

Hospice Aide On-the-Go™ In-service



Comfort Measures for the Terminally Ill Patient

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**BEACON
HEALTH**



Recent changes in lifestyle and medical advancement have dramatically increased life expectancy into the twenty-first century. People are living longer and dying later in life. This, coupled with an increased desire to die at home in comfort and dignity, has led to an increase in the number of patients receiving care from hospice programs in the home setting. Hospice aides play an important role in caring for loved ones who are dying.

Symptoms of Terminal Illness

Dying patients experience many common symptoms including pain, poor circulation, changes in gastrointestinal/urinary and respiratory systems, skin breakdown, changes in sleep patterns, and psychosocial symptoms. Some of these symptoms can be uncomfortable for both the patient and the patient's family. The hospice aide assignment should address each patient's individual needs.

PAIN: Pain relief is a primary focus of the hospice care plan. A dying patient's pain may range from mild to agonizing, and individual patients experience these levels in different ways. Effective pain management blends techniques and principles to control pain.

- **MEDICATIONS:** Taking medications regularly as prescribed can make pain easier to control.
- **IMAGERY:** Creating pleasant images in the mind may help a person reduce pain.
- **DISTRACTION:** Patients who are able to focus on areas of interest may be able to "forget about" the pain. Watching a favorite movie, paging through a family photo album, writing memoirs, or concentrating on a hobby may help.
- **ALTERNATIVE THERAPIES:** Techniques such as massage therapy and hot or cold applications may bring comfort.

CIRCULATORY SYSTEM: Signs and symptoms of poor circulation may not appear until a patient is bedridden or forced to remain in a sitting position for long periods of time. As the heart begins to fail, the patient's hands and feet begin to swell. Each patient experiences the decrease in circulation differently. Some feel cold, others hot. Some find that any attempt to warm cold areas is uncomfortable. *Tip:* Use caution with electric blankets, heating pads, or hot water bottles to warm hands and feet. A dying person cannot feel when something is too hot and may experience a burn.

GASTROINTESTINAL/URINARY SYSTEMS: Most symptoms in the gastrointestinal tract occur as the internal organs shut down and pain medications are given. A decrease in activity and food intake also slows down the gastrointestinal system.

- **CONSTIPATION:** Constipation may be uncomfortable and even painful. Left untreated it can progress to intestinal blockage, which causes nausea and vomiting. *Tip:* Monitor the patient's bowel movements and contact the hospice registered nurse when there is a change.
- **DEHYDRATION:** Many patients experience thirst, but in the dying patient, this symptom is not associated with

Key Terms

Cheyne-stokes breathing

Shallow breaths followed by bursts of rapid breaths

Delirium

Confusion and disorientation to time, place, or person

Dyspnea

Shortness of breath

Death Rattle

Noisy and moist breathing

Restraints

Physical, verbal or medical methods that block the patient from performing normal activities

Terminal Angst

Restlessness, crying out, and general unrest



fluid status. Supplemental fluids given by IV and tube feeding do not alleviate this thirst. *Tip:* Provide liquids as tolerated.

- **THIRST AND DRY MOUTH:** These symptoms are not associated with the patient's fluid status, so tube feedings and IV therapies do not alleviate them. *Tips:* Provide frequent mouth care. Moisten the patient's lips and apply a lip lubricant. Offer small sips of fluid, ice chips, or hard candy. During the active dying stage, moisten and clean the patient's mouth with a mouth sponge or washcloth.
- **HUNGER:** Studies show that most actively dying patients do not experience hunger, even when they have inadequate caloric intake. A reduction in patient appetite is a normal response to the dying process because the internal organs are shutting down. At this point, the organs cannot handle the processing of nutrients and liquids. *Tips:* If symptoms of hunger do occur, provide small amounts of food or fluids. This can be in the form of nutritional supplements or favorite foods and drinks.
- **INCONTINENCE:** A patient's ability to use the toilet or commode will diminish. Talk with family members about the use of incontinence briefs and underpads to protect bed linens, clothing, and the patient's skin. *Tip:* Once the patient is bedridden, check every two hours for incontinence and change bedding and clothing as needed.
- **NAUSEA AND VOMITING:** Treatments for cancer often causes nausea and vomiting, as does constipation. Medications can help control these symptoms. *Tips:* Contact the hospice nurse about medications used to relieve nausea or vomiting.

Constipation and Pain Medications

A best practice is for a patient on pain medication to take a laxative and a stool softener unless there is medical reason not to do this.

RESPIRATORY SYSTEM: Respiratory symptoms often occur during the dying process as heart function decreases and the patient is unable to cough up normal secretions. Problems associated with breathing, such as dyspnea, are often the most distressing symptoms for the patient and caregivers. Inability to breathe can be frightening. *Tip:* Know methods that provide relief for the most common respiratory problems.

Safety Tip

Oxygen is combustible. Never have an open flame around a patient who is using oxygen.

- **CHEST CONGESTION:** Dying patients may experience difficulty breathing. This condition, often called the "death rattle," can sound like marbles moving around in the patient's chest. This is not painful, but patients and caregivers may become anxious when the patient feels unable to breathe. *Tip:* If ordered, the patient should use oxygen. If the patient does not have oxygen, or if the oxygen is not helping, call the hospice nurse to report these symptoms and obtain further instructions for care.
- **DYSPNEA:** A patient with dyspnea, or shortness of breath, is likely to feel anxious and depressed. Sitting with the body leaning forward and arms resting on a table may help to alleviate symptoms. Others prefer lying down with head elevated. *Tips:* Focus on energy conservation when providing assistance with activities of daily living. Provide good air movement near the patient, keep the room temperature cool, and try to minimize the patient's exertion or anxiety. A patient may appreciate massage, quiet music, or an audio book. Oxygen or air can significantly reduce dyspnea in patients with advanced cancer.



- **SECRETIONS:** A healthy adult produces one to two liters of saliva per day. The terminally ill patient can experience excessive secretions as the ability to swallow decreases. *Tips:* Repositioning the patient to one side or the other can help to open an airway and alleviate discomfort. Suctioning is not recommended because it often provides more stress than relief.

SKIN BREAKDOWN: The skin is the largest organ of the human body and one of the most susceptible to injury. When a patient becomes bedridden, poor nutritional status, elimination problems, and immobility contribute to skin breakdown. Reddening of an area may lead to a deep pressure ulcer or bedsore. When skin breakdown occurs, infection often follows. *Tips:* Reposition the patient every two hours. Keep the skin clean and dry.

CHANGES IN SLEEP PATTERNS: Many different sleep patterns occur during the dying process. These range from no sleep at all to patients who sleep most of the time.

- **EXCESSIVE SLEEPINESS:** The patient may begin to spend more and more time sleeping. This happens because of a decrease in the body's metabolism. *Tip:* Remind family and friends that they can sit with the patient who is sleeping, read aloud to them, even hold hands. Be sure to ask patients first if they wish to have visitors while sleeping.
- **LACK OF SLEEP:** The patient may suffer from lack of sleep due to discomfort, fear of not waking up, restlessness, day/night confusion, or too many visitors. *Tips:* Keep a night light on to help a patient who wakes up confused or disoriented. A clock is helpful for orientation to time, day, date, and outside temperature.
- **RESTLESSNESS:** Restless patients may be constantly up and down or may thrash around in bed unable to sleep. This is caused by a decrease in oxygen circulation to the brain. *Tips:* Attempt to calm the patient with music, a soothing voice, or a favorite activity such as looking through a photo album or watching television. Do not interfere with restless behavior unless it creates an unsafe situation.

Psychosocial

The patient's mental health and functional capacity during the final stages of life affect not only the patient but the family, friends, and caregivers as well. The dying patient is likely to express negative feelings of anger, sadness, anxiety, and fear. This is a part of the dying process, and it is important that family, caregivers, and hospice staff acknowledge these feelings. *Tip:* Find out whether the patient wants company or prefers to be alone. If the patient would like company, complete your assigned activities of daily living and then sit for a while to provide companionship.

- **AGITATION:** This symptom is distressing to the family and caregivers who want to know how to fix it. It can be a normal part of a disease process, or it can be the result of pain, lack of sleep, or the lack of control over one's own care. *Tip:* Ask a family member if the patient has medication for agitation. Check your assignment sheet for activities that may help to decrease agitation. If there are no medications or alternative treatments available in the home, or if the family is not present, call the hospice nurse immediately for instructions. Do not use physical or mental restraints unless ordered by the patient's attending physician and the hospice Interdisciplinary Group. There are specific requirements for the use of restraints. If the patient's family or caregiver wants to apply a restraint, contact the hospice registered nurse immediately.



- **CULTURE:** Many cultures have rituals that surround the dying process and these may affect the aide's ability to provide comfort care. *Tip:* Ask questions of the patient and family: *Does the patient have cultural taboos that would affect care? Is there a family spokesperson who handles all decisions? Does the patient know his or her terminal diagnosis?* Identify these issues by asking questions in a respectful way about the patient's beliefs.
- **DELIRIUM:** Confusion and disorientation to time, place, or person may appear and disappear at random. Some studies report this symptom in 70 to 90 percent of those near death. *Tip:* Orient the patient to time, place, or person, but do not argue. The presence of family members and friends, along with light and music, help reorient the patient.
- **LACK OF CONTROL:** As death approaches, patients lose the ability to provide self-care. This loss and the inability to do the things they have always done are disturbing to some individuals. *Tip:* Give patients the ability to make what choices they can.
- **SPIRITUALITY:** In many faith traditions, one role of prayer or meditation is to help with pain, fear, and uncertainty. This often provides relief for symptoms. *Tip:* If the patient or family would like spiritual support from the hospice or would like to talk with the hospice chaplain, contact the hospice registered nurse for a referral.
- **"VISITS" FROM DECEASED LOVED ONES:** Do not mistake a patient's description of visits from deceased loved ones as delirium or confusion. Labeled by some as hallucinations, these occurrences are not uncommon. They can comfort the dying patient. *Tip:* Do not argue with the patient about the reality of these visits.

Signs of Death

The signs of death include non-response, lack of breathing, lack of pulse, incontinence of urine and stool, large, fixed pupils, and a relaxed jaw that may open. Sometimes the body will expel its air.

Contact the hospice registered nurse immediately to report the lack of a pulse or breathing.

Signs of Impending Death

Several common signs indicate that death is approaching.

- **CHEYNE-STOKES BREATHING:** Breathing patterns change when a patient is near death. Breaths become shallow, with periods of no breath followed by bursts of rapid breaths. This change in breathing occurs as the patient's vital internal organs receive less oxygen. *Tips:* Report Cheyne-stokes breathing to the hospice registered nurse immediately. If available, use oxygen as a comfort measure. Reassure the family that this type of breathing is not a sign of pain, simply the final stage of dying. Your presence can comfort both the patient and the family.
- **DEATH RATTLE:** Approximately 60 to 90 percent of patients who are within several days of death will develop noisy and moist breathing often called the "death rattle." The patient usually appears unaffected by the noisy breathing, but the family and caregivers may be concerned. *Tips:* Elevating the patient's head will often make breathing easier.
- **TERMINAL ANGST:** Some dying patients experience restlessness, crying out, and general unrest. These symptoms may be a sign of unfinished business. By the time the terminally ill patient experiences this, it may be too late to resolve the problem. *Tip:* Speak softly and calmly to the patient and provide distractions.



Common Treatment Methods Used in Hospice to Alleviate Symptoms

The focus of hospice treatment is palliative, not curative. The goal of treatment is to support and provide comfort to the terminally ill patient. Here are some common methods used:

- **MEDICATIONS:** The patient's attending physician or hospice physician may order medications to address symptoms that occur during the dying process. *Tip:* To control symptoms, be sure the patient takes the medications on a regular basis, either as scheduled or when needed.
- **IMAGERY:** Guiding a patient through imaginary sights, sounds, tastes, smells, and feelings can often help shift attention away from an uncomfortable symptom. By creating images in the mind, a person can replace what was there with something more pleasant. *Tip:* If an Interdisciplinary Group member has worked with the patient to develop a personalized imagery tool, remind the patient use it when symptoms are present.
- **DISTRACTION:** When symptoms appear, redirect patient focus to areas of interest such as hobbies and family memories. Patients may not be able to perform the activities they did in the past, but simply viewing television, movies, or family photo albums may be helpful. *Tip:* If your patient is interested, offer to talk or listen to music or watch a video on a topic of interest.
- **RELAXATION:** Relaxation exercises such as deep breathing and stretching help some patients reduce discomfort. *Tip:* When a patient is anxious, suggest stretching and deep breathing.
- **ALTERNATIVE THERAPIES:** Techniques such as gentle massage and hot and cold applications can bring comfort.

ROLE OF THE HOSPICE AIDE

Provide care and comfort

Patients in the final stages of life may or may not be fully aware of the world around them. Be gentle with your patient. Offer fresh air or a warm, lightweight blanket. Provide favorite foods and drinks in small quantities. Sit a minute to hold a hand and listen to music. Assist with repositioning in a chair or in bed. Check for incontinence frequently and change the patient's clothing and bedclothes as needed.

Observe and Report

In your role as hospice aide, you will often be the first to observe changes in the patient's medical, nursing, rehabilitative, and social needs. Report these changes to your supervisor:

- A fall
- Bleeding that will not stop
- Constipation
- Excessive secretions
- Facial expressions and sounds that demonstrate discomfort
- Inability to take oral medications



- Inability to urinate or empty the bowels
- Incontinence (new)
- Irregular breathing
- Nausea or vomiting
- Lack of available pain medication
- Pain that is not relieved by prescribed medication or comfort measures
- Restlessness
- Shortness of breath
- Skin breakdown
- Spiritual need
- Unavailability of a caregiver
- Anticipatory grief beyond what is expected of the family
- A request from the patient or family that you contact the hospice registered nurse

Document Care and Symptoms Identified

After following the instructions of the hospice registered nurse, document on your visit note the care provided, the patient's tolerance of this care, and any symptoms reported. Also on the visit report, address each assigned duty along with information reported to the nurse about the patient's condition. This includes date, time, reason for calling, the name of the nurse contacted, and any instructions received from the nurse.

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

George Miller, 85 years old, was diagnosed with prostate cancer 12 years ago. After radiation therapy, the cancer went into remission. For the next 11 years his wife faithfully scheduled follow-up treatments, injections to prevent the cancer's spread. After the death of his wife last year, Mr. Miller quit the treatments. His family did not know. One day last month, his daughter Candy found him collapsed on the floor in his home. While he was in the hospital, Mr. Miller's doctor determined that he had acute kidney failure caused by the cancer's spread. Given his age and extent of his disease, Mr. Miller and his family chose hospice care rather than aggressive curative treatment. BHC Hospice's Interdisciplinary Group reviewed the case and admitted Mr. Miller to the program. His daughter began to look forward to help from the hospice aide, whose assignment included comfort measures and personal care assistance with bathing, shampooing, oral care, and meals.

When Sally, an experienced hospice aide, arrived for her first visit, she found her patient still resting in bed. His daughter said he had not had a good night and that he seemed weaker. Mr. Miller complained of pain in his abdomen and hips and some nausea. Sally asked Mr. Miller when he had last taken his pain medication. He said he had quit all the medications because they were making him sick to his stomach and not helping the pain. Sally called the nurse, who then talked to Candy. After the call, Candy gave her father pain medication with some sherbet and said the nurse would visit to review all medications. As Sally helped reposition Mr. Miller in bed, she noticed Johnny Cash CDs on the nightstand. "The best country music ever," Mr. Miller said. Sally put one CD in the player and made Mr. Miller a cup of tea. About 20 minutes later, she helped him to wash up and put on clean pajamas. Sally completed some light housekeeping tasks and then proceeded with Mr. Miller's personal care.

THINK ABOUT IT

1. What symptoms of terminal illness did Mr. Miller show?
2. What comfort measures did Sally use?
3. Can you name other good points of care that Sally performed during the visit?
4. What should Sally report to her supervisor about this visit?
5. Can you think of other comfort measures Sally might have used?

Comfort Measures

HOSPICE AIDE ON-THE-GO IN-SERVICE



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