



# Hospice Austin's Caregiver Guide

The more you understand about how you can best care for your loved one, the richer and more meaningful your time together will be. The information that we provide should help you recognize changes, what the changes mean, and how to provide care as these changes occur. It is our hope that this guide, along with all of the other support Hospice Austin provides, will help you through this emotional time. Caregiving advice is also available by visiting [HospiceAustin.org/caregiving](https://www.hospiceaustin.org/caregiving). Please call us any time you have a question or concern.

## Nutrition

We connect food with life. When a person doesn't eat, not only are the comforting routines of meal times lost, but fears about survival are common. Family members work hard to prepare foods that might be appealing, only to have the person take a few bites and report feeling full or that the food doesn't taste good.

Family members feel frustrated, helpless and afraid of what will happen if the patient doesn't eat. The patient can sense the frustration and feel pressured to eat to please loved ones.

### Why do patients have a loss of appetite or the ability to eat?

A change in the ability to eat is a natural consequence of an advanced disease process. As the body slows down, the digestive process slows as well. This change usually begins as mild distaste for certain foods, progresses to a desire for only a few foods and finally results in an almost complete lack of ability to eat. Your loved one may experience feelings of sadness or depression; however, the lack of appetite is directly related to the disease process and the body's deterioration.

### What strategies are most effective?

- Accept the loss of appetite as an expected and normal part of the disease.
- Allow your loved one to select food and drinks. Offer different choice but don't push!
- Find other ways of showing love and concern such as giving a foot massage, reading aloud or playing cards.
- Recognize that this is a loss, and like all losses that are part of this illness, talking about it may make it less burdensome.
- Know that prolonged use of intravenous fluids and artificial nutrition usually are not effective for people with advanced disease. This can actually complicate care and physical well-being. As the ability to digest decreases, the food or supplements can accumulate and cause increased pain, nausea and suffering.

## At mealtime, try the following suggestions:

- Offer medication for pain or nausea one hour before eating.
- Serve food in a pleasant environment, preferably at the table if it's comfortable for the patient.
- Ask what tastes best. Many people do not tolerate red meat, fried, or spicy foods. Cool, bland and soft foods are often the most appealing. Experiment with supplements and powdered breakfast drinks.
- People at the end of life have stated that dehydration is not painful, but the mouth does get dry. You can use ice chips, artificial saliva and lip moisturizers.
- Flavored ice cubes (made from fruit juice) crushed into ice chips can be enjoyable.

## Basic Hygiene

### Mouth Care

Your loved one may develop a dry mouth. Relief can be provided by following these steps:

- Moisten mouth swab with baking soda mouthwash (1 teaspoon salt and 1 teaspoon baking soda in 1 quart of water).
- Clean inside the mouth and around teeth.
- Clean the roof of the mouth.
- Repeat this process every 30 minutes to 1 hour, depending on comfort needs.  
To prevent dry lips, try applying a thin layer of petroleum jelly. **If your loved one is using oxygen, use a non-petroleum-based lubricant** (Aloe Vera, Beeswax products). Perfumed lip balms and lemon-glycerin swabs can be drying and irritating.

If your loved one is unable to brush teeth, you can provide mouth care at least twice a day. Gently brush natural teeth or remove dentures and clean them. If your loved one is unresponsive, a mouth swab should be used in the mouth. Either a swab or a 4"x4" gauze pad squeezed almost dry with mouth wash can be used to clean and refresh the mouth (your nurse will supply mouth swabs). Remember, your loved one may not be able to swallow, so use only a small amount of liquid.

### Bathing

When providing help with bathing:

- Gather wash basin, towel, and wash cloth or sponge.
- Frequently change water. Water should be warm rather than hot. Use mild soap.
- Wash, rinse and completely dry separate areas. Wash the face and neck first, then the trunk and arms, legs and feet and lastly, the private areas. Always dry each area completely.
- Add a little powder or deodorant.
- Look for any reddened areas, especially the bony parts or pressure areas (elbows, heels, upper buttocks, shoulders, even ears). Apply lotion to reddened areas.

## Skin Care

Keeping the skin in good condition is very important, especially if your loved one is bed-bound or is not able to change position often. A good time to check the skin is during the bath.

Dry skin may look flaky and white, may itch, or be red and look like a rash. This may be the beginning of a bedsore. Although it is up to the nurse and doctor to decide what treatment will help the area heal, there are several things you can do to lessen the risk of bedsores:

- Change your loved one's position frequently in bed or help shift him or her from side to side in a wheelchair.
- Apply lotion gently to the bony areas. Make sure pain medication is given to a person who has pain. This will make your loved one more willing to move and make it easier to do so.
- Keep skin clean and dry. Keep the sheets dry, and smooth out any wrinkles. Do not use extra cushioning or "donut" pillows around the bony areas as this actually increases the pressure. Your Hospice Austin team can provide a special mattress that can help make your loved one more comfortable.

## Getting Someone Out of Bed

Nurses can demonstrate the correct way to perform this procedure.

- Roll the person on his or her side facing the caregiver.
- If using a hospital bed, raise the bed.
- If not, place your arms under your loved one's underarms and gently pull to a sitting position.
- Bring his or her legs around to dangle from the bed.
- If your loved one is unable to sit up, you can support the head and trunk to move him or her to a sitting position.
- Reposition yourself to ensure a stable balance.
- Place your hands in a hugging position under the person's arms.
- Brace the knee against your loved one's knee by placing one leg between the person's legs and gently lift up.
- When both parties are standing, pivot towards a chair and gently let the person sit.
- Remember to have the chair in a nearby position to make moving easier. Also, if lifting to a wheelchair, be sure it is in a locked position.

## Getting On and Off the Bedpan

If your loved one is not able to get out of bed or if it is easier to use a bedpan at night, use these steps:

- Wear protective gloves (Your Hospice Austin team can provide gloves).
- When lying on his or her back, begin by crossing your loved one's legs.
- If you will be rolling to the left, place your loved one's right leg over the left, and cross their right arm over the chest (do this with the opposite side if turning to the right).
- Your loved one may be able to grab the side rail to help roll onto the side.
- Place the bedpan as close to the buttocks as possible and then roll the person onto the pan.
- If using a fracture pan, place the handle to the front and the flat part against your loved one's back.
- When finished, you will repeat these steps above to remove the pan.

- When the pan is removed, keep your loved one on his/her side to wash and dry the area. It is easier to clean the private area while the person is still on his or her side.
- To finish, roll into a comfortable position.

## Positioning a Patient in Bed

- Use pillows to place behind your loved one's back to prevent rolling.
- Use small pillows or soft thin blankets to place between the legs and arms to prevent pressure.
- Remember, it is very important to change position often for a person who is lying in bed.
- After positioning, always look and see if your loved one is comfortable. If the position seems comfortable, it most likely is. It is also okay to ask.

## Using a Draw Sheet

If your loved one is unable to move, draw sheets can be very helpful. Draw sheets usually consist of a soft blanket or folded sheet, large enough to reach from shoulders to mid-thigh, with six inches or more on either side in order for the caregiver to grab hold of it.

- Place the sheet under your loved one using the same technique of rolling from side to side (see bedpan placement).
- Keep the draw sheet wrinkle-free underneath to prevent pressure sores.
- When the draw sheet is underneath, your loved one can then be scooted higher or lower in the bed or rolled from side to side using the draw sheet.
- Use two people to hold either side of the draw sheet.
- Roll the draw sheet up to your loved one on both sides.
- On the count of three, move the person in unison.

## Elimination

When a person becomes very ill, he or she may have problems controlling urine and stool. This can be upsetting and embarrassing to both of you, but is a normal bodily function. Remember that urine output will lessen due to the decreased fluid intake and decreased circulation.

### Urine and stool incontinence

- Use adult briefs or place a disposable underpad under a person with loss of bladder and bowel control.
- Wearing protective gloves, change your loved one when he or she is soiled with either urine or stool.
- Wash the area with warm soapy water, rinse and completely dry.
- Apply lotion to reddened areas. Use the technique of rolling from side to side (see getting off of bedpan above) to change the underpad or briefs.

### Foley Care

Many people come home from the hospital with a Foley catheter. This is a small, flexible rubber-like tube anchored with a balloon inserted into the bladder, which allows urine to flow through to a large collection bag. This enables a person to remain dry and comfortable without having to get out of bed.

If your loved one has a catheter, here are some tips to help you keep it clean:

- Put on protective gloves
- Wash the area where the tube enters the body with warm soapy water, washing and rinsing away from the body.
- Rinse well and completely dry. This should be done at least once a day.
- Make sure that the tubing from the bladder to the collection bag is without kinks or folds.
- Always place the collection bag below your loved one's bladder. This is so gravity will draw urine into the bag.
- Sometimes a catheter will leak. If that happens, place an absorbent disposable pad under the person. Call your Hospice Austin team so that they can evaluate the problem.
- Empty the collection bag twice a day. There is a special spout at the bottom of the bag. The nurse or home health aide will demonstrate how this is done.

## Constipation

Your loved one may experience constipation due to decreased physical activity, changes in diet, and some

medications. Here are some suggestions that may help:

- Increase activity, if possible.
- Increase fluids and fiber in the diet, if tolerated, such as water, juices, fruits, bran, and vegetables.
- Provide stool softeners and laxatives as instructed.

## Diarrhea

Poor digestion and absorption along with certain treatments and medications may cause your loved one to experience diarrhea. Here are some guidelines to follow:

- Review the person's dietary intake for the past 24 hours.
- Increase fluid intake.
- Encourage eating small amounts frequently. Provide foods that are mild and tend not to cause diarrhea, e.g. rice, bananas, applesauce (no skins) or toast.

## Fatigue

Fatigue (generalized weakness) will increase. As it does, it will become more difficult for your loved one to move around in bed. Being unable to move can be uncomfortable. To decrease discomfort, you can help by performing gentle guided movement of your loved one's extremities, and this can be done throughout the day. These are called Passive Range of Motion Exercises. Your Hospice Austin nurse can show you how to perform them.

There may come a time when your loved one will need help to change positions in bed. If turning is tolerated, try doing this as frequently as every two hours. Your Hospice Austin nurse will teach which positions are best and how to use a draw sheet to help this process.

## Pain Management

Our primary objective is to keep your loved one in his or her chosen place of residence and free from pain.

Here are a few guidelines to follow to keep pain under control:

- Give oral pain medication at the prescribed times, even if pain is not currently present. This maintains a level of pain medication and will help keep your loved one comfortable.
- When awake and alert, your loved one can say when pain occurs.
- When unresponsive, look for signs of restlessness, moaning or wincing. Continue to give medication as prescribed and change the patient's position for comfort.
- If your loved one is having difficulty swallowing a pill, call your nurse. Pain medication can be prescribed in a different form or prepared in a different manner.
- Some medications are given as a suppository. The Hospice Austin nurse can teach you how to administer a dosage.
- Pain does not normally increase as a person approaches death. However, if it does, your Hospice Austin team will be able to help manage that pain with appropriate medications and, if possible, other comfort measures.

## Shortness of Breath

Sometimes people can experience trouble breathing and shortness of breath. Signs include restlessness, rapid, short, shallow breaths and anxiety. If this happens to your loved one, this can be very frightening to both of you. However, there are some steps you can take:

- Keep the room cool and well-ventilated.
- Allow for adequate rest between meals and after a bath.
- Raise the head of the bed or have your loved one sit up. Put pillows behind the head to ensure good support. Have the person lean forward and encircle his or her arms around a pillow or over an over-the-bed table. Place your loved one in the position identified as most comfortable.
- Stay calm and reassure him or her.
- Place a small oscillating fan at the bedside to help the person feel as if he or she is receiving more air.
- Check the person's temperature and notice any changes in mucous (especially thickness). Offer warm fluids and a room humidifier if mucous is thick.
- Remove all highly scented items from the area.
- Ensure that no one is smoking in the immediate area.
- If oxygen is in the home, administer it until shortness of breath subsides.
- Minimize visitors at the bedside to one at a time. One-to-one support is best. Take turns if necessary.
- Have the person do deep breathing exercises (this helps to slow breathing and increase oxygen flow):
  - o Breathe in and out slowly through the nose, using the stomach muscles.
  - o Feel the abdomen rise and fall with each inhalation and exhalation.
- Try pursed-lip breathing. Breathe in slowly through the nose. Hold this breath and count to three. Purse the lips as if to whistle. Breathe out slowly through pursed lips, to the count of six.

# Agitation

The last days and hours of life can be a time of peace and comfort. However, some patients may experience restlessness. Restlessness is when the patient experiences agitation in the days or hours prior to death.

## Signs of Restlessness

Prior to death, the patient may become agitated, confused, and very restless. Some signs of this restlessness may include:

- Making faces, clenching teeth.
- Pulling or picking at bed linens.
- Attempting to remove clothing.
- Constantly moving in bed, trying to get out of bed, or sleeping very little.
- Crying out, moaning.

It is not always possible to determine why restlessness occurs. Your Hospice Austin team will look for these and other possible causes so that the symptoms can be managed: pain, constipation, inability to urinate, lack of oxygen, fear.

## What You Can Do

Caring for a patient with restlessness can make you feel tired, overwhelmed, and frustrated. Call your Hospice Austin team immediately if the patient shows any signs of restlessness. They can work with you and your doctor to find treatments to help decrease the restlessness.

Some things you can do to help the patient are:

- Keep the patient safe by padding the sides of the patient with pillows or placing pillows against the bed's side rails.
- Provide constant supervision. Ask family members, friends, and your Hospice Austin team to help.
- Keep the room as peaceful and quiet as possible. Keep noise levels low.
- Gently reassure the patient and give the patient time to talk about any worries.
- Turn down bright lights.
- Try playing soft, soothing music.
- Explain to visitors the need for quiet, soothing surroundings.
- Talk to the patient in a calm, quiet voice. When giving care, softly explain what you are doing.
- Take time for yourself. Ask someone to stay with the patient while you rest, go for a walk, run an errand, or do an activity you enjoy.
- Talk to your Hospice Austin team about any concerns you may have.

Please feel free to call your Hospice Austin team at (512) 418-9270 any time for questions or concerns about restlessness. They will help you draw from your own resources and those available to you through Hospice Austin to ease this difficult time. You are not alone.

## Emotional Care

Emotional care is every bit as important as the relief of physical pain. Many people feel anger or depression at the thought of dying; feelings of guilt or regret over the past are also common. Ultimately, with loving, caring support from family, friends and Hospice Austin staff, most terminally ill people come to terms with the thought of death.

A great cause of anxiety may be fear of a painful end. You can reassure your loved one that adequate pain relief will be maintained at all times, and that even when death is near, there is no need to fear suffering. Most people drift into unconsciousness just before the end, and die in their sleep.

Many people are concerned that they will die alone. Hospice Austin has a special volunteer program to help ensure that the person and/or family has a supportive presence there with them if they so wish.

Preparing for death may include practical matters such as writing a will or planning funeral arrangements. It may include less tangible things such as saying "I'm sorry," "thank you," or "goodbye." Speaking with a clergy member is also important for some people. Perhaps the most pressing need for the terminally ill person is open, honest communication. Relatives, friends and caregivers must be willing to share the dying person's concerns.

Family, friends, and caregivers should be sensitive to the following needs of their loved one:

- The need for open, honest communication.
- The need for emotional stability.
- The need to talk and share feelings.
- The need to be included.
- The need for someone to listen.
- The need for unconditional love, time and patience.
- The need for intimacy through human touch.
- The need for laughter and pleasure .

## Taking Care of Yourself

Taking care of a loved one at home can be very rewarding. It can also be physically and emotionally draining to you. Sometimes you will feel like you have no time for yourself and that responsibilities are overwhelming. Emotionally, you may be trying to deal with the impending loss of your family member and at the same time feel like you have to hold your entire family together. Many times you may think that you have no one to talk to about your own personal problems. Physically, caring for the needs of the patient, a home and a family can be difficult as well. When doing all of these things, remember to not neglect a very valuable piece of the puzzle . . . yourself.

If you don't take care of yourself, you won't be able to take the best care of your loved one. Some of the things you can do to perform self-care are:

### Get enough rest.

Your outlook and ability to deal with things are greatly improved with adequate rest. Try to get at least six hours of sleep a night, and nap during the day while your loved one is sleeping. Sometimes it is difficult to wind down, so try deep breathing exercises, listen to music, or take a warm bath. If you are having trouble falling asleep, try some warm milk, or read for a while.

### **Eat well.**

You will be able to resist colds and other common sicknesses much better if you eat a balanced diet at regular times. Eating well will save energy. It's not advisable to diet during this stressful time. Watch your caffeine intake to help manage your stress.

### **Delegate.**

Ask your family members to share in the care of your loved one. You can also ask your friends or neighbors to take over to allow for a few hours by yourself. If you or your loved one attend church, ask if there are members willing to help with things like meals, shopping, cleaning or respite. Take people up on their offers of help.

### **Request a Hospice Austin volunteer.**

Volunteers can provide a calm, listening presence for every member of the family and can provide respite for up to four hours a week.

### **Talk to someone.**

Find a person to confide in or talk to the Hospice Austin social worker, nurse, spiritual care advisor or volunteer. They are experts in communication.

### **Take time for yourself.**

Schedule time off to do things that you enjoy. If you are taking a leave of absence from work, arrange to have lunch with a friend or coworker. Sometimes asking people to come over can help and they can bring something such as food, as well. Remember that taking time out for yourself is not selfish, and don't be afraid to find humor in everyday life. Laughing has healing powers.

**Ask your nurse or social worker if you need additional support from a nurse, nurse aide, or volunteer.  
You do not have to do this alone.**

**512-418-9270**