Recognizing approaching death allows the patient, family members, and interdisciplinary team to prepare for the actively dying phase. The nurse has two primary responsibilities at this time: providing symptom management and preparing the family for what to expect as death is approaching. Nurses also have additional responsibilities regarding organ donation, postmortem care, and facilitating arrangements.

It is essential for nurses to ensure that patients and their family members have access to the interdisciplinary team in the final days before death. Developmentally appropriate education should be provided to the patient, family, and/or other caregivers about what to expect during the final hours of life, as well as immediately following the patient’s death. Early access to hospice support should be facilitated whenever possible to optimize care outcomes for the patient and the family.¹

Nurses have a responsibility to carry out and respect the patient’s wishes to the extent they can. Each individual patient is different, and what works best for one patient might not work well for another. Dying is a multifaceted process that is unique to every patient. Providing a “good death” for patients means respecting their preferences and offering support for them and their family.

The nurse assumes multiple roles of advocate, professional caregiver, educator, and supporter and is frequently the one to facilitate a dignified death no matter the setting where death occurs. Nurses must be comfortable in “providing presence” and “bearing witness” with dying patients and their families. Rhythms of care (i.e., vital signs and routine assessments) often change during these final hours; be aware if these actions provide comfort or are burdens causing discomfort.²

Avoid overwhelming the family with too much medical jargon. Provide simple answers in accordance with the patient’s and family’s understanding and readiness for responses. Family members may be tired, emotional, and have difficulty
concentrating. Because they may be in crisis and unable to retain much information, you may need to answer the same
questions or provide the same information repeatedly.³ It is helpful to provide family members written resources about
what to expect. A commonly used resource in hospice care that can be very comforting for family members is Gone
From My Sight: The Dying Experience. It is an inexpensive resource available to order online if it is not available at your
facility.

There is no typical death. Each person dies in their own way, at their own time, with their own beliefs and values, and
with unique relationships with family, friends, and significant others. Many people experience similar psychological and
emotional responses during this time, such as fear of the dying process, fear of abandonment, fear of the unknown,
nearing death awareness, and withdrawal. The nurse is essential in addressing patient’s fears and managing their
symptoms according to their preferences.

Managing Common Symptoms During the Dying Process

Most patients experience the dying process as a natural slowing down of physical and mental processes. Two roads to
death have often been described. One road involves sedation and lethargy leading to a comatose state and death.
Another road involves confusion, restlessness, muscle jerks, seizures, and death.⁴

Pain and Dyspnea

During the final hours of life, changes in level of consciousness can make assessment and management of pain
challenging. Consider behavioral cues such as grimacing and posturing, as well as previous pain issues. Some patients
also demonstrate signs of increased dyspnea, commonly referred to as “air hunger,” with labored and increased work of
breathing.

Pain pumps may be used to relieve severe pain, especially cancer-related pain. Medication can also be administered
orally, even up to the last hours of life, for pain and dyspnea.⁵ For example, Roxanol is a highly concentrated solution of
morphine sulfate that can be administered sublingually for pain and/or air hunger. The typical dosage is 20 mg/mL.
Morphine not only relieves pain, but also is used to relax respiratory muscles and improve air exchange to relieve air
hunger. However, the nurse should always balance providing analgesia with the patient’s goal for maintaining alertness.

Principle of Double Effect

Nurses and family members may be hesitant to administer morphine in the last few hours of life, fearing that it may
hasten death, yet also not wanting to see the patient suffer. The American Nurses Association and the Palliative Care
Nurses Association support the nurse in this dilemma that is often referred to as the Rule of Double Effect. If the intent
is good (i.e., relief of pain and suffering), then the act is morally justifiable even if it causes an unintended result of
hastening death. Thus, the nurse should provide pain relief, without fear of sedation or respiratory depression that
typically limits the administration of opioids, in the final days and hours of a patient’s life.⁶
Terminal Secretions

Terminal secretions, commonly known as the “death rattle,” can be a distressing and frightening symptom for family members and those involved in the patient’s care. Terminal secretions are usually observed 3-23 hours before death. Anticholinergic medications, such as atropine or scopolamine, can be used to dry the secretions. It is also helpful to reposition the patient on their side, if feasible. Suctioning is not recommended because it is not typically effective for these types of secretions and can cause increased agitation and distress in the patient. Family members caring for patients at home under hospice care should be warned about this phenomenon and instructed about potential treatment. [7]

Note

View a supplementary video (11 minutes) on Lessons from a hospice nurse: Alia Indrawan at TEDxUbud [8].

Phases of Dying

There are typically four phases that a person progresses through when dying. These phases include actively dying, transitioning, imminent death, and death.

Actively Dying

A patient in this phase will experience symptoms such as pain, dyspnea, fatigue, cough, incontinence, nausea and vomiting, depression, anxiety, and seizures. Treatments during this phase are focused on symptom management and emotional support to both the patient and the family. Read more about symptom management in the "Palliative Care Management" section of this chapter.

Educating the family and patient on what to expect is essential. Include written materials and progressive education as the patient’s condition changes. It is often helpful to provide guidance to the family in anticipation of upcoming phases of dying.

Transitioning

This is the phase between actively dying and imminent death where the patient withdraws physically. The patient begins to demonstrate decreased interest in activities of life with less frequent interactions with others and often has hallucinations. Other signs of this phase include hypoxia and acidosis. It is important for the nurse to keep the patient’s environment as comfortable as possible, such as keeping lights low and minimizing alarms and other noises.

Imminent

Death will occur at any point during the imminent phase due to multisystem organ failure. This phase usually occurs within 24 hours before death with common, recognizable signs. See Table 17.5 for typical signs that occur during this stage and indicate that death is imminent.
Table 17.5 Typical Signs as Death Becomes Imminent

<table>
<thead>
<tr>
<th>System</th>
<th>Signs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiovascular</td>
<td>Cool, clammy skin; mottled extremities; rapid or irregular pulse</td>
</tr>
<tr>
<td>Musculoskeletal</td>
<td>Inability to ambulate, move, or turn in bed</td>
</tr>
<tr>
<td>Neurological</td>
<td>Confusion, restlessness, increased lethargy, hallucinations</td>
</tr>
<tr>
<td>Respiratory</td>
<td>Increased respiratory rate, inability to clear secretions, Cheyenne-Stokes respirations, noisy breathing (i.e., terminal secretions)</td>
</tr>
<tr>
<td>Urinary</td>
<td>Decreased or dark urine output</td>
</tr>
</tbody>
</table>

During this stage, the family often requires additional support from the nurse as death becomes more of a reality. Vital signs are usually no longer assessed because they do not provide a benefit for the patient. The nurse should offer support by encouraging reminiscence, calming music, touch, light massage, presence, and prayer (according to family preferences) as the patient begins their transition.

The dying process is variable for each individual. Families often ask for a definitive time frame when death will occur. Although these signs that indicate progression within 24 hours, a specific time line cannot be predicted. Some patients seem to instinctively know when death will occur.

Be aware of religious practices and beliefs that are sacred to the patient and/or their family members at this time. Provide spiritual comfort through presence and prayer (based on patient preferences and the nurse’s comfort level). Call the agency chaplain and/or the patient’s clergy as indicted. (Read more about chaplains in the “Spirituality” chapter.) Encourage family members to bring in favorite hymns, scriptures, or symbols (i.e., a rosary) so the patient can experience these spiritual comforts through different senses (hearing, seeing, touching).

Consider coaching family members about the five tasks that may serve as parting words with their loved one:

- To ask forgiveness
- To forgive
- To say “Thank you”
- To say "I love you"
- To say “Goodbye”

Note

Read more about parting tasks in the book by Ira Byock, M.D. titled *The Four Things That Matter Most*.[10]
Death Vigil by Family Members

Family members have historically desired to be at the patient’s bedside during the days to hours before death. See Figure 17.27[11] for artwork depicting the death vigil by family members when George Washington died.

Figure 17.27 Death Vigil

Family members have common fears, such as the following:

- The patient being alone when they die
- Not knowing how to react or what to do
- Watching the patient suffer
- Not knowing if the patient has died
- Giving the “last dose” of medication at home and inadvertently causing death

It is important for the nurse to address family members’ fears proactively and provide education and support.

Death and Postmortem Care

Clinical death occurs when blood circulation ceases, the heart stops beating, and respirations stop. Within 4-6 minutes of clinical death, CPR can be performed to attempt resuscitation. However, because most patients receiving palliative or hospice care have Do Not Resuscitate (DNR) orders in place, CPR is not performed. After this time window, brain cells die from lack of oxygen, followed by death of cells in other organs. This is called biological death. Rigor mortis, stiffening of muscles, will begin to set in several hours following death and be at its peak 12-18 hours following death. Rigor mortis disappears 48 hours following death. The nurse should listen to the apical heartbeat for one full minute to ensure and document that death has occurred.

When a resident or patient passes away, the nurse should perform and document a final nursing assessment that includes the following:

- Date and time of the assessment
• Patient name
• Time of physician contact
• Individuals present at time of death (i.e., family members, friends)
• Lack of response to stimuli
• Absence of apical pulse
• Arrangement for transport to the morgue or funeral home

Care following a patient’s death requires sensitivity for the dignity of the deceased, as well as time for the care of family members. Following the death pronouncement, family members may feel numb and confused about what to do next. In a quiet and private place, explain the process for care of the body immediately following death.\[12\]

Following death, medical supplies and equipment tubes should be removed unless a coroner must approve of such measures. The goal is to provide a more personal closure experience for the family, leaving them memories of the deceased as a loved one rather than as a patient. Bathing, dressing, and positioning the body show respect and provide dignity for the patient and family. Position the body in proper alignment and place dentures in the mouth. Place dressings on leaking wounds and apply incontinence products as needed. Remember to honor cultural practices regarding care of the body after death and who should provide that care.\[13\]

The nurse should continue to provide support for the family and offer assistance as needed, such as contacting other family members to inform them of the death. Some family members may want to take pictures, comb their loved one’s hair, wash their face, hold their hand, kiss them, or crawl into bed and hold them. Support families in their various ways of saying goodbye.

Ask if the family completed preplanning for burial or cremation, but do not rush their final visit. In some cases, families will not have had time for making prearrangements. If they have made prearrangements, contact the funeral home. Be aware of county and agency policies that require notification of the local coroner prior to calling the funeral home.\[14\]

When burial is chosen, the body will be embalmed, which is removing blood from the body and replacing it with an embalming solution that contains formaldehyde and other chemicals. The embalming process temporarily preserves the body to be shown at a funeral or memorial service. Cremation is the process of using heat to reduce the body to ashes that can be placed in a container called an urn. In some cultures, cremation is an ancient tradition. Depending on the family’s cultural beliefs and preferences, the ashes may be buried, placed in a mausoleum, or kept at home in an urn. See Figure 17.28\[15\] for an image of a burial in a memorial garden.
In hospital settings, there may be a sense of urgency to get the room cleared as soon as possible so that another patient can be admitted. However, the nurse should advocate for the patient and make arrangements so the family does not feel rushed. After the family has said their goodbyes and left the room, it is the nurses responsibility to ensure identification tags are applied to the body and the patient is moved to the morgue.

Organ Donation

If the patient is an organ or tissue donor, follow procedures as planned and in accordance with state and care setting guidelines, policies, and procedures. The patient’s drivers license may have information about their organ donation wishes. Federal law and Medicare regulations mandate that hospitals give surviving family members the chance to authorize donation of their loved one’s organs and tissues. Many family members feel consolation in helping others through organ donation despite their own loss. There is no cost for organ or tissue donation.