

Nurses are obliged to provide comprehensive and compassionate end-of-life care. They are responsible for recognizing patients' symptoms, taking measures within their scope of practice to administer medications, providing other measures for symptom alleviation, and collaborating with other professionals to optimize patients' comfort and families' understanding and adaptation. The nurse's role in the final weeks, days, or hours of a patient's life is crucial in minimizing both patient and family suffering.

Although death can be caused by multiple etiologies and may have had a disease-specific trajectory, the final period of life in serious illness is characterized by signs and symptoms that are nearly universal.

## **SIGNS & SYMPTOMS**

Care for the patient in the final weeks of life shifts and changes rhythm as the patient's condition changes and should be focused on the patient's expressed goals of care and the provision of comfort. Comprehensive and compassionate end-of-life care includes recognizing when death is near and conveying that information to families to allow for adequate preparation as much as possible.<sup>1</sup>

A patient's decline to death is best measured with validated assessment tools, such as the Palliative Performance Scale (PPS), Functional Assessment Staging Test (FAST) for patients with dementia, Karnofsky Performance Status (KPS) scale, and Eastern California Oncology Group (ECOG) Performance Status tool for cancer patients. They can be utilized for baseline assessment and reassessment as a patient declines to death.

A patient may exhibit signs of decline and impending death that may or may not present as symptoms or require treatment. The anticipated signs of approaching death include the following:

- Weeks remaining: decreasing socialization, mental status changes, decreased oral intake, fatigue, bedbound with potential for skin breakdown, decrease in functional status as evidenced by declining PPS/KPS/FAST scores. Patient may state, "I just want to be left alone" or "I'm not hungry and don't have energy to get up anymore."
- Days remaining: oliguria or anuria, little or no response to auditory or visual stimuli, terminal secretions (audible "noisy" respirations from accumulation of saliva and secretions related to decreased swallowing), "rally day" (surge of unexpected energy or level of consciousness), temperature fluctuations, increased heart rate, near-death awareness experiences
- Hours remaining: cooling and mottling of extremities, bradycardia, terminal secretions, prolonged periods of apnea, cyanosis, waxy facial appearance, obtundation

Some patients may exhibit discomfort in their last days. Commonly occurring symptoms requiring interventions are pain, dyspnea, nausea, anxiety, agitation, and terminal secretions.

## INTERVENTIONS

Management of symptoms at the end of life may include nonpharmacological, pharmacological, interventional, behavioral, and complementary treatments. Utilize interdisciplinary team resources to address spiritual, psychosocial, and cultural considerations or concerns.

- Reassess the patient’s and family’s desire to receive information related to illness progression.
- If the patient can participate, revisit definition of quality of life and wishes for end-of-life care. Include desired family members in discussions and reviews.
- Reassess the patient and family frequently for changing needs and responses to interventions.
- Monitor and manage symptoms with a focus on comfort.
- Simplify medication regimens and retain only those needed for active symptoms.
- Use interventions that are minimally invasive and culturally appropriate.
- Prior to implementing interventions, ensure that the family can safely and effectively manage and administer medications or treatments.

NONPHARMACOLOGICAL INTERVENTIONS	PHARMACOLOGICAL INTERVENTIONS
<ul style="list-style-type: none"> <li>• Investigate reversible causes while pursuing quality of life and symptom management.</li> <li>• <b>Dyspnea:</b> Positioning, cool environment, and direct airflow from a fan may be effective.</li> <li>• <b>Anxiety/agitation:</b> Explore the possibility of reversible causes (e.g., bladder or bowel distention, anxiety, drug or alcohol withdrawal, pruritus). Maintain a quiet environment with dimmed lights, calming music, etc.</li> <li>• <b>Pain:</b> Use techniques for distraction, repositioning, relaxation, mindfulness, and meditation.</li> <li>• <b>Nausea:</b> Provide a calm, odor-free environment. Stop or reduce tube feedings and intravenous fluids.</li> </ul>	<ul style="list-style-type: none"> <li>• All pharmacological interventions should be based on review and necessity of current medications for comfort.</li> <li>• <b>Dyspnea:</b> concentrated immediate-release morphine or oxygen therapy (depending on underlying disease)</li> <li>• <b>Anxiety/agitation:</b> haloperidol or lorazepam (used with caution) in liquid or crushed tablet form</li> <li>• <b>Pain:</b> opioids administered by sublingual, subcutaneous, rectal, or intravenous routes</li> <li>• <b>Nausea:</b> haloperidol or lorazepam liquid, crushed tablets, or prochlorperazine suppository</li> <li>• <b>Terminal secretions:</b> anticholinergics (e.g., glycopyrrolate, hyoscyamine, atropine, sublingually or scopolamine patches)</li> </ul>

<ul style="list-style-type: none"> <li>• <b>Terminal secretions:</b> Reposition to the side for optimal oral drainage. Encourage frequent oral hygiene.</li> <li>• Outline expected changes as desired by patient and family.</li> <li>• Use effective and compassionate communication to support peaceful death.</li> <li>• Facilitate expression of emotions.</li> <li>• Be aware of the unique nature of the individual's dying process and tailor care accordingly.</li> <li>• Integrative therapies such as aromatherapy, pet therapy, or music therapy may assist with all symptoms.</li> </ul>	
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### SIGNS THAT DEATH HAS OCCURRED

- Unresponsive
- Absence of heartbeat and respirations
- Body color pale and waxy as blood settles
- Pupils fixed and dilated
- Decreased temperature
- Muscles that relax then stiffen four to six hours after death as rigor mortis sets in
- Possibly opened eyes, relaxed jaw

### COMPASSIONATE POSTMORTEM CARE

- Patient and family members should be given privacy for final moments.
- The body of the deceased is always to be treated with respect and protection of dignity.
- Facilitate family participation, if desired, in final preparation of the body and spiritual or cultural practices.
- Follow organizational protocols for death pronouncement, notifications, medication disposal, and transfer of body.
- Participate in a sacred pause—a ritual performed at a patient's death to honor the lost life, recognize the efforts of the healthcare team, reflect on the experience, and bring closure when possible. <sup>2</sup>

## FAMILY & TEAM DISCUSSIONS

### Patient and Family Education and Support

- Explore realistic expectations for symptom trajectory with reassuring education on continued management strategies to allay fears and facilitate coping.
- Provide education on medication management to include response to therapy reporting and team communication parameters.
- Provide education and demonstrations on suggested nonpharmacological interventions.
- Offer reassurance that interdisciplinary support is available 24/7 and confirm that family has contact information readily available.

### Interprofessional Team:

Successful interventions in caring for patients at the end of life benefit from multiple perspectives to anticipate, prevent, and treat physical, psychological, social, and spiritual needs.

Consider social work support, bereavement counseling, or spiritual care specialists for palliative and hospice patients and families. Multiple modalities can be used to address concerns regarding caregiver support, grief, fear, anxiety, guilt, depression, spiritual and cultural rituals, and financial concerns as culturally appropriate.

The team should consider strategies for collective debriefing, reflection, and sharing of self-care strategies. This is especially important for teams that are repeatedly exposed to frequent deaths, such as intensive care units, emergency departments, palliative care and hospice inpatients units, and hospice home care staff.

## DOCUMENTATION EXAMPLE

1. **An 82 yr old female is a hospice patient in the final stage of advanced dementia** as evidenced by FAST score 7f and PPS 10% per previous nursing visit x 2 days ago. Family caregiver has called in to report a change of condition, stating, “My mom’s breathing is very slow, and her hands and feet are cold and purplish.” A visit nurse is dispatched and reports the following: Patient reclining prone in bed, color pale yellow, heart rate 56, respiration rate 4 and shallow, lung fields clear but with audible secretions in upper airway. Cooling and mottling of all extremities noted. Patient is unresponsive to auditory and visual stimuli. No grimacing or restlessness noted; appears comfortable. Caregiver at bedside; instructions given related to oral hygiene and position change for secretion drainage. After position change, small amount of clear saliva drained with cessation of audible respirations. Caregiver assisted with position change and demonstrated effective oral hygiene techniques. Patient unresponsive to change in position; no evidence of skin breakdown on pressure areas. Discussed signs of impending death with family members, who expressed tearful understanding. Emotional support provided through active listening; hospice chaplain contacted per family request.

## DESIRED NURSING OUTCOMES

- Promote shared decision-making and informed discussions related to the patient's goals and preferences in the face of disease progression and impending death.
- Acknowledge multiple psychosocial and spiritual needs, including anticipatory grief, and collaborate with skilled team members to support the family.
- Maximize patient comfort and quality of life (as defined by the patient) until death.
- Equip the family by normalizing the dying process and providing supportive bedside interventions.
- Facilitate bereavement support for family members and caregivers.

## REFERENCES

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