

# Hospice Aide On-the-Go™ In-service



## Respiratory Changes in the Terminally Ill

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The human body breathes automatically during sleep or when in a coma. It is also able to consciously control breathing at times, such as underwater and in the presence of smoke or foul odors.

Breathing difficulty that results in shortness of breath is called dyspnea. When the heart is unable to pump enough blood to supply oxygen to the brain, muscles, or other organs, a sense of breathlessness may occur. Healthy people may experience dyspnea when they are frightened or anxious. Others experience dyspnea after strenuous exercise. Breathing difficulty may also be the result of obstruction of the air passages of the nose, mouth, or throat.

Hospice patients often experience dyspnea and symptoms are different for each patient. The terminally ill patient or family will generally report one of the following: a shortness of breath, air hunger, choking, grasping for air, heavy breathing, or periods of short gasps alternated with periods of no breathing. There may also be a sense of panic. That's because panic may present as dyspnea, and dyspnea may induce panic.

## Causes of dyspnea

Changes in breathing can be due to disease, obstruction of the airway, or panic and anxiety related to the dying process. In many cases, the patient's terminal illness is the cause of breathing difficulty.

**CANCER:** Dyspnea in patients with advanced cancer is common and it is difficult to treat. Cancerous tumors may block specific areas of the upper or lower airways or the circulatory system. Cancer treatments may damage parts of the body and affect oxygenation of the blood. *Tip:* Oxygen and circulating air can reduce dyspnea in patients with advanced cancer. Elevating the upper body and turning it to one side may improve passage of air.

**Heart Disease:** Congestive heart failure (CHF) occurs when a person's heart is unable to pump enough blood or when the blood does not contain enough oxygen to meet the body's needs. This creates a cycle of problems that affect the capillaries, the tiny blood vessels that permit the exchange of oxygen, carbon dioxide, and fluids in the body. Tissue in the lungs begins to swell, making it more difficult for the patient to breathe. *Tips:* Elevating a patient's swollen feet will help circulation, as will anti-embolism stockings and loose, comfortable shoes. A low-salt diet and medications can reduce fluid retention, easing the patient's breathing.

**LUNG DISEASE:** Chronic obstructive pulmonary disease (COPD) is the second leading cause of disability in the United States and one of the major causes of dyspnea in the hospice patient. These patients have dyspnea at rest caused by pneumonia and other infections. Inhaled irritants such as cigarette smoke damage the body's airways, obstructing the flow of air both into and out of the lungs. Mucus blocks passageways. The lower airways may collapse when a person exhales, trapping air in the lungs and leading to dyspnea, coughing, increased sputum,

## Key Terms

### Apnea

Brief periods of time during which breathing stops or is markedly reduced.

### Carbon Dioxide

A product of cell respiration, carried by the blood to the lungs and exhaled.

### Cough

A sudden audible expulsion of air from the lungs.

### Dyspnea

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

### Respiratory Rate

The normal rate of breathing at rest, about 12 to 20 inspirations per minute.

### Secretions

Fluids in the respiratory system.



and fatigue. *Tips:* Many hospice patients use inhalers and many use oxygen all the time. Know where both are located in the home when caring for a patient with COPD. Let these patients move at a pace that is comfortable. Do not try to hurry them.

Pneumonia is a lung infection caused by several kinds of bacteria or virus. The lungs fill with mucus, reducing the exchange of air between the air sacs and the capillaries. Pneumonia can cause chest pain and lead to death in hospice patients. The hospice patient may or may not be prescribed antibiotics. The decision depends on such factors as the type of infection, the patient's current condition and quality of life, how the infection is likely to respond to treatment, and the desires of the patient and family. *Tip:* If oxygen is in the home, be sure it is nearby. During care, focus on conserving energy and managing pain.

## Other breathing changes that occur close to death

Dyspnea is only one of several breathing changes that occur as the terminally ill patient progresses through the final stages. A patient may also experience coughs, hiccups, respiratory depression, Cheyne-stokes breathing, and the death rattle.

### Dyspnea Rating Scale

Dyspnea is a personal experience influenced by many factors, both physical and psychological. In that way, it is similar to pain. The hospice patient can use a rating scale to report the severity of dyspnea. This rating helps the attending physician, patient, family, and hospice staff understand how the patient feels.

1. No problems
2. Minimal problems
3. Moderate problems
4. Severe problems
5. Crisis

**COUGH:** Coughing is a protective response that clears the respiratory system of fluid and foreign material. It is a common symptom of diseases of the lungs and throat. Hospice patients who have a cough may also have pain associated with the cough and muscle weakness. This may prevent the expulsion of air from the lungs, trapping irritants. *Tip:* Provide instruction and assistance in effective coughing and deep breathing exercises. Contact the hospice registered nurse, who may supply medications that suppress the cough and provide comfort.

**HICCUPS:** There are almost one hundred causes for hiccups, which may be natural or drug induced. Hiccups lasting up to 48 hours are considered acute; longer than 48 hours, persistent; and more than two months, intractable. Long-lasting hiccups can have a significant negative impact on quality of life for the patient. Family and caregivers become distressed by hiccups that

last a long time and may try to help by startling the patient or by attempting other unusual forms of treatment.

*Tip:* When hiccups continue for an extended period of time, contact the hospice registered nurse. There are medications and treatments that may help.

**RESPIRATORY DEPRESSION:** Many factors can affect breathing and depress a patient's respirations. The most common are pain medication, high oxygen rates, and the dying process itself. *Tip:* Never increase pain medication or oxygen rates higher than ordered by the patient's physician. Report all episodes of respiratory depression to the hospice registered nurse.

**CHEYNE-STOKES BREATHING:** Hospice personnel often note the presence of Cheyne-stokes breathing as a patient



nears death. Breathing becomes shallow and slow. It may stop for several seconds or as long as a minute. This is followed by a sudden, deep, exaggerated breath. This pattern may go on for some time as the body tries to compensate for low oxygen and high carbon dioxide levels in the blood. It continues until death occurs or until the patient has a temporary short-term return to normal breathing. Patients who are able to speak after such episodes do not report distress associated with the breathing, although it can be disturbing to the family. *Tips:* Provide general comfort measures for the patient and emotional support to family. Turn the patient every two hours to prevent skin breakdown. Clean the patient's mouth with a wet mouth sponge or washcloth. Check often for incontinence and change wet or soiled linens.

**DEATH RATTLE:** As many as 60 percent to 90 percent of patients who are within several days of death will develop the noisy and moist breathing often called the "death rattle." Although these patients usually appear unaffected by the noisy breathing, the family and caregivers may be distressed. Patients who receive artificial hydration or nutrition before death experience more secretions than patients who are slightly dehydrated and have a more comfortable, natural death. *Tips:* Elevating the upper body will often help the patient to breathe easier. Suctioning is not recommended as it is often more distressing than helpful.

## THE AIDE'S ROLE

The hospice aide assignment sheet will give you specific instructions. Because the condition of a hospice patient can change rapidly, check the assignment sheet at every visit and follow the instructions carefully.

### Take measures to ease dyspnea

Find a way to provide care that requires the least amount of energy. Plan ahead. Allow for rest periods between scheduled activities. For example, it may be too taxing for the patient to ambulate to the kitchen immediately after a bath.

Remind the patient and the family or caregivers that following the medicine schedule and the treatment plan are important to ease dyspnea. The use of an inhaler or other medications before strenuous activities can help the patient's breathing.

Help your patient maintain correct posture. Breathing is more difficult for a patient who is slumped in a chair. A seated patient can improve breathing by leaning forward with arms resting on a table. Remember that prolonged sitting in this position may result in muscle aches and soreness. Bedridden patients breathe better when they lie slightly tilted towards the right side with the head and upper body elevated. This position does not obstruct the heart.

Organize the patient's room. Place frequently used items such as the phone, reading glasses, TV remote control, and water glass within easy reach of someone who is confined to bed or to a wheelchair.

Pay attention to small comforts that can make a big difference. Use lightweight clothing and bedding. Use a fan





to circulate the air in a patient's room or open a window for a cool breeze.

Reinforce the use of breathing exercises and other relaxation techniques. If the nurse has taught these, remind the patient how to do them properly.

Know how the use of durable medical equipment such as a hospital bed, portable oxygen, walker, wheelchair, bedside table, or bedside commode can limit exertion and decrease breathing problems.

The use of oxygen, either continuous or occasional, can reduce symptoms of dyspnea in most patients. Assist the patient on oxygen with oral hygiene and skin and nostril care. If the nasal cannula has a lip protector, the tape that holds it in place may make the patient's skin sore. Talk to the hospice registered nurse for instructions. It may require a change in the type of tape used or where you put the tape. You may be asked to use a skin shield, a dressing that is put on the skin under the tape. Check the position of the cannula often. Patients who are confused or distressed may not tolerate oxygen administration, especially if a mask is constricting.

## Help with oxygen

Know your role in oxygen administration and the maintenance of equipment. Follow agency instructions for patients who are on oxygen. The agency will teach you about the delivery system being used, the proper rate of flow, maintenance of equipment, and when the patient should use it. Never adjust the flow rate of the oxygen unless you are instructed by the registered nurse.

## Provide support and encouragement



Some patients appreciate massage or distractions such as music or an audio book. Relaxation techniques, guided imagery, and meditation may help. Provide emotional support. Listen to what the patient has to say and offer reassurance. Family members and friends can help with quiet conversation and reminiscing. Remember that the signs of dyspnea may be quite distressing to the family but not the patient.

## Observe and report

Every hospice patient experiences a change in

## Safety Points

An oxygen-rich environment is a risk for fire and explosion. The oxygen supplier, the patient, the family, and the hospice share responsibility for safe oxygen use.

- Never permit smoking or open flame in a room where oxygen is running. To prevent sparks, turn off an electrical appliance before unplugging it. Keep oxygen away from heaters and radiators and out of direct sunlight.
- Keep an ABC fire extinguisher near the oxygen supply and know how to use it. Post an "Oxygen in Use" sign, and keep the fire department phone number near each telephone.



breathing at some point during care. Symptoms may progress more rapidly for some patients than for others. Your role as a hospice aide is to be alert for these signs and symptoms and to call the hospice registered nurse when you observe them.

- Rate, rhythm, depth, ease, and sounds of respiration
- What the patient was doing at the onset of symptoms
- Any physical or emotional factors present at the onset of symptoms
- Increase in heart rate
- Dry or congested cough
- Shortness of breath that occurs at rest, lying down, or during normal conversation
- Statements or behaviors that show confusion
- Sputum that may be frothy, blood-tinged, yellowish, or greenish
- Noisy respirations — the patient may feel the wheezing or the crackling
- Changes in the color of the skin, especially the face, lips, and nails — pale, bluish, mottled, or reddened
- Dizziness
- Any patient complaints of pain

## Relaxation Techniques

Have the patient close her eyes and imagine herself in a calm, beautiful place such as the beach or mountains. If possible, play audio sounds of nature during the exercise. Controlled breathing may help reduce anxiety. If your patient is feeling anxious or distressed during your visit, remind him to do the assigned exercises.

## Document

Although your role will be different with each individual, patients with dyspnea share common symptoms. Document the date, the time of onset, and the duration of an episode of dyspnea. Document the care you provide during each visit and record how the patient tolerates this care. When you call the hospice RN to report symptoms, document the symptoms and the call. Document any instructions you receive from the hospice RN, your implementation of them, and how the patient responds. Also notify your supervisor when a patient is not compliant with taking medications, oxygen, or treatments.

## OUTCOMES AND THE HOSPICE AIDE

Many terminally ill patients experience respiratory changes that create discomfort, anxiety, even panic and pain. A hospice aide must know how to identify and report changes in breathing patterns, how to ease the symptoms of breathing difficulty, and how to promote the patient's comfort. By doing this, the aide will also provide comfort for the family.

## 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

Mrs. Miller has been hospitalized several times in the past year for end-stage congestive heart failure. Upon her return home from her last admission, she elected the Medicare hospice benefit through Beacon Hospice. The hospice Interdisciplinary Group assigned Sharon Rose, a new hospice aide, to care for her.

After caring for Mrs. Miller for two weeks, Sharon Rose noticed that Mrs. Miller's bed had not been slept in for several nights. When asked about it, Mrs. Miller said, "Well, I have had a little trouble breathing lately and I have been sleeping in the chair. But I'm all right now."

While preparing her patient for a bath, Sharon Rose noticed that Mrs. Miller seemed to be breathing more rapidly than usual. Mrs. Miller said she was very tired and asked if she could wash up at the sink instead. When Sharon Rose suggested her patient should rest before they did anything else, Mrs. Miller said, "Heck, never mind that, let's just get this done." Once Mrs. Miller was in the tub, she had problems sitting up and began to slump. Sharon Rose quickly finished the bath. She got Mrs. Miller out of the tub, sat her on a nearby stool, and retrieved her oxygen tubing and nasal cannula, which Mrs. Miller put on immediately. After she was dressed, Mrs. Miller breathed her oxygen for another ten minutes before she felt able to stand and walk to the kitchen. There Mrs. Miller sat at the table, leaning on her elbows, where she remained short of breath. Sharon Rose suggested to Mrs. Miller that she should lay down for a rest and used the wheelchair to transport her to the bedroom. Mrs. Miller agreed. Moving slowly, the two worked together and Mrs. Miller was soon tucked into her hospital bed under a lightweight comforter. Sharon Rose raised the head of the bed and checked to be sure the oxygen was on correctly.

After a short nap, Mrs. Miller felt somewhat better. As Sharon Rose put things away, she noticed that some of Mrs. Miller's pills from the day before were still in the box. Mrs. Miller explained why she had not taken them. "I wasn't feeling well and those pills make me go to the bathroom all the time."

Sharon Rose finished her assignments and left.

## THINK ABOUT IT

1. What signs and symptoms led Sharon Rose to believe Mrs. Miller's breathing was worse today than the day before?
2. Can you identify any factors that may have contributed to her increased dyspnea?
3. What are some of the things Sharon Rose should document on her visit note? Is there anything she should report to the hospice RN? If so, what?
4. Judging by what Mrs. Miller is doing and saying, what do you think might happen within the next few days? What can Sharon Rose do?