

Hospice Aide
On-the-Go™ In-service



The Actively
Dying Patient

Volume 1 • Number 12

BEACON
HEALTH[®]
HCPRO



As life is ending, the body begins a natural process that lowers consciousness and alters bodily functions. Because the hospice aide may be with a dying patient more often than others on the care team, the aide has three important roles to play throughout this final stage of life. During the active dying phase, it is important for the hospice aide to observe and report the common signs of dying, provide comfort measures for the patient, and give support to family members.

COMMON SIGNS OF IMMINENT DEATH

Most dying patients experience some of the common signs of the active dying process, which are described below. Comfort measures for the patient support the natural process and are key hospice aide services.

Skin and circulatory symptoms

- **COOL ARMS AND LEGS:** The hands, arms, feet, and legs of most actively dying patients feel cool as the circulation of blood decreases. There is often discoloration of the hands, feet, and around the mouth. It may be difficult to feel the pulse at the patient's wrist.
- **BLUISH COLORATION:** Fingers, earlobes, lips, and nail beds may turn blue.
- **PURPLE COLORATION ON THE LEGS:** Also called "mottling," this blotchy coloring is one of the clearest signs that death is approaching.

Use a lightweight blanket or sheet to keep the patient warm. Some patients may be sensitive to pressure on their feet and require careful placement of blankets. Reposition the patient often to prevent skin damage and pressure ulcers.

Respiratory symptoms

- **CONGESTED BREATHING:** Noisy breathing is sometimes called a "death rattle." As fluids build up in the lungs, a patient may not be able to cough up these secretions. Eventually, the secretions dry up because the patient's body becomes dehydrated.
- **IRREGULAR BREATHING:** Breathing may become deeper or slower. A patient may even stop breathing for several seconds at a time, although they aren't aware of these changes. This is called Cheyne-Stokes respiration or breathing and can be difficult for people to listen too. Mouth breathing is common, so good oral hygiene is important to keep the lips and tongue moist.

Key Terms

Agonia

In Spanish medical texts, the time preceding death when active dying begins

Apnea

Brief periods of time during which breathing stops or is noticeably reduced

Cheyne-Stokes respiration

Breathing that is shallow and slow; may stop for several seconds or as long as a minute

Death rattle

Noisy, moist breathing that may be distressing to family; avoid the use of this term

Dyspnea

Difficulty breathing; breathing that may be fast and shallow, labored, noisy, or even painful

Imminent

About to happen; happening soon

Myoclonus

Involuntary movement, including changes in heart rate, loss of reflexes in the legs and arms, and abrupt spasms of muscles or muscle groups



If the patient has noisy respiration, reposition the patient often to facilitate drainage of pooled secretion. Avoid using the term “death rattle” because this may be distressing to the family and caregivers.

If the patient has congested breathing or dyspnea, keep the head of the bed raised. Direct a fan toward the patient’s face, open a window to let in fresh air, or reposition the patient.

Gastrointestinal symptoms

- **DECREASED APPETITE:** A dying patient may have little or no appetite. Offer ice chips, small sips of liquid, and food as the patient desires and tolerates.
- **DECREASED DIGESTION:** As a person’s digestive track slows down, they may experience nausea and/or vomiting. Their abdomen may swell, and constipation or fecal impactions may occur. Keep the patient clean and provide needed relief from fecal impactions.

Urinary symptoms

- **DISCOLORED URINE:** As the patient stops taking in liquids, there is less urine, and it becomes darker in color.
- **INCONTINENCE:** A patient may experience incontinence as the muscles that control bowel movements and urination relax. It is important to keep the patient clean and dry.

If the patient is incontinent, keep him or her clean and dry using incontinence pads. Reposition the patient every few hours.

Other symptoms

- **BLURRED VISION:** A patient’s eyes may appear glassy and unfocused. Patients often blink less, and their eyes may become dry, resulting in crusting on the eyelids. Extra care is needed to remove the crusts and provide moisture.

If the patient has reduced or blurry vision, use soft lighting, and stand near the head of the bed so the patient can see you. If crusting builds up around the eyes, soften with a warm, wet washcloth and gently wipe off. Eye lubricants may be ordered.

- **CONFUSION AND REDUCED COMMUNICATION:** Most patients will lose consciousness for a period of time before dying. It is important to know that while the patient may not be able to speak, he or she may still be able to hear. Everyone in attendance should continue talking to the patient, letting him or her know who is there and that he or she is not alone.

Listen carefully and observe signs of nonverbal communication. Reposition the patient’s body frequently and utilize compassionate

Mouth care

- It may be necessary to provide oral care as often as every hour. If the patient wears dentures, be sure the dentures are cleaned regularly and do not insert them in the patient’s mouth if sores exist.
- Keep the patient’s mouth moist with a sponge or swab.
- Rinse or mist the patient’s mouth with water.
- Keep the patient’s mouth clean and free of dried secretions.
- Keep the patient’s lips lubricated.
- Offer ice chips or, if the patient can swallow, small amounts of fluids.



nonverbal and verbal communication. Stay focused on what is going on in the patient's surroundings. If the patient is no longer able to speak, talk to the patient using a soothing voice and hold his or her hand.

If the patient exhibits confusion, speak in short phrases, repeat the names of people in the room, and remind the patient of the date and time. The patient may talk about people who have died, wanting to go home, or other themes, such as traveling. Avoid correcting the patient; rather support the patient's conversation. Encourage family members to participate in the conversation with the patient to the extent that they are able.

- **INVOLUNTARY MOVEMENTS:** These movements, called myoclonus, include changes in heart rate, loss of reflexes in the legs and arms, and abrupt spasms of muscles or muscle groups.

PLAN AHEAD

A hospice aide caring for an actively dying patient should refer frequently to a plan that lists appropriate comfort measures and what actions the aide should take as death happens. The plan should include:

- Whom the aide should call when the patient has died
- What responsibilities the aide has for postmortem care
- Whether there are religious or cultural practices of which the aide should be aware

THE HOSPICE AIDE'S ROLE

When caring for an actively dying patient, the hospice aide's most important role is to keep the patient as comfortable and pain-free as possible. Hospice aides should monitor the pain level of an actively dying patient and alert the hospice nurse when something changes. There are medications the nurse can use to relieve pain.

The hospice aide can take the following measures to ensure that the patient is comfortable in the final phase of life:

- **Watch for signs of pain.** Utilize non-drug measures such as massage and repositioning, and diversionary activities such as music, prayer, and reading. The nurse may provide medication for pain management prior to care.
- **If the patient is sensitive to sound, avoid loud noises and television, and consider playing soft music.** Continue to address the patient and tell the patient what you are doing and who is present.
- **Because smells can be particularly unpleasant to a sick person, personal hygiene becomes even more important.** Pay attention to any ulcers, irritated skin, mouth areas, or wounds that have a bad odor. Eliminate these odors to maintain the person's dignity and well-being. Avoid wearing perfume, cologne, or other products with scent.
- **Provide for psychosocial support of the patient.** If possible, allow the patient to have control over the environment and how care is provided. Maintain the patient's dignity. Always assume that the patient is aware of his or her surroundings, even if unable to speak. Provide for privacy. Be sensitive to possible fears.



- **Provide for spiritual support of the patient.** Be sensitive to the patient's spiritual needs and requests for religious support. According to the plan of care, be prepared to contact a priest, minister, or representative from the patient's faith community. The hospice aide may read from scripture, participate in prayers, and put religious articles in place based on the plan of care or as requested by the patient or representative. Being careful not to impose spiritual or religious beliefs or practices on others is an important part of the hospice aide's role.
- **If the patient is agitated, create a quiet and peaceful atmosphere.** Avoid asking questions and lots of talking. Do not interfere with or try to restrain the patient's movements. Protect the patient from self-inflicted harm.
- **Some patients will become agitated when family members are present.** Recommend to the patient's family that it may be helpful to decrease the number of people around the bed.

Comfort the family and caregivers

The hospice aide also plays a role in providing for the comfort and emotional care of the family and other caregivers during this time.

- Be aware of the concerns and needs of family members and other caregivers and listen carefully.
- Allow the family to be in control of what is happening in the environment as much as possible, and provide meaningful suggestions based on the patient's needs.
- Pay attention to, and be respectful of, the various roles that different family members play.
- Demonstrate respect for each family member's and caregiver's unique response to the situation. Know that some people will feel comfortable being near the patient and other people will not. Acknowledge the individual preferences and roles non-judgmentally.
- Anticipate and support family members in their fears, which may include fear of how the patient will die (pain, bleeding, and so on), fear of being alone with the patient, fear of not knowing what to do when the patient dies, fear of "causing" the patient's death by something they do (such as giving medication, turning the patient, giving a sip of water, and so on), and fear of how they will live without the patient.
- Support the family in saying their good-byes to the patient. Family members may benefit from encouragement in saying their message of love, thanks, forgiveness, memories, or wishes.
- Accept the family's cultural, spiritual, and religious traditions. Remain non-judgmental, yet supportive.
- Anticipate and accept tears and other expressions of grief.

Recognize death

Because actively dying patients undergo a natural shutting-down process, it can be difficult to identify when death has occurred. Signs that the patient has died include:



- There is no breathing or pulse.
- The eyes do not move or blink, and the pupils are dilated (enlarged). The eyelids may be slightly open.
- The jaw is relaxed and the mouth is slightly open.
- The body releases the bowel and bladder contents.
- The patient does not respond to being touched or spoken to. Never shake a patient to assess the condition.

When death happens, it is not an emergency. Stay calm and offer the family some time alone with the patient. There is no rush. When you are able to leave the patient's immediate area, contact the hospice RN. The RN is responsible for managing the care following the patient's death. Based on the assignment, the hospice aide may assist with preparing the body. In this case, demonstrate ongoing, gentle respect. Some family members and caregivers may want to participate and assist. Ongoing support of family members and other caregivers is part of the aide's role. Encourage family members and other caregivers to be with the body and to take their time saying good-bye. There is no need to rush this special time. Family members may wish to recall details of the patient's final hours for some time.

Document care

Your role will be different with each individual patient. Document the care you provided and record how the patient responded to your care. Also, document the care you provided to family members and other caregivers, who was present at the time of death, and how they responded to the care provided. Note when you called the hospice RN, and document any instructions you received, your implementation of them, and how the patient responded.

OUTCOMES AND THE HOSPICE AIDE

The hospice aide plays a major role in achieving successful outcomes during the last days of life and immediately following a patient's death. Outcomes include helping the patient experience end-of-life closure goals, supporting the family and caregivers in their roles as death draws near, providing ongoing comfort measures to support the natural dying process and minimize symptoms, and offering comfort as the patient, family members, and other caregivers deal with their grief.

Hospice aides, as members of the interdisciplinary team, also experience the reality of dealing with the loss of the team's patients. Being aware of and sensitive to one's own grief and the grief of other members of the team is an important outcome for the hospice aide. Seeking support and providing support is part of being a hospice employee.

Caring for actively dying patients can be a stressful time for hospice aides. It is common for aides to develop strong emotional attachments to their patients, and aides will often grieve when patients die.

CMS Expectations

A hospice must maintain a quality assessment and performance improvement (QAPI) program that involves all services, including hospice aides. This program, among other things, will take actions to demonstrate improvement in hospice care and palliative outcomes.





CASE STUDY

Sue has been in the hospice program for two weeks. Her terminal illness is breast cancer that has spread to her brain. A few days ago, she moved into the hospice residential setting because her care was more than the family thought they could manage. The residence is staffed by hospice aides around the clock, and the hospice RN on call is available as needed.

Sue is 71 years old. She is actively dying, and her pain is well managed. Her husband Paul is with her. When the RN reviewed the hospice material about the last hours and days of life with Sue and her husband, she answered their questions about common symptoms of dying and how the family could provide care.

Sue is perspiring a lot, is incontinent of urine and stool, and is mouth breathing. Cheyne-Stokes respiration started yesterday, and she has long periods of apnea. The aide is to provide personal care every two hours and more often if needed to help her stay comfortable. She can have ice chips, which Paul likes to give her, although she hasn't been responsive during the night shift. Sue seems to be agitated when there is commotion in the room.

During the night, the aide provides frequent care. Paul is at Sue's side. He says, "She seems so far away, but I think she knows I'm here." When her daughters arrive, they ask, "Is she dying?" The aide turns to the hospice material and reviews it with them. The girls would like to have individual time alone with their mother, so Paul tries to get some sleep in another room.

At 5:10 a.m., Sue's call light goes on. The family gathers around the bed and Paul says, "We think something is different." Sue is still having Cheyne-Stokes breathing, but seems more relaxed. As the aide provides care, she points out that Sue's feet and hands are bluish. Then she realizes that Sue is no longer breathing. She puts on the call light and asks another aide to call the RN.

While waiting for the RN, the aide offers support and provides the family with fresh water, juice, and breakfast rolls. The aide explains that there is no rush. They can stay with Sue's body if they would like, and the aide reminds them about the private family area. When the RN arrives, she contacts the funeral home and then supports the family as they begin to contact others. When it comes time to prepare the body, one daughter wants to help. Paul and the other daughter prefer to wait in the family room. When the funeral home staff departs with Sue's body, the family spends some time in the room before leaving, saying they'll be back later to get her things.

You finish your documentation, noting details about Sue's dying, the family's response, your communication with the RN, and after-death care. You, the RN, and the other staff take a few minutes to talk about Sue, her family, and how hard it is to lose someone you are just beginning to know.

THINK ABOUT IT

1. What were Sue's symptoms of dying?
2. What comfort measures did the aide provide? What else could this aide have done?
3. How might this case be different if it had occurred in a hospital, a skilled nursing facility, or a private home?
4. What support measures for dealing with grief are available to you and others on the team?

