

**Final Hours**  
**Supplemental Materials**

**Physical Signs, Symptoms and Interventions of the Actively Dying**

<b>Symptoms/Description</b>	<b>Cause/Etiology</b>	<b>Interventions</b>
<p>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.</p>	<p>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)</p>	<p>Differentiate between nearing death awareness, confusion, disorientation and delirium.</p> <p>Assess cause and treat as appropriate.</p> <p>Implement safety measures including 24-hour supervision.</p> <p>Speak clearly and truthfully with the patient when something needs to be communicated to patient. Do not patronize.</p>
<p>Weakness and fatigue increase as patient gets closer to death.</p> <p>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.</p>	<p>Disease progression</p>	<p>If bed bound, 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>Change in character and intensity of pain.</p> <p>Actively dying patient’s family, nurse and/or other health care workers may have concerns about giving the “last dose” of</p>	<p>Disease progression</p>	<p>Assess pain frequently.</p> <p>Adjust medications, dosages based on principles of pain management.</p>

<b>Symptoms/Description</b>	<b>Cause/Etiology</b>	<b>Interventions</b>
<p>pain medication for fear the dose will cause or hasten the death.</p>		<p>If pain control principles are followed, the disease and not the medication will cause the death.</p> <p>Remember, there will always be a “last dose” and it is the disease, not the pain medication that will take the patient’s life.</p>
<p>Patient may transition from increased sleeping periods to diminishing consciousness and then coma.</p>	<p>Disease progression</p>	<p>Hearing may be one of the last senses to be lost, so tell the comatose 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>For family members “visitng” via cellphone or laptop, educate them about signs and symptoms of disease progression and the importance of speaking to comatose patient as if they could physically respond.</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>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.</p>

Adapted from:

**Psychosocial and Spiritual Signs, Symptoms and Interventions of the Actively Dying**

<b>Signs and Symptoms</b>	<b>Cause/Etiology</b>	<b>Interventions</b>
<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>(Doka &amp; Morgan, 1993)</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 – this is frightening as many are dying alone from the coronavirus as family cannot be present</p> <p>May present as patient anxiety, pressing call button frequently.</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 a nurse with the patient.</p> <p>Provide presence.</p> <p>For family member doing bedside vigil, encourage frequent breaks, offer respite. Family members may need permission from nurse to care for themselves.</p>
<p>Fear of the unknown</p>	<p>Fear of what will happen after they die.</p>	<p>Exploration of fear.</p> <p>Companionship, presence.</p>

Signs and Symptoms	Cause/Etiology	Interventions
	Fear that belief systems regarding afterlife will be different than perceived and/or lived.	<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. (Callanan &amp; Kelley, 1997)</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>Do not contradict, explain away, belittle, humor or argue with the patient about these experiences. As long as they are not frightening, there is no need for pharmacologic intervention (i.e. using haloperidol for delirium)</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>
<p>Patients may withdraw from family, friends, the nurse and other health care professionals.</p>	<p>Transition from this life, patient "letting go" of this life.</p>	<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>

Signs and Symptoms	Cause/Etiology	Interventions
		Family may need to be encouraged to say goodbyes.

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

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.

## **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.<sup>1</sup> Decisions around withholding and/or withdrawing these therapies are often central to advance care planning.<sup>2</sup> In 1983, the President's Commission for the study of ethical problems in medicine and biomedical research published, *Deciding to Forgo Life-Sustaining Treatment*. 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<sup>3</sup>:

- 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 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.
- Using 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. They encompass choice of care treatments and are different from euthanasia, or assisted suicide.<sup>4</sup>

In the 1990s, the U.S. Supreme Court rejected the argument that limitations to life support constitute physician assisted suicide or euthanasia.<sup>5,6</sup> Setting limits to life-sustaining therapies has become common practice in North American and European ICUs.<sup>7,8</sup> The American Nurses Association, in its position statement *Registered Nurses' Roles and Responsibilities in Providing Expert Care at the End of Life* states: "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."<sup>9</sup> Respect for persons is a fundamental principle of bioethics; ensuring respect for persons includes honoring their wishes regarding treatment decisions.<sup>10</sup>

In the same respect that a patient's values are honored, so too, are the nurse's values honored.<sup>11</sup> If the nurse is uncomfortable with withholding or withdrawing treatments, he or she may remove themselves from the care of a patient, after finding another nurse to replace them.<sup>12</sup> Should there be disagreement between the patient, family, nurse, and healthcare team, ethics committees should be sought out for consultation to assure that views of all sides are represented.<sup>12</sup>

### **Position Statement**

This 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 or refuse and/or 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

- Palliative care nurses shall assure their professional development in the ethical principles and their relationship to withholding and withdrawal of life sustaining treatments.
- Palliative nurses possess sufficient knowledge about the issues surrounding the use of continuing, withholding, and withdrawing life-sustaining therapies to inform patients, families, and other health care providers in making decisions about their use.

#### Clinical Practice

- 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. If for some reason, it is not possible for a health care team to honor advance directives or wishes, they must document the reason they cannot do so.<sup>13</sup>
- Palliative care nurses shall assure that nursing care is continued through the withholding or withdrawal of treatments. In particular, that 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 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 to state, local and institutional regulations.
- Parents/guardians have legal authority to make decisions regarding treatment for their children if the child is under the age of 18, and the parents are considered to have their 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), is 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 are available to assist the child as well as the family.<sup>13</sup>

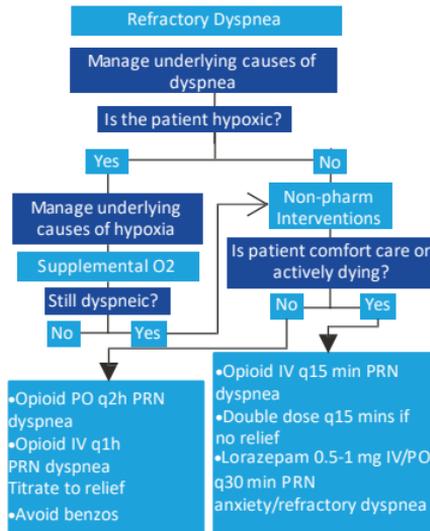
#### Leadership

- Palliative nurses must help the public understand the difference between withholding and withdrawing life-sustaining therapies and euthanasia and assisted suicide.<sup>4</sup>
- 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 his/her surrogates.

# Palliative Care for COVID-19



## Relief of Dyspnea



### Non-Pharmacologic Interventions:

- Bring patient upright or to sitting position
- Consider mindfulness, mindful breathing

### Pharmacologic Interventions:

- Opioids are treatment of choice for refractory dyspnea
- For symptomatic patients, using PRN or bolus dosing titrated to relief is more effective and safe compared to starting an opioid infusion

### Dosing Tips:

- For opioid naive patients
  - PO Morphine 5-10 mg
  - PO Oxycodone 2.5-5 mg
  - IV/SC Morphine 2-4 mg
  - IV/SC Hydromorphone 0.4-0.6 mg
- Consider smaller doses for elderly/frail



## Opioid Quick Tips

### Pharmacodynamics of Opioids:

- Time to peak effect / Duration of Action
- PO Opioids: 30-60 minutes / 3-4 hours
- IV Opioids: 5-15 minutes / 3-4 hours
- Time to peak effect is the same for analgesia, relief of dyspnea, and sedation

### Other Opioid Principles:

- If initial dose of IV opioid is ineffective after 2 doses at least 15 minutes apart, double the dose
- Typically need 6-8 hours of controlled symptoms to calculate a continuous opioid infusion
- If starting a continuous infusion, do not change more often than every 6 hours. Adjust infusion dose based on the 24 hour sum of PRNs

### Relative Strengths & Conversion

Opioid Agent	Oral Dose	IV Dose
Morphine	30	10
Oxycodone	20	--
Hydromorphone	7.5	1.5

\*Avoid fentanyl due to shortage

### Using Opioids, Start a Bowel Regimen:

- Goal is 1 BM QD or QOD, no straining
- Senna 2 tabs q HS, can increase to 4 tabs BID
- Add Miralax 17 gm daily, can increase to BID
- Bisacodyl 10 mg suppository if no BM in 72 hrs