

ELNEC Module 8 Final Hours:

Table 2: 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. These symptoms may be a reaction to fever, some physiologic change or drug reaction and may go away with treatment.	Disease progression 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)	Differentiate between nearing death awareness, confusion, disorientation and delirium. Assess cause and treat as appropriate. Implement safety measures including 24-hour supervision. Speak clearly and truthfully with the patient when something needs to be communicated to patient. Do not patronize. In home care setting, provide respite for the caregiver as needed due to increased patient care needs and caregiver fatigue. Professional caregiver/volunteer support.
Weakness and fatigue increase as patient gets closer to death. 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. Family/caregiver fatigue due to increased patient care needs at home.	Disease progression	Offer and provide increased assistance with ADLs (activities of daily living such as bathing, grooming, feeding, mobility with increase support from nurse, nurse's aides, volunteers, family). Provide assistive equipment as needed such as shower stool, hospital bed, wheelchair, walker as needed. If bed bound, passive ROM, turn and position, draw sheet, skin breakdown including air mattress as appropriate, rubbing

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		in circular motion over bony prominences to improve circulation and shift edema. In home care setting, educate family on patient needs and care. Provide respite for family caregiver in home care setting as needed. Social work, pastoral care support for anticipatory grief as needed. Increase patient care support including hospice, family, friends. If patient questions meaning of weakness in relation to disease progression, answer patient's questions openly, honestly.
Change in character and intensity of pain. Actively dying patient's family, nurse and/or other health care workers may have concerns about giving the "last dose" of pain medication for fear the dose will cause or hasten the death.	Disease progression	Assess pain frequently. Adjust medications, dosages based on principles of pain management. <i>[Refer to Module 2: Pain Management]</i> If pain control principles are followed, the disease and not the medication will cause the death. Listen to family/caregiver concerns, educate regarding principles of pain management, and explore choices regarding dying in pain and extending suffering versus comfortable death.
Patient may transition from	Disease progression	Hearing may be one of the last

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increased sleeping periods to diminishing consciousness and then coma.		senses to be lost, so tell comatose patient who you are upon entering room, what you will be doing and continue to speak to the patient during care and procedures. Educate family about signs and symptoms of disease progression and the importance of speaking to comatose patient as if they could physically respond. Allow transition through peaceful, quiet surroundings, soft music, quiet presence, gentle touch and reassurance that they are not alone. Encourage family to say what they need to say. Assess and explore spiritual needs during this time. Due to increased risk of withdrawal symptoms, do not abruptly stop pain medications because the patient becomes comatose. Assess pain and follow principles of pain management.

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

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Table 3: Psychosocial and Spiritual Signs, Symptoms and Interventions of the Actively Dying

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

Signs and Symptoms	Cause/Etiology	Interventions
		frequent breaks, offer respite. Family members may need permission from nurse to care for themselves.
Fear of the unknown	Fear of what will happen after they die. Fear that belief systems regarding afterlife will be different than perceived and/or lived.	Exploration of fear. Companionship, presence. Pastoral care or patient's clergy for exploration of life, afterlife, faith system beliefs. Support cultural and spiritual beliefs.
Nearing death awareness: 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." Statements may seem out of character, gesture or request. Patients may tell family members, significant others when they will die. (Callanan & Kelley, 1997)	Attempt by the dying to describe what they are experiencing, the dying process and death. Transition from this life. 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.	Do not contradict, explain away, belittle, humor or argue with the patient about these experiences. Attentively and sensitively listen to the patient, affirm the experience, and attempt to determine if any unfinished business, patient needs. Encourage family/significant others to say goodbye, give permission for patient to die as appropriate. Support to family and other caregivers. Educate about the difference between nearing death awareness and confusion, provide education to family and other caregivers.
Patients may withdraw from family, friends, the nurse and other health care professionals.	Transition from this life, patient "letting go" of this life.	Normalize withdrawal by educating family about transition. Presence, gentle touch. Family members may need to

Signs and Symptoms	Cause/Etiology	Interventions
		be educated, encouraged to give permission to patient to die. Family may need to be encouraged to say goodbyes.

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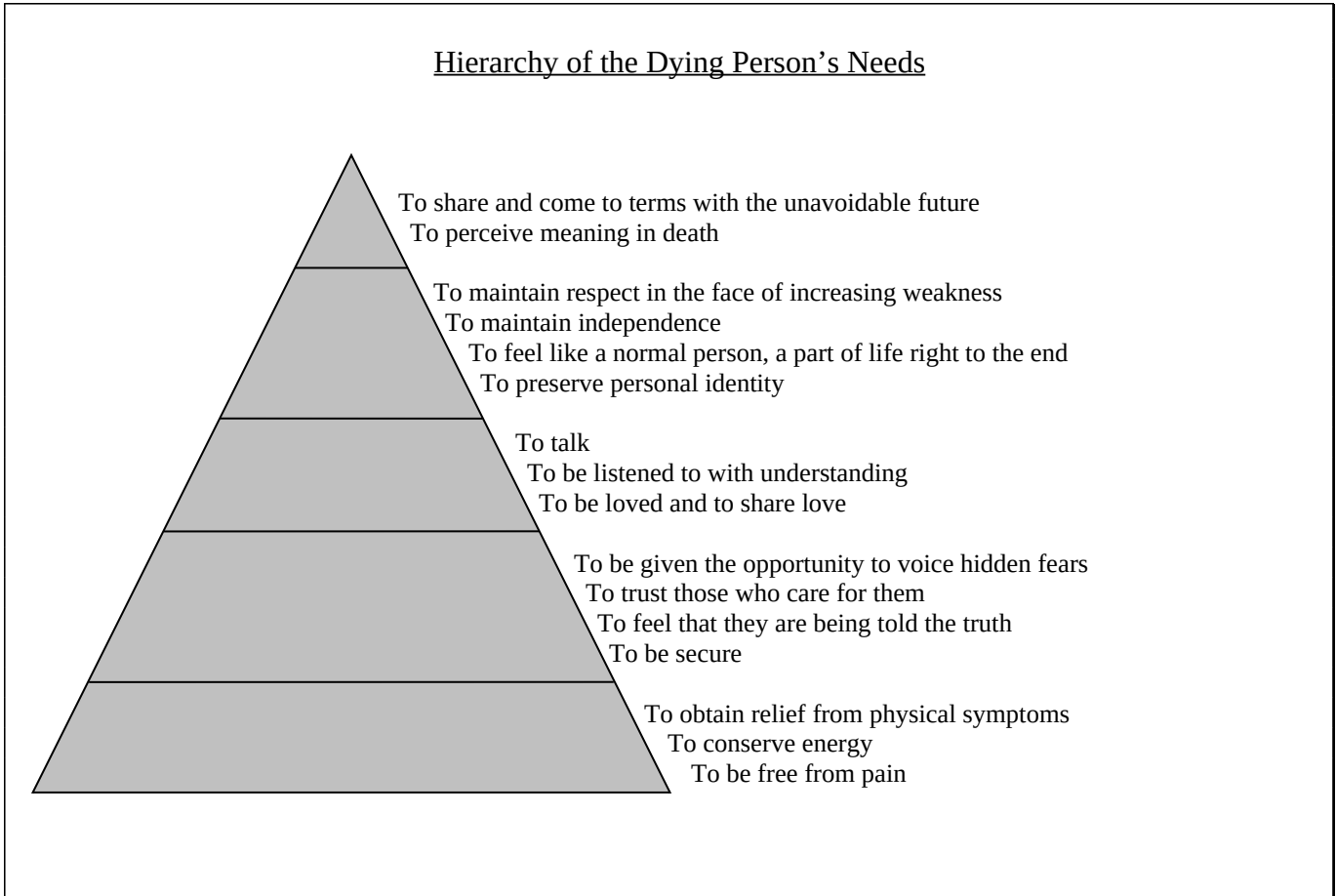
References:

Callanan, M., & Kelley, P. (1997). *Final gifts: Understanding the special awareness, needs & communication of the dying*. New York, NY: Bantam Books.

Doka, K., & Morgan, J. (1993). *Death and spirituality*. Amityville, NY: Baywood Publishing Co.

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Figure 1: Hierarchy of the Dying Person's Needs



Source:

Ebersole, P., & Hess, P. (1994). *Toward healthy aging* (p. 752). St. Louis, MO: Mosby, Inc. Reprinted with permission.

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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:

- Do not contradict, explain away, belittle or argue with them. These experiences can be very comforting to the patient.
- 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 such as “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 Hospice 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 Hospice 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 Hospice 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

Background

As life-sustaining therapies have emerged, so have the ethical and legal discussions about the appropriate use of these treatments. Decisions around withholding and/or withdrawing these therapies are often central in end-of-life decision-making. In 1983, the President's Commission for the study of ethical problems in medicine and biomedical research published, *Deciding to Forgo Life-Sustaining Treatment*.¹ This document still stands as the cornerstone for ethical decisions relating to withholding and withdrawing therapies in current practice. Tenets from the President's Commission report include:

- The voluntary and informed choice of a competent patient should determine whether a life-sustaining therapy would be undertaken.
- Healthcare professionals serve patient's best interest by maintaining a presumption in favor of sustaining life, while recognizing that competent patients 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.
- An appropriate surrogate, ordinarily a family member, should be named to make decisions for patients who have insufficient capacity to make their own decisions.

The American Nurses Association, in its preamble of the Code for Nurses states that when "making clinical judgments, nurses base their decisions on consideration of consequences and of universal moral principles, both of which prescribe and justify nursing actions. The most fundamental principle is respect for persons."² Respect for persons is a fundamental principle of bioethics; ensuring respect for persons includes honoring their wishes regarding treatment decisions.

Position Statement

This is the position of the HPNA Board of Directors:

- Every person with decision-making capacity has the right to initiate, any medical therapy that offers reasonable probability of benefit, and to withhold and/or withdraw any medical therapy.
- Patients have the right to appoint a surrogate decision maker.
- It is the duty of the healthcare team to honor any previously communicated advance directive, including those that appoint a surrogate decision maker if the patient loses decision-making capacity.
- Patients who lack decisional capacity and who do not have a previously designated surrogate decision-maker should have one named in accordance to state, local and institutional regulations.
- Parents/guardians have legal authority to make decisions regarding treatment for their children if the patient is under the age of 18, and are considered to have their child's best interest at heart.
- All life-sustaining therapies may be withheld or withdrawn.

- Palliative care nurses shall assist as needed to facilitate decision-making and advocate care that is consistent with the stated wishes of the patient and his/her surrogates.

Definitions of Terms

Forging life-sustaining treatment: To do without a medical intervention that would be expected to extend the patient's life. Forgoing includes withholding (non-initiation) and withdrawing (stopping).

Life-sustaining therapies include but are not limited to: Cardiopulmonary resuscitation; cardiac support devices (pacemakers, internal cardioverters/defibrillators, intraaortic balloon pumps) and cardiac medications; respiratory support devices (invasive and non-invasive mechanical ventilation, oxygen, and respiratory medications); renal support devices (dialysis in any form) and renal medications; blood products; parenteral and enteral nutrition and hydration; cancer treatments; and surgery.

References

1. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. *Deciding to Forgo Life-Sustaining Treatment: Ethical, Medical and Legal Issues in Treatment Decisions*. Washington, DC: US Government Printing Office; 1983.
2. American Nurses Association. *Code for Nurses with Interpretive Statements*. Kansas City, MO: American Nurses Association; 2001.

Developed by:

Peg Nelson, MSN, APRN, BC-PCM
Meg Campbell, PhD, RN, FAAN
Maureen Lynch, RN, NP, MS, CS
Christy Torkildson, RN, MSN, PHN

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This position statement reflects the bioethics standards or best available clinical evidence at the time of writing or revisions.

To obtain copies of HPNA Position Statements, contact the National Office at
Penn Center West one, Suite 229, Pittsburgh, PA, 15276
Phone (412) 787-9301
Fax (412) 787-9305
Website www.HPNA.org