

Restlessness

The restlessness that commonly occurs during the dying process is also called terminal or agitated delirium. It can also result from pain, bladder distention or stool impaction. The patient must be protected from injury and the family needs to be supported. Consider the following:

- Give a trial dose of opioids to rule out pain.
- Assess for bladder distention and insert indwelling catheter if needed.
- Assess for impaction if appropriate.
- Consider antipsychotics: haloperidol or chlorpromazine.
- Consider benzodiazepines: lorazepam or midazolam.
- Maintain calm environment.
- Minimize bright lights.
- Play patient's favorite music.
- Talk softly to patient; maintain use of touch and presence
- Comfort patient by saying: "You are safe. We are with you. We love you."
- Consider aromatherapy.

Unfinished business may cause restlessness discuss with family possible causes of anxiety.

- Review with the family the importance of saying good-bye and to give permission to stop fighting.
- Question family about an important family event or anniversary.

Educate the family:

- Patient lacks awareness of behavior.
- Possible to be peacefully confused.

Emotional Support

Providing emotional, spiritual, psychosocial and cultural support to the patient and family allows us to care for the soul. This is the very foundation of caring for the dying. It is important to know your resources:

- Notify supportive care medicine team members for assistance.
 - Be specific if resources are for patient, staff, or both.
- Always work to retain the patient's dignity and feelings of value.
- Remember every family is unique and grieves differently.

Good communication is essential:

- Insure communication exists with the family and all disciplines.
- Take your cues from the family. Do not assume you know what they are thinking or feeling.
- Clarify how much the family wants to know.
- Clarify goals of care.
- Clarify privacy needs.
- Just be with patient and family and sit in silence.
- Work with family to provide favorite activities, smells, sounds, etc.
- Support rituals and assist with obtaining desired clergy or equipment.

Emotional Support (continued)

Other activities and methods of support to consider:

- Your humanity is needed the most now. Always be available. Your very presence is reassuring to the family.
- The family is an important part of your patient care and becomes your focus as the patient becomes more unresponsive.
 - Be sure families are getting rest, and breaks.
 - Provide coffee, water, etc.
 - Continue to be available to answer questions.
 - You cannot take away their pain. Acknowledge their emotions and be present.
- Play patient's favorite music.
- Position bed to see out a window.
- Encourage family to provide patient's favorite hat, clothing, etc.
- Lower or mute lighting.
- Consider bringing in favorite pet.

"It is the power of our own humanity that can make a difference in the lives of others. We must value this as highly as our own expertise."

– Puchalski and Ferrell, 2010

Self Care

The health-care provider must allow themselves to be human and expect some personal emotional response to the death of their patient and for the grieving family. Palliative/Supportive Services are available to staff. Often a review and debriefing can assist with professional grieving and promote emotional health by:

- Recognizing the stressful event and thanking supportive team members.
- Reviewing what went well and what challenges need to be addressed.
- Sharing bereaved family comments.
- Addressing moral distress issues.
- Expressing issues of death anxiety and obtaining support.
- Exploring challenges and privilege of assisting a fellow human being through the dying process.
- Acknowledging the spiritual impact of witnessing death.
- Exploring how your care made a difference to the grieving family.
- Reviewing effective communication techniques, available resources and support.

C.A.R.E.S.

A Tool for the Care of the Dying



The following are recommendations for care of the dying based on the End of Life Nursing Education Consortium (ELNEC) project and the second edition (2009) National Consensus Project for Palliative Care Clinical Practice Guidelines for Quality Palliative Care. The recommendations are arranged in the acronym CARES (Comfort, Airway, Restlessness, Emotional support, and Self care) to organize the most common needs and education requirements to support the dying patient and their family. The tool is intended to prompt nurses to obtain orders for symptom management, increase awareness of resources and promote communication with the ultimate goal of achieving a peaceful death for their patient and family.

"...there are worse things than having someone you love die. Most basic, there is having the person you love die badly, suffering as he or she dies. Worse still is realizing later on that much of his or her suffering was unnecessary."
- Ira Byock, 2012

Permission to reproduce can be obtained from Bonnie Freeman at bofreeman@coh.org.

Comfort

Pain Management

You must act as an advocate for your patient to control their pain. Pain control is an essential need for all dying patients.

- The route of the medication determines time to maximum effect:
 - IV peak effect is 15 minutes
 - PO in 60 minutes
 - Sub-q in 30 minutes
 - Transdermal 4 to 6 hours
- Terminal pain/pain during dying is best managed by around the clock, scheduled, or a continuous infusion of opioid (such as from a PCA pump) and additional doses (boluses) given as needed for breakthrough pain.
- There is no maximum dose of opioids for pain control.
- Nurses are often frightened the opioid they give a patient will cause them to die prematurely.
 - There will always be a last dose when caring for a dying patient. Keep in mind the legal and ethical concepts of intent.
 - The patient is dying because of their disease process not the opioid.
- Adjustments in dosage or type of opioid may be required in the presence of renal failure, and if the pain medication does not help to control the patient's pain.
 - Consider fentanyl if the patient is in renal failure and if the patient is having small seizure like tremors (myoclonus).
 - Opioids stay in the system longer with renal failure. Dosage is usually smaller.
 - Consider changing the type of opiate if pain remains uncontrolled.

Comfort (continued)

The focus of care for the dying patient is comfort. All unnecessary procedures, tests and activities should be evaluated. Providing as much time for the patient and family to be together should be the priority. Consider obtaining orders as appropriate for the following:

- Stop or modify vital signs
 - Stop oral medications if unable to swallow and all nonessential medications.
 - Clarify IV options: stop or reduce.
 - Stop or reduce tube feedings.
 - Turn off monitors and alarms.
 - Stop or decrease labs per physician and family preference.
 - Discontinue isolation.
- You can provide the following comfort measures without an order:
- Turn and position patient only for comfort.
 - Modify bathing or stop per family request.
 - Consider re-enforcing dressings only.
 - Provide frequent oral care.
 - Provide oral suctioning if family requests.
 - Provide temperature comfort measures such as a cool wash cloth and ice packs.
 - Explain mottling and cyanosis as part of dying process and not from being cold.

Airway

The use of supplemental oxygen during the dying process is often ineffective but may help to minimize the family's fears of their loved one suffering. Review goals of care established by the patient and family for supplemental O2.

- Consider use of a fan.
- Provide nasal cannula per M.D.'s orders.
- Reposition patient as needed.

The dying process results in irregular breathing with periods of apnea. Secretions often pool in the back of the patient's throat resulting in loud congestive sounds. Patients can become restless and anxious. Consider obtaining orders for:

- Glycopyrrolate, scopolamine patch or Atropine 1% ophthalmic solution.
- Morphine IV or Sub-q: The patient is dying and will stop breathing due to their disease and the dying process, and not from receiving morphine.
- Consider using anti-anxiety agents and/or antipsychotics.

Provide family education as needed. Some common issues to address are:

- Breathing patterns of the dying. Breathing becomes progressively irregular, shallow and slowed. Episodes of apnea will extend. This is all from brain stem activity. It is involuntary and the patient is not suffering.
- Emphasize the calming effects of touch and talking to the patient.

Comfort
Airway
Restlessness
Emotional support
Self care

