Module W – End of Life Care
Teaching Guide

Objectives

• Describe the nurse aide’s role in end of life care.
• Describe cultural differences in dealing with end of life.
• Examine own feelings about the end of life.

Instructional Resources/Guest Speakers

• #2W Policies: Policies regarding religious observances and requirements to be followed when death occurs, from local long-term care centers

Advance Preparation – In General

• Review curriculum and presentation materials
• Add examples or comments in Notes Section
• Set up computer/projector

Advance Preparation – Activities

• #1W Attitude Toward Caring For Residents Who Are Near Death Self-Inventory/How Do I Feel: Duplicate student worksheet for each student.
Module W – End of Life Care
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

**Post Mortem Care** – care of the body after death
### Module W – End of Life Care

#### (S-1) Title Slide

#### (S-2) Objectives

1. Describe the nurse aide’s role in end of life care.
2. Describe cultural differences in dealing with end of life.
3. Examine own feelings about the end of life.

#### (S-3) End of Life Care and Key Terms

<table>
<thead>
<tr>
<th>Content</th>
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<tbody>
<tr>
<td>• Defined – support and care provided during the time surrounding death; may last days, weeks, or months</td>
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<tr>
<td>• Terminal illness – an illness or injury from which the person will not likely recover; a terminal illness ends in death</td>
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<tr>
<td>• Dying – the near end of life and near cessation of bodily functions</td>
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<td>• Post mortem care – care of the body after death</td>
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#### (S-4) 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

#### (S-5) Death

• Death is natural conclusion to life
• Death may be sudden and unexpected or expected
• Resident’s response to death is based on personal, cultural and religious beliefs and experiences; affects both emotions and behavior
• A nurse aide’s feelings about death affect the care given
• Because nurse aides are often the caregiver closest to the resident, the nurse aide must understand the dying process and know how to react and approach the resident with care, kindness, and respect

#### (S-6) Grief

• Grief – deep distress or sorrow over a loss; a dynamic and personal process
• The dying resident and family may pass through five stages of grief, according to Dr. Elizabeth Kubler-Ross
• Five stages of grief are denial, anger, bargaining, depression, and acceptance
• Each person may experience stages at different rate or time; some may stay in one stage until death; others may bounce back and forth between stages
• May not even be possible for person to pass through
### Module W – End of Life Care

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<tr>
<th></th>
<th>Belfast Section (Begin at S-1)</th>
<th>Belfast Section (End at S-12)</th>
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<tr>
<td><strong>1st Stage – Denial</strong></td>
<td>Begins when people are told of impending death; may refuse to accept diagnosis or discuss situation; may believe that a mistake was made and demands that lab work be repeated; may act like it is not really happening; the “no, not me” stage.</td>
<td><strong>Advance Care Planning</strong></td>
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<td><strong>2nd Stage – Anger</strong></td>
<td>Expressions of rage and resentment; normal and healthy reaction; 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 throughout life; the nurse aide may be the target of anger, but must not take it personal; the “why me” stage.</td>
<td><strong>Advance Directive</strong></td>
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<td><strong>Module W – End of Life Care</strong></td>
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<td>the right to accept or refuse treatment; also give persons the right to make advance directives; also requires that health care facilities that receive Medicare/Medicaid funds give residents who are newly admitted information about their rights related to advance directives</td>
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<td>• Advance directive – legal documents that allow people to decide what kind of medical health care they wish to have in the event they cannot make those decisions themselves</td>
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<td>• Includes living wills and durable powers of attorney</td>
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<td>• Can be changed or cancelled at any time by the person</td>
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<td>• Legally, the nurse aide must honor advance directives</td>
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**Advance Directives Documents**
- Living will – a document that outlines the medical care a person wants or does not wants in case the person cannot make those decisions; living will must be written while resident is mentally competent or by resident’s legal representative
- Durable Health Care Power of Attorney – a signed, dated, and witnessed legal document that appoints someone to make healthcare decisions for the person in the event he/she cannot do so

**Do Not Resuscitate (DNR)**
- A choice of the resident
- A medical order that instructs medical professionals not to perform cardiopulmonary resuscitation (CPR) if the person no longer has a pulse and/or is breathing
- Tells health care team that the resident does not wish any extraordinary measures to be used if resident suffers cardiac or respiratory arrest; extraordinary measures – interventions used to restore heart beat or respiratory effort (cardiopulmonary resuscitation or CPR)
- Typically written for
  - A person with a terminal illness
  - A person who almost certainly could not be saved if CPR was initiated
- Legally, the nurse aide must honor the resident’s DNR order and not initiate CPR

**Physician Orders for Life-sustaining Treatment (POLST)**
- Doctor’s order stating what treatments are to be used when person is very sick
- Includes medical measures the resident wants to receive and not those to be withheld
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- Based on conversations between the resident and the doctor – beliefs, goals, diagnosis, prognosis, and options (that include benefits and detriments for each option); decisions become medical orders

### (S-17) Hospice Care
- Health care agency or program for people who are dying (usually less than six months to live)
- Purpose is to improve the quality of life for a person who is dying
- Provides comfort measures and pain management
- Preserves dignity, respect and choice
- Offers empathy and support for the resident and the family
- Works with staff as well as resident and family

### (S-18) Palliative Care
- In hospice care, goals are the resident’s comfort and dignity
- Type of care given to residents who are dying that focuses on relieving pain, controlling symptoms, and minimizing side effects and complications
- Nurse aide’s role – be a good listener, respect privacy and independence, individualize care, be aware of own feelings and stress nurse aide may feel
- Nurse aide must take care of self to provide palliative care to others

### Teaching Tip #1: The Nurse Aide – Take Care of You

Ask students to state ways they can take care of themselves as a nurse aide when they are away from work’

[Potential answers – reading a book, taking a bubble bath, going out with friends and family, cooking, meditating, taking a quiet walk]

### (S-19) End of Life Care – Importance

- Most people die in hospitals or long-term care facilities
- A nurse aide’s feelings about death affect care given
- A caring, kind, and respectful approach helps the resident who is dying and family

### (S-20) End of Life Care – Nurse Aide’s Feelings About Death

- Nurse aide must recognize and deal with own feelings and attitudes toward death in order to provide essential support to residents who are dying
- Many factors influence attitudes, such as age, personal
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- experiences, culture, and religion
  - First encounters with death and dying can be frightening
  - Nurse aide can use co-workers as support system for dealing with the experience

**ACTIVITY #1W: Attitude Toward Caring For Residents Who Are Near Death Self-Inventory/How Do I Feel? (Individual)**

Refer to student instructions. Distribute to students. Either collect for a homework or activity grade, or discuss in class.

**(S-21) Environmental Needs of The Resident Who is Dying**

- Keeping resident’s environment as normal as possible
  - Room – well lighted and well ventilated
  - Open drapes and door
  - Play resident’s favorite music

**(S-22) Physical Needs of The Resident Who is Dying**

- Positioning
  - 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-23) Emotional And Psychological Needs Of A Resident Who is Dying and the Family**
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- Identify incidents that affect resident’s moods; note behavior changes and report to nurse immediately
- Approach resident and dying process with dignity
- Respect each resident's idea of death and spiritual beliefs
- Offer support/understanding
- Respect resident preference regarding solitude or interaction
- Use touch where appropriate
- Listen to resident and family
- Communicate with resident, even if non-responsive; identify self and explain everything being done
- Be aware of resident's sensitivity to what is being said/ability to hear when other senses diminish
- Be guided by resident’s attitude
- Present a positive attitude and provide positive physical and emotional care
- Give resident and family privacy, but not isolation
- Spend time with the resident even when not providing care.
- Do not take anger directed at you personally
- Be supportive
- Respect the resident's and family's spiritual beliefs
- Encourage family members to participate as much as they can

(S-24) *End of Life Care – Culture and Religion*

- Culture and religion provide framework within which personal experiences with death take on meaning
- Personal experiences, culture, religion, and age influence resident’s individual set of beliefs in ways that may differ from nurse aide's personal beliefs about death
- Nurse aide must not impose beliefs upon the resident who is dying, the family, or those people close to the resident who is dying
- It is important for team to discover specific, cultural issues in order to provide respectful care to resident who is dying
- Individuals from different cultures appreciate being asked about practices. Health care team may ask:
  - Who is allowed to provide personal care? (In some cultures, a member of the opposite sex cannot provide care)
  - Does the resident or family have any special customs?
  - Are there specific post mortem customs that the staff
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**End of Life Care**

**(S-25) * End of Life Care – Culture and Religion**
- Some cultures believe dying at home is preferable while others fear death at home
- **Chinese culture**
  - Traditional healing practices include using herbal preparations given only once
  - Autopsy and disposal of body are not permitted by religion; therefore, organ donation encouraged
  - Japanese culture – number four means death, so getting medication four times a day could be problematic
- **Vietnamese culture**
  - Believe in reincarnation, so quality of life is more important than length of life
- **Hindu culture**
  - Persons are often accepting of God’s will
  - 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

**TEACHING TIP #3W: Policies**

Describe policies regarding religious observances and requirements to be followed, when death occurs, from local long-term care centers.

**(S-26) Feelings and Responses By The Resident's Family, Friends And Other Residents During The Dying Process**

- Realize that even if the dying process is prolonged, staff and the family may not be prepared for the actual moment of death
- Staff may be shocked or surprised when death actually happens; these feelings are normal
- Recognize variety of feelings/responses may be displayed – guilt, anger, sadness/depression, avoidance, denial, acceptance, relief
- Listen empathetically
- Demonstrate caring, interested attitude
- Observe for changes in other residents (such as signs of depression, etc) and report/record appropriate information.

**(S-27) Impending Death: Signs That the Resident is**
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**Within Hours or Days of Death and Should be Reported to 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 – 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
  - Noisy respirations
  - Mucus collects in airway, a rattling or gurgling sound as the resident breathes (what some people refer to as “death rattle”)
  - 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 very small amounts due to decreased blood supply to the kidneys
  - Incontinence due to relaxed muscles
- Muscle tone
  - Starting in the feet and legs movement and muscle tone are lost
  - Eventually mouth muscles relaxes and jaw sags; Body becomes limp
- Sensory – sensory perception 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

*(S-28) Death: Signs That the Resident has Died; Notify Nurse Immediately*
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- 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

(S-29) Nurse Aide’s Role in Performing Postmortem Care

- Defined – care of the body after death and is done to maintain a good appearance of the body
- Begins when resident is pronounced death
- Consult with nurse to find out if
  - Dentures are inserted or left out and placed in denture cup
  - If rings are removed and secured per policy or left on
  - The family wants to view the body
- Within 2 to 4 hours after death, rigor mortis develops; important to position in normal alignment before rigor mortis occurs
- Understand that because post mortem care involves movement of the body, air may escape from the lungs and expelled from the intestines causing sounds to be heard; do not let these sounds scare you as they are normal and to be expected
- Wash body and comb hair; put on gown and cover perineal area with a pad
- Position body in supine position, legs straight and arms folded across abdomen with one pillow under head
- Each facility has its own policy regarding post mortem care; nurse aides must follow this policy and perform only tasks delegated to them

(S-30) Nurse Aide’s Role – Care of the Family After Death

- Show family members to a private place to sit where they can talk privately
- Inquire if there is anyone that they would like called
- Provide water or a beverage
- If family members would like to visit with the deceased, provided privacy and close door quietly; do not rush family
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- Nurse aides respond differently to the death of a resident; may not know what to say; may cope with stress by talking too much; the nurse aide should offer support without talking too much; listen patiently when family members want to talk and do not interrupt.

- What to say? Key is to be sincere and understand that a simple, “I’m sorry” is enough; avoid the non-therapeutic response of “she is in a better place” or “it is for the best”; the nurse aide could possibly say something like “your mom will be missed here” if it is true, this response is both kind and supportive.
Activity #1W How Do I Feel?
Self-Inventory of Attitudes About Caring for Residents who are Dying

Directions for Students

Purpose: In this activity, you will answer questions that will help you understand more about your feelings about caring for residents who are dying. The better you understand your own responses to death and loss, the better you will be able to deal with patients and families experiencing death and loss. Regardless of the type of nursing you plan to do, you will have patients who die. This activity will help prepare you 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 #1W – How Do I Feel?
Self-Inventory of Attitudes Toward Caring for Resident who is Dying

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

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Undecided</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
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<tbody>
<tr>
<td>I am afraid to care for a resident who is dying.</td>
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<td>I am very uncomfortable around people who are sad or crying.</td>
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<td>I do not want to touch a resident who is dying.</td>
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<td>A resident who is dying should be left in peace, not given usual nursing care such as bathing and turning.</td>
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<td>Residents who are terminally ill should not be told that they are dying.</td>
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<td>If I cry around residents who are dying or their families, I am not being professional.</td>
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<td>I am afraid to go into the room after a resident has died.</td>
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<td>If one of my residents were to die unexpectedly, I would feel that I must have made an error in care.</td>
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<td>I don’t want residents who are dying to talk to me about their feelings; it makes me feel frightened.</td>
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<td>I am afraid that I might have to care for children or young adults who are dying.</td>
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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 indicate that you have a great deal of anxiety about caring for residents who are dying.
- Scores of 31-40 indicate that you are unsure and slightly anxious about caring for residents who are dying.
- Scores of 21-30 indicate that you are fairly confident in your ability to care for residents who are dying.
- Scores of 10-20 indicate that you are quite confident in your ability to care for residents who are dying.