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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
### 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

- Cultural, spiritual, and religious beliefs 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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### The Dying Process: Culture and Diversity
Culturally Relevant Issues

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

The Dying Process: Culture and Diversity (S. Lopez, 2007)

• 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
Perspective

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

(From: 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

- 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

### Comfort Care: Approach to Death and Dying

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

### Comfort Care Domains

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

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)

Physical Comfort Care
### Physical Comfort Care: Pain

<table>
<thead>
<tr>
<th>Non-Pharmacologic Approaches</th>
<th>Pharmacologic Approaches</th>
</tr>
</thead>
<tbody>
<tr>
<td>Light massage (Hokka et al., 2014)</td>
<td>NSAIDs (Campbell, 2015)</td>
</tr>
<tr>
<td>Cognitive-behavioral therapies (CBT):</td>
<td>Antidepressants (Campbell, 2015)</td>
</tr>
<tr>
<td>• Relaxation techniques (Hokka et al., 2014)</td>
<td>Neuroleptics (Campbell, 2015)</td>
</tr>
<tr>
<td>• Guided imagery (Hokka et al., 2014)</td>
<td>Corticosteroids (Campbell, 2015)</td>
</tr>
<tr>
<td>• Music therapy (Hokka et al., 2014)</td>
<td>Opioids: (Campbell, 2015)</td>
</tr>
<tr>
<td>• Prayer or meditation (Hokka et al., 2014)</td>
<td>• Opioid naïve patients — Morphine 5 mg IV = 15 mg PO</td>
</tr>
</tbody>
</table>

### Physical Comfort Care: Nausea

<table>
<thead>
<tr>
<th>Non-Pharmacologic Approaches</th>
<th>Pharmacologic Approaches</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avoid foods with strong odors (Bischoff &amp; Renzer, 2006)</td>
<td>Prochlorperazine 10 mg IV/PO q6h PRN (Ishiguro et al., 2013)</td>
</tr>
<tr>
<td>Avoid fried/fatty foods (Bischoff &amp; Renzer, 2006)</td>
<td>Metoclopramide 10 mg IV/PO q6h PRN (Lindqvist et al., 2013)</td>
</tr>
<tr>
<td>Take most meds (except antiemetics) after eating (Bischoff &amp; Renzer, 2006)</td>
<td>Haloperidol 1 mg IV/PO q6h PRN (Lindqvist et al., 2013)</td>
</tr>
</tbody>
</table>

### Physical Comfort Care: Constipation

<table>
<thead>
<tr>
<th>Non-Pharmacologic Approaches</th>
<th>Pharmacologic Approaches</th>
</tr>
</thead>
<tbody>
<tr>
<td>Encourage fluid or fiber intake as appropriate</td>
<td>Docusate Sodium 300 mg/daily (Campbell, 2015)</td>
</tr>
<tr>
<td>Activity as tolerated</td>
<td>Senna 8.6 mg bid (Campbell, 2015)</td>
</tr>
<tr>
<td></td>
<td>Polyethylene Glycol 17 gm daily (Campbell, 2015)</td>
</tr>
<tr>
<td></td>
<td>Bisacodyl Suppository 10 mg PRN (Campbell, 2015)</td>
</tr>
</tbody>
</table>
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)

Pharmacologic Approaches

- For opioid naïve patients
  - Morphine 5 mg PO or 2 mg IV q4h PRN (Campbell, 2015; Sandvik et al., 2016)
- For opioid tolerant patients
  - Use current PRN medication
  - Goal is respiratory rate (RR) < 22

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 opioids
  - Decreased appetite is a normal part of the dying process, allay fears of "starving to death"

Physical Comfort Care: Feeding Problems

<table>
<thead>
<tr>
<th>Feeding Problems</th>
<th>Approaches</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early satiety</td>
<td>Offer small, frequent meals, use salad plate/saucer, keep favorite foods on hand, offer sips and nibbles</td>
</tr>
<tr>
<td>Difficulty swallowing</td>
<td>Provide mouth care, swabs</td>
</tr>
<tr>
<td>Patient hungry</td>
<td>Provide thickened liquids, yogurt, and ice cream</td>
</tr>
<tr>
<td>Nausea or vomiting</td>
<td>Eliminate offending foods, tastes, and smells</td>
</tr>
</tbody>
</table>

(Patient hunger, 2014)
### 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.

**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.

**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 mealtimes 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.
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 (MacFarlane et al., 2014)
- Behavioral approaches: relaxation, environmental changes, etc. [not in narration]

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 to be mentioned]
Comfort Care: Mental and Emotional Needs

**Behavioral Approaches**
- Validate feelings (Chochinov et al., 2005)
- Increase opportunities for control
- Treat underlying symptoms
- Chaplaincy, social worker, or psychiatric consult

**Pharmacologic Approaches**
- Lorazepam 0.5 mg IV/PO q6h PRN (Campbell, 2015)
- Clonazepam 0.5 mg q8h PRN (Campbell, 2015)

Pharmacologic Approaches (not all with an approved indication)
- Haloperidol 1-2 mg IV/PO q6h
- Olanzapine 2.5 mg-5 mg nightly
- Chlorpromazine 25-50 mg q6h
- Lorazepam 0.5-1 mg q6h (use with caution)

Non-Pharmacologic Approaches
- Keep room dark during the night
- Reduce external stimuli
- Reorient as needed
- Keep familiar objects in the room
- Avoid physical restraints

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
- Dependency or becoming a burden to others
- Fear and anxiety
- Loss of control of self
- Death itself

Comfort Care: Mental and Emotional Needs

Agitation

- Keep room dark during the night
- Reduce external stimuli
- Reorient as needed
- Talk softly and calmly; explore and address unmet needs
- Keep familiar objects in the room
- Avoid physical restraints
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”

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

(Rando, 1986, p. 24)
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).

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 (Hagman, 2016).

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
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 misdemeanors. 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

Practical Tasks

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)

Comfort Care: Practical Tasks

End of Life Decisions – The Conversation Project

What Do People Want at the End of Life?
### 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/](http://theconversationproject.org/)

### 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

### 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
### 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)

### 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](http://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, it gives PAs, APNAs, and senior medical residents the power to sign the medical directive

**Advanced Care Planning Using a Medical Order (Continued)**
- [www.polst.org](http://www.polst.org)
### 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

### 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)
**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

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

<table>
<thead>
<tr>
<th>Five Wishes</th>
<th>Wish 1: The person I wish to make decisions for me when I can't make them for myself</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Health care power of attorney who can interpret the instructions based on his/her understanding of the patient’s wishes</td>
</tr>
<tr>
<td></td>
<td>Wish 2: My wish for the type of medical treatment I want or don’t want</td>
</tr>
<tr>
<td></td>
<td>Allows the person to define what “life support treatment” means to him/her</td>
</tr>
<tr>
<td></td>
<td>Expresses general instructions for health care providers and caregivers</td>
</tr>
<tr>
<td></td>
<td>Can be tailored to specific health statuses, such as coma or has severe brain damage</td>
</tr>
<tr>
<td></td>
<td>Allows for personalization</td>
</tr>
<tr>
<td></td>
<td>It is NOT a Do Not Resuscitate (DNR) order or a POLST order</td>
</tr>
<tr>
<td></td>
<td>It is considered a living will and is useful for discussing a DNR order</td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>Five Wishes</th>
<th>Wish 3: My wish for how comfortable I want to be</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Stresses that you want your pain managed properly</td>
</tr>
<tr>
<td></td>
<td>Allows you to indicate how alert and/or medicated you wish to be</td>
</tr>
<tr>
<td></td>
<td>Provides direction regarding comfort care</td>
</tr>
<tr>
<td></td>
<td>Wish 4: How you want people to treat you</td>
</tr>
<tr>
<td></td>
<td>What others should keep in mind if you become seriously ill</td>
</tr>
<tr>
<td></td>
<td>Whether you want people around you and/or physically touching you</td>
</tr>
<tr>
<td></td>
<td>If you want prayers said for you</td>
</tr>
<tr>
<td></td>
<td>Ideas for your surroundings (e.g., photos of loved ones)</td>
</tr>
</tbody>
</table>
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

Practical Tasks: End of Life Decisions – Five Wishes

- **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

Practical Tasks: Additional Considerations

- **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**

<table>
<thead>
<tr>
<th>Assess</th>
<th>Signs of Impending Death</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sleep</td>
<td>Decreased responsiveness, frequently unarousable</td>
</tr>
<tr>
<td>Eyes</td>
<td>Glazed fixed stare, partly open, dilated pupils</td>
</tr>
<tr>
<td>Respirations</td>
<td>Death rattle, tachypnea, Cheyne-Stokes pattern</td>
</tr>
<tr>
<td>Neurological</td>
<td>Delirium, decreased arousal, may see a “rally”</td>
</tr>
<tr>
<td>Abdomen/Edeema</td>
<td>Decreased distention, decreased edema</td>
</tr>
</tbody>
</table>

**Assessment Question 5**

*Signs of impending death include all the following except:*  
a) Extreme weakness, mouth droop, minimal involuntary movement  
b) Improved appetite  
c) Cyanosis, mottling, cooling  
d) Death rattle, tachypnea, Cheyne-Stokes pattern breathing

**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
• 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

The Clinician’s 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

The Clinician’s 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)
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

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.

## Summary

- There are four domains of comfort care at the end of life.
- Physical, mental, emotional, and spiritual issues require attention.
- Non-pharmacologic and pharmacologic approaches are necessary.
- Five Wishes and The Conversation are tools for patient instruction.
- The clinician’s Pause is a moment for respect and self-centering.

## Resources

- [Five Wishes](https://agingwithdignity.org/five-wishes/about-five-wishes)
- [The Conversation](http://theconversationproject.org/)
- [POLST](http://www.polst.org/programs-in-your-state/)
- [Hospice Foundation](https://hospicefoundation.org/End-of-Life-Support-and-Resources/Coping-with-Terminal-Illness/Signs-of-Approaching-Death)