



Hospice Austin Caregiving 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 in the communication binder you received upon admission to Hospice Austin's services.

Please call us any time you have a question or concern.

512-342-4700



Managing Symptoms

Hospice Austin's primary objective is to keep your loved one comfortable. Please call us any time you have a question or concern – 512-342-4700.

Pain Management

Pain is whatever your loved one says it is.

It may include discomfort, aching, restlessness, anxiety or cramping.

Here are a few guidelines to keep pain under control:

- Give schedule 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. **Don't skip a dose or wait for the pain to get worse before giving medicine or the pain will be harder to control.**
- When awake and alert, your loved one can say when pain occurs. Ask them to rate with number between 0 and 10. 0 is no pain, 10 is unbearable pain.
- 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.
- Pain does not normally change as a person approaches death. Your Hospice Austin team will work with you to help manage that pain with appropriate medications or other comfort measures.

Taking Pain Medications

Be sure to tell your nurse if your loved one is having any side effects from the pain medication. Common side effects are nausea, constipation or sleepiness. Your nurse can help you manage these symptoms.

The best way to control pain is to prevent it.

- Give medication as directed at the proper time. Don't skip a dose or wait for the pain to get worse before giving scheduled medicine or the pain will be harder to control.
- Ask your nurse about how and when to give nonscheduled medication. If some activities make your loved one's pain worse, it may make sense to give medication before engaging in activities like bathing.
- Other treatments may be used along with medication to address discomfort. Relaxation and breathing exercises, cold packs, moist heat and massage can be helpful. Please talk to your Hospice Austin nurse.

**If these interventions are unsuccessful, contact your Hospice Austin team: 512-342-4700.
We will help you make your loved one comfortable.**

Shortness of Breath

Shortness of breath is also called **dyspnea** or **breathlessness**. It may occur during activities or at rest.

Signs of shortness of breath include:

- rapid, short, shallow breaths
- restlessness
- a feeling of not getting enough air
- fatigue
- anxiety

The feeling of not getting enough air can be very frightening.

If this is a new symptom, call Hospice Austin 512-342-4700

What you can do:

- Keep the room cool and well-ventilated. A small fan to circulate air can help.
- There are many medications that can improve shortness of breath.
- Talk to your Hospice Austin nurse about oxygen or other treatments that may make your loved one more comfortable.
- Use a cool mist humidifier to increase the moisture in the room.
- Eliminate allergens such as smoke, dust, and mold.
- Elevate the head with pillows and/or request an adjustable bed.
- Sit upright and lean forward. Sometimes leaning on a small table is helpful.
- Plan activities to conserve energy. Take frequent breaks.
- Minimize emotional upsets and too many visitors.
- Try relaxation techniques, music and visualizations.
- Breathe in and out slowly through the nose, using the stomach muscles.
- Breathe in slowly through the nose, hold for 3 counts, purse the lips as if to whistle and breathe out slowly to the count of six

If these interventions are unsuccessful, contact your Hospice Austin team, 512-342-4700.

We will help you make your loved one comfortable.

Constipation

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

What you can do:

- Increase fluids and fiber in the diet, if tolerated, such as water, juices, fruits, bran, and vegetables.
- Provide stool softeners and laxatives as instructed.
- Be sure to inform your Hospice Austin nurse for changes in bowel function.

Diarrhea

Poor digestion and absorption along with certain treatments and medications may cause more frequent or loose stools.

What you can do:

- 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.
- Do not give medications for diarrhea without consulting your Hospice Austin nurse.
- Be sure to inform your Hospice Austin nurse for changes in bowel function.

**If these interventions are unsuccessful, contact your Hospice Austin team: 512-342-4700.
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Nausea

If your loved one is suffering from nausea or vomiting, your Hospice Austin team will work closely with you to identify what is causing it and to develop a treatment plan to bring relief.

What you can do:

- Have your loved one eat small, frequent meals and do not drink liquids with meals.
- Avoid fatty, greasy, fried or spicy food; citrus; dairy products; and caffeine such as coffee and chocolate.
- Eat food at room temperature, not hot.
- Keep the room cool and free from cooking odors.
- Suck on ice chips or take frequent sips of a liquid such as ginger ale.
- Try crackers, angel food cake, chicken without skin (not fried), bland fruits and vegetables, toast and sherbet.
- Rest sitting up after eating for 1-2 hours.
- Try deep breathing exercises.
- If your loved one vomits, try a teaspoonful of clear liquid every 10 minutes, gradually increasing to one tablespoon every 20 minutes and then two tablespoons every 30 minutes. Gradually work up to a regular diet.

Please call your Hospice Austin team right away if your loved one is unable to keep down medications to control nausea; throws up more than twice in two hours; if the vomit looks like coffee grounds or is bloody; or if symptoms include weakness, dizziness or thirst.

Fatigue

A lack of energy is very common in those with serious illnesses. Your loved one's ability to take care of the things in life that are important to him or her matters very much to us. Please talk to us about your concerns.

What you can do:

- Consider using Hospice Austin home health aides to help with bathing and hygiene so that your loved one can focus energy on other activities.
- Eat small, frequent meals throughout the day.
- Rest between activities.
- Prevent falls by having your loved one sit up and rest before rising to a standing position; use adaptive devices such as a cane, walker, toilet seat and shower bench; and move rugs and objects from walkways.
- Avoid activities such as driving, handling machinery or cooking when dizzy or drowsy.
- Take family and friends up on their offers to help.

Please be sure to call your Hospice Austin team if your loved one falls; has sudden weakness or dizziness; has changes in the ability to move around, eat or drink; or if you have questions or concerns.

If these interventions are unsuccessful, contact your Hospice Austin team: 512-342-4700.

We will help you make your loved one comfortable.

Anxiety/Sadness

Sadness is a natural response to the physical and emotional changes associated with a serious illness. Being nervous or anxious is uncomfortable and can affect the quality of life. Helping identify the source of these feelings is the first step in dealing with it.

Some common causes of anxiety may include:

- Fear of the unknown
- Changes in how the disease is advancing
- Fear about relieving symptoms such as constipation, pain, or shortness of breath
- Concerns about medications
- Fear about receiving care or being dependent on others for care
- Fear of physical or emotional loss
- Concerns about family or loved ones
- Concerns about moving to a nursing or assisted living facility
- Fear related to making decisions about the future
- Financial concerns

Signs and symptoms of anxiety:

- Overwhelming sadness
- Restlessness or not being able to relax
- Irritability
- Stomach upset or nausea, butterflies in the stomach, lump in the throat
- Muscle tension, aches, soreness or feeling tense
- Feeling exhausted, headaches
- Trouble falling/staying asleep or having nightmares
- Trouble concentrating or feeling overwhelmed
- Sweating, clammy hands, heart palpitations, rapid breathing, trouble concentrating
- Panic or feeling something needs to be done but feeling unable to do anything
- Increase in pain

What you can do:

- Allow yourself and your loved one to cry.
- Talk about feelings, fears, and concerns. Your Hospice Austin Team is available to help navigate through these difficult conversations.
- Take slow, deep breaths; listen to soothing music.
- Enjoy a relaxing activity. Give a foot or hand massage or read a book to your loved one.
- Provide a quiet space, and some time alone to allow your loved one to process feelings.
- Seek spiritual support from your clergy and/or the Hospice Austin chaplain.
- Talk to your Hospice Austin team if you are concerned your loved one is anxious. Your physician may be able to prescribe medications to help.

**If these interventions are unsuccessful, contact your Hospice Austin team: 512-342-4700.
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Agitation/Restlessness

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

Signs of Agitation

Prior to death, your loved one may become irritable, confused, and very restless. Some signs of this 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

Caring for a patient with agitation can make you feel tired, overwhelmed, and frustrated. Call your Hospice Austin team: 512-342-4700

What you can do::

- Has the patient urinated and had a BM in the last 24 hours? if not, call Hospice Austin.
- Keep the patient safe by padding the patient's sides with pillows or placing pillows against the bed's side rails.
- Provide constant supervision. Ask family members and friends to help. Your Hospice Austin social worker may also be able to assist with other options.
- Keep the room as peaceful and quiet as possible. Keep noise levels low.
- Gently reassure your loved one and give them 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. Your Hospice Austin social worker could help arrange a hospice volunteer to provide short periods of respite for caregivers.
- Talk to your Hospice Austin team about any concerns you may have. Please feel free to call your Hospice Austin team at (512) 342-4700 any time for questions or concerns about agitation. 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. Your Hospice Austin team is here to walk along with you on this journey.
512-342-4700**

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.

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. 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.
- Eat well
- Delegate
 1. Ask your family or friends to share in the care of your loved one.
 2. Take people up on their offers of help. Give them a task such as running an errand or housework.
- Talk to your Hospice Austin social worker about volunteer support.
- Talk to someone.
- Remember that taking time out for yourself is not selfish.
- Don't be afraid to find humor in everyday life. Laughing has healing powers

Medication Administering

Giving your loved one medications and keeping track of what has been given are two of the most important jobs you will have. Your hospice team will create a plan detailing how much and how often to give medications, as well as go over how to give them.

Your job is to make sure you administer them exactly the way the plan indicates, and track each time you do. This ensures your loved one has the correct dose at the correct time, keeping them comfortable and safe. Use the sheets in this binder to help. If your loved one has side effects from any medications, or the medications do not seem to be having the desired effect, call Hospice Austin immediately: 512-342-4700.

Medications can be given in several different ways and your hospice nurse can show you how best to give them.

1. **By mouth or orally:** Most pills, tablets, and capsules can be swallowed with liquid. Some tablets can also be crushed and placed in soft food, like applesauce. NOT all pills can be safely crushed so ask your hospice nurse before you crush any medications.
2. **By syringe:** Some medicines, such as liquid morphine, must be drawn into a syringe. Drops from a syringe can be placed under the patient's tongue or between the cheeks and gums.
3. **By inhalation:** Oxygen, as well as other breathing treatments, are inhaled. This usually involves breathing in the medicine by wearing a facemask or tube over the mouth or nose.
4. **Topically:** Creams and gels are rubbed on to the skin. Always wash your hands and put on gloves before applying a cream medication. Other topical medications may be patches worn on the skin. Remember to apply patches as directed and to look for any skin irritation or rashes under or around them. Rotating application sites will help this.
5. **Some medications may be given rectally.** Talk with your nurse if you have questions.

While it may feel overwhelming, remember that your Hospice Austin team is here to help. If you have questions or concerns about giving or tracking medication, contact us immediately;

Hospice Austin 512-342-4700

Comfort Care Medication Kit

If ordered from your doctor, your Hospice Austin team will provide you with a comfort care medication kit to keep at home, which will help manage symptoms in a timely manner. This kit contains small amounts of different medicines to treat symptoms that may occur toward the end of life. Note, different medications may be found in some comfort kits.

IMPORTANT: Before using any of the kit medications, call Hospice Austin: 512-342-4700

Medication	Purpose	How to Take	Most Common Side Effects
Morphine Sulphate Immediate Release (MSIR)	A medication used for pain and or shortness of breath.	May be swallowed, crushed* or given under the tongue	Drowsiness, constipation and nausea
Lorazepam (Ativan)	Commonly used for anxiety, restlessness, insomnia, seizures and shortness of breath	May be swallowed, crushed* or given under the tongue	Weakness, drowsiness and agitation
Haloperidol Tablet (Haldol)	Commonly used for nausea, vomiting and or agitation	May be swallowed, crushed* or given under the tongue	Dry mouth, drowsiness and headache
Hyoscyamine Tablet (Levsin)	Commonly used for increased secretions	May be swallowed, crushed* or given under the tongue	Dry mouth, decreased urination

*When crushing pills, please add a small amount of water

Please do not use any medication in the comfort care medication kit until instructed to do so by your Hospice Austin team.

If you have any questions regarding the comfort care medication kit, call your Hospice Austin team, day or night: 512-342-4700

Medication Tracking

Tracking medications with this Medication Chart (see next page) helps caregivers and the hospice care team know exactly the care your loved one has received and helps the next caretaker or hospice care team member to pick up where you left off.

Medicine given in the right dosage amount at the right time is crucial to its effectiveness and can keep your loved one safe and comfortable. Because there may be multiple caregivers helping care for your loved one, it is critical to keep track of medications so that your loved one's medication works effectively.

Missing a medication dose, or receiving an incorrect dose, may cause dangerous side effects and complications.

Here are some tips on how to best keep track of medication:

- **Drug name:** Write the name of the drug. Include both its common name and the chemical name on the bottle, like Tylenol (acetaminophen).
- **Appearance:** Write the color and form, like pink circular pill, clear injectable liquid, or white cream. Medications may appear different from one prescription to the next. Keeping track of what a medication looks like can reduce the chance of giving the wrong medicine.
- **Amount given:** Be as specific as possible. Instead of writing 1 pill, write 1 pill – 250 milligrams.
- **Time:** Write the time given and whether it was before or after 12:00 noon (use AM or PM).
- **Symptom relief:** Record why the medication was given. Was it for pain, nausea, shortness of breath?

Symptom Management Record

[illegible]

* Pain Rating:

1-3 = mild pain/discomfort
4-6 = moderate pain/discomfort
7-10 = excruciating pain

**** Relief Rating After 1 Hour:**

0 = complete relief
1 = lots of relief
2 = moderate relief
3 = minimal relief
4 = no relief

Destroying Medications

Please refer to the “Use and Disposal of Controlled Medications” policy in the back section of this binder.

Per Drug Enforcement Agency (DEA) guidelines, all controlled medications belong to the patient/legal representative. It is the patient/legal representative’s responsibility to destroy the controlled medication once they have been discontinued. You may do this in two ways:

1. Render them irretrievable (see procedure below).
2. Take them to a pharmacy registered as a collection site with the DEA. Your Hospice Austin team can assist you in finding a location in your area.

Procedure for Destroying Medications (Making them irretrievable in order to discard in trash)

Please place medications in the trash rather than flushing them. Landfills have liners that are designed to keep the trash from leaching into the soil around it. When medications are flushed, everything goes into the water system.

Supplies You Will Need:

- Sealable plastic bag (quart or gallon size) OR an empty milk carton
- Cat litter or used coffee grounds
- Gloves
- Alcohol wipes
- Scissors
- Trash bag or other container
- Liquid dish soap

Procedure

- Place meds in carton or bag (double-bagging is good).
- Add any suppositories.
- If there are patches, remove plastic backing, stick sides together, and cut in half; place in bag.
- Add dish soap and gently squeeze to mix contents.
- Add enough cat litter/coffee grounds to make it clump. You may need to add some water.
- Zip bag; mix contents.
- Place bag in plastic grocery bag, tie up, and place in trash.



Daily Care

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 food that might be appealing, only to have their loved one 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. However, appetite changes are an expected change with a life-limiting disease.

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, so does the digestive process. 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 desire to eat.

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 choices 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. They 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:

- If pain or nausea are problematic, offer medication to treat the symptom about one hour before eating.
- Start with small portions, allow your loved one to ask for seconds.
- Ask what tastes best. Fresh fruits, cool, bland and soft foods are often the most appealing. Many people do not tolerate red meat, fried, or spicy foods.
- Flavored ice cubes (made from fruit juice) crushed into ice chips can be enjoyable

Remember, the desire for food (and the body's need for food) is minimal. The most important thing is for your loved one to enjoy whatever food or drink is taken.

Flavoring Suggestions for Nutrition Supplements

The taste of commercial nutrition supplements can become boring in a short period of time. You can stir or blend the ingredients below to vary the taste.

<u>Flavor</u>	<u>Ingredients</u>
Butterscotch	1 Tablespoon Butterscotch Syrup OR Pudding mix
Chocolate	1-2 Tablespoons Chocolate syrup
Coffee	Add instant coffee or sweetened coffee drinks
Extracts	Almond, lemon, orange, vanilla, etc.
Fruit	Powdered drink mix or gelatin mix in desired flavors
Mocha	Combine chocolate syrup and instant coffee
Peanut Butter	Creamy peanut butter

Calorie & Protein Boosters

If you are trying to increase the number of calories and/or protein in your diet, below is a list of suggestions that may help achieve this goal.

<u>Item</u>	<u>Suggestions</u>
Butter or margarine	Add to oatmeal, puddings, casseroles, sandwiches, etc.
Carnation Instant Breakfast	Add to milk or use to make milkshakes
Cheeses	Add to sandwiches, casseroles, potatoes, vegetables & soup
Eggs	Add to casseroles, meat loaf, mashed potatoes, mac & cheese
Gravies & Sauces	Use liberally on rice, mashed potatoes & meats.
High-Protein Foods	beef, chicken, fish, turkey, lamb, yogurt, cottage cheese, eggs
Dressings	Use liberally on sandwiches, salads, as a dip for raw vegetables
Peanut Butter	Serve on toast, crackers, bananas, apples or celery
Powdered Milk	Add 2-4 T. to 1 cup of milk. Mix into soups, ground meats
Sweetened Condensed Milk	Add to pies, puddings & milkshakes. Mix 1-2 Tbsp. with peanut butter & spread on toast.

People nearing 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 to address this.

Hygiene

Your loved one is likely to develop more dependence on others to complete life's routine activities, including maintaining basic hygiene. See below for tips which may be helpful and always discuss such care with your nurse if questions or problems arise.

Mouth Care

Many illnesses and medications result in a dry mouth. Keeping the mouth clean and moist can provide comfort. Assist to 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 for cleaning (your nurse can provide swabs). When using swabs for an unresponsive person:

- Your loved one may not be able to swallow, so use small amounts of liquid.
- Moisten mouth swab with water or a diluted non-alcohol mouthwash solution.
- Clean inside the mouth and around teeth as well as the roof of the mouth and tongue.
- Repeat this process periodically as needed for comfort.
- To prevent dry lips, try applying a lubricant. **If oxygen is in use, use a non-petroleum-based lubricant such as aloe vera, coconut oil or beeswax products.**
- Lemon-glycerin swabs can be drying and irritating.

Bath Care/Skin Care

Keeping the skin in good condition is very important, especially if one is bed-bound or is not able to change position often. All bed bound persons should be repositioned periodically for comfort.

Tell your nurse about any changes you find, especially any red areas on pressure sites (tailbone, heels, elbow)

- 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.
- Look for reddened areas, especially on the bony parts or pressure areas (elbows, heels/feet, hips, tailbone, shoulders, even ears). Apply lotion to bony or reddened areas and inform your nurse of changes.

A good time to check the skin is during the bath. When providing help with bathing:

- 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.
- Gather wash basin, towel, mild soap and wash cloth or sponge.
- Frequently change water. Water should be warm rather than hot.
- Wash, rinse and completely dry separate areas individually. Start with the face and neck, then the trunk and arms, legs and feet and lastly, the private areas. Always dry each area completely.
- Leave a towel over the areas you are not cleaning to keep your loved one warm. You may even want to heat towels in the dryer just prior to bathing.

Bowel and Bladder Changes

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 to change the underpad or brief. Your nurse can teach you this technique.

Changes in bowel function

Changes in medications, diet and activity can have a profound effect on bowel function. Please see symptom management section for further details on constipation and diarrhea management (page 18).

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, position the person comfortably.

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.

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.

Remember the #1 rule:

Always lift with your legs and not with your back. Take an extra moment to think about lifting in order to get balanced.

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 moved 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.

Preventing Falls

A person with a life-limiting illness often has increased weakness, fatigue or other illness-related symptoms that result in increasing their likelihood of falling. Your nurse will work with you in trying to prevent falls.

Here are a few basic techniques:

- Change positions gradually.
- Remind your loved one to use equipment such as cane or walker as appropriate and to ask for assistance when they are walking, standing or sitting.
- Provide adequate lighting so no one trips over unseen objects.
- Reduce trip or slip hazards such as clutter, loose rugs or wet or waxed floors.
- Provide grip on slippery surfaces with rubber mats in the bath and socks or shoes with tread

In the event of a fall, please call Hospice Austin
even if your loved one is not injured.

Practical Considerations for Families

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,” “I forgive you,” “I love you,” or “goodbye.” Sometimes the most pressing need for the terminally ill person is open, honest communication. Bear in mind, there are times when there is nothing to do other than provide a loving presence.

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

- The need for open, honest communication.
- The need to be included.
- The need for respect, time and patience.
- The need for intimacy through human touch or presence.
- The need for laughter and pleasure.

Paperwork and arrangements

1. Find out where all important papers and monies are kept.
2. Find out important passwords/account numbers.
3. Be sure there is a Will or have one made.
4. Learn what kind of health and life insurance the patient has.
5. Discuss the tax consequences with a tax expert.
6. Be sure at least one survivor knows how to manage the business(es) and duties which were part of the patient’s responsibilities.
7. Make all funeral arrangements, including having a discussion with clergy if one is to be involved.
8. Plan the obituary notice, with all appropriate biographical data.
9. Learn how to recognize the signs of imminent death, and know whom to notify.
10. Educate everyone about the procedure to follow at time of death.
11. Make a list of people who must be notified at time of death (family, friends, clergy, etc.)

Hospice Austin has a document on our website called “The Gift” to help patients and families organize their affairs. This is a tool designed to provide basic step-by-step information to your family about your assets, liabilities and wishes. You can download a copy of The Gift from HospiceAustin.org/TheGift.



Patient and Caregiver Safety

It is of utmost importance to prevent injury and illness in the home. The following simple steps can help ensure safety while providing care in the home.

Hand-washing is the single most effective way to prevent the spread of infections. Wash your hands before and after handling anything that touches a person with decreased immunity or who has a cold or cough, before handling any food or before food preparation, and whenever your hands are obviously soiled. Be sure to soap hands for at least 20 seconds.

Barrier Precautions

Use gloves whenever there is a possibility of exposure to body fluids. For example, use gloves when providing oral hygiene, personal care, or wound care.

Sharps Disposal

- Place any sharp object (needles, syringes, and lancets) in a hard plastic or metal container with a screw-on or tightly secured lid.
- A coffee can will do as long as the lid is reinforced with heavy duty tape.
- Do not use glass or clear plastic containers.
- Do not put sharp objects in any container that will be recycled.
- If recyclable material is used, write, “Not for Recycling” on the container to protect sanitation workers and others from possible injury.
- Make sure any container with sharp objects is kept out of reach of young children and pets.
- Sharps containers may be placed in a regular trash receptacle.

Handling and Disposal of Used Supplies

Soiled bandages, disposable sheets and medical gloves or similar items should be double-bagged and securely fastened before placing in the garbage bag with other trash.

Cleaning Equipment

If potentially infectious material should spill (for example, blood), clean the area with a bacteriostatic cleanser or a household bleach solution (recipe below):

- Mix one part bleach with 10 parts water and wipe the spill up.
- This solution may also be used to clean any equipment that may become soiled.
- Spot test a small area first, as bleach will remove the color from fabrics and carpets.

Laundry

All laundry may be washed as before. Use hot water for any items with potentially infectious material (blood or other bodily fluids).

Oxygen Safety

Oxygen is a DRUG and is effective and safe only when used as prescribed by a physician. Never change the oxygen liter flow without first consulting a hospice nurse or physician.

Fire Safety

- Oxygen is not flammable and will not explode. However, oxygen does support **combustion**. This means that oxygen will make things burn faster and ignite more easily.
- Oxygen should be used and stored in a **well-ventilated** area because oxygen will accumulate around the user and immediate surroundings.
- Never use or store oxygen in a confined space such as a cabinet or closet.
- **Do not use petroleum-based ointments** or lotions in or around the nose are such as Vaseline, Vicks, Chapstick, etc. Oxygen can react violently with these oily substances and cause burns.
- Take care to **avoid open flames** while using oxygen. This includes matches, fireplaces, BBQ's, stoves, space heaters, etc.
- **Do not smoke** within 8 feet of a patient using oxygen or the oxygen system itself.
- Avoid toys or appliances that may produce sparks or static electricity (i.e. electric razors, toys that move by friction)
- A smoke detector and fire extinguisher are recommended when using oxygen in the home.
- Plan an evacuation route for the entire family in the event of a fire.

Oxygen Storage and Handling

- Oxygen tanks should always be stored in a stand or cart to prevent tipping or falling. Store extra unsecured tanks lying flat on the ground. **Do not** allow tanks to stand or lean in an upright position while unsecured.
- Do not store oxygen systems in unventilated areas such as closets or cabinets.
- Do not store oxygen systems near heat or ignition sources.
- Do not store oxygen systems in the trunk of a car.
- While transporting oxygen in a vehicle, make sure containers are secure and positioned properly.
- Oxygen should be transported in the passenger compartment of a vehicle with the windows open slightly (2-3 inches) to permit adequate ventilation.

Oxygen Concentrator Safety

- Concentrators are electrical devices which should only be plugged into a **properly grounded** outlet.
- **Do not use extension cords.**
- **Do not use multi-adaptors** (such as power strips).
- Avoid using power sources which create heat or sparks.
- Use a power supply or electrical circuit which meets or exceeds the amperage requirements for the concentrator.

Respiratory Equipment Cleaning Instructions

Oxygen Supplies

- Humidifier
 1. Refill with distilled water as necessary. Discard any remaining water before filling.
 2. Clean humidifier every week: wash in warm, soapy water and rinse with water; soak in a 1 to 1 mixture of white vinegar and water for 30 minutes, discard mixture, and rinse with water.
- Nasal Cannula
Discard every 2 weeks and more frequently if someone has a cold.
- Oxygen Tubing
Discard and replace when performing maintenance every 60-90 days or as needed.
- Hand Held Nebulizers
 1. After each treatment, disassemble nebulizer, "T" piece and mouthpiece and rinse thoroughly under warm tap water.
 2. Allow to dry on a clean paper towel.
 3. Once each day, after rinsing, soak for 30 minutes in a 1 to 1 mixture of white vinegar and water and rinse thoroughly with water. Discard vinegar and water mixture daily.
 4. Allow to dry on a clean paper towel.
- Tubing
 1. Wipe with damp cloth if soiled.
 2. DO NOT attempt to soak/clean tubing.

Suction Machines

- Cannister
 1. Discard contents daily into toilet.
 2. Wash canister daily in warm soapy water.
 3. Disinfect weekly by soaking canister in a 1 to 1 mixture of white vinegar and water for 30 minutes and rinse with water. Discard vinegar and water mixture daily.
- Tubing and Suction Instruments
 1. Suction up a small amount of water after each use to clear the tubing and attachments.
 2. Soak daily in warm, soapy water.
 3. Soak suction instruments daily in a 1 to 1 mixture of white vinegar and water for 30 minutes and rinse with water. Discard vinegar and water mixture daily.
 4. Assure that canister top is replaced securely on canister and unused ports plugged.

Patient & Family Emergency Preparedness Plan

Evacuation Category

As part of general emergency preparedness, your team will routinely assess your evacuation category. These assessments may change as your condition changes. Please talk to your team if you feel that there have been changes. Your team has put a check next to your assigned category at this time:

- ☐ Category I: Patients who have specific skilled needs requiring daily care, and/or have no caregiver support.
 - Visits: Daily, pending staff are able to access patient
 - Social Worker to offer to assist patient sign up with the “State of Texas Emergency Assistance Registry (STEAR)
 - If Evacuation Needed: Hospice Austin will help coordinate with County Emergency Management to assist with the evacuation

- ☐ Category II: Patients who require moderate level of skilled care requiring visits within 24-48hrs.
 - Visits: May be postponed 24-48 hours without adverse effect on the patient. Patients in this category must have a phone call within 24hrs in order to determine if a visit is needed.
 - Caregiver available to assist with communications and needs
 - If Evacuation Needed: Hospice Austin will help coordinate with County Emergency Management to assist with the evacuation if caregiver not able to transport.

- ☐ Category III: Patients in this category can forego a routine assessment as their condition is more stable and/or they are in a facility or have good caregiver support.
 - Visits: may be postponed 72-96 hours without adverse effect on the patient
 - Condition stable with reliable caregiver support and ability to transport if needed (i.e. Nursing Facility)
 - If Evacuation Needed: Caregiver or Facility will take care of evacuation arrangements. Please notify Hospice Austin of evacuation destination and contact phone number.

In the event of an emergency or disaster, it is necessary that patients and family members be prepared to take the appropriate actions. We must be prepared for both internal and external emergencies.

- Internal Emergencies include those that occur in your home (i.e. fires, loss of electricity, unsafe conditions).
- External Emergencies include those that occur outside the home (i.e. weather related: tornadoes, hurricanes, ice, flood, wind; widespread power outages, terrorism, chemical emergencies)

What to expect from Hospice Austin during a disaster

Hospice Austin will do its best to continue to provide care during a disaster/emergency but may be limited due to road conditions or other extenuating circumstances.

- When we have advanced warning of an impending potential disaster (i.e. ice storm, hurricane) Hospice Austin will order additional medications/supplies and supplemental portable oxygen for those that need it. As long as the phones are working, patients and family will continue to have access to medical personnel to assist in providing care.
- **The State of Texas has an Emergency Assistance Registry (STEAR) for the purpose of identifying patients who may need additional assistance evacuating.** Hospice Austin can assist you in registering for this service should you so desire. Please refer to insert for additional information. Should local authorities recommend evacuating, please notify Hospice Austin immediately at 512-342-4700.
- Hospice Austin will work with you, your family and Emergency personnel to assist you with an emergency localized to your home.
- Your Hospice Austin team will review each patient's needs and evacuation status to schedule visits and call their patients as appropriate.
- Hospice Austin will not physically evacuate patients to a shelter.

Patients and visitors at Hospice Austin's Christopher House

You will shelter in place unless otherwise directed by the Charge Nurse. Hospice Austin's Christopher House staff will assist you in moving to safe areas within the building when necessary. Should evacuation be required, the Charge Nurse will explain what will happen and to where you are being evacuated. Please take note of several facility exits, including the patio doors located in each patient room, should you need to escape a fire.

Patient and Family Responsibilities before an Emergency/Disaster Happens

- Maintain a current list of emergency contact numbers
- Maintain adequate emergency supplies. Assemble an emergency supply kit and have it ready to go at a moment's notice. It should contain the following items:
 - radio and flashlight with extra batteries
 - extra eye glasses
 - medications and prescriptions
 - special products for babies and the elderly
 - bottled water and non-perishable food
 - clothes
 - bedding and important documents sealed in waterproof containers
- Have a plan to reach out to individual support (family, friends, neighbors, etc.)
- Have an evacuation plan identified. This plan must be reviewed periodically.

How to take care of yourself in your home during an emergency

- Notify Hospice Austin as soon as possible if you have been impacted by an emergency
- Notify your Individual support system to assist during the emergency
- Listen for instructions from your local emergency broadcast system (have battery powered radio available and /or cell phone)
- If you must evacuate, take necessary food, water, and supplies. Also remember all medications and medical equipment (i.e. oxygen)
- Take Hospice Austin contact numbers with you
- Notify Hospice Austin once you reach a safe location
- Notify Hospice Austin immediately with any safety questions/concerns or emergencies.

Fire

- Talk with all household members about a fire escape plan and practice the plan twice a year.
- Test smoke alarms once a month; if they're not working, change the batteries, if needed.
- If a fire occurs in your home, GET OUT, STAY OUT and CALL for help.
- Install smoke alarms on every level of your home, inside bedrooms and outside sleeping areas.
- Keep oxygen and tubing away from any open flame or heat source to prevent fires.
- Never smoke in bed.

The City of Austin has a program to offer free smoke alarms to any resident of Austin who is in need. The only prerequisites are that the citizen reside in a privately-owned home and has a need for genuine assistance. To participate in this program, please call (512) 974-0299.

You may also request a free home hazard assessment. The assessment will be performed by Austin fire-fighters after installing the free smoke alarms. Please visit austintexas.gov/departments/smoke-alarms.

Flash Floods

- If you are in a low-lying area when flooding is occurring, get to higher ground quickly. If you need assistance with evacuation, call 911.
- If evacuated, please call Hospice Austin at 512-342-4700.

Tornadoes or Severe Weather Threats

- Pay attention to local news sources for developing conditions.
- Seek shelter in an interior room on the lowest floor of your home, such as a bathroom, closet or room without windows. Close curtains and blinds. Cover yourself with a mattress or cushions.
- If you are in a mobile home, leave and take shelter in a nearby building. If there is none, lie flat in a ditch or ravine.
- Learn the difference between a Tornado Watch and a Tornado Warning. A Tornado Watch means watch the sky -- a tornado is possible but has not yet been seen. A Tornado Warning means a tornado is on the ground and you must seek shelter immediately.

Winter Storm

- Remain indoors if possible. If you must go out, dress to fit the weather, with layered, wind-resistant clothing, a hat, and gloves or mittens to protect yourself against frostbite.
- Have emergency heating equipment approved for indoor use and appropriate fuel for it. Emergency heating equipment includes kerosene or propane heaters and wood stoves.
- Have emergency lighting in case the power goes out: flashlights or lanterns with a supply of batteries or fuel.
- Keep an emergency supply of ready-to-eat non-perishable food and an emergency supply of water on hand.
- Listen to your radio or TV to obtain weather and emergency information. Have a battery-powered radio with spare batteries in case your electricity goes off.
- Travel only if absolutely necessary. If you must travel, do so in daylight. Have emergency supplies in your vehicle.

Power Failure

- If you lose power, notify Hospice Austin.
 - If you are using oxygen, Bipap, Trilogy, suction or any other critical piece of equipment that requires electricity to run, notify Hospice Austin immediately if you lose power.
 - Hospice Austin will work with our equipment provider to get extra portable tanks delivered to you.

Chemical, Biological, Nuclear

- Stay tuned via emergency radio, TV, &/or internet for official news and information provided by emergency personnel.
- If an attack warning is issued, take cover as quickly as you can. Stay inside for at least 24 hours unless told otherwise by authorities.
- Check with your doctor to ensure all required or suggested immunizations are up to date for yourself, your children and elderly family members.
- For more information on preparing for disasters, go to www.ready.gov

STATE OF TEXAS

EMERGENCY ASSISTANCE REGISTRY (STEAR)

Do you or anyone you know need some form of assistance during times of an emergency/disaster event? The state of Texas offers Texans the option to register with the STEAR program, a FREE registry that provides local emergency planners and responders with additional information on the needs in their community.

(Texas communities use the registry information in different ways. Registering yourself in the STEAR registry DOES NOT guarantee that you will receive a specific service during an emergency. Available services will vary by community. For more information on how your community will use information in the STEAR registry, contact your local emergency management office.)

Who Should Register?

- People with Disabilities
- People with access and functional needs:
 - People who have limited mobility
 - People who have communication barriers
 - People who require additional medical assistance during an emergency event
 - People who require transportation assistance
 - People who require personal care assistance

How to Register:

- <https://STEAR.dps.texas.gov>
- Dial 2-1-1 or use your video phone relay option of choice to contact 211
- Printed or electronic forms (Contact your local government)

Required Information to Register:

- Name
- Address
- Phone Number
- Primary Language

Additional questions asked to capture vital information for local emergency planners and responders:

- Emergency Contact Information
- Caregiver Information
- Pets
- Transportation assistance for home evacuation
- Communication Barriers
- Disability, Functional or Medical Needs

Registration is **VOLUNTARY**.

All of the information you provide will be kept **COMPLETELY CONFIDENTIAL**.

Local Emergency Management Offices

Travis County Office of Emergency Management

5010 Old Manor Rd. #330
Austin, TX 78723
(512) 974-0450

Bastrop County Office of Emergency Management

104 Loop 150 W.
Bastrop, TX 78602
(512) 581-4022

Hays County Office of Emergency Management

2171 Yarrington Rd.
San Marcos, TX 78666
(512) 393-7300

Williamson County Office of Emergency Management

911 Tracy Chambers Lane
Georgetown, TX 78626
(512) 864-8200

Caldwell County Office of Emergency Management

1403 Blackjack Street, Suite E
Lockhart, TX
(512) 328-1822

Texas Department of Emergency Management

1033 La Posada Dr.
Austin, TX 787S2
(512) 424-2208