

Module 7: Final Hours Supplemental Teaching Materials/Training Session Activities Contents

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Module 7: Final Hours
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Table 1: Physical Signs, Symptoms and Interventions of the Actively Dying

Symptoms/Description	Cause/Etiology	Interventions
Confusion, disorientation, and delirium may be one of the patient’s greatest fears.	Disease progression Infection Opioids Pain Full bladder Constipation Side effects medications (possible reversible) Hypoxemia Metabolic imbalances, acidosis Toxin accumulation due to liver and renal failure Disease-related factors (non-reversible)	Discern etiology using nursing assessment. Consider nearing death awareness, confusion. Treat as appropriate to goals of care and comfort Communicate honestly with patient and family. Implement safety measures as necessary with consideration to the setting. In home setting, provide respite for the caregiver as needed due to increased patient care needs and caregiver fatigue.
Weakness and fatigue increase as patient gets closer to death. At home or skilled setting, family/caregiver fatigue due to increased needs of patient for ADLs and personal care. Increased weakness may trigger patient anticipatory grief due to loss of independence, loss of function, and/or awareness of weakness as a result of disease progression.	Disease progression	Offer and provide increased assistance with ADLs (activities of daily living such as bathing, grooming, feeding, mobility with increase support from nurse, home health or hospice aides or care attendants, volunteers, family). Provide assistive equipment as needed such as shower stool, hospital bed, wheelchair, and walker.

Symptoms/Description	Cause/Etiology	Interventions
		<p>If bed bound, offer and teach family to provide passive ROM, turn and position, draw sheet, skin breakdown including air mattress as appropriate, rubbing in circular motion over bony prominences to improve circulation and shift edema.</p> <p>In home setting, educate family on patient needs and care.</p> <p>Provide respite for family caregiver in home setting as needed. This includes home health care, hospice, and friends.</p> <p>Social work, pastoral care support for anticipatory grief as needed.</p> <p>In</p> <p>If patient questions meaning of weakness in relation to disease progression, answer patient's questions openly, honestly.</p>
<p>Change in character and intensity of pain.</p>	<p>Disease progression Death</p>	<p>Assess and reassess pain frequently. Review pain type and medications</p> <p>Adjust medications, dosages based on principles of pain management.</p> <p><i>[Refer to Module 2: Pain Management]</i></p> <p>Support family/caregiver concerns, educate regarding principles of pain management, and explore choices regarding dying in pain and extending</p>

Symptoms/Description	Cause/Etiology	Interventions
		<p>suffering versus comfortable death.</p> <p>Provide education about dosing medication near end of life. If pain control principles are followed, the disease and not the medication will cause the death.</p>
<p>Withdrawal, diminishing consciousness, increased sleepiness, and coma</p>	<p>Disease progression Dying process</p>	<p>Educate family about signs and symptoms of disease progression and the importance of speaking to their family member as if they could physically respond.</p> <p>Hearing may be one of the last senses to be lost, so tell the obtunded patient who you are upon entering room, what you will be doing and continue to speak to the patient during care and procedures.</p> <p>Allow transition through peaceful, quiet surroundings, soft music, quiet presence, gentle touch and reassurance that they are not alone.</p> <p>Encourage family to say what they need to say.</p> <p>Assess and explore spiritual needs during this time.</p> <p>Assess pain and follow principles of pain management. Due to increased risk of withdrawal symptoms, do not abruptly stop pain medications because the patient becomes</p>

Symptoms/Description	Cause/Etiology	Interventions
		comatose.

Adapted from:
The Hospice of the Florida Suncoast, 1999.

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Table 2: Psychosocial and Spiritual Signs, Symptoms and Interventions of the Actively Dying

Signs and Symptoms	Cause/Etiology	Interventions
<p>Fear of the dying process:</p> <p>Fear of the dying process may be greater than the fear of death.</p>	<p>Cause of fear will be specific to the individual.</p> <p>Fear of the unknown - how they will die, what will happen during the dying process.</p> <p>Fear of painful death and suffering such as breathlessness, physical pain, loss of mental competence and decision-making ability, loss of control, loss of ability to maintain spiritual belief systems and faith.</p> <p>Fear of judgement, punishment related to guilt and subsequent pain and suffering during dying process.</p> <p><i>(Doka & Morgan, 1993)</i></p>	<p>Explore fears and cause/etiology of fears including physical, psychosocial and spiritual.</p> <p>Educate patient and family on physical, psychosocial and spiritual signs and symptoms of dying process.</p> <p>Ask patient/family how they would like the dying process to happen.</p> <p>Normalize feelings.</p> <p>Provide reassurance that patient will be kept as comfortable as possible.</p> <p>Provide presence and increase as needed.</p>
<p>Fear of abandonment:</p> <p>Most patients do not want to die alone.</p> <p>May present as patient anxiety, pressing call button frequently.</p> <p>Family members may continuously stay at bedside to honor patient's wish to not be left alone.</p>	<p>Fear of being alone.</p> <p>Fear of who will care for them when they are unable to care for themselves.</p>	<p>Provide reassurance that everything will be done to have someone with the patient.</p> <p>Provide presence.</p> <p>Explore options of increasing presence around the clock including health care professionals (nurse, social worker, nurse's aide) and family, friends, volunteers, church members, etc.</p> <p>For family member doing bedside vigil, encourage frequent breaks, offer respite.</p>

Signs and Symptoms	Cause/Etiology	Interventions
		<p>Family members may need permission from nurse to care for themselves.</p> <p>Implement the “No Veteran Dies Alone” program if available: https://www.wehonorveterans.org/working-for-veterans/volunteering/no-veteran-dies-alone/</p>
<p>Fear of the unknown</p>	<p>Fear of what will happen after they die.</p> <p>Fear that belief systems regarding afterlife will be different than perceived and/or lived.</p>	<p>Exploration of fear.</p> <p>Companionship, presence.</p> <p>Pastoral care or patient’s clergy for exploration of life, afterlife, faith system beliefs.</p> <p>Support cultural and spiritual beliefs.</p>
<p>Nearing death awareness:</p> <p>Patients state they have spoken to those who have already died or have seen places not presently accessible or visible to family and/or nurse. May describe spiritual beings, bright lights, “another world.”</p> <p>Statements may seem out of character, gesture or request.</p> <p>Patients may tell family members, significant others when they will die</p> <p>Veterans may “return to the battlefield.”</p>	<p>Attempt by the dying to describe what they are experiencing, the dying process and death.</p> <p>Transition from this life.</p> <p>Attempting to describe something they need to do/accomplish before they die, such as permission to die from family, reconciliation, see someone, reassurance that survivor will be okay without them.</p> <p>The conscious mind starts receding and the unconscious starts expanding (Grassman, 2017)</p>	<p>Do not contradict, explain away, belittle, humor or argue with the patient about these experiences.</p> <p>Attentively and sensitively listen to the patient, affirm the experience, and attempt to determine if any unfinished business, patient needs.</p> <p>Encourage family/significant others to say goodbye, give permission for patient to die as appropriate.</p> <p>Support to family and other caregivers.</p> <p>Educate about the difference between nearing death awareness and confusion, provide education to family and other caregivers.</p>

Signs and Symptoms	Cause/Etiology	Interventions
		Support Veteran and family, let them know they are in a safe place.
Patients may withdraw from family, friends, the nurse and other health care professionals.	Transition from this life, patient “letting go” of this life.	<p>Normalize withdrawal by educating family about transition.</p> <p>Presence, gentle touch.</p> <p>Family members may need to be educated, encouraged to give permission to patient to die.</p> <p>Family may need to be encouraged to say goodbyes.</p>

Adapted from:
The Hospice of the Florida Suncoast, 1999. Reprinted with permission.

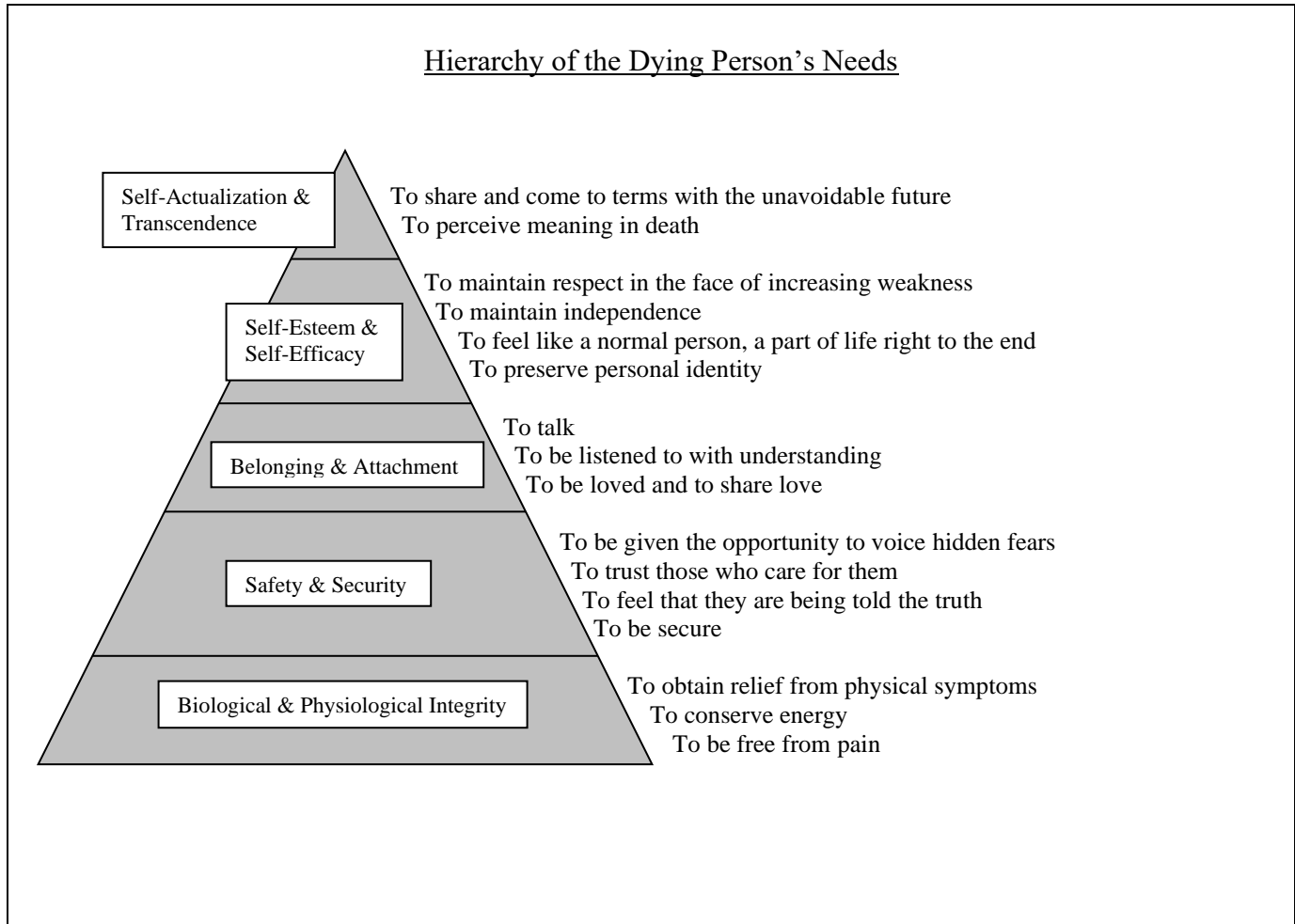
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Figure 1: Hierarchy of the Dying Person's Needs



Source:

Touhy, T.A., & Jett, K.F. (2016). *Ebersole & Hess' toward healthy aging* (p. 490). St. Louis, MO: Mosby, Inc.
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Figure 2: Nearing Death Awareness

(An example of a patient/family caregiver written educational material)

Nearing death awareness is a special communication of the dying. It usually occurs when patients are approaching or are in the dying process. Most patients who have signs of nearing death awareness are more peaceful after the experience. Not all patients will have this experience.

Signs of Nearing Death Awareness

People who are experiencing signs of nearing death awareness may:

- Appear confused and disoriented.
- State that they have spoken to those who have already died.
- Speak to people and see places not visible to you.
- Describe spiritual beings and bright lights.
- Talk aloud to people who have died before them, such as their mother, father, or close friend.
- Make “out of character” statements, gestures, or requests.
- Describe another world of peace and beauty.
- Tell you exactly when they will die.
- Make hand gestures, reach for or hold unseen objects, or wave to unseen beings.

These behaviors do not mean that they are confused, hallucinating, or having a reaction to their medications. It is believed that the person is beginning to transition from this life. The person may be trying to describe the dying experience or something they need to do before they die. These messages of the dying may be a symbolic communication to ask for permission to die or address a need. Some things they may need include resolving previous conflicts, receiving a visit from a friend, or knowing that you will be okay without them. What they say often has meaning to them and is linked between this life and death. For example, if they traveled a lot, they may say, “I need to pack my bags” or “I need to get on the plane.” A patient who was a boater may talk about the tides. A rancher may describe his horse waiting to take him for a ride.

What You Can Do:

- These experiences can be very comforting to the patient. Do not contradict, explain away, belittle or argue with them.
- Be present with the person. Simply sit at their bedside and be open to their attempts to communicate.
- Listen attentively and sensitively and acknowledge the experiences.
- Ask gentle questions about what your loved one is saying or doing. Questions include “Who do you see?”, “What are you seeing?”, and “How does that make you feel?”
- Allow the person to share this experience with you.
- Discuss these communications with your team. The person who is closest to the patient may best understand what is being said.

When patients experience nearing death awareness and describe death as peaceful, they are providing others with a better understanding of the death experience. This may be their final gift to you. Please feel free to call your team at any time for questions or concerns you may have about nearing death awareness. They will help you draw from your own resources and those available to you through to ease this difficult time. You are not alone.

For more information on nearing death awareness, you may want to read the book *Final Gifts* by Maggie Callanan and Patricia Kelley.

Source:

Lo, K. (1996). *Care at the time of death*. Largo, FL: The Hospice Institute of the Florida Suncoast. Reprinted with permission.

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Figure 3: Hospice & Palliative Nurse’s Association (HPNA) Position Statement: Withholding and/or Withdrawing Life Sustaining Therapies

It is the position of HPNA that:

- All life-sustaining therapies may be withheld or withdrawn. There is no difference, ethically or legally, between the decision to not initiate a treatment that may not be beneficial or stop or remove a treatment that is not beneficial and/or no longer wanted.
- Every person with decision-making capacity has the right to initiate any medical therapy that offers reasonable probability of benefit and to withhold/withdraw any medical therapy.
- Patients have the right to appoint a surrogate decision-maker, who would make decisions on their behalf if they are unable to do so.

Education

- HPNA will continue to develop evidence-based educational materials that support all levels of hospice and palliative nurses to provide optimum care to patients and their families during the continuum of the illness trajectory including to the end of life. Palliative care nurses shall ensure their professional development in the ethical principles and their relationship to withholding/withdrawing life-sustaining treatments.
- Palliative nurses possess sufficient knowledge about the issues of using, continuing, withholding, and withdrawing life-sustaining therapies to inform patients, families, and other healthcare providers regarding decisions about their use.

Clinical Practice

- The healthcare team must honor any previously communicated advance directive, including those that appoint a surrogate decision-maker if the patient loses decision-making capacity. If, for some reason, it is not possible for a healthcare team to honor advance directives or wishes, they must document the reason they cannot do so.¹
- Palliative care nurses shall ensure continued nursing care when withholding/withdrawing treatments—limitation of life-sustaining treatment does not mean limiting care. Patients and families often need reassurance that a decision to forgo or limit treatment does not result in lack of appropriate personal care or lead to abandonment.

Policy

- Patients who lack decision-making capacity and who do not have a previously designated surrogate decision-maker should have such a person named in accordance with state, local, and institutional regulations.

- A parents/guardian has legal authority to make decisions regarding treatment for a child if the child is younger than 18 years and the parent/guardian is considered to have

the child's best interest at heart. However, the child's views and preferences for medical care, including assent and refusal for treatment (when developmentally appropriate), should be documented and given appropriate weight in decision-making. When the child's wishes differ from those of the adult decision-maker, appropriate professional staff members must assist the child as well as the family.¹

Leadership

- Palliative nurses must help the public understand the difference between withholding/withdrawing life-sustaining therapies and euthanasia and assisted suicide.
- Palliative nurses support patients, families, and colleagues in the decision-making process.
- Palliative nurses shall facilitate decision-making and advocate for care that is consistent with the stated wishes of the patient and the patient's surrogates.

Background

When treatment outcomes are insufficient for a terminally ill patient to live a meaningful life, the treatment goal may transition toward care that is comfort-oriented. At that time, patients may consider DNR, which means that cardiopulmonary resuscitation will not be performed on patients in the terminal stage of incurable disease to allow them peaceful death.²

Decisions concerning withholding and/or withdrawing these therapies are often central to advance care planning.² In 1983, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research published *Deciding to Forgo Life—Sustaining Treatment*, which still stands as the cornerstone for ethical decisions relating to withholding/withdrawing therapies in current practice. Tenets from the President's Commission report include:³

- The voluntary and informed choice of a competent patient with decision-making capacity should determine whether a life-sustaining therapy would be initiated, withheld, or withdrawn.
- Healthcare professionals serve a patient's best interest by maintaining a presumption in favor of sustaining life, while recognizing that patients with decision-making capacity are entitled to choose to forgo any treatments, including those that sustain life.
- Whether a treatment is warranted depends on the balance of its usefulness or benefits for a particular patient and consideration of the burdens that the treatment would impose.

- It is often acceptable to use an appropriate surrogate, ordinarily a family member, to make decisions for patients who have insufficient capacity to make their own decisions.

Withholding and withdrawing life-sustaining therapies are considered the same in ethics. Both encompass choice of care treatments, unlike euthanasia or assisted suicide.⁴

In the 1990s, the U.S. Supreme Court rejected the argument that limitations to life support constitute physician-assisted suicide or euthanasia.^{5,6} The American Nurses Association states in its position statement *Registered Nurses' Roles and Responsibilities in Providing Expert Care and Counseling at the End of Life*:

“End-of-life choices are a quality-of-life issue. Nurses, individually and collectively, have an obligation to provide comprehensive and compassionate end-of-life care, including the promotion of comfort, relief of pain, and support for patients, families, and their surrogates when a decision has been made to forgo life-sustaining treatments.”⁷

Discontinuation of life-sustaining treatments that results in death may pose emotional challenges for the patient, provider team, and family members.^{8,9,10} Patients have the right to refuse medical treatments even if that decision results in death.⁸ A central issue in decision-making in situations of serious illness is the moral acceptability of actions that can be seen as hastening death.¹¹ If treatments are no longer effective or acceptable to the patient's personal wishes, it is both ethically and legally acceptable that the treatment be discontinued. Treatment discontinuation does not mean a physician is aiding the patient in dying, nor participating in manslaughter or assisted suicide.⁸

In the same manner that a patient's values should be honored, the nurse's values should be honored.¹¹ When nurses are uncomfortable with withholding/withdrawing treatments, they may remove themselves from patient care, after finding another nurse to replace them.¹² Should there be a disagreement among the patient, family, nurse, and healthcare team, ethics committees should be sought out for consultation to ensure that all sides are represented.¹²

Definition of Terms

Allow natural death: death from natural consequences of a disease or injury that emphasizes ongoing supportive care to promote comfort and optimize quality of life¹³

Autonomy (self-determination): the right of an individual to decide a course of action based on his or her personal goals and values^{14,15}

Beneficence: doing good and caring for patients in a way that they would want. Managing refractory symptoms is an example of this principle.^{14,15}

Capacity: the ability of a person to make a decision that is based on developmental and cognitive factors, including age and cognition, which impact the person's ability to receive information about the underlying illness and proposed treatments, understand the relevant information, and apply it to his or her own condition or the condition of an ill child. This also involves having insight into the condition and consequences of treatment options and the ability to communicate the decision and reasoning for choices.¹³

Dignity (respect for persons): the right to be perceived as worthy of honor and respect. It involves the ethical concept of autonomy, as individuals may fear the loss of control (loss of dignity) over their bodies in the dying process.^{14,15}

Do not resuscitate: an order written by an advanced practice provider in the medical record directing that no cardiopulmonary resuscitation is to be performed in the case of an acute event such as a cardiac, respiratory, or neurological decompensation¹³

Fidelity: commitment of healthcare professionals to keep our promises to patients and family members and to not abandon them and their needs, especially during the dying process¹⁴

Informed consent: Persons who possess medical capacity should be given the opportunity to choose what shall or shall not happen to them. The consent process has three elements: information, comprehension, and voluntariness—providing sufficient information about the treatment; understanding the consequences of a decision, its outcomes, and potential consequences; and deciding without coercion and undue influence. It may be appropriate at times to provide a written or oral test of comprehension.^{14,15}

When a person is considered incompetent (infants, children, mentally disabled patients, those who are terminally ill or comatose), respect requires giving them the opportunity to choose to the extent that they are able and seeking permission of other parties to protect the patient from harm. The third party chosen should understand the patient's condition and be willing to act in that person's best interest.¹⁵ It is important to provide the third party with sufficient information so that the person understands the consequences of a decision, its outcomes, and potential consequences just as the patient would be given.¹⁶

Life-sustaining therapies: interventions that may not control the patient's disease but may prolong the patient's life. These may include not only ventilator support, dialysis, and

vasoactive infusions, but also antibiotics, insulin, chemotherapy, and nutrition and hydration provided by tubes and intravenous lines.¹³

Nonmaleficence: not causing harm through omission of care or by not following a patient's request that could result in a loss of dignity, diminish the person's autonomy, result in abandonment, or ignore care wishes¹⁴

Principle of double effect: Both good and bad consequences can come out of a decision, but the decision/action is undertaken with the hope (ethical/moral) or intent that a good consequence will occur¹⁴

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This statement reflects the best available evidence at the time of writing or revisions.

Approved by the HPNA Board of Directors January 2022

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