

## ELNEC Final Hours- Adapted for COVID-19 Crisis

**Patients and families need us to be fully present- even when we have to be wearing PPE and respecting social distancing. During these challenging times, it is so important that we use our strong communication skills to help support patients and families, especially those facing the end of life.**

### Communication Tips:

- Open, honest communication fosters trust and informed decision making.
- In all communication, convey caring, nurturing, sensitivity, and compassion.
- Elicit patient and family understanding of condition/prognosis.
  - Patients may have a greater awareness of dying than those around them.
  - If patient asks if they are dying, explore the question. What makes you ask now? Has something changed for you?
  - Encourage open and honest communication between patient and family.
  - If the family is reluctant to address death with patient, address these concerns and fears:
    - Educate the family that the patient may already know they are dying.
    - Preparing for death leads to better bereavement outcomes.
- Provide information in simple, uncomplicated terms.  
 It might be important to communicate with only one designated family member- to cut down on multiple calls that keep you from being with the patients- encourage the family to set up a communication system to share information and updates with their friends and family- suggest using a platform such as Caring Bridge- that will cut down on their stress as well.
  - Avoid overloading or overwhelming with too much medical jargon.
  - Provide simple answers to questions in accordance with patient/family understanding/readiness for responses.
  - Information and understanding make for better choices and fewer regrets: options, benefits/burdens, outcomes.
  - Family members may be tired, have difficulty concentrating, and be focused on the present and not the future.
    - May need to answer same questions, provide the same information repeatedly, as patients/families may be in crisis and unable to retain some information.
- Maintain presence- **even with social distancing**
  - Address patient's/family's hopes.
  - Do not destroy hope: what are you hoping for? If cure from the virus is not possible, what else would you hope for?

- Provide presence: be available, listen, reflect, and connect- if you are communicating and being “present” through the phone or technology, make sure you establish a routine communication time to update family members who cannot see their loved ones- that will decrease their angst, knowing you will be calling them on a scheduled basis, unless there is sudden change in condition
- Provide assurance that someone will be available during the dying process.

**Ethical Issue:** It is not uncommon for patients to ask their healthcare professional to help hasten their death. The request may come because they have persistent symptoms that prolong suffering, loss of control, anxiety about the future, and fear of being a physical and financial burden to their loved ones. Though this request can cause healthcare providers angst, it is an opportunity to be aware of the patient’s suffering and to look at all ways to provide better assessment and care (Quill & Arnold, 2015 & 2016).

- The American Nurses Association (ANA) states that nurses are ethically prohibited from administering medical aid in dying medication(s) to patients as this act is in direct violation of Code of Ethics for Nurses with Interpretive Statements (ANA, 2015; herein referred to as The Code), the ethical traditions and goals of the profession, and its covenant with society. However, nurses must be comfortable supporting patients with end-of-life conversations, advocating optimized palliative and hospice care services, and know about aid in dying laws and how those affect practice. In the process of assessing the context of the medical aid in dying request, the nurse has an obligation to provide humane, comprehensive, and compassionate care and comfort that respects the rights and choices of patients who request medical aid in dying (ANA, 2019).
- Clarify what is being asked (Ramirez et al., 2019)
  - Explore motivations.
  - Explore alternatives to address issues raised:
    - Symptom management,
    - Psychosocial counseling.
  - Assure non-judgmental commitment to care.
  - Openly discuss patient’s request with others to eliminate secrecy.
  - Seek interdisciplinary support, as you care for the patient.

## Spirituality

- Many patients/family members may have an increased focus on spiritual issues at this time of impending/imminent death.
- Be aware of culture (e.g., religiosity, spirituality). Remember that nurses play a key role in orchestrating this care with the interdisciplinary team, in an effort to honor spiritual and cultural beliefs, traditions, rites, and rituals (Cormack et al., 2019). Spirituality is an important component of one’s identity and quality of life. Religious practices and beliefs may be a part of one’s spirituality. So be aware of traditions and rituals that are sacred to the

patient and family. Are they seeking meaning of this experience? Do they express hope and/or despair?

- What is the role of “religion” for this patient/family? Do they have a spiritual advisor/leader? If so, who is it? Ask patient/family if they would like for you to contact that spiritual leader.
- Provide spiritual comfort through presence, prayer, rites, and rituals. **If the patient or family asks you to pray with them and it is not something you are familiar with, it is fine to say, “I don’t know that prayer, but if you guide me I would be honored to be with you during this prayer.”**
- Encourage family members to bring in favorite hymns on CD, scriptures, symbols (e.g., rosary) so patient can experience these through different senses (hearing, seeing, touching).
- Remember to contact your pastoral care department, chaplains, priests, rabbis, imams, etc. as directed by the patient and/or family. **If visitation is limited due to the virus, try to set up a “virtual” spiritual visit with the appropriate pastoral care person.**
- Also, be aware of your staff, who witness suffering, moral distress, and other stresses related to caring for so many seriously ill patients. They may need these **services now more than ever before.**

### **Selected Symptoms Associated with End of Life**

- **Dyspnea:** In end-stage disease one should treat this symptom while assessing whether or not to treat the underlying cause. This would include treating infections or management of tumor progression. Symptom relief is the primary objective of care when the causes are no longer reversible. Opioids are the drug recommended for managing dyspnea.
- **Pain:** Frequent assessment of pain is critical in the final days and weeks of life. **If the patient has co-morbid conditions that have caused pain, pain must continue to be managed. Fears of opioids causing respiratory depression should not preclude pain management. Remember, patients get sleepy and are difficult to arouse when they have had too much opioid- in most instances, this will happen before respiratory depression**

If the patient did not previously have pain, but now appears to be in pain, or seems to have changes in pain behaviors, rule out other potential causes of distress such as:

- Constipation
- Delirium
- Decubitus ulcer(s) (check bony prominences)
- Mucositis (especially if patient is neutropenic)
- Extreme headache (especially if thrombocytopenic)
- Opioid toxicity if increasing analgesic use

### **Use of Opioids**

- As with all phases of pain treatment, the dose of opioids given during the last hours of life should be based upon appropriate assessment and reassessment.
- Many professionals often believe that opioid doses require extensive escalation during the last hours of life and fear that providing these doses will result in hastening death. Several studies indicate that for the majority of patients during the last 24 hours of life, the opioid doses remained low. For patients who did require significant increases, their survival was no different than patients who remained on stable dosing (Paice, 2019).
- **NOTE:** The dose of opioid needed to produce relief may be decreased during the final hours of life. This may be due to several factors, but decreased renal function is prominent. Renal function is altered due to decreased perfusion of the kidneys as well as the reduced volume of fluid as patients take in fewer liquids. The reduction in protein stores allows remaining fluid to enter peripheral tissues rather than remain in the vasculature. This changing renal status alters the clearance of opioids and other drugs, allowing more of the drug (and metabolites) to remain in the plasma for longer time periods. **Never abruptly discontinue an opioid (or benzodiazepine), as the patient can experience severe withdrawal, even if cognitively impaired or unresponsive.**
  - The **oral route** for drug administration is possible even in the last hours of life. In one study, researchers reported that 60% of patients in hospice were able to swallow until a few hours before death, another 25% required a dose or two of opioid by **suppository**, and only 15% required **injection** (Lacey, 2015).
- **Noisy breathing/respiratory congestion/terminal secretions:** also known as the “death rattle,” is a distressing and frightening symptom for those involved in the patient’s terminal care. **Remember to try to treat these secretions before the family has a “virtual visit” using technology- family members want to know their loved ones are comfortable.**
  - For patients who are alert, their noisy respirations can cause them to become agitated and fearful of suffocating.
  - Terminal secretions occur as the patient approaches and death and can no longer clear the secretions by coughing or swallowing. Most patients will die within 48 hours after developing terminal secretions (Donesky, 2019).
  - Assessment includes determining if causes (e.g., pulmonary embolism, myocardial infarction, fluid overload, pneumonia, etc.). of the terminal secretions /respiratory congestion can be treated.
  - Symptom management should focus on the underlying cause if appropriate to the disease/prognosis and patient/family wishes.
  - Pharmacological interventions include the use of anticholinergics as the primary mode of treatment. For example, scopolamine patch, starting with one (1.5 mg) and increasing by one patch daily. If at three patches the patient is without relief, begin an infusion of 50 mcg/hr. and titrate hourly to a maximum of 200 mcg/hr. Atropine (0.4 mg), either IV or SQ can be used, but this may cause tachycardia.
- Nonpharmacological interventions include:

- Attempt to reposition the patient (either on their side or semi-prone to assist with any postural drainage).
  - Keep head of bed elevated.
  - Suctioning is generally not recommended, as it can increase agitation and distress in the patient.
  - Reduce fluid intake.
- Support the patient and family
    - Using the term “death rattle” can be a frightening term to hear. Some have suggested using the term “respiratory congestion” or “terminal secretions” to describe this phenomenon to patients/family.
    - Be honest with families and let them know that this can occur before death, so that families caring for their loved one at home will know what may be available to relieve this symptom.
- **Delirium:** Delirium is frequently overlooked or misdiagnosed and yet is seen in 3%-45% of palliative care patients. For inpatients, delirium can be seen in 59%-88% in the weeks or hours before death
    - Good assessment and proactive management are critical. Review history, current medications, and perform a thorough physical exam are key to assessment.
    - Delirium can be a prognostic indicator of impending death (Burhenn, 2016).
    - As you consult with the interdisciplinary team, keep the patient’s goals of care in mind as you work to develop management strategies.
- **Myoclonus:** Or myoclonic jerking, is associated with multiple factors:
    - High-dose opioids (e.g., morphine, fentanyl, methadone, meperidine, and transdermal fentanyl), neuroleptics, and metoclopramide.
    - Discontinue any medications that may be causing myoclonus.
    - Assess for withdrawal from barbiturates, benzodiazepines, anticonvulsants, and alcohol.
    - Be aware of certain conditions such as cerebral edema, hypoxia, multi-organ system failure(s), and AIDS dementia.
    - The primary treatment for myoclonus is opioid rotation, especially if the patient is on high doses of an opioid and has poor renal function.
    - Consider a preservative-free solution as the preservatives and antioxidants in high doses of opioid infusion may lead to adverse effects.
    - Other treatments include use of benzodiazepines. Clonazepam is the most frequently used and most effective. Untreated myoclonus can progress to seizures. Treatment is essential (Schwartz, 2019).

**Imminent Death-** Many patients fear dying alone and many families would prefer to be with their loved one who is imminently dying. **With visitor restrictions, this may be difficult in some institutions, especially if hospice is not involved. Advocate for 1-2 family members to be able to be with the patient in the last hours of life. If this is not possible, try to use technology (smart phones, facetime, ipads etc.) to connect the patient and family- and**

**remind the family that we believe the sense of hearing is the last sense to go, so even if they cannot be with the patient, or if the patient is unresponsive, the patient can still hear them.**

### **Care after death**

- Removal of tubes, medical supplies and equipment:
  - Following the death in any setting, medical supplies, equipment, tubes such as catheters, IVs, etc. should be removed from the room immediately.  
**NOTE:** An exception would be instances if the death was a coroner's case, where such tubes would need to be left in place until a coroner approves removal of tubes/equipment, etc.
  - The goal is to provide a more personal closure experience for the family, leaving the family with memories of the deceased as a loved one rather than as a patient. **This is true even if the family is seeing their deceased loved one "virtually".**
- Bathing, dressing, and positioning body shows respect and provides dignity for the patient and family.
- Position the body in proper alignment, place dentures in mouth.

- If a patient dies in the hospital, there is usually a sense of getting the room “cleared” as soon as possible, so another patient can be admitted. **This is especially true during the coronavirus crisis where beds are limited.** But, the nurse needs to advocate for the family at this time so that they can at least say their goodbyes. Family should **never** have to do that in a morgue.

## Final Hours

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