



NC DEPARTMENT OF
**HEALTH AND
HUMAN SERVICES**
Division of Health Service Regulation

State-approved Curriculum Nurse Aide I Training Program

MODULE W End-of-Life Care and Death

Teaching Guide 2024 Version 1.1



NC DEPARTMENT OF
**HEALTH AND
HUMAN SERVICES**



North Carolina Department of Health and Human Services
Division of Health Service Regulation
North Carolina Education and Credentialing Section

NCDHHS is an equal opportunity employer.

Module W – End-of-life Care and Death Teaching Guide

Objectives

1. Define death and end-of-life care
2. Describe stages of grief
3. Explore cultural differences in dealing with death and dying
4. Examine own feelings about end-of-life
5. Describe the nurse aide's role in end-of-life care

Advance Preparation – In General

- Review curriculum and presentation materials
- Add examples or comments in Notes Section
- Set up computer
- Establish internet connection

Supplies – optional

Handouts- optional

Guest Speakers - optional

Advance Preparation – Teaching Tips

- **#W7 How Do I Feel: Self Inventory Attitude Toward Caring for Residents Who Are Near Death** Duplicate student worksheet for each student.

Definition List

Acceptance - the final stage of grief (in response to near death) when person has worked through feelings and understands that death is imminent

Advance Directive – a living will written while resident is mentally competent or by resident’s legal representative which outlines choices about withdrawing or withholding life-sustaining procedures, if terminally ill

Anger – the second stage of grief (in response to near death) when person expresses rage and resentment; often upset by smallest things; lashes out at anyone

Apnea – respiration stops

Bargaining – the third stage of grief (in response to near death) when person tries to arrange for more time to live to take care of unfinished business; bargains with the doctors or God

Cheyne-Stokes Breathing – when resident takes several shallow breaths followed by periods of no breathing for 5, 30, or even 60 seconds; does not cause the resident discomfort

Death – the end-of-life and cessation of bodily functions

Denial – the first stage of grief (in response to near death) when a person is told of impending death; person may refuse to accept diagnosis or discuss situation

Do Not Resuscitate (DNR) – an order written by a doctor at the request of a resident, which tells the health care team that the resident does not wish any extraordinary measures to be used when resident suffers cardiac or respiratory arrest

Depression – the fourth stage of grief (in response to near death) when person begins the process of mourning; cries, withdraws from others

Dying – the near end of life and near cessation of bodily functions

End-of-life care – support and care provided during the time surrounding death

Extraordinary Measures – interventions used to restore heart beat or respiratory effort (cardiopulmonary resuscitation or CPR)

Five Stages of Grief – stages of grief in response to near death, based on personal, cultural, and religious beliefs and experiences, according to Elizabeth Kubler-Ross

Hospice Care – health care agency or program for people who are dying (usually less than six months to live) that provides comfort measures and pain management, preserves dignity, respect, and choice, and offers empathy and support for the resident and the family

Mottling – changes in skin color (pale and bluish) of the hands, arms, feet, and legs when death is near

Obituary – a description (typically placed in a local newspaper) of a resident's life, including listing of relatives, birth information, accomplishments/activities, and death, written upon the death of the resident

Postmortem Care – care of the body after death

Terminal Illness – incurable illness that leads to death

Module W – End-of-Life Care

<p>(S-1) Title Slide (S-2) Objectives</p> <ol style="list-style-type: none"> 1. Define death and end-of-life care 2. Describe stages of grief 3. Explore cultural differences in dealing with death and dying 4. Examine own feelings about end of life 5. Describe the nurse aide’s role in end-of-life care 	
<p>(S-3) Advance Care Planning</p> <ul style="list-style-type: none"> • Planning for future decisions about one’s medical care • Typically determined if one becomes incapacitated or cannot speak for themselves • Based on personal values, preferences, and discussions with loved ones 	
<p>(S-4) Advance Directives</p> <ul style="list-style-type: none"> • Allow individuals to decide what kind of medical health care they wish to have in the event they cannot make those decisions themselves • Omnibus Budget Reconciliation Act of 1987 (OBRA) and Patient Self-Determination Act (PSDA) gives people the right to accept or refuse treatment and to make advance directives • Includes living wills and durable powers of attorney • Can be changed or cancelled at any time by the individual • Living will <ul style="list-style-type: none"> — Outlines the medical care a person wants or does not want in case the person cannot make those decisions — Must be written while resident is mentally competent or by resident’s legal representative • Durable Health Care Powers of Attorney <ul style="list-style-type: none"> — Signed, dated, and witnessed legal document — Appoints someone to make healthcare decisions for the person in the event they cannot do so • Legally, the nurse aide must honor advance directives 	
<p>(S-5) Advance Directive - Do Not Resuscitate (DNR)</p> <ul style="list-style-type: none"> • A medical order instructing medical professionals not to perform cardiopulmonary resuscitation (CPR) if the person no longer has a pulse and/or is not breathing • Tells health care team the resident does not wish any extraordinary measures to be used if resident suffers cardiac or respiratory arrest 	

Module W – End-of-Life Care	
<ul style="list-style-type: none"> • Legally, the nurse aide must honor the resident’s DNR order and not initiate CPR 	
<p>(S-6) Palliative Care</p> <ul style="list-style-type: none"> • Type of care given to residents who are dying. Care focuses on relieving pain, controlling symptoms, and minimizing side effects and complications • Goals are to improve the quality of life, provide comfort measures and pain management • Preserves dignity, respect and choice • Nurse aide should use active listening skills, respect privacy and independence, individualize care, and examine own feelings and stressors • Nurse aide must take care of self to provide palliative care to others • Hospice is a form of palliative care for someone who has a terminal illness and less than six months to live <ul style="list-style-type: none"> — Offers empathy and support for the resident and the family — Goals for resident are comfort and dignity 	
<p>(S-7) Nurse Aide’s Response to Death</p> <ul style="list-style-type: none"> • Recognize and manage own feelings and attitudes toward death to support residents who are dying. • Various factors influence attitudes toward dying such as age, personal experiences, culture, and religion • First encounters with death and dying can be frightening. • Seek support from coworkers when caring for residents who are terminally ill. <p>ACTIVITY #W7: Attitude Toward Caring For Residents Who Are Near Death Self-Inventory/How Do I Feel? (Individual) Refer to student instructions. Distribute to students. Options to collect for a homework assignment, small group discussion, in class assignment.</p>	
<p>(S-8) Environmental Needs of the Resident - End-of-life Care</p> <ul style="list-style-type: none"> • Keep environment as normal as possible • Keep the resident’s room well-lit and well ventilated • Open drapes and door • Play the resident’s favorite music 	
<p>(S-9) Physical Needs of The Resident - End-of-life Care</p> <ul style="list-style-type: none"> • Positioning 	

Module W – End-of-Life Care

- Place resident in most comfortable position for breathing and avoiding pain
- Maintain body alignment
- Change resident’s position frequently to avoid pressure ulcers
- Cleanliness
 - Providing skin care, including back rubs
 - Bathe and groom resident frequently to promote self-esteem
- Mouth and Nose
 - Clean sores or bleeding in mouth following Standard Precautions
 - Provide oral care as needed. Cover lips with thin layer of petroleum jelly
 - Check for difficulty swallowing or choking
 - Gently clean nose
 - Offer drinking water as often as possible
- Nutrition
 - Offer resident’s favorite foods; include liquids or semi-liquids
 - Offer foods frequently and in small amounts
 - A balanced diet is not a primary concern
- Elimination
 - Keep the resident’s skin and linen clean
 - Provide perineal care as often as necessary

(S-10) The Resident and Loved Ones Emotional and Psychological Needs – End-of-life Care

- Identify incidents that affect resident’s moods
- Document the resident’s behavior changes and report to nurse immediately
- Approach the resident and dying process with dignity
- Respect each resident’s idea of death and spiritual beliefs
- Offer support and understanding
- Respect the resident’s preference regarding solitude or interaction
- Use touch when appropriate
- Listen to the resident and loved ones
- Communicate with the resident, even if non-responsive
- Identify self, and explain tasks being done
- Be aware of the resident's sensitivity to what is being said and ability to hear when other senses diminish
- Be guided by the resident’s attitude
- Present a positive attitude and provide positive physical and emotional care

Module W – End-of-Life Care	
<ul style="list-style-type: none"> • Give resident and loved ones privacy, but not isolation • Spend time with the resident even when not providing care • Do not take anger directed at you personally • Respect the resident’s and loved one’s spiritual beliefs • Encourage loved ones to visit and participate as much as they can 	
<p>(S-11) End-of-life Care – Culture</p> <ul style="list-style-type: none"> • Some cultures believe dying at home is preferable while others fear death at home • It is important for the healthcare team to address specific cultural issues in order to provide respectful care to resident who is dying • Nurse aide must not impose beliefs upon the resident. • Individuals from different cultures appreciate being asked about practices. Healthcare team may ask: <ul style="list-style-type: none"> — Who is allowed to provide personal care? — In some cultures, a member of a different sex cannot provide care — Does the resident or family have any special customs? — Are there specific post mortem customs that the staff should know? • Chinese culture. Traditional healing practices include using herbal preparations given only once. Autopsy and disposal of body are not permitted by the religion. • Japanese culture, the number four means death, so getting medication four times a day could be problematic. • Vietnamese culture believes in reincarnation, so quality of life is more important than length of life. • Hindu culture, individuals are often accepting of God’s will and express desires to be clear-headed at time of death. Prayer helps deal with anxiety and conflict. Blood transfusions, organ transplants, and autopsies are allowed. Cremation is preferred. Believes in reincarnation <p>TEACHING TIP #W11: Policies Describe policies regarding cultural observances requirements to be followed when death occurs from local long-term care centers</p>	
<p>(S-12) End-of-life Care – The Healthcare Team</p> <ul style="list-style-type: none"> • Staff and family may not be prepared for the actual moment of death 	

Module W – End-of-Life Care

- Staff may be shocked or surprised
- Recognize variety of feelings and responses
- Listen empathetically
- Demonstrate caring, interested attitude
- Observe for changes in other residents
- Report and record appropriate information

(S-13) Signs of Impending Death

Signs the resident is within hours or days of death and should be reported to the nurse.

- Psychological and physical withdrawal
- Decreased level of alertness with increased periods of sleeping
- Body temperature rises
- Feels cool, looks pale, and perspires
- Circulatory system fails
- Pulse is fast or slow, weak, and irregular
- Blood pressure drops
- Extremities become cold and pale, mottling occurs (bruise-like discoloration)
- Respiratory system fails with erratic breathing patterns occurring
- Irregular, rapid and shallow or slow and heavy
- Cheyne-Stokes breathing is when resident takes several shallow breaths followed by periods of no breathing for 5, 30, or even 60 seconds; does not cause the resident discomfort
- The “death rattle” is a sign that death is near. Also known as "end-stage wet respirations," it is when saliva and mucus build up in the airways due to the weakening of the muscles in the lungs and trachea (windpipe). With each breath, the passing of air through these fluids causes a rattling sound
- At this stage, the focus will be placed on preventing the resident from choking. Turn resident on their side or elevate the head.
- Apnea, respiration stops
- Digestive system slows down
- Distention of abdomen
- Fecal incontinence due to relaxed muscles
- Nausea and vomiting
- Urinary system
- Dark-colored urine in small amounts due to decreased blood supply to the kidneys
- Incontinence due to relaxed muscles

Module W – End-of-Life Care	
<ul style="list-style-type: none"> • Muscle tone diminishes • Starting in the feet and legs movement and muscle tone are lost • Eventually mouth muscles relax and jaw sags. • Body becomes limp • Sensory decline • Blurred and failing vision; may stare yet not respond, lack of blinking. • Touch is diminished • Hearing is believed to be the last sense to be lost • Pain decreases with loss of consciousness • When a resident is nearing the end of life, the resident will experience a variety of characteristic symptoms: pain, shortness of breath, anxiety, constipation, loss of appetite, fatigue, and change in skin tone and texture are just a few • Death is considered imminent with the loss of bowel control, delirium, and the "death rattle" 	
<p>(S-14) Signs of Death</p> <ul style="list-style-type: none"> • Notify the nurse immediately • No pulse/heartbeat • No respirations • No blood pressure • Pupils are fixed (do not respond to light) and dilated (big) • No response when resident is talked to or touched • Eyelids may remain opened; enlarged pupils that do not respond to changes in light • Mouth may remain open • May have bowel and bladder incontinence 	
<p>(S-15) Exploring Responses to Death</p> <ul style="list-style-type: none"> • Death may be sudden and unexpected or expected • An individual's reaction to death is based on personal, cultural, religious beliefs and experiences • The nurse aide's feelings about death may affect the care given to the resident • In long term care facilities, the nurse aide is often the caregiver closest to the resident • A nurse aide's understanding of the dying process enables a care approach based on dignity and respect 	
<p>(S-16) Stages of Grief</p> <ul style="list-style-type: none"> • In 1969, Dr. Elizabeth Kubler-Ross, a Swiss born American psychiatrist and pioneer in the study of death 	

Module W – End-of-Life Care

<p>and dying identified The Five Stages of Grief experienced by the dying and family/friends.</p> <ul style="list-style-type: none"> • Each person experiences stages differently • May not even pass through stages if death is fast or unexpected. • A nurse aide’s understanding of the stages allows for appropriate support, care, and assistance. • Grief is defined as deep distress or sorrow over a loss. Grief is a dynamic and personal process. <ul style="list-style-type: none"> – The five stages of grief are denial, anger, bargaining, depression, and acceptance. – Each person may experience stages at different rates or times. Some individuals may stay in one stage until death, others may bounce back and forth between stages. – It is possible for an individual to pass through all the stages of grief if death is fast or unexpected. – Nurse aides should not take anger demonstrated by the dying personally. – Use active listening skills and be available to assist as needed. 	
<p>(S-17) 1st Stage - Denial</p> <ul style="list-style-type: none"> • The “no, not me” stage • Begins when people are told of an impending death • May refuse to accept diagnosis or discuss health prognosis • May believe a mistake was made • May act like it is not really happening 	
<p>(S-18) 2nd Stage - Anger</p> <ul style="list-style-type: none"> • The “why me” stage • Expressions of rage and resentment • Often upset by smallest things; lashes out at anyone • Begins to face possibility of upcoming death • May be angry because of the healthy lifestyle maintained • Nurse aide may be the target of anger. Should not take expressions of anger personally. 	
<p>(S-19) 3rd Stage - Bargaining</p> <ul style="list-style-type: none"> • The “yes me, but” stage • Tries to arrange for more time to live to take care of unfinished business. • Bargains with doctors or a higher power • Stage is usually private and spiritual 	
<p>(S-20) 4th Stage - Depression</p> <ul style="list-style-type: none"> • The “yes me” stage 	

Module W – End-of-Life Care	
<ul style="list-style-type: none"> • Begins the process of mourning; cries, withdraws from others • May become weaker with worsening signs • May lack the strength to do simple things • May need additional assistance with physical care and emotional support • Nurse aide needs to demonstrate understanding and willingness to listen 	
<p>(S-21) 5th Stage – Acceptance</p> <ul style="list-style-type: none"> • Reaching this stage does not mean death is imminent • Has worked through feelings • Begins to get affairs in order • May make plans for the care of others and pets • May plan the funeral • May or may not make it to this stage before death 	
<p>(S-22) 6th Stage – Meaning</p> <p>In 2019, Dr. Kubler-Ross’ family granted David Kessler, a grief specialist, permission to add a sixth stage to her model of The Five Stages of Grief</p> <p>The Sixth Stage is “Meaning”</p> <ul style="list-style-type: none"> • Relative and personal • Takes time • Does not require understanding <p>Kessler notes “We can’t move into the future without leaving the past. We have to say goodbye to the life we had and say yes to future.”</p>	
<p>(S-23) Dealing with Grief – An Obituary</p> <p>A notice of a death, in a newspaper or other media outlets, typically including a brief biography of the deceased person</p> <ul style="list-style-type: none"> • Composing an obituary can be part of the grieving process by paying respect to the person who died • Recalling the life of a loved one is an important part of grieving • Sharing with family, friends and the community allows for one to process the loss 	
<p>(S-24) Postmortem Care</p> <ul style="list-style-type: none"> • Each facility has its own policy regarding post mortem care. Nurse aides must follow the policy and perform only tasks delegated to them by the nurse • Provide privacy throughout the process • Obtain a postmortem kit • Wash hands and put on gloves 	

Module W – End-of-Life Care

- Close the eyes
- Give a complete bed bath
- Dress the resident in a clean gown
- Place a pad in the perineal area
- Consult with nurse to find out if dentures are inserted or left out and placed in denture cup.
- Refer to facility policy for removing jewelry
- Within 2 to 4 hours after death, rigor mortis develops. It is important to position in normal alignment before rigor mortis occurs
- Post mortem care involves movement of the body, air may escape from the lungs and expelled from the intestines causing sounds to be heard. These sounds are normal and to be expected although it may scare or shock the nurse aide
- Position body in supine position, legs straight and arms folded across abdomen with one pillow under head

(S-25) Role of the Nurse Aide - Care of the Family

- Provide a private place for family members
- Inquire if any specific person should be contacted
- Provide water or a beverage
- If family members visit with the deceased, provide privacy, and quietly close the door
- Nurse aides respond differently to the death of a resident. Show sincerity and compassion
- Express empathy. "I'm sorry," is enough

Activity #W7 How Do I Feel?
Self-Inventory of Attitudes About Caring for Residents who are Dying

Directions for Students

Purpose: In this activity, the students will answer questions that will help them to understand more about their feelings about caring for residents who are dying. The better the students understand their own responses to death and loss, the better as nurse aides they will be able to deal with residents and loved ones experiencing grief and death. The activity will help prepare students to care for residents who are dying.

Instructions: Work individually on this activity. Read the self-inventory and mark the number that most describes your feelings about the statement. Total your score and compare it to the scoring scale

Application: After scoring your self-inventory, write a paragraph about your strengths and weaknesses in caring for dying patients based on the following:

- What experiences in your life have given you insight into loss?
- What experiences have given you a desire to avoid being near others who are grieving?
- How will you draw on and overcome these experiences to care for residents who are dying?
- Hand in your paragraph to your instructor

LEARNING ACTIVITY #W7 – How Do I Feel?

Self-Inventory of Attitudes Toward Caring for Resident who is Dying

Place a checkmark in the space that corresponds to feelings about each statement.

Statement	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
I am afraid to care for a resident who is dying.					
I am uncomfortable around people who are sad or crying.					
I do not want to touch a resident who is dying.					
A resident who is dying should be left in peace, not given usual nursing care such as bathing and turning.					
Residents who are terminally ill should not be told they are dying.					
If I cry around residents who are dying or their families, I am not being professional.					
I am afraid to go into the room after a resident has died.					
If one of my residents was to die unexpectedly, I would feel I must have made an error in care.					
I do not want residents who are dying to talk to me about their feelings; it makes me feel frightened.					
I am afraid I might have to care for children or young adults who are dying.					
TOTAL					

Scoring the self-inventory:

- Give yourself 5 points for every answer marked Strongly Agree.
- Give yourself 4 points for every answer marked Agree.
- Give yourself 3 points for every answer marked Undecided.
- Give yourself 2 points for every answer marked Disagree.
- Give yourself 1 point for every answer marked Strongly Disagree.

Interpreting the score:

- Scores of 41-50
Indicates a great deal of anxiety about caring for residents who are dying.
- Scores of 31-40
Indicates uncertainty and slightly anxious about caring for residents who are dying.
- Scores of 21-30
Indicates fairly confident in ability to care for residents who are dying.
- Scores of 10-20
Indicates quite confident in ability to care for residents who are dying.