's Social Well-Being

- **Interrupts Veteran's life**
- **Interrupts their family's life**
- **Disrupts financial stability**
- **Promotes isolation**
- **Interrupts dreams**



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When caring for a Veteran with serious illness, keep in mind that there are many other issues that their disease is disrupting—it's not just physical, but also psychologically, socially, culturally, spiritually/existentially, financially, etc.

- Serious illness can result in isolation
  - Changes in physical appearance - Loss of hair, surgical scars, loss of body parts
  - Changes in weight
  - Clothes don't fit anymore, need a wig, need assistive device (wheelchair, cane, crutches)
  - Awkward social interactions - Friends stay away/don't know what to say
- Serious illness can interrupt hopes, aspirations, and dreams for the future
  - Pursuing education
  - Hoping for promotion at work
  - Wanting to travel
  - Wanting to have children/see grandchildren grow up
  - Inability to be totally present with children/spouse/friends

## Meaning in Illness

*“Is it that patients seek to find meaning in illness or is that they seek to find meaning in the life that is now left, in relationships and, in all that we value? Terminal illness often forces one to reappraise the meaning and purpose of life. If one allows space in life for the process of meaning in illness to unfold, one then moves from the superficial to the profound.”*

Borneman & Brown-Saltzman, 2019

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- Nurses are committed to preventing suffering. Yet, many times when Veterans are seeking the meaning of their illness, their suffering is creating one of the greatest challenges to uncovering that meaning. This can be seen through physical and emotional pain, spiritual distress, and anticipatory grieving (Borneman & Brown-Saltzman, 2019).
- Veterans are frequently seen “broken”—both physically and spiritually. This brokenness allows their souls to cry to cry out and ask an existential question.....” Why?” Though the answer may not come, it does provide meaning.
- The nurses’ role (Borneman & Brown-Saltzman, 2019):
  - Respect the Veterans suffering and their various attempts to make sense of the illness
  - Provide opportunities for “telling”—allowing the patient to share their story
  - It is vital that nurses be present and attend to these patients. If not, nurses violate the providing supportive care to the dying. Accessed July 28, 2022, from: <https://www.nursingworld.org/practice-policy/nursing-excellence/ethics/code-of-ethics-for-nurses/> (ANA, 2015).



- Traumatic lifetime experiences can complicate peaceful dying and cause wounds such as PTSD, soul injury and moral injury to reemerge at the end of life.
  - Moral Injury results from events that are considered morally injurious if the events transgress deeply held moral beliefs and expectations. (Grassman et al., 2021). The VA and Department of Defense (DOD) use this term.
  - Soul injury is an overlooked, unassessed wound that separates a person from his/her own sense of self. (Grassman et al, 2021)
- “Raising awareness about soul injury can help deepen personal insight during the dying process, facilitate meaningful discussions, and promote appropriate grieving” (Grassman et al, 2021).
- Symptoms of soul injury include
  - lying, hiding, masking personal thoughts and feelings from others and/or self
  - disconnecting from a perception of one's own inner goodness and beauty
  - feeling empty or that a part of self is missing
  - having a vague or profound sense of worthlessness, inadequacy, or loss of meaning

- yearning to be someone else, belong, be approved of, feel “normal” or “good enough”
- using numbing agents to shut down loss, hurt, guilt, or shame (Grassman et al., 2021)

For more information on soul injury see OPUS Peace <https://opuspeace.org/>

**Teaching Tip:**

Have participants complete a soul injury inventory questionnaire and discuss <https://opuspeace.org/soul-injury-inventory/>

The anchoring heart technique (Opus Peace, 2022) is a simple intervention that nurses may use to help Veterans: <https://opuspeace.org/soul-injury-inventory/soul-restoring-resources/anchoring-heart/>

## **Serious Illness: It's Impact on Sexuality and Intimacy**

- **Inability to cope with many physical changes related to sexuality and intimacy can exacerbate suffering and promote isolation**
- **“How has your illness affected your sexuality? Your intimacy?”**
- **In your role, do you ask these questions?**

Shaw & Fronk, 2019

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- Throughout serious illness, there are different stages and each of the stages affect both sexuality and sexual functioning. Yet rarely is sexuality considered part of the social, emotional, or psychological coping or a “medical concern,” hence, it is infrequently assessed (Katz, 2018).
- As Veterans get sicker and closer to death, they become more fatigued, lack desire, and physical symptoms may prevent traditional sexual expression. Generally, patients still want to be close and intimate with friends and family. In one study, 86% of the 65 patients admitted to an acute pain and palliative care unit stated that sexuality was so important to them that they wanted to talk to a knowledgeable clinician (Bober et al., 2021).
- Best practice is that long before a Veteran is entering the final days/weeks of their life, the healthcare team has obtained a sexual history. Sexuality and intimacy are key components to quality of life. Because a patient is nearing the end of their life, their desire for sexual expression and intimacy should not be overlooked. It is important to know what a patient considers as “family.” “How has your illness affected your sexuality? Your intimacy?” (Shaw & Fronk, 2019).

## Ways to Foster Intimacy

- **Allow for privacy**
- **Encourage loved one(s) to lie in bed with the Veteran if desired**
- **Allow loved one to bathe the Veteran, apply lotion, which would encourage touch**

Katz, 2018; Shaw & Fronk, 2019

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- Allow for privacy (Katz, 2018; Shaw & Fronk, 2019).
- Encourage partner to continue lie in bed with their loved one no matter what the setting
- Support the partner in providing physical care for their loved one, such as bathing the patient and applying lotion, which encourages touch.



## Grateful Words to Nurses: Written By a Young Husband Who Witnessed the Death of His Wife

- *After his 34-year-old wife suffered a devastating asthma attack and later died, the Boston writer Peter DeMarco wrote a letter to the intensive care unit staff of CHA Cambridge Hospital who cared for her and helped him cope.*

<https://www.nytimes.com/2016/10/06/well/live/a-letter-to-the-doctors-and-nurses-who-cared-for-my-wife.html>

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.....“They (the nurses) asked me to leave the room for a moment, and when I returned, they had shifted Laura to the right side of her bed, leaving just enough room for me to crawl in with her one last time. I asked if they could give us one hour without a single interruption, and they nodded, closing the curtains and the doors, and shutting off the lights. I nestled my body against hers. She looked so beautiful, and I told her so, stroking her hair and face. Pulling her gown down slightly, I kissed her breasts, and laid my head on her chest, feeling it rise and fall with each breath, her heartbeat in my ear. It was our last tender moment as a husband and a wife, and it was more natural and purer and comforting than anything I’ve ever felt. And then I fell asleep. I will remember that last hour together for the rest of my life. It was a gift beyond gifts, and I have Donna and Jen to thank for it.”

~Peter DeMarco

To view the letter in entirety:

- <https://www.nytimes.com/2016/10/06/well/live/a-letter-to-the-doctors-and-nurses-who-cared-for-my-wife.html> [Accessed June 24, 2022]
- It is important that nurses understand signs/symptoms of the various types of grief so they can consult with other members of the interdisciplinary team as needed. No matter what the Veterans’ culture is, grief is a universal experience and should be assessed.

## Gen Silent: LGBT Aging



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- Have you witnessed discrimination against the lesbian, gay, bisexual, transgender, questioning, intersex, asexual/allied (LGBTQIA) community?
- What is the nurse's role in protecting those in the LGBTQIA community during these difficult and vulnerable times?
  - The life review is one method that can be utilized to create a welcome and affirming environment for the LGBTQIA Veteran. Life review is beneficial for older adults, in allowing them the opportunity to disclose the most personal aspects of their lives (e.g., sexual orientation). Nurses can provide a welcoming and nonjudgmental environment and use reflective listening in hearing a Veteran's story (Pelts et al, 2018).

Resources [last accessed June 24, 2022]:

We Honor Veterans LGBTQ Veterans at End of Life Webinar:

<https://www.wehonorveterans.org/resource-library/is-it-ever-too-late-understanding-lgbtq-veterans-at-the-end-of-life/>

LGBTQ VA Webpage: <https://www.patientcare.va.gov/lgbt/>

National LGBT Health Education Center: <https://www.lgbthealtheducation.org/>

SAGE (Advocacy and Services for LGBT Elders) <https://www.sageusa.org/>

National Resource Center for LGBT Aging

<https://www.lgbtagingcenter.org/resources/resource.cfm?r=854>

American Nurses Association. Nursing Advocacy for LGBTQ+ Populations. Position Statement. 2018. <https://www.nursingworld.org/~49866e/globalassets/practiceandpolicy/ethics/nursing-advocacy-for-lgbtq-populations.pdf>

**Suggested Video:**

- A Life of Honor: A Gay Veteran Recalls Serving in Silence: [https://www.youtube.com/watch?v=98vvuE38oBs&ab\\_channel=StoryCorps](https://www.youtube.com/watch?v=98vvuE38oBs&ab_channel=StoryCorps)
- *Gen Silent, The LGBT Aging Documentary*: <https://www.youtube.com/watch?v=fV3O8qz6Y5g>

## What are Veterans Basic Needs at the End of Life?

- **Control physical symptoms**
- **Shelter**
- **Assistance with elimination and hygiene**
- **Nourishment, fluids, if possible**
- **Companionship**
- **Recognition of their continued existence**

McHugh & Buschman , 2016

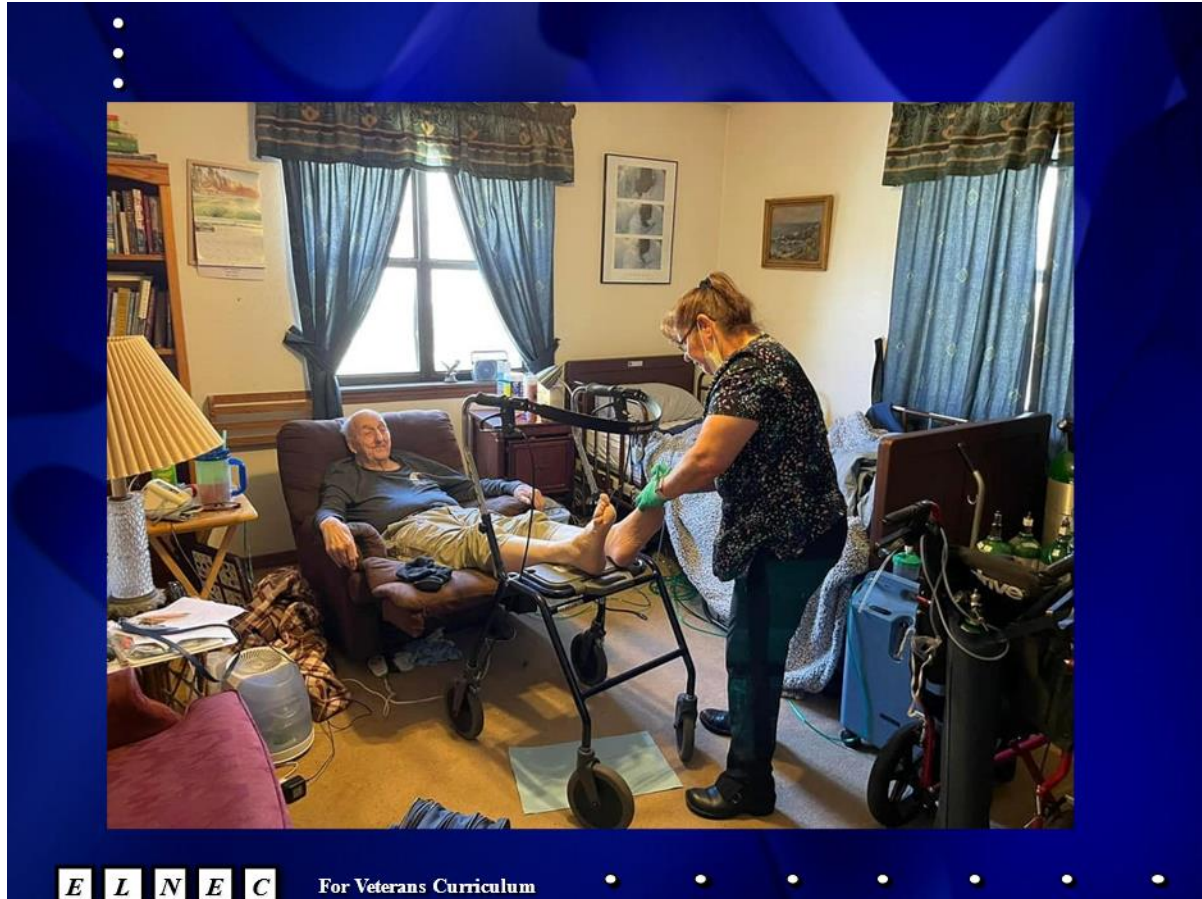
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- Each of the basic needs of Veterans near the end of their lives are outlined above (McHugh & Buschman, 2016). In recognizing these needs, it is important that our words and actions promote the very best care:

*“We will keep you warm and we will keep you dry. We will keep you clean. We will help you with elimination, with your bowels and your bladder function. We will always offer you food and fluid. We will be with you. We will bear witness to your pain and your sorrows, your disappointments and your triumphs; we will listen to the stories of your life and will remember the story of your passing.” ~ Byock, 1997*

## Slide 16



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- It is important for nurses to understand how Veterans and their families comprehend loss. In order to better understand loss, grief, and bereavement, nurses must be willing and committed to spend time with Veterans and their families—hearing their stories, being present, and bearing witness. Remember, we cannot always fix everything. But we are always present – which is vital and necessary.
- In this picture, Rhonda, a VA nurse uses her time to have deep discussions with Veterans, hearing their story as she performs nursing duties such as foot care. Rhonda who is also an Army Veteran commented “When caring for young wounded Active Duty women, I would ask if they wanted me to shave their legs, this seemingly little thing made such a difference in their self-esteem.”
- **\*This Concludes Section I**

## Section II: Factors Influencing the Grief Process in Survivors

Survivor personality

Coping skills, patterns

History of substance abuse

Relationship to deceased

Spiritual beliefs

Type of death

Survivor ethnicity and culture

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- There are many factors that affect the grief process:
  - Personality
  - Coping skills
  - History of substance use disorder
  - Relationship to the deceased
    - ◆ Age (survivor and deceased)
    - ◆ Nature of relationship (conflicting, adoring, congenial)
    - ◆ Financial arrangements (e.g., VA benefits)
  - Type of death and preparation
    - ◆ Sudden event
    - ◆ Long, chronic illness
    - ◆ Suicide
    - ◆ Accident/trauma
  - Survivor religious/spiritual belief system (Rosa, 2019; Taylor, 2019)
  - Survivor ethnicity, cultural traditions, rites and rituals
    - ◆ There are variations among rituals and mourning practices in different cultures which provides a context for the grief experience. It gives members a sense of security and of coherence, and the emotional, social, and physical resources in which to frame it (Cormack et al., 2019).
  - Other factors

- ◆ History of mental illness (i.e., depression, suicidal episodes)
- ◆ Support systems
- ◆ Concurrent stressors
- ◆ Experience and history of loss

The slide features a dark blue background with a subtle pattern of overlapping, semi-transparent shapes. At the top, a white banner with a black border contains the title "Transitions of Fading Away" in a large, bold, black serif font. Below the title is a bulleted list of seven items in a white sans-serif font. A quote in a white italicized serif font follows the list. At the bottom right of the slide, the text "Stajduhar & Dionne-Odom, 2019" is written in a small white font. At the bottom left, the acronym "ELNEC" is displayed in white letters inside black boxes, followed by the text "For Veterans Curriculum" in a white sans-serif font. A row of seven small white dots is positioned at the bottom center of the slide.

## “Transitions of Fading Away”

- **Redefining**
- **Burdening**
- **Struggling with paradox**
- **Contending with change**
- **Searching for meaning**
- **Living day to day**
- **Preparing for death**

*“The dimensions do not occur in linear fashion; rather, they are interrelated and inextricably linked to one another.”*

Stajduhar & Dionne-Odom, 2019

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- While various research studies have looked retrospectively and separately at families, spouses, and children who have experienced the death of their loved one, few actually include the patient and the entire family. Since palliative care is family-focused, it is vital to understand the perspective from both the patient and family members. Looking at this research reveals several themes that will be referred to as “fading away” (Stajduhar & Dionne-Odom, 2019).
- “Fading away,” occurs when family members realize that their ill family member is no longer LIVING with a serious, complex illness, but is DYING from it. “Oh my....mom’s renal failure is not getting better and she is going to die.”
- There are various dimensions that both patients and their families experience. These do not occur in a linear fashion; rather they are interrelated and inextricably linked to one another (Stajduhar & Dionne-Odom, 2019).
  - **Redefining:** A shift for patients and their family from “what used to be” to “what it is now”
  - **Burdening:** As patients may experience a lack of purpose and become more dependent, they may feel they are a burden to their family—physically, financially, emotionally,



socially, and spiritually. Yet, families do not always feel the care they are providing to a loved one is a burden, rather just “something you do for someone you love.”

- Struggling with paradox: Patients may struggle with the fact that they are living and dying—“I am living with cancer, but also dying from cancer.” They want to live, but they know they will not survive. Spouses want to provide care to their loved one, but they also want to lead a “normal life” too.
- Contending with change: Patients and their families change roles, socialization and work patterns, etc. They know that the life they use to have will soon be gone.
- Searching for meaning: Patients tend to journey inward, seek spiritual reflection, and become more connected to important family and friends. Family members will also search for meaning or will just tolerate the situation.
- Living day to day: For patients who find meaning in their illness, they are better equipped to live each day with a more positive attitude. Family who look at “making the best of it” make efforts to enjoy the limited time left with their loved one.
- Preparing for death: Patients want to leave a legacy. Spouses/partners/family want to meet every need of their loved one.

## Caregiving: The Human Toll

- **Caregivers are an extension of the healthcare workforce- they work 24/7**
- **VA caregiver support system**
- **Most patients have “family” caregivers**
  - **Most are women**
  - **37 billion hours in unpaid care/year**
  - **\$470 billion**



Fetterman, 2018

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- This slide is intended to show the importance of caregivers and the tremendous amount of time and effort this work takes. Most patients have “family” caregivers, which are an extension of the healthcare workforce. Most caregivers are women, who provide 37 billion hours in unpaid care to relatives or close friends per year, valued at \$470 billion (Fetterman, 2018).

### **STOP & CONSIDER:**

- Always remember to assess how the caregiver is doing when you see them with the patient in the long term care setting, clinic, acute-care, or home/community setting.
  - Provide the caregivers with encouragement.
  - Acknowledge that you know this work is very difficult.
  - Praise them for their selfless efforts.
  - Giving you the words to acknowledge their work: *“What you are doing for your husband is so difficult and takes great courage. Many caregivers have shared with me that while the work of caregiving is extremely challenging, they are grateful for this opportunity to spend this extra time with their loved one. What are your thoughts?”* These statements help to normalize the over-whelming difficulties and challenges of caregiving.

- A 2012 study showed that the best way to support family caregivers is to assist them in their caregiving role (i.e., help them identify friends/family who can go to the grocery store; can stay with the patient while the caregiver goes to a doctor's appointment, etc.), rather than focus on personal needs (Robinson et al., 2012).
- The VA has an extensive caregiver support system, with easily accessible resources. Information can be found the **VA Caregiver Support Program** website <https://www.caregiver.va.gov/>

## What Do Family Caregivers Want When They Are Grieving?

- **Loved one's wishes honored**
- **To be included in decision-making**
- **Practical help**
- **Honesty**
- **To be listened to**
- **To be remembered**
- **Know they did all they could possibly do**

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- What do family caregivers really want when they are grieving?
  - They want to know that their loved one's wishes are being honored.
  - The caregiver wants to be included in decision-making.
  - They want support/assistance and practical help (i.e., ask caregiver if there is a neighbor, a friend, a colleague who could contact others to assist with food, grocery shopping, going to the pharmacy, etc.).
  - They want honest conversation.
  - They want to be listened to—presence is so important.
  - They want to be remembered as being a “good” and compassionate caregiver.
  - They want to be assured that they did all they could possibly do for their loved one.

### Resources for Caregivers [Accessed June 25, 2022]:

- American Association of Retired Persons (AARP): *Family Caregiving* (information about self-care, financial/legal responses. List of local resources, stories from other caregivers) <https://www.aarp.org/caregiving/>
- National Alliance for Caregiving (NAC): Information for healthcare professionals, programming, mental health issues in caregiving, etc. <https://www.caregiving.org/resources/>

# A Grief and Bereavement Program is a Core Component of the Palliative Care Program

- **Interprofessional team**
- **On-going reassessment**
- **On-going support staff**
- **Complicated grief risk(s)**
- **Intensive support and prompt referrals**
- **Bereavement services available at least 13 months after death of loved one**
- **Culturally and linguistically appropriate information**
- **Respect of developmental, cultural, and spiritual needs**
- **Assess, resilience, cumulative loss, and grief of IDT**

NCP, 2018

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- According to the 2018 National Consensus Project for Quality Palliative Care, the components listed on this slide must be present in a grief and bereavement program (NCP, 2018).
- How do you and your organization address grief and bereavement? Do you have a formalized program?
- If you think back to slide 4 where listed are some familiar scenarios, what policies/procedures are already in place in your institution to meet these needs:
  - Young boy killed in a motorcycle a motorcycle accident, mother is Veteran.
  - Spouse grieving the loss of their husband who committed suicide.
  - A man experiencing intense grief over the unexpected death of his partner caused by a heart attack.
  - A Vietnam Veteran grieving the loss of his spouse of 60 years.
- Are there ways to improve and/or expand your program?

## The Grief Process

- **Both loss and growth can occur—but distress may still be experienced**
- **Emotional ‘waves’/oscillation is normal and expected**
- **Grief? Or depression?**
- **Cultural aspects**
- **Spiritual considerations**

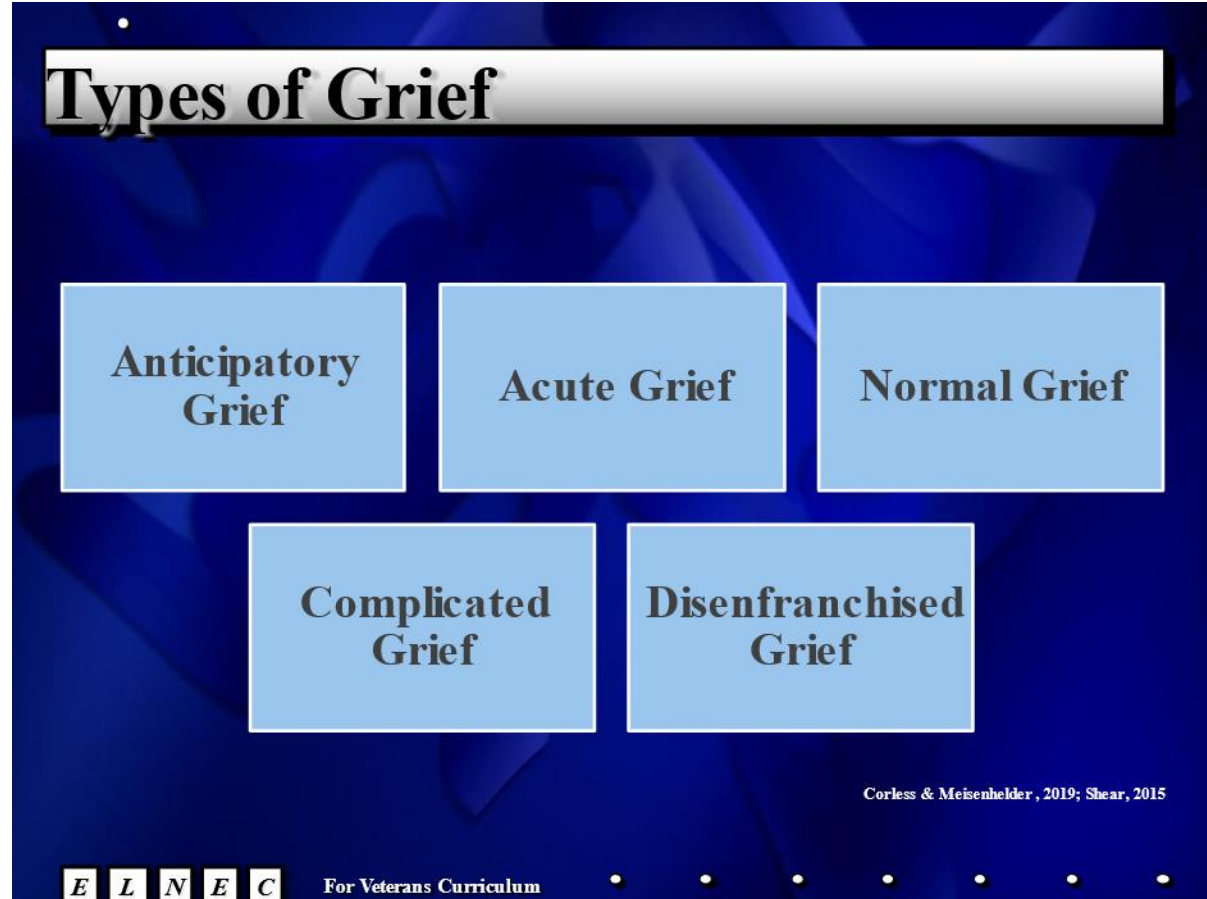


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- Grief is a process and is the response to bereavement. It begins before the death for the patient and survivor, as they anticipate and experience loss.
- The grief process is not always orderly and predictable—people will speak about growing through the loss, while still experiencing great distress.
- Emotional oscillation is normal and expected. There are “waves” or periods of oscillation when the one experiencing the loss feels “in control” and accepting, and there are times when they are not in control, and the pain of the loss is unbearable.
- Grief cannot be prevented. Grieving is a normal and necessary experience.
- Distinguishing between grief and depression can be challenging. Remember that depression is not a normal aspect of dying. Therefore, it should be carefully assessed and treated. Feelings of sadness are associated with grief, while depression is associated with loss of self-worth. How do you begin a dialogue to distinguish the difference between sadness and depression? Simply start by asking, “Are you sad or are you feeling depressed?” (Hallenbeck, 2015).

- Culture may also dictate how long one mourns and how the survivor “should” act during the bereavement period. In addition, outward expression of loss may be influenced by the individual’s personality and life experiences (Corless & Meisenhelder, 2019).
- Remember that assessing spirituality is vital, as it can assist in reconciliation and self-worth, resolving guilt, providing forgiveness, and “setting right” a relationship with God/Higher Being.



- Anticipatory grief is defined as grief before a loss, associated with diagnosis, acute, chronic, and terminal illness experienced by patient, family, and caregivers (Corless & Meisenhelder, 2019). Examples of anticipatory grief include: Actual or fear of potential loss of health, loss of independence, loss of body part, loss of financial stability, loss of choice, loss of mental function.
- Acute grief: begins after the death of a loved one and includes:
  - Separation response
  - Response to stress
- During this period of acute grief, the bereaved person may be confused/uncertain about their identity or social role. They may disengage from usual activities and may experience disbelief/shock that their loved one is gone (Shear, 2015).
- Normal grief is described as usual feelings, behaviors, and reactions to a loss. Normal grief reactions to a loss can be:
  - Physical
  - Emotional
  - Cognitive



- Behavioral
  - Cultural
  - Active grieving may take years. No one “gets over” the loss, but the relationship with the deceased changes. There is a reconnection with the world of the living.
- Complicated grief is seen in 10-20% of bereaved individuals (Claxton & Reynolds, 2015) and estimates are higher for parents losing a child (Shear, 2015). It is critical that nurses work closely with mental health professionals to make sure these individuals are cared for.
  - There are four types of complicated grief:
    - Chronic grief is characterized by normal grief reactions that do not subside and continue over very long periods of time. This has also been called Prolonged Grief Disorder and has been added to the Diagnostic and Statistical Manual of Mental Disorders (DSM). Accessed July 28, 2022 from <https://psychiatry.org/news-room/news-releases/apa-offers-tips-for-understanding-prolonged-grief>
    - Delayed grief is characterized by normal grief reactions that are suppressed or postponed and the survivor consciously or unconsciously avoids the pain of the loss (e.g., refuses to talk to anyone about the grief, not interested in bereavement groups, etc.).
    - Exaggerated grief is intense reaction that may include nightmares, delinquent behaviors, phobias (abnormal fears), and thoughts of suicide.
    - Masked grief is where the survivor is not aware that behaviors that interfere with normal functioning are a result of the loss (e.g., cancels lunch with friends, so they can go to the cemetery every day to see their loved one’s grave).
  - Risk factors for complicated grief include sudden or traumatic death, suicide, homicide, dependent relationship with deceased, chronic illness, death of a child (Limbo et al., 2019), multiple losses, unresolved grief from prior losses, concurrent stressors, difficult dying process such as pain and suffering, lack of support systems, lack of faith system. Complicated grief is also higher in women 60+ years of age (Shear, 2015).
  - Factors that contribute to complicated grief in the **older adult** include:
    - Lack of a support network
    - Concurrent losses
    - Poor coping skills
    - Loneliness
  - Disenfranchised grief is defined as any loss that is not validated or recognized. Society may not want to acknowledge the grief and does not know how to deal with the loss. Those affected by this type of grief do not feel the freedom to openly acknowledge their grief.
  - Those at risk include:
    - Partners of individuals with end stage HIV
    - Ex-spouses
    - Ex-partners
    - Fiancées
    - Friends, lovers, mistresses, co-workers
    - Children experiencing the death of a stepparent.

- Women (and husbands/partners) who have experienced a terminated pregnancy or a stillbirth

**Module 7 Suggested Supplemental Teaching Materials:**

Table 1: Types of Grief

Table 2: Normal Grief Reactions

Table 6: Inventory of Complicated Grief

# Grief Assessment

- **Begins at time of admission or diagnosis**
- **Should be ongoing to detect complicated grief**

Corless & Meisenhelder, 2019



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- Grief assessment includes the patient, family members, significant others. Grief assessment begins at the time the patient is, diagnosed with serious illness. Grief assessment is ongoing throughout the course of an illness for the patient, family members, and significant others and for the bereavement period after the death for the survivors. Grief should be assessed frequently during the bereavement period to alert the nurse to possible signs/symptoms/reactions of complicated grief (Corless & Meisenhelder, 2019).
- It is important to be honest in all aspects of care—time of diagnosis, development of goals of care, review of treatment options. Being ambiguous only promotes further confusion and grief. Seek assistance from other healthcare professionals (i.e., social workers, chaplains, psychiatrist, psychologists, child life specialists, etc.) as needed. Some questions to ask during this time include (Hallenbeck, 2015):
  - “Since receiving the news of your serious illness, how are you doing?”
  - “Are you frightened?”
  - “What is going on in your mind?”
- Brief Grief Questionnaire: A 5-item screening tool to assess for complicated grief. The questionnaire is scored on a 0-2 Likert scale where 0=not at all; 1=somewhat; 2=a lot

(Claxton & Reynolds, 2015). Recommendations by experts stress that individuals with scores of  $\geq 5$  should undergo a diagnostic evaluation by a mental health professional.

- How much time are you having trouble accepting the death of your loved one?
  - How much does your grief interfere with your everyday life?
  - How much are you having images or thoughts of your loved one when he or she died or other thought about the death that bothers you?
  - Are there things that you used to do when your loved one was alive that you don't feel comfortable doing any more that you avoid? How much are you avoiding these things?
  - How much are you feeling cut off or distant from people since your loved one died, even people you used to be close to like family or friends?
- Culturally and linguistically appropriate information/resources on loss and grief should be made available before and after the death. These may include support groups, counseling, and collaborative hospice partnership. Developmental, cultural, and spiritual needs must be assessed and supported (NCP, 2018).

**FACULTY NOTE:** If time permits, review Case Study #2- Heather: A Sudden Death. This will provide an opportunity to reinforce the concepts of loss, grief, bereavement, and mourning. In addition, it will prepare the participants for the next section on family grief.

# Children's Grief

- Based on developmental stages
- Can be normal or complicated
- Symptoms unique to children

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- Children's grief is based on developmental stages and can be normal and/or complicated.
- Symptoms of grief in **younger children** are numerous: Nervousness; uncontrollable rages; frequent sickness; accident proneness; rebellious behavior; hyperactivity; nightmares; depression; compulsive behavior; memories fading in and out; excessive anger; excessive dependency on remaining parent; recurring dreams of wish-filling; denial and/or disguised anger.
- Symptoms of grief in **older children** include: Difficulty concentrating; forgetfulness; poor school work; insomnia or sleeping too much; reclusiveness or social withdrawal; antisocial behavior; resentment of authority; overdependence; regression; resistance to discipline; talk of or attempted suicide; nightmares; symbolic dreams; frequent sickness; accident proneness; overeating or undereating; truancy; experimentation with alcohol/drugs; depression; secretiveness; sexual promiscuity; staying away or running away from home; compulsive behavior.
- In one study, 29% of children whose parents were diagnosed with cancer showed post-traumatic stress disorder (PTSD) symptoms serious enough to justify psychological help (Huizinga et al., 2010).

**Module 7 Suggested Supplemental Teaching Materials:**

Table 7: Interventions for Grieving Children

## Grief Interventions for Survivors: Listen to Their Story

- Provide presence
- Engage in or use active listening, touch, silence, reassurance
- Identify support systems
- Use bereavement specialists & resources
- Normalize & individualize the grief process
- Actualize the loss & facilitate living without deceased

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- Nurses have opportunities to provide grief interventions for survivors. Nurses can provide:
  - Presence, active listening, touch, silence. They all have a story. Veterans need to know that someone cares—someone wants to hear their story. Open communication with healthcare providers may be the first step in coming to terms with the actual loss.
  - Assistance in identifying support systems (i.e., extended family, friends, and support groups).
  - Collaboration and referral to bereavement specialists/bereavement resources.
  - Normalization of the grief process.
  - Individualization of the grief process.
  - Actualization of the loss and facilitating living without the deceased.
- It is the nurse's responsibility to be aware of the cultural characteristics of grief and mourning for patients, family members, and survivors they care for.

**NOTE:** Nurses must continue to assess the bereaved. Work with interprofessional colleagues, especially those in grief counseling, psychology, and psychiatry.

### **Module 7 Suggested Supplemental Teaching Materials:**

Table 4: Unhelpful & Helpful Comments in Speaking with Bereaved

Figure 3: Opportunities for Reminiscing

**Everyone Has a Story**

**View this video from the Veterans Legacy Project, which provides a platform for families to remember a deceased Veteran:**

**[https://www.youtube.com/watch?v=nQwc6qHR2LY&t=270s&ab\\_channel=GovCIOMedia%26Research](https://www.youtube.com/watch?v=nQwc6qHR2LY&t=270s&ab_channel=GovCIOMedia%26Research)**

**(4 minutes, 32 seconds)**

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- Listen to Matt Heisey’s story:  
[https://www.youtube.com/watch?v=nQwc6qHR2LY&t=4s&ab\\_channel=GovCIOMedia%26Research](https://www.youtube.com/watch?v=nQwc6qHR2LY&t=4s&ab_channel=GovCIOMedia%26Research)
- The Veterans Legacy Memorial (VLM) is a digital platform dedicated entirely to the memory of the nearly 4.5 million Veterans interred in VA's national cemeteries. The VLM has interactive features that allow family, friends, and others to preserve their Veteran’s legacy by posting comments, uploading images, sharing their Veteran's military service timeline and achievements, biographical information, historical documents and more. The site allows visitors to share Veteran profile pages by email and post them to Facebook and Twitter. Additionally, VLM users can also "Follow a Veteran" to receive email alerts when new content is added to that Veteran's page. (NCA, 2022)

**Discussion Questions:**

1. What did you learn from this story?
2. Did you have a thought that was particularly poignant? If so, describe.
3. After seeing this video, how might it change your practice?



4. Were there concepts in this video that we could transfer to our institution, in an effort to better hear people's story?

**Suggested Videos:**

Based on your audience other videos from the VLM project could be used. Those videos can be found at: [https://www.cem.va.gov/videos/Preserving\\_Veterans\\_Legacies.asp](https://www.cem.va.gov/videos/Preserving_Veterans_Legacies.asp)

## Interventions for Children, Parents, and Grandparents

- **Recognize developmental stage of child**
- **Refer to support groups**

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- Attention to interventions are vital, no matter what age the survivor.
- For **children** who have experienced the loss of a parent, a sibling, a grandparent, or friend, it is important that their grief be assessed, dependent on their developmental stage. Children may be limited in their ability to verbalize and describe their feelings or grief. Their cognitive development may interfere with their ability to understand the irreversibility, universality, and inevitability of death. This can lead to emotional confusion, as they filter through their own personal thoughts, as well as seeing their parents mourn (Limbo et al., 2019). Use the word “death,” not “gone away,” “passed on,” or “gone to sleep.” Use child life specialist to assist in developing a plan of care for children.
- For **parents**, the death of a child has often been described as one of life’s most devastating experiences. The death affects not only the parents, but the siblings, grandparents, other relatives, friends, and the community as a whole. For the survivors, emotional, spiritual, and practical needs for support continue beyond the child’s death.
- For **grandparents**, the grief can be two-fold: they experience their own grief, plus they witness the grief of their own child, the parent of the deceased child. Studies are clear that grandparent’s grief is seldom acknowledged (Limbo et al., 2019).

- For **children and families**, StoryCorps has developed an online resource to aid grieving children and families in sharing their stories. “StoryCorps DIY: Road to Resilience” includes strategies to encourage meaningful dialogue about the impact of grief, including animations and audio interviews. Other resources include techniques for developing recordings of interviews, including question guides and planning worksheets. Accessed July 28, 2022 from: <https://storycorps.org/supporting-children-in-grief-with-storycorps-diy-road-to-resilience/>
- Grief interventions for children and adults include:
  - Follow-up phone calls or visits by healthcare providers who cared for the deceased are generally appreciated by families.
  - Encouraging children and adults that their grief is “normal” gives them comfort.
  - Everyone grieves uniquely, so telling someone “how to grieve” is inappropriate.
  - Play is the universal language of children—use it as often as possible.
  - Refer children/parents/families to grief therapists. Make sure families are aware of local support groups, memorial services, or grief workshops (Limbo et al., 2019; Stajduhar & Dionne-Odom, 2019).

**Module 7 Suggested Supplemental Teaching Material:**

Table 8: Supporting Grieving Families

# Grief Support Should Be Provided in a Variety of Ways

- On-line support
- Bibliotherapy
- Individual counseling
- Group support
- Community support
- Rituals



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- Those experiencing grief and loss should be offered a variety of options for support:
  - On-line support has grown over the years. This is helpful for many, as they usually get immediate attention after posting something.
  - Bibliotherapy is an expressive therapy, where the person uses books, poetry, etc., as therapy. Bibliotherapy can also be combined with writing therapy—writing of one’s thoughts, etc.
  - Individual counseling, group support, community support, and rituals can also be helpful to people. Veterans often describe the attachment and bonding they feel with other Veterans. Some state that the relationships they have built with other Veterans (many went through training and deployment together) are the closest they have formed in their lives.
  - Rituals such as honoring veterans for their service can be meaningful for both the Veteran and the family.
- Many use a variety of these support systems.

## Completion of the Grieving Process: Is It Possible?

- **Grief work is never completely finished**
- **Healing occurs when the pain is less**
- **Letting go**



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- Grief work is never completely finished, as there will always be times when a memory, object, anniversary of the death, or feelings of loss occur.
- Grief can diminish and healing can occur, as characterized by:
  - The pain of the loss is less.
  - The survivor has adapted to life without the deceased.
  - The survivor has physically, psychologically, and socially “let go.”
- “Letting go” is difficult. This is a process. One can “let go” and still love, find uniqueness, and secure true meaning in the relationship they had with the one who died. Memories should still be cherished.

**NOTE:** The survivor, however, will continue to experience memories of the deceased.

## Case Study

- **Susan, age 54, is a caregiver to her partner Tom, age 72. They have lived together for 6 years. Tom is a Vietnam Veteran who served in the Navy. Tom was diagnosed with ALS 2 years ago. His disease is progressing rapidly and he has just returned home after 4 weeks in the ICU. He does not talk about his Vietnam experience and is angry most of the time. He is now on a ventilator.**
- **Susan is exhausted, she can't sleep or eat. They have little community/family support.**

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- Nursing assessment is vital (Chovan, 2019). Components of the nursing assessment for Susan and Tom may include:
  - Type of grief: anticipatory, normal, complicated (including risk factors for complicated grief), disenfranchised—could be all of these types of grief
  - Grief reactions: normal or complicated?
- Factors that may affect the grief process—If Susan and Tom have little community and/or family support, Susan may have great difficulty managing Tom's complicated care alone. She may be experiencing lack of control, lack of autonomy. She is frightened. Does she feel confident to manage the ventilator and all the care it entails?
- Many caregiver survivors do not care for themselves while caring for their loved one. As such, an assessment should also include (Corless & Meisenhelder, 2019):
  - General health check-up and assessment of somatic symptoms.
  - Dental/eye check-ups.
  - Nutritional evaluation.
  - Sleep assessment.
  - Examination of ability to maintain work and family roles.
  - Assessment of social networks.

- Determination of whether there are major changes in presentation of self.
- Assessment of changes resulting from the death and the difficulties with these changes.

**STOP & CONSIDER:**

If you were the hospice nurse caring for Tom at home, how would you assess Susan's needs? How would you assist her with her basic needs of food and sleep? Are there other members of the interprofessional team who could help? If so, who?

**\*This Concludes Section II**

## Section III: The Nurse: Prevention of Moral Distress and Compassion Fatigue

### Nurses witness:

- **Medical futility**
  - Prolongation of suffering
  - Denial of palliative care services



### Nurses experience:

- **Moral distress**

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*“...we have the gift and the curse of extreme empathy and we suffer. We feel the feelings of our clients. We experience their fears. We dream their dreams. Eventually, we lose a certain spark of optimism, humor and hope. We tire. We aren't sick, but we aren't ourselves.” ~C. Figley, 1995*

- With the advancement of technology and the ability to prolong life, nurses frequently witness non-beneficial medical treatments, which lead to prolonged suffering and denial of palliative care services for their patients and intense moral distress for themselves. Many times, these experiences will lead a nurse to become frustrated and powerless to change “the system.” Nurses’ distress and discouragement can be devastating, as many will experience compassion fatigue, and some will choose to leave the nursing profession.
- Examples of non-beneficial medical care that nurses frequently witness include:
  - Aggressive care denying palliative care.
  - Code status or resuscitation not being discussed.
  - Ventilator/life support, nutrition, hydration, feeding tube, blood transfusions chemotherapy, dialysis being recommended and knowing it will provide non-beneficial care and increase patient suffering.
  - Poor pain and symptom management.
  - Violation of patient preferences, beliefs, and decisions.



- Nurses experience a great deal of moral distress regarding medically non-beneficial care and this can lead to a variety of responses and emotions (Coyle & Kirk, 2019; Ferrell, 2006; Ferrell & Coyle, 2008). These may include:
  - Advocacy for patients and their families.
  - Torture, assault, violence, or cruelty to Veterans receiving non-beneficial care.
  - Personal frustration, distress, anger, demoralized, powerless, helpless, or hopeless.
  - It is vital that nurses identify these various conflicts and emotions and collectively give a voice to these topics through greater support of the nursing profession, scholarship, and advocacy for their patients and families.

## Sound Familiar

- You just finished a long day and you were supposed to join friends at the pool for water aerobics. You decide you are too tired, so you drive through McDonald's for a quick dinner.
- Your oldest son plays basketball on his junior high team. The season is almost over, and you have yet to go to a game, because of other commitments.
- Instead of looking at what is around you (trees, blue sky, and a few birds passing by) you are stressed because traffic is jammed.
- Your boss has called you in twice over the past 2 months because patients/families have reported your rude behavior.
- You haven't been away on vacation in over 5 years.

## Hazards in the “Helping Professions”

- **Intense emotional energy due to patient care situations**
  - **Constant, stressful end of life scenarios**
  - **Physical suffering**
  - **Emotional distress**
  - **Psychological pain**
  - **Moral distress**

Kravits, 2019

**E L N E C**

For Veterans Curriculum

- Palliative care providers, by nature of their work, are exposed to patient care situations that require the intense emotional energy (Kravits, 2019).
  - Constant and stressful end-of-life care scenarios
  - Physical suffering
  - Emotional distress
  - Psychological pain
  - Moral distress
- Often these palliative care issues places the palliative care providers at risk for compassion fatigue and burnout.

**Cumulative Loss**

- **Listen to the story of Vietnam Nurses:**
  - **[https://www.youtube.com/watch?v=-6RMDQ-KgIk&ab\\_channel=VietnamVeteransMemorialFund](https://www.youtube.com/watch?v=-6RMDQ-KgIk&ab_channel=VietnamVeteransMemorialFund)**

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- Cumulative loss is a succession of losses experienced by nurses who work with patients with life-threatening illnesses and their families, often on a daily basis (Borneman & Brown-Saltzman, 2019).
- Many times, nurses do not have time to acknowledge losses before another loss occurs. It is not uncommon that a patient from the operating room or emergency department is placed in the same bed and room where a patient who had just died two hours prior. This does not provide nurses and other members of the interprofessional team an opportunity to remember the patient who just died and their family. No time for rituals (placing a rose on the bed for 24 hours where a patient has died, etc.).
- Nurses can experience anticipatory and normal grief before and after the death of a patient.
- Not only is loss painful, but when the nurse is exposed to death frequently, they may not have time to resolve the grief issues of one patient before another patient dies.
- These losses have been compounded by loss of our own loved ones and colleagues during the COVID-19 pandemic. Close to 1 million healthcare personnel have been infected with and 2300 have died from COVID-19. And interventions designed to control the pandemic, such

as quarantine and limitations on social gatherings, have complicated gatherings and rituals designed to address grief and loss. Accessed July 28, 2022 from: <https://covid.cdc.gov/covid-data-tracker/#health-care-personnel>

**Module 7 Suggested Supplemental Teaching Material:**

Table 5: Coping with Professional Anxiety and Terminal Illness

Figure 1: Personal Loss History

Figure 2: Loss Exercise



Healthcare professionals, particularly nurses, are at risk for moral injury, moral distress, compassion fatigue – and these can lead to burnout. Understanding the differences between these can guide assessment and direct interventions:

**Moral Injury:** The distressing psychological, behavioral, social, and sometimes spiritual aftermath of exposure to traumatic events. A moral injury can occur in response to acting or witnessing behaviors that go against an individual's values and moral beliefs. Feelings such as guilt, shame, disgust and anger are some of the hallmark reactions of moral injury. (Čartolovni, et al., 2021; Dean, Talbot, & Dean, 2019)

**Moral Distress:** Occurs when one knows the ethically correct action to take but feels powerless to take that action. For example, when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue this course of action. (Morley, et al., 2019)

**Compassion Fatigue:** A syndrome that results from constant exposure to the stress of working with individuals with significant health issues, as well as death, dying, and suffering. This can lead a person to being unable to love, nurture, care for, or empathize with someone's suffering. It can also impact personal relationships (i.e., spouses, children, friends, other family members, etc.). (Figley, 1995)

Burnout: A broad-based syndrome that develops gradually as a person interacts within the conditions, time pressures, or stressor of a workplace. Burnout is associated with a situation rather than an individual. Can be manifested physically and psychologically: decrease in loss of motivation; emotional exhaustion; cynicism; and inefficiency (Kravits, 2019; Todaro-Franceschi, 2013)

The U.S. Surgeon General has acknowledged that health worker burnout is an urgent public health issue and has developed an advisory to direct system wide solutions. “Addressing Health Worker Burnout: The U.S. Surgeon General’s Advisory on Building a Thriving Health Workforce” (2022). Accessed July 28, 2022 from: <https://www.hhs.gov/sites/default/files/health-worker-wellbeing-advisory.pdf>



- The Office of the Surgeon General (2022) produced an advisory on health care worker burnout. This exhaustive review of the literature revealed numerous factors contributing to burnout. **Societal and Cultural:** Factors in this domain include as the politicization of science and public heal, structural racism, health inequities, health misinformation, and unrealistic expectations of health care workers
- **Health Care System:** Burdensome paperwork and technologies, poor care coordination, along with misaligned regulations and reimbursement all contribute to health care worker burnout. **Organizational:** Variables such as lack of leadership, excessive workload, and a disconnect between values and key decisions all contribute to organizational contributors to burnout.
- **Workplace and Learning Environment:** Limited flexibility, autonomy and voice contribute to feelings of powerlessness. A lack of culture of collaboration compounded by limited time with patients and colleagues adds to a negative work environment. Inadequate attention to health care worker well-being or even harassment, violence and discrimination advance a toxic workplace.



**Bullying**

**Bullying: “repeated, unwanted, harmful actions intended to humiliate, offend and cause distress in the recipient”**

- **Contributes to poor work environment and greater staff turnover**
- **Associated with lower patient satisfaction scores and poor outcomes**

American Nurses Association, 2022

**ELNEC** For Veterans Curriculum

- Unfortunately, we all have witnessed some form of bullying in our careers. Bullying can take many forms, such as experiencing behavior that is unwelcome, offensive, unsolicited.
- Bullying contributes to a poor nurse work environment, lower patient satisfaction scores, increased risk to patients with poor outcomes, and greater nurse turnover, which leads to increased costs.
- For more information on this subject go to [Websites last accessed June 25, 2022]:
  - <https://nurse.org/articles/how-to-deal-with-nurse-bullying/>
  - <https://www.americannursetoday.com/just-eating-young-workplace-bullying-strikes-experienced-nurses/>
  - <https://www.nursingworld.org/practice-policy/work-environment/violence-incivility-bullying/>

# Self-Awareness: Being Proactive With Caring for Ourselves

- **Self reflection**
- **Self efficacy**
- **Body monitoring**
- **Wellness plan**



Kravits, 2019

**E L N E C**

For Veterans Curriculum

- Throughout life, there are opportunities to stop and pay attention to warning signs of compassion fatigue, vicarious trauma, and burnout. Here are some questions to consider:
  - How does my behavior change?
  - How do I communicate differently?
  - What destructive habits tempt me?
  - How do I project my inner pain onto others?
- By becoming self-aware, we can be more successful in implementing self-care strategies. Effective self-care creates well-being. Elements of self-care include (Kravits, 2019):
  - **Self reflection:** Examines expectations for positive outcomes. Conducted with compassion and should be nonjudgmental. Beneficial when includes past failures as well as past successes.
  - **Self efficacy:** Positive self-efficacy is an individual's knowledge that he/she is capable. Believing in oneself is often difficult to do but is necessary for positive self-care.
  - **Body monitoring:** Is frequently used as one element of self-care strategies to manage chronic illnesses such as heart failure and diabetes. It is a regular assessment of bodily processes through intentional redirection of attention to the body. Healthcare providers are vulnerable to this because regardless of how they "feel" in a professional situation,

they learn to ignore their feelings in order to provide safe and effective care. However, it is important to listen to your body's voice in order to achieve "well-being."

- **Well-being planning:** Writing plans down increases the chance that they will be accomplished. This is true with wellness plans.

**Module 7 Suggested Supplemental Teaching Material:**

Figure 6: Self-care Strategies for Nurses

**Emotional Labor**

- **Requires energy and resources**
- **Without taking time to rest:**
  - **stress**
  - **emotional exhaustion**
  - **cynicism**
  - **inefficiency**
- **When we have balance in our life, it promotes:**
  - **self-efficiency**
  - **optimism**
  - **hardiness**
  - **resiliency**

Kravits, 2019

**ELNEC** For Veterans Curriculum

Providing palliative care demands “emotional labor” to accomplish its goals. This requires a tremendous amount of energy and resources. Overusing personal energy and resources without taking time for rest and/or renewal can lead to stress, emotional exhaustion, cynicism, and inefficiency in our work and persona responsibilities (Kravits, 2019).

# Factors Influencing the Nurse's Adaptation

- **Professional education**
- **Personal death history**
- **Life changes**
- **Support systems**



Vachon et al., 2015

**E L N E C**

For Veterans Curriculum

- There are numerous factors that influence the nurse's adaptation process.
- Professional education
  - In the past, healthcare professionals were often told to control emotions and to emotionally distance themselves from patients and families. Patients with serious illness require intense interpersonal involvement and compassionate care.
  - Verbalizing feelings and expressing emotions helps the nurse process grief and loss.
- Personal death history
  - Past experiences with death on a personal and/or professional level and possible unresolved grief issues can influence the professional's ability to cope with caring for dying residents and their families.
  - Practice environments will impact reactions to death. For example, staff who work in long-term care may not be optimistic about growing old, as they see the minimal respect and value that the older adults in their care receive.
- Life changes
  - Life changes may include a death in the family, caring for elderly parents, separation from loved ones, children leaving home, divorce, and illness.

- These changes may signify losses, trigger grief responses, and make it difficult for the nurse to cope with caring for dying patients and their families.
- Support systems
  - The presence or absence of support systems can influence the ability to move through the stages of adaptation.
  - Emotional support provided by peers, family, coworkers, and nursing faculty greatly increases the capacity to adapt to and cope with the care of the dying.

**Suggested Video:** *Self Care*; Video can be accessed at:  
<https://vimeopro.com/reliaslearning/el nec/video/137167046>

**Module 7 Suggested Supplemental Teaching Material:**

Figure 7: Exercise & Spiritual Practice for Stress Reduction, Health & Well Being

# Personal Well-being

- **Unique for each person**
- **Balance**
- **Holistic care**
- **Role model good selfcare for your staff**

**E L N E C** For Veterans Curriculum

- Taking care of yourself is unique to each person. Some of the items to consider are:
  - Balance/different priorities: work hard/play hard
    - Travel
    - Read
    - Journal
    - Meditate
    - Humor
  - Holistic care:
    - Physical
    - Psychological,
    - Social
    - Spiritual
    - Cultural/Emotional
  - Role model well-being for your staff

**Module 7 Suggested Supplemental Teaching Materials:**

Figure 4: Self Care Assessment

Figure 5: Mindfulness and Self-Care

Figure 6: Self Care Strategies for Nurses



# We Honor Veterans Program

**ELNEC** For Veterans Curriculum

The We Honor Veterans program is a program is a source of information and support for nurses caring for seriously ill Veterans. Palliative care and hospice programs can demonstrate commitment to providing Veteran centric care, through this program at no cost.

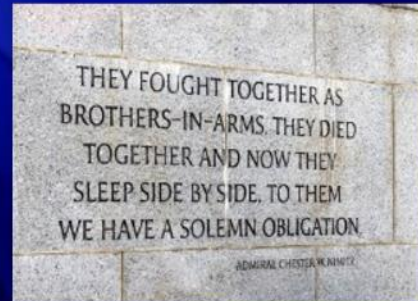
When staff are empowered with information on how to best care for Veterans and families it serves as a support system for all.

More information on the WHV program is available at <https://www.wehonorveterans.org/>



## Conclusion

- **Nursing care does not end with the death of a patient**
- **Nurses must recognize and respond to their own grief**
- **Bereavement care is interprofessional care**
- **Nurses must role model excellent care**



**E L N E C** For Veterans Curriculum

- Nursing care and responsibilities to the dying patient and their family do not end with the death of the patient.
- Loss, grief, and bereavement should be assessed upon admission and bereavement care should continue after the death of the patient.
- Nurses, as with all professionals, must recognize and respond to their own grief in order to provide quality palliative care.
- Bereavement care is interprofessional care, and our psychosocial colleagues have much to offer.
- Nurses role model excellent care in grief, loss, bereavement and well-being .

**\*This Concludes Section III**