# Interprofessional Geriatrics Training Program

## The Dying Process

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# Acknowledgements

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# The Dying Process: Social and Personal Context

- Death is a universal experience, yet the dying process can be upsetting and unfamiliar
- Health care professionals are deeply ingrained in the person's dying process and clinicians should remember:
  - Each person's death is unique
  - Each person has their own understanding, views, and attitudes toward death
  - Personal attitudes toward death may change over the lifespan

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# Learning Objectives

Upon completion of this module, learners will be able to:

1. Discuss death and dying in a social, cultural, and personal context
2. Describe the four domains of comfort care at the end of life
3. Identify non-pharmacologic and pharmacologic approaches to managing symptoms and issues of dying
4. List the signs of impending death
5. Recognize *The Conversation* instructions for end of life decisions
6. Summarize the value of the clinician's *Pause*, including how it can be applied to your practice

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# Culture and Diversity

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# The Dying Process: Culture and Diversity

- Cultural, spiritual, and religious beliefs [not in narration] and other contributing factors may affect the way patients and their families respond to death and the process of dying
  - Understand differences *between* and *within* different social groups

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# Culturally Relevant Issues

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# The Dying Process: Culture and Diversity

- Health providers and caregivers need to consider the following culturally relevant issues:
  - The patient and family's perspectives on:
    - Death and dying
    - Health and suffering
    - Hospice and palliative care services
    - Acceptance of Western health care practices
    - Use of alternative traditional practices

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(S. Lopez, 2007)

# The Dying Process: Culture and Diversity

- Health Providers and caregivers need to consider the following culturally-relevant issues (continued):
  - The roles of:
    - Spiritual and religious beliefs and practices
    - Family, including who is considered part of the family
    - The patient in problem-solving and the process of decision-making
  - How the patient and family communicates includes the need for an interpreter or culturally-relevant terminology around illness and dying

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(S. Lopez, 2007)

# Perspective

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# Death and Dying: Our Own Perspective

- Consider how our own personal experiences of death and the dying process may affect how we interact with patients and their end of life decisions
- Be aware of our own personal and professional beliefs about the dying process and end of life decisions
- Consult with others regarding the degree to which your attitudes, values, and beliefs could affect or bias the care you provide around death and dying



(American Psychological Association , 2015)

# Stages of Death and Dying

- *On Death and Dying* by Elisabeth Kübler-Ross, MD, (1969) was a seminal work increasing our understanding of how people cope with and adjust to the reality of death and the dying process
- The book is based on numerous conversations with dying individuals
- Five Stages of Grief:
  - Denial
  - Anger
  - Bargaining
  - Depression
  - Acceptance

# Comfort Care

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# Comfort Care: Approach to Death and Dying

- Comfort care is an essential part of medical care at the end of life
  - Helps or soothes a person who is dying
  - Goal: Prevent or relieve suffering as much as possible, while respecting the dying person's wishes

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(National Institute on Aging, 2012)

# Comfort Care Domains

- Comfort care near the end of life is comprehensive and addresses various domains:
  - Physical comfort
  - Mental and emotional needs
  - Spiritual issues
  - Practical tasks

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(National Institute on Aging, 2012)

# Assessment Question 1

***Which of the following domains should be addressed when providing comprehensive comfort care to a dying patient?***

a) Emotional

b) Physical

c) Practical

d) Spiritual

e) All of the above

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# Assessment Question 1: Answer

***Which of the following domains should be addressed when providing comprehensive comfort care to a dying patient?***

a) Emotional

b) Physical

c) Practical

d) Spiritual

**e) All of the above (Correct Answer)**

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# Physical Comfort Care

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# Physical Comfort Care: Pain

## Non-Pharmacologic Approaches

Light massage (Hokka et al., 2014)

Cognitive-behavioral therapies (CBT):

- Relaxation techniques (Hokka et al., 2014)
- Guided imagery (Hokka et al., 2014)
- Music therapy (Teut et al., 2014)
- Prayer or meditation (Buck & Meghani, 2012)

## Pharmacologic Approaches

NSAIDs (Campbell, 2015)

Antidepressants (Campbell, 2015)

Neuroleptics (Campbell, 2015)

Corticosteroids (Campbell, 2015)

Opioids: (Campbell, 2015)

- Opioid naïve patients – Morphine 5 mg IV = 15 mg PO

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# Physical Comfort Care: Nausea

| Non-Pharmacologic Approaches | Pharmacologic Approaches |
| --- | --- |
| Avoid foods with strong odors (Bischoff & Renzer, 2006) | Prochlorperazine 10 mg IV/PO q6h PRN (Ishiguro et al., 2013) |
| Avoid fried/fatty foods (Bischoff & Renzer, 2006) | Metoclopramide 10 mg IV/PO q6h PRN (Lindqvist et al., 2013) |
| Take most meds (except antiemetics) after eating (Bischoff & Renzer, 2006) | Haloperidol 1 mg IV/PO q6h PRN (Lindqvist et al., 2013) |

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# Physical Comfort Care: Constipation

| Non-Pharmacologic Approaches |
| --- |
| Encourage fluid or fiber intake as appropriate |
| Activity as tolerated |

| Pharmacologic Approaches |
| --- |
| Docusate Sodium 300 mg/daily (Campbell, 2015) |
| Senna 8.6 mg bid (Campbell, 2015) |
| Polyethylene Glycol 17 gm daily (Campbell, 2015) |
| Bisacodyl Suppository 10 mg PRN (Campbell, 2015) |

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# Physical Comfort Care: Dyspnea (Difficulty Breathing)

| Non-Pharmacologic Approaches |
|---|
| Comfortable positioning (Campbell, 2015) |
| Relaxation exercises: Prayer, meditation, or music (Pan et al., 2000) |
| Use a fan (Kamal et al., 2012) |
| Alleviate dry mouth (Labori et al., 2006) |
| Supplemental oxygen [not on narration] (Campbell, 2015) |

| Pharmacologic Approaches |
|---|
| For opioid naïve patients<br>• Morphine 5 mg PO or 2 mg IV q1h PRN (Campbell, 2015; Sandvik et al., 2016) |
| For opioid tolerant patients<br>• Use current PRN medication |
| Goal is respiratory rate (RR) < 22 |

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# Physical Comfort Care: Anorexia and Feeding Problems

- Symptoms that provoke the greatest distress in the last week of life include anorexia, fatigue, and cachexia
- Family members may be more concerned than the patient about anorexia
- Beliefs about feeding: improves quality of life, can help the illness, and increases lifespan

**Reality**

- Artificial hydration may increase suffering with pulmonary secretions, urinary output, nausea, vomiting, and edema
  - Oral intake naturally decreases as death nears; lack of water increases endogenous opiates
  - Decreased appetite is a normal part of the dying process, allay fears of "starving to death"

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(Ishiki et al., 2015)

# Physical Comfort Care: Feeding Problems

| Feeding Problems | Approaches |
|---|---|
| Early satiety<br>(Ribera-Casado, 2014) | Offer small, frequent meals, use salad plate/saucer, keep favorite foods on hand, offer sips and nibbles |
| Difficulty swallowing<br>(Buning & Bullock, 2015) | Provide mouth care, swabs |
| Patient hungry<br>[addressed in upcoming narration] | Provide thickened liquids, yogurt, and ice cream |
| Nausea or vomiting<br>(Bischoff & Renzer, 2006) | Eliminate offending foods, tastes, and smells<br>Provide cold or room temperature foods, bland foods, and avoid eating or drinking 1-2 hours after vomiting |

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# High Quality Alternative to Tube Feeding: Intensive Individualized Comfort Care

- Perception by family that health care staff lack concern and their family member is "starving to death" often leads to inappropriate use of feeding tubes
- The frequently used phrase "comfort measures only" implies that care is being limited or diminished
- Likewise, the more recent term "comfort feeding only" suggests that the quality of meals and assistance provided will be limited or lessened in some fashion

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(Palecek et al., 2012)

# High Quality Alternative to Tube Feeding: Intensive Individualized Comfort Care

- Instead, Dr. Ruth Palan-Lopez (2012) proposes that family members be provided with the option of "intensive individualized comfort care"

- Aims of this paradigm of care are to aggressively seek and attain comfort to meet individual patient needs and provide family member support



(Palecek et al., 2012)

# High Quality Alternative to Tube Feeding: Intensive Individualized Comfort Care

- Applying the principles of intensive individualized comfort care to this larger view of mealtimes, Dr. Palan-Lopez (2012) suggests that three components of mealtime should be addressed within the context of meals as a shared experience: past, present, and future

- Those implementing intensive individualized comfort care for mealtimes should encourage family members to provide information about food preferences, values and beliefs, and cultural background to create individualized meal plans

- They should use familiar foods, flavors, and rituals as a means of remaining connected to the individual and maintaining their familial relationships, while little emphasis should be placed on weighing or counting calories

(Palecek et al., 2012)

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# Physical Comfort Care: Other Physical Symptoms

- Fever and headache
  - Acetaminophen 650 mg PO/PR q4h PRN
- Upper airway secretions
  - Scopolamine patch q72h (Lindqvist et al., 2013)
  - Glycopyrrolate 0.2-0.4 mg IV q6h PRN (Lindqvist et al., 2013)
- Dry eyes
  - Ocular lubricant ointments, as directed
- Insomnia
  - Zolpidem 5 mg nightly PRN (MacFarlane et al., 2014)
  - Lorazepam 0.5 mg IV/PO nightly PRN (Lindqvist et al., 2013)
  - Behavioral approaches: relaxation, environmental changes, etc. [not in narration]

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# Mental and Emotional Needs

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# Comfort Care: Mental and Emotional Needs

- Each person and his/her family will have a unique response to illness and impending death
  - Nature of the illness
  - Past experience with death
  - Stage of the life cycle
  - Coping skills/past coping
  - Cultural values
  - Family structure and support
  - Spirituality/religious resources
  - Other stressors [not in narration]

(Endacott et al., 2016)

# Comfort Care: Mental and Emotional Needs

| Behavioral Approaches |
|---|
| Validate feelings (Chochinov et al., 2005) |
| Increase opportunities for control |
| Treat underlying symptoms (Dy et al., 2008) |
| Chaplain~~cy~~, social worker, or psychiatric consult (Haley et al., 2003) |

| Pharmacologic Approaches |
|---|
| Lorazepam 0.5 mg IV/PO q6h PRN (Lindqvist et al., 2013) |
| Clonazepam 0.5 mg q8h PRN (Lindqvist et al., 2013) |

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# Comfort Care: Mental and Emotional Needs

- Common issues patients confront during the dying process:
  - Coming to an understanding of the meaning of the illness (Breitbart et al., 2004)
  - Loss of dignity or function (Chochinov et al., 2005)
  - Dependency or becoming a burden to others (Chochinov et al., 2005)
  - Fear and anxiety (Chochinov et al., 2005)
  - Loss of control of self (Chochinov et al., 2005)
  - Death itself (Chochinov et al., 2005)

# Comfort Care: Mental and Emotional Needs
# Agitation

| Non-Pharmacologic Approaches |
| --- |
| Keep room dark during the night (Barr et al., 2013) |
| Reduce external stimuli (Barr et al., 2013) |
| Reorient as needed (Irwin et al., 2013; Martinez et al., 2012) |
| Talk softly and calmly; explore and address unmet needs (Einang Alnes et al., 2011) |
| Keep familiar objects in the room (Martinez et al., 2012) |
| Avoid physical restraints (Skrobik, 2011) |

| Pharmacologic Approaches (not all with an approved indication) |
| --- |
| Haloperidol 1-2 mg IV/PO q6h (Campbell, 2015; Sandvik et al., 2016) |
| Olanzapine 2.5 mg-5 mg nightly (Campbell, 2015) |
| Chlorpromazine 25-50 mg q6h (Lindqvist et al., 2013) |
| Lorazepam 0.5-1 mg q6h (use with caution) (Campbell, 2015; Sandvik et al., 2016) |

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# Spiritual Issues

# Comfort Care: Spiritual Needs
# Anticipatory Grief and Family Issues

**Anticipatory Grief**

"Encompassing the process of mourning, coping, interaction planning, and psychosocial reorganization that are stimulated and begin in part in response to the awareness of the impending loss of a loved one and recognition of associated losses in the past, present, and future"

(Rando, 1986, p. 24)

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# Comfort Care: Spiritual Needs
# Anticipatory Grief and Family Issues

Anticipatory grief allows families to prepare for the death of their loved one

- Allows the idea of the loss of the person to “sink in”
- Families may address unresolved interpersonal issues as necessary
- Provides time for planning for funerals
- Allows the process of adjustment and healing to begin

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(Rando, 1986)

# Comfort Care: Spiritual Needs
# Grief and Healing After the Loss of a Loved One

- Bereavement affects people in numerous ways, including behaviorally, cognitively, interpersonally, emotionally, physically, and spiritually (Shear et al., 2013)

- Key elements of the mourning process:
  - Accepting the reality of the loss
  - Processing the pain of grief
  - Adjusting to an environment without the deceased
  - Withdrawing emotional energy from the deceased and investing it in other relationships (Worden, 2009)

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# Comfort Care: Spiritual Needs
# Grief, Mourning, and Bereavement

- Grief: Emotional reaction to loss
- Mourning: Process of adjusting to the void created by the loss
- Bereavement: The period after a loss when grief is experienced and mourning takes place
- Losses occur during the entire dying process, not only at the moment of death

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(Hagman, 2016)

# Assessment Question 2

***Clara is a 68-year-old woman in hospice who repeatedly expresses anxiety about dying out of fear of God's punishment for her past misdeeds. To help Clara, you might consider:***

a) Telling Clara that her fears are unfounded
b) Asking Clara if she would like to speak with a Chaplain
c) Sharing your own fears of death with Clara
d) Suggesting to Clara that she pray for forgiveness
e) None of the above is an appropriate response

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# Assessment Question 2: Answer

***Clara is a 68-year-old woman in hospice who repeatedly expresses anxiety about dying out of fear of God's punishment for her past misdeeds. To help Clara, you might consider:***

a) Telling Clara that her fears are unfounded

**b) Asking Clara if she would like to speak with a Chaplain (Correct Answer)**

c) Sharing your own fears of death with Clara

d) Suggesting to Clara that she pray for forgiveness

e) None of the above is an appropriate response

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# Practical Tasks

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# Comfort Care: Practical Tasks
# End of Life Decisions – *The Conversation Project*

**What Do People Want at the End of Life?**

- 90% of respondents said it was important to discuss end of life care with loved ones, but only 27% have actually done so (Conversation Project Survey, 2013)

- 82% of respondents said it was important to put their wishes in writing, but only 23% have actually done it (California Healthcare Foundation, 2012)

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# Practical Tasks: End of Life Decisions – *The Conversation Project*

- *The Conversation Project* from the Institute for Healthcare Improvement (IHI)
  - Goal of *The Conversation Project*: To ensure that everyone's end of life wishes are expressed and respected
  - Includes step-by-step instructions for how to consider and discuss crucial end of life issues
    http://theconversationproject.org/

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(Conversation Project National Survey, 2013)

# Assessment Question 3

***The goal of The Conversation Project from the Institute for Healthcare Improvement (IHI) is to:***

a) Ensure everyone's end of life wishes are expressed and respected
b) Have a conversation about the family's values and wishes
c) Allow the provider to voice his/her opinion about clinicians' end of life values
d) Discuss the costs of end of life care

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# Assessment Question 3: Answer

***The goal of The Conversation Project from the Institute for Healthcare Improvement (IHI) is to:***

a) **Ensure everyone's end of life wishes are expressed and respected (Correct Answer)**

b) Have a conversation about the family's values and wishes

c) Allow the provider to voice his/her opinion about clinicians' end of life values

d) Discuss the costs of end of life care

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# Practical Tasks

# Practical Tasks: Communication

**Effective Communication is Essential to End of Life Care**

- Listening is key to understanding the patient's wishes, concerns, fears, etc. (Sinuff et al., 2015)
- Honesty is important (Sinuff et al., 2015)
- Be willing to talk about death (Sinuff et al., 2015)
- Be sensitive in delivering bad news to the patient and the family (Rollins & Hauck, 2015)

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# Practical Tasks: End of Life Decisions

**Advanced Directives**

- Living Will: Allows a person to put into writing wishes about medical treatments for the end of life in the event that they cannot communicate these desires directly
- Health Care Power of Attorney: Also called a "health care proxy," a person designated by the patient to make health care-related decisions in the event that the patient is incapacitated

# Practical Tasks: End of Life Decisions

**Advanced Directives**

- Valid in all 50 states and become effective immediately
- No attorneys are needed for advanced directives, but some states have their own particular wording

  www.caringinfo.org

# Advanced Directives: POLST

**Advanced Care Planning Using a Medical Order**

- Provider Order for Life-Sustaining Treatment (POLST)
- POLST is a medical order that MUST be followed
- Opportunity to discuss other options:
  - IV solutions
  - Feeding tubes
  - Pain medications
  - Hospice treatment
- In addition to MDs, [not in narration] it gives PAs, APNAs, and senior medical residents the power to sign the medical directive

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# Advanced Directives: POLST

**Advanced Care Planning Using a Medical Order (Continued)**

- www.polstil.org

- Find your state program: http://www.polst.org/programs-in-your-state/

# Assessment Question 4

***A living will is an important document in end of life care because it:***

a) Provides information about the patient's wishes regarding medical treatment

b) Tells the patient's survivors how to dispense the patient's assets upon death

c) Can serve as a reference if the patient is uncommunicative

d) All of the above

e) Options a and c only

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# Assessment Question 4: Answer

***A living will is an important document in end of life care because it:***

a) Provides information about the patient's wishes regarding medical treatment

b) Tells the patient's survivors how to dispense the patient's assets upon death

c) Can serve as a reference if the patient is uncommunicative

d) All of the above

**e) Options a and c only (Correct Answer)**

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# Practical Tasks

# Practical Tasks: End of Life Decisions – *Five Wishes*

***Five Wishes* Document**

- Recognized as meeting legal requirements for advanced directives in 42 states
- In the other 8 states it can be attached to the state's form
- Uses everyday language to guide the user through the process of specifying end of life wishes — personal, spiritual, medical, and legal
- Useful tool for family discussions
- Copyrighted



(Aging with Dignity, 2015)

# Practical Tasks: End of Life Decisions – *Five Wishes*

***Five Wishes***

- Wish 1: *The person I wish to make decisions for me when I can't make them for myself*
  - Health care power of attorney who can interpret the instructions based on his/her understanding of the patient's wishes
- Wish 2: *My wish for the type of medical treatment I want or don't want*
  - Allows the person to define what "life support treatment" means to him/her
  - Expresses general instructions for health care providers and caregivers
  - Can be tailored to specific health statuses, such as coma or has severe brain damage
  - Allows for personalization
  - It is NOT a Do Not Resuscitate (DNR) order or a POLST order
  - It is considered a living will and is useful for discussing a DNR order



(Aging with Dignity, 2015)

# Practical Tasks: End of Life Decisions – *Five Wishes*

***Five Wishes***

- Wish 3: *My wish for how comfortable I want to be*
  - Stresses that you want your pain managed properly
  - Allows you to indicate how alert and/or medicated you wish to be
  - Provides direction regarding comfort care
- Wish 4: *How you want people to treat you*
  - What others should keep in mind if you become seriously ill
  - Whether you want people around you and/or physically touching you
  - If you want prayers said for you
  - Ideas for your surroundings (e.g., photos of loved ones)



(Aging with Dignity, 2015)

# Practical Tasks: End of Life Decisions – *Five Wishes*

***Five Wishes***

- Wish 5: *What you want your loved ones to know*
  - Allows you to express deep sentiments about your relationships with family and friends
  - Allows you to offer love and forgiveness to those who have hurt you
  - Communicates practical matters concerning burial wishes



(Aging with Dignity, 2015)

# Practical Tasks: Additional Considerations

- Vital signs: May no longer be necessary
- Foley catheter: For comfort and to avoid having to toilet
- IV Fluids: May be discontinued as they can promote suffering at end of life
- De-prescribing medications [not in narration]



(Aging with Dignity, 2015)

# Practical Tasks: Signs of Impending Death

| Assess | Signs of Impending Death |
| --- | --- |
| Activity | Extreme weakness, mouth droop, minimal voluntary movement |
| Nutrition | Anorexia |
| Elimination | Oliguria, bowel incontinence/diarrhea |
| Pain | May be increased or decreased |
| Skin | Cyanosis, mottling, cooling |

# Practical Tasks: Signs of Impending Death

| Assess | Signs of Impending Death |
|---|---|
| Sleep | Decreased responsiveness, frequently unarousable |
| Eyes | Glazed fixed stare, partly open, dilated pupils |
| Respirations | Death rattle, tachypnea, Cheyne-Stokes pattern |
| Neurological | Delirium, decreased arousal, may see a “rally” |
| Ascites/Edema | Decreased distention, decreased edema |

# Assessment Question 5

***Signs of impending death include all the following <u>except</u>:***

a) Extreme weakness, mouth droop, minimal involuntary movement

b) Improved appetite

c) Cyanosis, mottling, cooling

d) Death rattle, tachypnea, Cheyne-Stokes pattern breathing

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# Assessment Question 5: Answer

***Signs of impending death include all the following except:***

a) Extreme weakness, mouth droop, minimal involuntary movement

**b) Improved appetite (Correct Answer)**

c) Cyanosis, mottling, cooling

d) Death rattle, tachypnea, Cheyne-Stokes pattern breathing

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# The Clinician's *Pause*

- Witnessing death over and over again takes a toll
  - Over time, clinicians can become numb or burned out
  - One solution is the *Pause*, developed at the University of Virginia, Charlottesville, in which following the death of a patient everyone stops, and pauses
- The *Pause*
  - The team just stops and pauses, just for a minute
  - "It makes it so we can actually view the person as a person rather than as a patient that we see on an everyday basis," Jack Berner, EMT



(Lofton, 2015)

# The Clinician's *Pause*

- The *Pause* (continued)
  - "You can relate more to the case [knowing] it's somebody's father or mother, their sister or uncle, rather than somebody you just see for five minutes" (Jack Berner)
  - The idea began to spread throughout their hospital, particularly to emergency department workers
  - The *Pause*, as it has become known, also is being taught as part of the curriculum at UVA in Charlottesville
  - Jack Berner says it helps him handle the toughest cases



(Lofton, 2015)

# The Clinician's *Pause*

- The *Pause* (continued)
  - They hope the *Pause* will help medical workers like Berner accept the loss without disconnecting emotionally
  - "So you are able to feel and you are also able to sense and give back," Berner said, even if it's not a relative, a worker can have a sense of being a part of a loss
  - "I can also acknowledge the pain that I bore witness to in caring for that family and caring for that patient" (Jack Berner)



(Lofton, 2015)

# Summary

- Death and dying is affected by social, cultural, and personal contexts
- There are four domains of comfort care at the end of life that require both non-pharmacologic and pharmacologic approaches to managing symptoms and issues of dying

  These domains are:

    - Physical
    - Mental and emotional issues
    - Spiritual issues
    - Practical tasks

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# Summary

- There are numerous signs that indicate impending death
- *Five Wishes* and *The Conversation* are two useful tools patients can use to provide instruction for their own end of life care
- The clinician's *Pause* allows the clinical team to stop for a moment out of respect for the person who has died and to center themselves in the midst of performing the numerous tasks of caring for the dying and deceased

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# Resources

https://agingwithdignity.org/five-wishes/about-five-wishes Accessed October 10, 2016

www.caringinfo.org Accessed October 10, 2016

http://theconversationproject.org/ Accessed October 10, 2016

http://www.polst.org/programs-in-your-state/ Accessed October 10, 2016

https://hospicefoundation.org/End-of-Life-Support-and-Resources/Coping-with-Terminal-Illness/Signs-of-Approaching-Death Accessed October 10, 2016

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