



## ***Patient and Caregiver Handbook***

**Notify Journeys Hospice of Texas immediately for all:**

- \* Changes in Condition (i.e., fever, nausea, vomiting, pain)**
- \* Medication Refills**
- \* Before Scheduling a Doctor's appointment**
- \* Before Calling 9-1-1**

**Office/On-Call #: 833-467-5468**

## **Patient and Caregiver Informational Packet**

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# How to Reach Journeys Hospice of Texas

**Journeys Hospice of Texas Office Number: (833) 467-5468**

**On-Call Number: (833) 467-5468**

If you need to reach a staff member, please call the office for assistance to ensure we can assist you immediately!

## **Your Journeys Hospice of Texas Team:**

**Case Manager RN:** \_\_\_\_\_

**LVN:** \_\_\_\_\_

**Social Worker:** \_\_\_\_\_

**Chaplain:** \_\_\_\_\_

**Hospice Aide:** \_\_\_\_\_

**Volunteer:** \_\_\_\_\_

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## **Journeys Hospice of Texas**

Most patients and families seek hospice care in their homes. Home is where ever the patient resides. Care is delivered to these patients by a primary caregiver (usually a family member or friend) and the assistance of our hospice team.

Individuals living in extended care facilities, such as nursing homes or an assisted living apartment, may also receive hospice home care services.

Members of our staff visit the home or extended care facility regularly to assess, teach and counsel, as well as to implement and direct the hospice plan of care. During our initial visit, we will assess the patient's needs and provide the necessary supplies and equipment needed for Hospice care. These supplies may include a hospital bed, wheelchair and oxygen.

The Hospice Program also provides medications needed for comfort and symptom management related to the patient's diagnosis. When a patient is not able to remain at home to, hospice works with the patient and family to find appropriate accommodations in a local extended care facility or hospice inpatient facility where available to address comfort and symptom management.

If a patient at home has increased medical needs for acute symptom management, continuous care may be available for a limited period. In addition, respite stays for five days or less are available when the caregiver is in need of relief from 24-hour caregiving responsibilities.

### **Eligibility**

Hospice care can begin when curative treatment is no longer desired or expected to be effective. Hospice neither hastens nor postpones death, but recognizes dying as a normal process and seeks to help patients and their families prepare for death mentally and spiritually.

Hospice patients have life expectancies that are expressed in months, weeks or days. An individual's attending physician makes this determination. The Hospice Program will not deny services to anyone on the basis of race, religion, age, color, national origin, creed, sex, and/or physical or mental handicap.

### **Financial information**

Medicare and Medicaid cover all the costs of hospice care, including visits from team members, equipment, supplies, medications, and comfort-related therapies. Private insurance policies vary.

Upon enrolling in the Hospice Program, the Hospice team will contact the insurance company to determine Hospice benefits. Admission to Hospice is based on need, rather than ability to pay. If a patient has no coverage for Hospice services, the hospice provides financial counseling if needed.

### **Bereavement support**

People who have not experienced great grief may think there's a timetable for recovery. They often don't mention the loved one who has died because it makes them uncomfortable. Yet, people often need to talk about those who have died not just to mourn their death, but also to celebrate their life.

## **Hospice Patient Information on Face-to-Face Encounters**

### **Medicare Hospice Benefit Services**

#### **Requirement for a Face-to-Face Encounter between the Patient and the Hospice Physician or Nurse Practitioner (NP)**

Medicare covers hospice services for individuals who elect to receive hospice care instead of other Medicare benefits for treatment of a terminal illness. To be eligible to begin hospice services, a patient's physician (if he or she has one) and the hospice medical director must certify that the patient's life expectancy is six months or less if the illness runs its normal course. A patient is eligible for two 90-day hospice benefit periods followed by an unlimited number of 60-day benefit periods; for the 2nd and for each additional benefit period a hospice physician must recertify that you continue to be eligible for hospice.

If you are approaching your 3rd or later benefit period, you will be contacted by a staff member of the team of Journeys Hospice of Texas to arrange for a face-to-face meeting with a hospice physician or hospice nurse practitioner. This meeting must take place within 30 calendar days of you entering the 3rd or later hospice benefit period. While you may see your personal physician during that same time period for care, only a meeting between you and physician or hospice nurse practitioner connected with Journeys Hospice of Texas will satisfy the new requirement.

- As part of the certification requirements for a hospice patient's 3rd or later benefit period, a hospice physician or hospice nurse practitioner must have a face-to-face encounter with the patient to gather clinical findings to support continuing eligibility for hospice care.
- The face-to-face meeting may take place in the patient's residence, or the patient may go to the hospice physician or nurse practitioner for the meeting if medically appropriate.

## ***What can I expect From a Hospice Volunteer?***

- CAN give generously of their time to provide support and assistance to both the patient and
- CAN prepare a light meal/snack and help feed the patient.
- CAN help patient with personal grooming. (Brush hair, apply makeup)
- CAN Provide assistance with transferring patient from chair to bed/bed to chair, changing undergarments, assisting them to the bathroom/ bedside commode/bed pan.
- CAN contact the appropriate team members to request for spiritual support per patient and family requests.
- CAN Coordinate help of Friends, neighbors, and relatives with permission of patient and family
- CAN help change bed linens — fluff a pillow.
- CAN encourage the patient to tell their life story.
- CAN listen to the patient's/Family's concerns.
- CAN do light housekeeping tasks such as tidy a room

### **Volunteers Can:**

- ❖ CAN be a comforting, supportive presence and companion to the patient which allows the caregiver time to take care of his/her see, get some fresh air, run errands, etc.
- ❖ CAN be a trusted listener.
- ❖ CAN provide emotional support to both the patient and family.
- ❖ CAN shop, run errands, write and mad letters, make phone calls.
- ❖ CAN participate in patient's interests such as reading, playing games, crafts, watch TV shows, discussing current events.

## **WAYS THE VOLUNTEER CANNOT HELP IN THE HOME:**

- CANNOT give nursing care or do anything of a medical nature.
- CANNOT give shots, enemas, or measure out/give medications.
- CANNOT answer medical questions. Volunteers are not present as a medical professional. (\*Please direct your medical questions to your physician or Hospice Nurse")
- CANNOT be a regular housekeeper nor do anything of a heavy housekeeping nature. (Such as, but not limited to scrubbing Floors or washing windows.)
- CANNOT do professional counseling.
- CANNOT take temperatures, blood pressures, weigh the patient, etc.

### **Comforting Thoughts...**

- ❖ Hospice Volunteers have participated in and completed the "Hospice 101" training sessions prior to entering the home.
- ❖ Every Hospice Volunteer has cleared a background checks and has met aft requirements set by the agency.
- ❖ Hospice Volunteers serve as an essential member of the Hospice Team. -various settings such as your loved ones home, nursing home, assisted living facility, in-patient, and respite care.
- ❖ Volunteers maintain open communication with and reports regularly to the Volunteer Coordinator.
- ❖ Hospice Volunteers are aware of and Follow all HIPAA regulations.

**If you find that you have questions or you would like to request a volunteer, please talk to your Hospice Nurse or call the Hospice office at: (833) 467-5468**

**Journeys Hospice of Texas will be with you,  
when your loved one has passed.....**

You will know that death has occurred when your loved one has completely stopped breathing for several minutes and their heart is no longer beating. **Remember**, you and your hospice team have worked together to allow your loved one to pass away with comfort and dignity in their home environment in accordance with their wishes for their end of life care.

1. Nothing must be done immediately. However, **Please Call Journeys Hospice of Texas at: (833) 467-5468** as soon as possible. **A Nurse will be dispatched to assist you, promptly.**
2. You may want to spend some time alone with your loved one.
3. If you desire a chaplain or social worker to come also, please tell the nurse. The nurse will make all the necessary official phone calls. They will notify the funeral home to come when you are ready. Please have the funeral home number available for their use.
4. You may wish to notify family members and friends of the death. If you wish, they may visit at this time.
5. A hospice team member will stay with you until the funeral home arrives and transports your loved one. Equipment will be removed in the next 24-48 hours when you are available.
6. The nurse will dispose of any controlled medications per our medication disposal policy.
7. The Journeys Hospice of Texas Members are available to you if you should need us in the days ahead. Our bereavement staff will follow you for the next 13 months as part of our bereavement program. Please call us anytime you need us: **(833) 467-5468**



## ***Additional Helpful Information:***

### **For the Care Giver**

It is important to realize that although disease and its symptoms happen to the patient, illness has an effect on the entire family. Caring for the hospice patient at home can be rewarding; however, it is physically and emotionally draining for both the caregiver and the family.

During the illness, the patient at times may act angry or strange towards the caregivers. This can cause hurt feelings or anger on your part. In most cases, the patient's lashing out actually means, "Why did this have to happen to me?" This behavior is most often directed towards the persons the patient knows will continue to love and care for them in spite of these bad moods. Try to realize that this anger is a result of frustration. If the patient does act angry or hostile, try to discuss your feelings with them. Be aware, however, that the patient may not realize that they are acting differently. You can share your fears and frustrations with members of the hospice team. They are there to help the entire family cope with this difficult time.

The physical demands of care for the hospice patient are often tireless. It is important that you, the caregiver, take time for yourself, as well as to take care of yourself. You'll need moments of rest and relief if you are to keep physically and emotionally able to help the patient. Plan time for yourself to get out of the house. Other family members or friends can help, and sometimes they are just waiting to be asked.

Try to get at least six hours of sleep each night, and take naps while the patient is sleeping during the day. If you find that you are becoming exhausted, let your primary nurse know. The nurse may be able to suggest an easier plan to meet the patient's needs. Using community help, or perhaps the services of a home health aide, are other alternatives. Try to remember that you are only one person and cannot do everything. Time spent on your regular responsibilities, such as household chores, yard work, and shopping should be lessened or may have to be taken on by others.

### **Other Family Members:**

Each member of the family is unique and will deal with the patient and their needs in their own way. Although facing illness and death as a family makes it easier, not all families can be open and share their feelings. Sometimes sources outside the family (your nurse, social worker, minister, priest, rabbi or counselor) can help with the situation. They can help to bring family members together to talk, listen, and help one another.

### **Children:**

Have some special needs in dealing with illness and the impending death of someone they love. Depending upon their age and stage of development, death may have different meanings to them. It is important to answer their questions honestly and in a way they can understand. Having the children spend time with the patient as well as letting them help with the care of the patient is a good idea. This involvement will usually go along way to lessen their fears. Children will need extra comfort, affection, and structure during this time since their normal routine has been upset.

### **Spiritual Care:**

For some hospice patients and their families, a religion, a church community, and their own personal relationship with God can be a strong source of strength during a difficult and searching time. You may want your local clergy or a pastoral counselor or minister from the hospice team to become more involved with your family at this time. Your primary nurse can help you to contact a clergy person if you desire one. The nurse can help to explain the patient's situation to the clergy person before their first visit to your home. Although some families find meaning and comfort in their faith, others may not find religion to be a source of help. Neither approach is better than the other. Each person's needs and beliefs are different and will be respected by the hospice team.

### **Volunteers:**

Volunteers are part of the team to provide additional support to the patient and family. These volunteers are specially trained to work with dying patients and their families. They can offer you, the primary caregiver, a chance to get out of the house without having to worry about the patient. A volunteer may also provide companionship, and an open ear to listen to your fears and frustrations.

### **Social Worker:**

Most hospice programs have a social worker available to the patient and family. The social worker provides support and counseling to the patient and family as they attempt to deal with changes in their roles and relationships. Support may include help identifying community resources and providing advice concerning financial problems that occur with a prolonged illness. In addition, the social worker acts as a patient and family advocate in a variety of other ways, such as assistance in planning funeral arrangements.

### **Friends:**

It is important to realize that some of your friends, as well as friends of the patient, will be able to provide support and assistance. Others will be unable to cope and seem to disappear out of your lives during this time. Those friends who want to help may need some direction from you. When they offer to help, make a simple request such as going to the store or fixing a meal. Sitting with the patient and sharing common fond memories can also be enjoyable and good for all.

### **HYGIENE**

It is a good idea to provide the bed-bound patient with a bath each day. Often the hospice will send an aide to bathe the patient.

This activity provides cleanliness and comfort and helps to refresh the patient in both body and spirit. A bath is usually given in the morning when they may have more energy to help; however, anytime during the day, as the patient prefers, is the best time.

### **Things you will need if you are caring for the hospice patient:**

- large bowl and warm water
- soap and towels
- light bed cover to prevent chills
- skin protectant lotion, cream or ointment

### **How To:**

To avoid chilling the patient, only a small area should be bathed at a time. Gently soap the skin, then rinse and dry. Begin washing at the patient's face and then work down towards their feet. Don't forget to wash the back and apply lotion. After washing the feet, the water will need to be changed before doing the buttocks area. Daily washing of the genital area is especially important since bacteria tend to collect there. Wash between the patient's legs from the front toward the back. Rinse well and dry gently with a towel. A skin protecting lotion or ointment should be applied to this area if control of stool or urine is a problem. After care of the genital area is completed, ask the patient to turn on their side so that the waterproof under pads and lift sheet can be changed. These should be changed daily or more often if they become dirty or soiled. If possible, bed sheets should be changed once a week. This task usually requires two people. Flat bottom sheets are recommended, since they are easier to secure under the mattress.

### **Things to remember about body cleansing**

- If movement causes pain, give the patient pain medication about one hour before their bath.
- Ask the patient if you are rubbing too hard or too lightly; everyone has a different sense of touch.
- Provide privacy for the patient during the bath (close the door and drapes, reduce interruptions).
- If the patient is in a hospital bed, raise the level of the bed to lessen the strain on your back.
- Keep the patient's body covered with a light blanket or sheet during the bath to avoid chilling.

- If the patient feels unable to tolerate a complete bath, try to wash the face, hands, back, underarms and genitals daily.
- Do not use powders, except under the arms; powder tends to cake in body creases. Instead, cornstarch can be sprinkled lightly between the patient and the linens.
- Brushing and styling the hair, as well as shaving can also be done around bath time. For some patients, attention to usual personal habits will help lighten their spirits.

### **Mouth Care**

Cleansing the mouth provides several benefits for the hospice patient. Regular care helps to prevent sores and may improve the patient's appetite and desire to eat.

#### **Things You'll Need:**

- soft toothbrush and toothpaste
- cool water
- small bowl
- mouthwash
- dry cloth
- Vaseline®

#### **How To:**

The patient may be able to do this unaided and, if so, will probably prefer to be independent. If the patient needs assistance, raise the head and trunk to a half-sitting position to prevent choking and put a dry cloth under the patient's chin. Give the patient a sip of water to moisten the inside of the mouth. Brush the teeth and gums gently with toothpaste, trying to thoroughly remove all food particles and crusted materials.

The patient can then spit into the bowl and rinse with cool water, followed by a mouthwash rinse. Try to clean the patient's mouth twice daily. Denture patients should continue to follow their usual mouth care routine during illness. After eating, remove and clean the dentures. Gently clean the patient's mouth with a soft toothbrush or cloth. Have the patient rinse with cool water, followed by a mouthwash rinse. As the patient loses weight, they may find their dentures no longer fit properly.

This may be caused by a change in the shape of the jaw. A poor denture fit may result in mouth sores. If refitting by a dentist is not possible, the dentures should be left out. Continue to provide mouth care twice daily. After completing mouth care, apply a moisturizer such as Vaseline® to the lips and both corners of the mouth to prevent cracking. Reapply the moisturizer throughout the day as needed.

#### **Things to Remember about Mouth Care:**

- Don't put the toothbrush too near the back of the patient's throat or the patient will gag.
- Do not give the patient mouth care as explained here if they are lying flat or are unable to swallow. The patient may choke on the liquid.
- If the patient cannot swish and remove liquid from the mouth, your primary nurse can give you special instructions for mouth care.
- If mouth soreness develops, tell your primary nurse. She will ask your doctor for medicine to treat the sores.

#### **EXERCISES:**

If moving does not cause pain, then the patient's arms and legs can be exercised during or after their bath. Please check with your primary nurse before exercising the patient's arms or legs.

### **SKIN CARE**

It is important to try and keep the skin in good condition. Unfortunately, this is one of the most difficult problems in caring for bed-bound patients. Pressure sores (also called bedsores) often occur on patients who

are confined to bed for a long time and don't change position in bed often enough. Bedsores occur over bony areas of the body.

**Sometimes pressure sores can be prevented if the following steps are taken:**

- Explain to the patient the importance of turning frequently.
- Provide pain medication as needed so that movement is easier.
- Use pillows to support the patient in a side-lying position.
- Keep the skin clean and dry.
- Keep the bed linens dry and wrinkle free.
- Very gentle massage around the reddened pressure areas is a good idea.
- Apply lotion around areas of pressure once or twice each day.

It is a good idea to check the patient's skin for reddened areas each day during the bath. If you see redness over pressure areas tell your nurse, and the nurse will check them during the next visit. Your primary nurse may suggest the use of devices such as air, water, or egg-crate mattresses to help reduce pressure. In addition, sheepskins, heel and elbow protectors can be used to reduce friction as the patient moves about on the bed linens. Even with the best care, skin breakdown may occur. Your primary nurse and doctor will suggest ways to treat these pressure sores and promote skin healing.

### **EATING:**

Eating is one of life's greatest pleasures. For many of us, food is associated with positive happy times, holidays, and parties. Gathering at the table to eat is one way we share our love and share our family traditions. When you have trouble chewing and swallowing, the act of eating can be scary and difficult.

Not being able to eat what everyone else is eating may make one feel uncomfortable. Family members tend to feel guilty that they are eating regular foods while their Mother or Father is eating pureed solids. Some family members resort to 'take out' or frozen meals to reduce the pleasing aroma of a tenderloin being grilled or a turkey roasting. Not being able to share family dinners may result in isolation.

If you are cooking for someone with a chewing or swallowing problem (dysphagia), there are many foods they can enjoy with a few modifications.

### **Types of Diets:**

**Regular:** (may be able to stay on regular until the end if there are no chewing or swallowing issues) **Soft:** A soft diet contains foods that are soft and easy to chew or swallow. Individuals with dental problems or extreme weakness often need a soft diet. The soft diet may sometimes relieve mild intestinal or stomach discomfort, and is especially helpful to those with digestive problems and sore mouths and throats. Soft diets include baked potatoes, cereals softened in milk, macaroni and cheese, mashed potatoes, cooked vegetables, scrambled eggs, yogurt, applesauce, ice cream, pudding and milkshakes. Fried foods, dried beans, nuts and seeds, raw fruit and vegetables and hard breads should be avoided.

**Full Liquid:** A full liquid diet is made up of foods that are liquid at room temperature, including fluids, ice cream, sherbet, creamy soups, tea, juice, milkshakes, pudding and popsicles. People on a full liquid diet cannot eat solid foods. A full liquid diet still provides proteins, fluids, salts and minerals needed for energy.

**Clear Liquid:** A clear liquid diet consists of clear liquids, such as water, broth, fruit juices without pulp, clear sodas, honey and plain gelatin, which are easily digested and leave no undigested residue in the intestinal tract. This diet may be prescribed before medical procedures or in people with digestive problems. Clear liquids help maintain hydration, electrolytes and provide some energy when a full diet is not possible.

**Finger Foods:** A finger food diet may be used for people who have trouble using silverware but wish to feed themselves and continue to eat the foods they love. Finger foods include chicken nuggets, sausage rolls, cheese sticks, chicken drumsticks or wings, sandwiches, pizza, hot dogs, fruit and bread.

Thickened Liquids: People who have difficulty chewing or swallowing may use a thickened liquid diet. Thickened liquids may be one of four levels of liquid thickness: thin, nectar thick, honey thick or spoon thick. Thin liquids include water, soda, juice and broth. Nectar thick liquids include fruit nectar, maple syrup, eggnog, Ensure, tomato juice and cream soups. Honey thick liquids include honey and liquids thickened to a honey consistency. A spoon thick liquid is a pudding. Some liquids are naturally thickened to the appropriate consistency; others may need a thickening agent.

People on a thickened liquid diet should eat in an upright position and remain in that position for at least thirty minutes for proper digestion.

### **How to Help**

- Do not force the patient to eat or constantly remind them of their decreased appetite. Although an encouraging, gentle approach may help, the choice to eat is the patient's.
- Serve the meal in a relatively comfortable, bright atmosphere. When feasible, eat in the room with the patient. Remove unpleasant odors and do not do unpleasant procedures around mealtime.
- Have the patient take a vitamin tablet each day to help meet their vitamin needs.
- Give mouth care prior to meals to freshen the mouth and stimulate taste buds.
- Appetite tends to decrease as the day goes on; make the most of breakfast time.
- Give pain medicines on a schedule to reduce discomfort before and during meals. For example, give pain medicine one-half hour prior to mealtime.
- Allow the patient to rest after meals, but keep the head of the bed elevated to promote digestion.
- Adjustments to the diet may have to be made if the patient can no longer wear their dentures. Soft foods or small bite-sized portions of meat, softened with gravy are recommended.
- If nausea is a problem, your primary nurse can talk to the doctor about ordering a medication to be given before meals to reduce nausea.
- Add small pieces of cooked meat to canned soup or casseroles to improve nutrient value in foods.
- Try new spices and flavorings for foods. It is common for a person's preferences to change during illness. Add sauces and gravies to dry food.
- Try small frequent meals and leave a high protein snack or drink at the patient's bedside. Your primary nurse can give you information and recipes for high protein supplements.

### **Liquids:**

Liquids are also important for the body. They're necessary to keep skin and mucous membranes moist and to promote the removal of the body's waste products in the urine.

### **Puree Secrets:**

A powerful mini food processor is an invaluable tool. Blenders and full size food processors don't work well because they are too big to efficiently puree one portion size. Broths, condiments, gravies, sauces, sour cream, vegetable juice, fruit juice, milk, and half and half are good to have on hand. Be careful how water is used. It can make solids less flavorful and deplete nutrients. Add small amounts of fluid initially. Use vegetable cooking water to restore vitamins when pureeing meats and vegetables. Potato flakes and rice cereal can help to thicken pureed foods that have been thinned too much. Dry milk powder added to food will increase calories and protein to a diet. Remember to include seasonings, butter, honey, syrup, sugar, salt and pepper to enhance foods. Quantities of favorite items can be prepared ahead and frozen in portion sizes. Sugar added to hot cereals (cream of rice/wheat, farina) tends to thin out the cereal.

**Fruit, Canned or Fresh:** Cut in chunks unless very ripe and soft. Remove peels, skin and seeds. If canned, drain the liquid but do not toss out. Excess liquid may be used to thin or used in juices. Blend until smooth. If too thick or not smooth enough, add juice. For some fruit, such as watermelon, you may need to use an instant food/liquid thickener.

**Starches:** Cut into chunks, add milk, broth or water and blend until smooth. French fries, cookies, cakes, oatmeal and potatoes can be pureed. Instant mashed potatoes are a time saver. If too thick or not smooth enough, add more liquid. Pasta needs to be overcooked. "Al dente" does not puree well.

- **Meats:** Be sure to cook meats well. Slow cookers tend to make pureeing easier. Lunch meat is great for pureeing. Trim fat and remove skin, especially with hot dogs and sausage. Cut into small pieces. Add milk, water or gravy. Blend until smooth. If too thick or not smooth enough, add more liquid.
- **Seafood:** Tilapia and flounder (white fish) are great for pureeing. Remove bones. Add broth, lemon juice, etc. and blend until smooth.
- **Salad:** Place a portion of only soft leafy greens in mini food processor with 2 tablespoons of broth or milk and puree until smooth. Add 1 tablespoon smooth salad dressing and half scoop of instant food thickener. It should look like a smooth soufflé. Avoid dressing with chunky ingredients.
- **Rolls:** Use only soft dinner rolls. No seeds or whole grains! Make into a slurry texture with 1/4 cup of chicken broth and half scoop of instant food thickener and mix until it thickens. Pull apart the roll and cover with the slurry. Set aside for about 10 minutes, until the roll has absorbed the slurry. Reheat as needed.
- **Pumpkin or Lemon Meringue Pies:** Use filling only. No crust.
- **Fruit pies** (apple, peach, etc): Puree the filling and no crust.

## TUBE FEEDING

### Things to Remember about Tube feedings

- Give the feedings at room temperature.
- Flush the tube before and after each feeding as directed.
- Change the tape and clean the skin around the tube each day. Your nurse will teach you how to change the dressing.
- Do not force food or medicine through the tube. If you meet resistance, attempt to flush the tube with water. Let your primary nurse know if you are unable to flush the tube.
- Before giving each feeding, you must check to see that the tube is still in the stomach.
- During feeding, as well as one hour after, the patient should stay in the sitting position.
- If the tube comes out, don't panic. Call your primary nurse and she will replace it.
- A patient receiving tube feedings should continue to receive mouth care.

As the patient's condition worsens, they will be taking in less food and liquids. This is usually more upsetting to the family than the patient who is no longer willing or able to continue to eat and drink. Trying to force a patient to eat will only cause conflict. It is a natural part of dying to begin to lose the desire to eat. Often a withdrawal from eating brings new awareness to the family of the patient's worsening condition and impending death. It is important for you to discuss your feelings about this with members of the hospice team, so you can continue to be supportive of the patient's right to choose, rather than acting angry or disappointed.

## SHORTNESS OF BREATH

For a patient who is very ill, the process of getting air in and out of the lungs can be difficult at times. Breathing difficulties are often referred to as "shortness of breath" or "air hunger." These difficulties can create a decreased oxygen level in the body. Signs of low oxygen may include a restless or anxious feeling, as well as a faster breathing rate. If these symptoms occur, there are some things you can do to help the patient breathe easier.

### Things You Can do to Help

- Be calm and reassuring.
- Raise the head of the bed or place more pillows behind the back and head.
- Have the patient sit up and lean forward. This position will help the lungs fill more easily.

## Oxygen Therapy

Your primary nurse will check the patient's breathing during each visit. Tell your nurse if you or the patient have noticed any breathing problems. If breathing problems exist, the nurse will discuss the possible need for oxygen. If oxygen therapy is needed, the doctor will decide how much the patient will need. The nurse will contact a medical supply company. The company will set up the oxygen therapy equipment and explain to you how to use it.

Two common ways of giving oxygen therapy are by face mask or nose cannula. Both of these devices increase the amount of oxygen available for the patient to breathe.

### **Things to Remember about Oxygen Therapy**

- Remove and clean the mask as needed.
- Do not smoke or light matches in a room where there is oxygen in use.
- Do not use oxygen around a gas stove.
- Place small cotton pads between the tubing and the skin to lessen irritation.
- The face mask must fit snugly on the patient's face.
- The prongs of the nasal cannula must be in the patient's nose.
- Watch your supply of oxygen; make sure you have a 24-hour supply, especially on the weekends.
- Carefully follow the instructions given by the supplier to ensure that the equipment will work properly.

### **Respiratory Congestion**

Respiratory congestion is identified by noisy, moist breathing. As patients become weaker, there is often a decreased cough reflex and secretions may collect in the airway.

It can be very distressing for the patient and family, since it may appear that the individual is drowning or suffocating from his or her own secretions. Although this symptom most commonly occurs when a patient has a decreased level of consciousness, if the person is alert, the respiratory secretions can cause the patient to feel extremely agitated and fearful of suffocating.

### **Things You Can do to Help**

Notify the hospice/palliative care team to ensure appropriate medications are ordered. Your primary nurse will assess the patient to determine potentially treatable underlying causes, including infection or inflammation. If physical findings suggest congestive heart failure, for example, the hospice team may start diuretic therapy for fluid overload; if pneumonia is present, antibiotic therapy will be initiated. If the onset is sudden and associated with acute shortness of breath and chest pain, it might suggest a pulmonary embolism or myocardial infarction.

### **How to Manage**

- Simple repositioning of the patient may help him or her to clear the secretions.
- If secretions can be easily reached in the mouth or throat, suctioning may be appropriate. Deep suctioning should be avoided since it can be very uncomfortable for the patient and cause significant agitation and distress.
- Pharmacological interventions or management are effective and may prevent the need for suctioning. If possible, primary treatment should be focused on the underlying disorder and/or appropriate to prognosis and the wishes of the patient and family.

### **Pain Free:**

The fear and reality of pain are often major problems for the hospice patient. Most experts on pain encourage us all to trust the patient and believe that the pain is something that the person experiencing it knows the most about. Therefore, the patient can best tell the doctor and nurse how effective the different ways of relieving pain have been. Your primary nurse will take the information that the patient (and you) are able to report about the pain experience, and use that information to work with you and your doctor to develop a pain management plan suited for the patient's needs.

During one of the first visits, your primary nurse will ask the patient some questions about their pain. It is important to encourage the patient to be honest about how bad and how often they feel pain. Many people report less pain than they are having. There are many reasons why this happens. Many people fear that an increase in pain means the disease is worsening, or that feeling pain and illness go hand-in-hand and must be tolerated. In addition, some religious beliefs hold that pain is either a punishment for past sins or a method of achieving salvation in the life beyond. Some cultures encourage people to be silent about their pain. Finally, fear of addiction to medications or fear that the use of strong pain medicine now will prevent good relief in the future if the pain worsens, may be reasons for reporting less pain. These reasons should be openly discussed, as they are often strong influences on the patient's ability to share and evaluate their pain.

It is important to remember that patients who have long-term pain will not act the same about their pain as someone who has new pain. The person with long-term pain may not show many of the signs we are used to seeing in people with pain. For example, they may not speak or moan about the pain, or may not be restless. Heart rate and breathing may not increase as expected. Just because the patient doesn't act like they are in pain doesn't mean the patient is not having pain. For these reasons it is important that you and the patient speak very openly and honestly with your nurse and doctor about the patient's pain. The doctor and nurse can only effectively work with you and the patient to control or lessen the pain if you are open with them.

### **What causes pain**

Pain appears to have a physical cause, meaning that some part of the disease is causing pain messages to be sent to the brain where pain is realized. It is important to try and discover the cause of the pain, but this is not always possible. This does not mean, however, that the pain is not real.

### **Types of pain medicine**

There are many different kinds of pain medicine. Pain medicines are most commonly available as pills, liquids, transdermal patches, rectal suppositories, and injections. The amount and type of pain medicine the patient should take will be decided by the doctor after talking with the patient and the primary nurse. It is important that the patient tell the doctor about the relief received or not received from the pain medicine. Your primary nurse may ask you and the patient to keep a written pain record between visits. This record will help in making necessary adjustments in the pain management plan. Questions regarding pain medicine should be discussed with the doctor or primary nurse.

There are other ways to help lessen the patient's pain. These may be used along with the pain medications. Some methods include distraction, massage, relaxation exercises, and the application of heat or cold near the painful area. Everyone expresses pain differently. Although some patients may talk freely about their pain, others may feel uncomfortable discussing the issue. If you suspect the patient is suffering, it is important to ask about pain. A good way of asking is to say: "How would you rate your pain level right now on a scale from 0 to 10, with 0 being no pain and 10 being the worst pain you ever had?"

### **Other questions might include:**

- Is it a new pain or has it happened before?
- Where is it located? Is it in more than one area? If so, which location is most bothersome?
- Is the pain sharp and stabbing or dull and aching?
- If the patient is taking pain medicine on schedule, were there times during the day that the patient experienced "breakthrough" pain? How many times did this happen today?
- Did the patient sleep through the night without pain?

In assessing the patient's condition, it may also help to look for behavior or body language that could be a response to pain, because the patient may be unwilling or unable to communicate about pain in words.

Behaviors to look for include: eyes that are closed tightly, knitted eyebrows, crinkled forehead (grimacing), clenched fists, groaning when moved or a stiffened upper or lower body that is held rigidly and moved slowly. Other signs may include rubbing certain parts of the body, slouched or bent posture, and avoiding sitting or standing.



## **Things to Remember**

The doctor and primary nurse need to know if the patient's pain has increased or become different in any way so that they can ensure the patient receives the correct medicine and remains as comfortable as possible. The following symptoms should be reported to the patient's primary nurse or doctor so that they can address how to best treat the pain if it has changed in any way:

- No relief after taking pain medicine as prescribed
- Some pain relief, but there is still a lot of pain 1 or 2 days after starting the medicine
- A new type of pain, pain in new locations, or new pain when moving or sitting
- Adverse side effects of pain medicines
- Changes in sleep
- Difficulty coping with pain - for example, if the patient becomes anxious, depressed, or irritable

The doctor will determine the proper amount of medicine for the patient. Questions regarding pain medicine should always be discussed with the doctor or primary nurse.

The elimination of urine and stool is the body's mechanism for removing waste products. Problems with elimination can cause the patient a great deal of anxiety, embarrassment, and discomfort. This is often a source of worry for the hospice patient.

## **URINE ELIMINATION**

Urine is a liquid composed primarily of the body's waste products dissolved in water. For this reason, it is important for the patient to attempt to drink a substantial amount of fluid in order to maintain a good urine flow. For the bed-bound patient, a bedpan (women) or aurinal (men) will be needed to collect the urine.

For some patients, the ability to control urination is lost. In other patients, the passage way for urine is blocked. If either of these conditions is present, it may be necessary for the nurse to place a catheter (tube) into the patient's bladder to drain the urine. This should only be done under the direction of your doctor following a discussion about the procedure with the patient. If it is decided that a catheter is needed, your nurse will put it in place and teach you how the system works and how to take care of it.

For some patients, diapers or external catheters (male patients only) may be used. Usually these are not good long-term solutions for urine elimination problems. You and the patient should discuss these options with your primary nurse and decide which method is the best choice for the patient.

### **Things to Remember about Urine Drainage Systems:**

- Always wash your hands before and after working with the catheter or drainage bag.
- Check the drainage tubing for any kinks, and make sure the drainage bag is below the level of the patient to encourage draining by gravity.
- Check for any leaking around where the catheter enters the body. If you see leakage around the catheter, let your primary nurse know.
- The drainage bag should be emptied one or more times per day.

## **BOWEL ELIMINATION**

Bowel habits differ from person to person. Some people move their bowels once a day, while others may only move theirs 2-3 times a week. In the hospice patient, many things may cause a less frequent bowel movement and difficulty passing stools, leading to constipation. The best treatment for constipation is prevention. A plan for prevention includes:

- Try to maintain well-balanced meals.
- Set aside a time each day (usually after breakfast) that the patient sits for a period of time on the bedpan, commode, or toilet.
- Maintain fluid consumption to two quarts a day (unless otherwise instructed by your doctor).

- Try to consume plenty of nectars, juices, and Jell-O. If prevention efforts don't work, and the patient has not had a bowel movement for 1-2 days, tell your primary nurse. Your nurse will want to know what has worked for the patient's constipation in the past, and may suggest nonprescription laxatives, which are available over the counter.

**Diarrhea** can also be a problem for the hospice patient. It is characterized by frequent watery stools and is often accompanied by stomach cramping. If the patient has diarrhea, you should keep a record of the frequency of stools. Your primary nurse will try to find the cause for this diarrhea and will talk with the doctor about a medicine to treat it. Some medicines can be obtained without a prescription, while others will require a prescription.

#### **Things to Remember When a Patient Has Diarrhea**

- Keep the bedpan close to the patient to avoid accidents.
- Place a waterproof bed pad under the patient. If stool leakage should occur, the pad may help to prevent additional changes of the entire bed.
- After each loose stool, the rectal area should be washed with mild soap and water and a skin protection lotion should be applied.
- Encourage the patient to increase liquids if diarrhea occurs.
- The patient can drink juices or liquid diluted Jell-O for both fluid intake and to provide some sugar for energy.
- If the patient is too weak and can't get to the bathroom, then it will be necessary for the patient to use either a commode (a chair with a bedpan inserted in the open center) or a bedpan.

#### **Things to Remember about Using Commodes and Bedpans:**

- Warm a metal bedpan by running warm water over it prior to use.
- Put a towel on the back side of the bedpan for padding.
- Sprinkle baby powder or cornstarch around the top of the bedpan so that the patient's skin will not stick to it.
- Keep the commode near the bed and help the patient to get on and off of it.
- If the patient is bed-bound, it is important to try and put them in a sitting position for elimination by raising the head of the bed.
- Remember to wash your hands after helping the patient with elimination and to wash the patient's hands as well.
- Give the patient time alone during elimination.

#### **PREPARING FOR DEATH**

Just as each person's life is unique, so is his or her death. Because of this, it is difficult to give hard facts about what the actual death of the patient will be like when it happens. Instead, some common concerns and approaches will be shared in this section. Although difficult, it is a good idea for some pre-death arrangements to be made by the patient and the family. This topic can be difficult to bring up, as it is another way of acknowledging the patient's approaching death. Your primary nurse and social worker can help open discussions on this topic.

The patient can provide for survivors and prevent legal problems for the family after his or her death by having a current well-prepared will. Your social worker can give you advice about whom to contact to draw up a will or to make changes in a current will.

Making funeral plans before the patient's death may seem morbid to you. However, it is a good idea to contact the funeral home you plan to use and discuss with them the patient's and your wishes for funeral arrangements. Although it is difficult to discuss this with the patient, involving him or her in planning for what could be a meaningful service can provide reassurance that you have acted according to the patient's wishes.

#### **THE PHYSICAL SIGNS OF DEATH**

Many caregivers wonder about the changes that occur in the patient just before death. They want to be prepared and take the right actions. Unlike the way death is portrayed in the movies, the patient usually slips into death similar to how they have fallen asleep each night of their lives. It is unusual for someone to convulse or hemorrhage just before they die, although this can happen.

There are some common signs seen in near-to-death patients. The skin becomes very cool, particularly in the arms and legs, and may feel clammy, damp or appear bluish. The number of times and how deeply the patient breathes will lessen until the patient stops breathing entirely. Breathing may become noisy due to mucous collecting in the throat. Decreased movement and loss of strength can be observed and sensation is gradually lost. Awareness will vary; the patient may or may not be conscious. Hallucinations may occur, or the patient may become restless or very anxious. Some or all of these changes may be seen in dying patients. Although watching their declining condition may be difficult for you, the patient is usually unconcerned about these changes.

Sometimes "active dying" occurs over a period of hours or days. Even when many of these signs are present, it is difficult to predict the amount of time before death will occur. Some patients will exhibit some of these changes and then for some unexplained reason their condition may begin to improve a little. Although the family is caring and loving towards the patient, these roller-coaster changes can be emotionally and physically exhausting for the caregiver.

Usually in the weeks and days prior to the death, your primary nurse will begin to visit more often and other members of the hospice team will increase their availability and support. As the patient's condition worsens and they begin to emotionally as well as physically withdraw from this world, caregivers can suffer from feelings of helplessness. Withdrawal is normal for the dying patient as he or she becomes less concerned about his or her surroundings. At this time, many of the tasks mentioned earlier in this booklet will no longer be appropriate. Alternative ways to keep the patient comfortable might include a sponge bath and moistening the lips with cool water. Holding the patient's hands can be very meaningful and comforting at this time. It is important to continue to talk to the patient and offer reassurance. Simply saying, "I'm here, I'll be with you" can offer the patient great support and comfort.

Tell visitors and other family members not to speak in front of the patient as if he or she isn't there, even if the patient appears to be sleeping. Nothing should be said that would distress the patient should the conversation be overheard.

When you feel that death is near, it is a good time to bring the family members together, since they may have some last thoughts or expressions of love to share with the dying person. You should also call your doctor and primary nurse to let them know that the patient's death is approaching. You will know that death has occurred when the patient stops breathing for several minutes and the heart is no longer beating.

## **AFTER DEATH CARE**

Soon after the patient dies, you should notify the funeral director so that he or she can come to your home and remove the patient's body. In some communities, the patient's body must be taken to the hospital so that a doctor can officially/legally pronounce them to be dead. Your primary nurse and doctor can give you information about the usual procedure in your area.

The final goal of hospice care is to help the family go on living after the patient's death. This means the members of the hospice team will continue to keep in touch with you and your family through visits and phone calls.

Often the period right after the patient's death is a time of regrouping and relief in the family. One should not feel guilty about the sense of relief. Later, more active grieving and sadness may occur and members of the hospice team are available to help you through this difficult time.

## Prescription Pain Relievers

### What Are The Different Kinds Of Prescription Pain Relievers?

For many years, the most widely used prescription pain relievers have been narcotics. Narcotics are drugs that relieve pain and cause drowsiness or sleep. In addition, they all have similar side effects. Historically, these drugs came from the opium poppy. They are also called opioids or opiates. Today, many narcotics are synthetic, that is, they are chemicals manufactured by drug companies. Frequently used opioid pain relievers include the following:

- Codeine
- Hydromorphone (Dilaudid)
- Levorphanol (Levo-Dromoran)
- Methadone (Dolophine)
- Morphine
- Oxycodone (in Percodan)
- Oxymorphone (Nurnorphan)

You can get these pain relievers only with a doctor's written prescription. They may be taken by mouth (orally or PO), by injection (intramuscularly or IM), through a vein (intravenously or IV), or by rectal suppository. There are also other methods of giving pain medicines for more continuous pain relief. Not all narcotics are available in each of these forms. Another group of prescription pain relievers is similar to ibuprofen (in large doses, ibuprofen requires a prescription). They are called nonsteroidal anti-inflammatory drugs (NSAIDs). Included in this group of pain relievers are Motrin, Naprosyn, Nalfon, and Trilisate. They are useful for moderate to severe pain. They may be especially helpful in treating the pain of bone metastasis. Because NSAIDs are not narcotics, their use does not result in drug tolerance or physical dependence. These drugs are used alone or with non-prescription pain relievers to treat moderate to severe pain. Some are more effective than others in relieving severe pain.

### How Do I Decide Which Pain Medications To Use?

This is not something you should decide alone. Discuss this with your doctor, nurse, or pharmacist before you use any drugs for pain. Medications that worked for you in the past or that helped a friend or relative may not be right for you at this time. Never take someone else's medicine! Only one doctor should prescribe your pain medicine. If a consulting doctor changes your medicine, be sure the two doctor's discuss your treatment. Otherwise, you may take too much or too little. Let your doctor or nurse know whether your pain medication gives you relief. Work together to find the medication or pain-relief program that is best for you. Remember, your need for pain medicine may change as your cancer treatment changes. It is important to record the name and amount of pain medicine you take. You can then give precise information to the doctor or nurse about its effect on your pain.

### Will I Become Addicted If I Use Narcotics For Pain Relief?

No. Narcotic addiction is defined as dependence on the regular use of narcotics to satisfy physical, emotional, and psychological needs rather than for medical reasons. Pain relief is a medical reason for taking narcotics. Therefore, if you take narcotics to relieve your pain, you are not an "addict", no matter how much or how often you take narcotic medicines. If you and your doctor decide that narcotics are a proper choice for your pain relief, use them as directed. Addiction is a very common fear of people who take narcotics for pain relief. Narcotic addiction is an emotionally charged subject. You may hear people use the term "addiction" very loosely without understanding exactly what it means- the compulsive use of habit forming drugs for their pleasurable effects. Drug addiction in cancer patients is rare. Generally, when narcotics are used under proper supervision the chance of addiction is very small. Most patients who take narcotics for pain relief can stop taking these drugs if their pain can be controlled by other means. It is important to remember that if narcotics are the only effective way to relieve pain, the patient's comfort is more important than any possibility of addiction. If you take narcotics for several weeks or more, be prepared for someone to express a concern about

addiction. Most people with prolonged pain who take narcotics have faced this problem. Remind yourself that other people's concerns about addiction are often due to lack of information. If you have concerns about addiction, share them with those who are caring for you. These fears should not prevent you from using narcotics to effectively relieve your pain.

### **What Is Drug Tolerance?**

When certain drugs are taken regularly for a length of time, the body doesn't respond to them as well as they once did, and the drugs at a fixed dose become less effective. Larger or more frequent doses must be taken to obtain the effect that was achieved with the original dose. People who take narcotics for pain control sometimes find that over time they will need to take larger doses. This may be due to either an increase in the pain or the development of drug tolerance. Increasing the dose of narcotics to relieve increasing pain or to overcome drug tolerance is not an addiction.

### **Can Taking Narcotics Be Dangerous?**

All medicines can be dangerous if not taken properly. The risk of improperly taking narcotics include overdose, drug interactions, and accidents resulting from drowsiness.

**Overdose:** Too large a dose of narcotic may cause breathing to slow down or stop (respiratory depression). Doses required for good pain relief are rarely, if ever, large enough to cause death. Doctors carefully adjust the dose of narcotic pain relievers so that pain is relieved with little effect on breathing. You may have heard of addicts dying from narcotic overdose. This usually is due to taking the narcotic with other drugs that interact with it, or to taking a much higher dose than would be necessary for pain relief, or to impurities in illegally obtained narcotics. The first sign of narcotic overdose is the feeling of unusual sleepiness or difficulty waking up. If you have either of these problems, someone should contact the doctor or nurse as soon as possible.

**Drug Interactions:** Combinations of narcotics, alcohol, and tranquilizers can be dangerous. If you drink alcohol or if you take tranquilizers, sleeping aids, antidepressants, antihistamines, or any other drugs that make you sleepy, tell your doctor how much and how often. Even small doses might cause problems. The use of alcohol or any of these drugs with narcotics can lead to overdose symptoms such as weakness, difficulty in breathing, confusion, anxiety, or more severe drowsiness or dizziness. These drug interactions may result in unconsciousness and death. Tell your doctor about any medicine or combination of medicines that makes you drowsy or sleepy.

**Accidents:** Narcotics often cause drowsiness or dizziness. If you are aware of this, you can be extra careful to avoid accidents. Sometime it might be unsafe for you to drive a car or even walk up and down stairs. Avoid operating equipment such as saws or drills, or performing activities that require alertness. Be aware of the effect narcotics have on you so that you can take necessary precautions.

### **How Much Narcotic Pain Reliever Is Safe For Me To Take?**

The amount of pain reliever you take you should be determined by your doctor. Analgesics affect different people in different ways. A very small dose may be effective for you, while someone else may need to take a much larger dose to obtain pain relief. You need to ask three questions:

- How much should I take? How often?
- If my pain is not relieved, can I take more?
- If the dose should be increased, by how much?
- Must I call the doctor before increasing the dose?
- What if I forget to take it or take it late?

Your doctor will try to prescribe the amount of narcotic that will be both safe for you and effective for your pain. Take the medicine as your doctor or nurse has prescribed but tell them at once if your pain is not controlled or if you have severe side effects such as extreme drowsiness or difficulty in breathing. If you do not

need as much narcotic as has been prescribed, your doctor or nurse will tell you how to reduce the dose or frequency.

### **What If The Medicine That Has Been Recommended Doesn't Relieve My Pain?**

Tell your doctor or nurse as soon as you can if you are not getting effective pain relief. Don't wait for your next appointment! They need to know:

- How much, if any, pain relief you get.
- How long the pain is relieved.
- Any side effects that occur or do not occur, especially drowsiness.
- How pain interferes with your normal activities such as sleep, work, eating, or sex.

With your doctor's help you can usually get good pain relief. When the medicine does not give you enough pain relief, the doctor may increase the dose or the frequency or prescribe a different drug. Some narcotics are stronger than others, and you may need a stronger one to control your pain. If your pain relief is not lasting long enough, ask your doctor about long acting forms of medicine. Morphine is now available in a tablet form that releases it over a long period of time (MS Contin or Roxanol SR). You may have developed drug tolerance if you have taken narcotics for a long time. As a result, doses that may have been too large for you a few weeks ago may be safe now.

The desired effect is pain relief with as few side effects as possible, regardless of the size of the dose. Some doctors are reluctant to prescribe large enough doses or stronger narcotics for pain control. However, with careful medical observation, the doses of strong narcotics (by mouth or injection) can be safely raised enough to ease severe pain. Do not increase the dose of your pain medicine on your own. Remember, you are the best judge of whether your pain is relieved. If you still have pain and your doctor does not seem to be aware of other alternatives, ask to see specialist in cancer pain management.

### **What Are The Side Effects Of Narcotics?**

Although not everyone has side effects from narcotics, some of the more common ones are drowsiness, constipation, and nausea and vomiting. Some people also might experience dizziness, mental effects (nightmares, confusion, hallucinations), a moderate decrease in rate and depth of breathing, or difficulty in urinating. You should always discuss side effects with your doctor or nurse. Side effects from narcotic pain relievers can usually be handled successfully.

### **What Can I Do About Drowsiness?**

At first, narcotics cause some drowsiness in most people, but this usually goes away after a few days. If the narcotic is giving you pain relief for the first time in a long time, your drowsiness might be the result of the decrease in pain, allowing you much needed rest. This kind of drowsiness will go away after you "catch up" on your sleep. Drowsiness will also lessen as your body gets used to the medicine. Call your doctor or nurse if you feel you are too drowsy for your normal activities after you have been taking the medicine for a week. If you are drowsy, be very careful to avoid situations in which you might hurt yourself as a result of not being alert such as cooking, climbing stairs, or driving. Here are some ways to handle drowsiness:

- Wait a few days and see if it disappears.
- Check to see if there are other reasons for the drowsiness. Are you taking other medicines that can also cause drowsiness.
- Ask the doctor if you can take a smaller dose more frequently.
- If the narcotic is not relieving the pain, the pain itself may be wearing you out. In this case, better pain relief may result in less drowsiness. Ask your doctor what you can do to get better pain relief.
- Sometimes a small decrease in the dose of a narcotic will still give you pain relief but no drowsiness. If drowsiness is severe, you may be taking more narcotic than you need. Ask your doctor about lowering the amount you are presently taking.

- Ask your doctor if you can take a mild stimulant such as caffeine, or your doctor can prescribe a stimulant such as dextroamphetamine (Dexedrine) or methylphenidate (Ritalin).
- If drowsiness is severe or if it suddenly occurs after you have been taking narcotics for a while, notify your doctor or nurse right away.

### **What Can I Do About Constipation?**

Narcotics can cause constipation in most people. The stool does not move along the intestinal tract as fast as usual and becomes hard because more water is absorbed. Your doctor will probably prescribe a stool softener and a laxative. After checking with your doctor or nurse, you can try the following:

- Eat foods high in fiber or roughage such as uncooked foods and vegetables and whole grain breads and cereals. Adding one or two tablespoons of unprocessed bran to your foods adds bulk and stimulates bowel movements. Keeping a shaker of bran handy at meal times makes it easy to sprinkle on foods. A dietician can suggest other ways to add fiber to your diet.
- Drink plenty of liquids. Eight to ten 8-ounce glasses of fluid each day will help keep your stool soft.
- Exercise as much as you are able.
- Eat foods that have helped relieve constipation in the past.
- Try to use the toilet or bedside commode when you have a bowel movement, even if that is the only time you get out of bed.
- Plan your bowel movements at the same time each day, if possible. Set aside time for sitting on the toilet or commode, preferably after a meal.
- Have a hot drink about half an hour before your planned time for a bowel movement.
- If you have difficulty eating bran or other foods high in fiber, check with your doctor, nurse, or pharmacist about using a bulk laxative such as Metamucil.

Be sure to check with your doctor or nurse before taking any laxative or stool softener on your own.

### **What Can I Do For Nausea And Vomiting?**

Nausea and vomiting caused by narcotics usually will disappear after a few days of taking the medicine. The following suggestions may be helpful:

- If your nausea occurs mainly when you are walking around (as opposed to being in bed), remain in bed for an hour or so after you take your medicine. This type of nausea is like motion sickness. Sometimes the doctor will tell you to use medicines (such as Bonine or Dramamine) that can be bought without a prescription to counteract this type of nausea. Do not take these medicines without checking with your doctor, nurse, or pharmacist.
- If pain itself is the cause of nausea, using narcotics to relieve the pain usually makes this nausea go away.
- Medicine (such as Compazine, or Torecan by mouth or by rectal suppositories) can sometimes be prescribed.
- Ask your doctor or nurse if some other medical condition or other medications you are taking such as steroids, anticancer drugs, or aspirin might be causing your nausea.

Some people mistakenly think they are allergic to narcotics if the narcotic causes nausea. Nausea and vomiting alone usually are not allergic responses. But nausea and vomiting accompanied by a rash or itching may be an allergic reaction. If this occurs, stop taking the drug and notify your doctor at once.

### **I've Heard That Some People Who Stop Taking Narcotics Have Withdrawal Effects. Is This True?**

You should not stop taking narcotic pain relievers suddenly. People who stop taking narcotic medicine usually are taken off the drug gradually so that any withdrawal symptoms will be mild or scarcely noticeable. If you stop taking narcotics suddenly and develop a flu-like illness, excessive perspiration, diarrhea, or any other unusual

reaction, tell your doctor or nurse. These symptoms can be treated and tend to disappear in a few days to a few weeks.

### **If My Pain Becomes Severe, Will I Need Shots For Pain Relief?**

Probably not. Intramuscular injections or "shots" are rarely used for relieving cancer pain. Narcotic rectal suppositories can be effective, and new methods of giving narcotic pain relievers have been developed. Long-acting morphine tablets are now available, and some narcotics provide quick pain relief when they are given under the tongue (sublingually). One narcotic drug, fentanyl, is now available as a skin patch which continuously releases the medicine through the skin for 48 to 72 hours. If you and your doctor have not been able to find a way to get good pain control with medicine you take by mouth, some kinds of pain medicine can be given intravenously. You may want to ask about patient controlled analgesia. With this method a portable computerized pump containing the medicine is attached to a needle that is placed in a vein. Whenever pain relief is needed, the patient presses a button on the pump that delivers a preset dose of pain medicine into the vein. A new simple, safe, and effective method of pain control is called continuous subcutaneous infusion. A small electric pump dispenses that drug automatically through a small needle placed under the skin. Another way of treating cancer pain is to inject pain medicine into the spinal cord (intrathecal) or into the space around the spinal cord (epidural). Your doctor or a pain specialist can give you more information about these advances in pain treatment.

### **Is It True That Severe Pain Can Only Be Relieved By Heroin?**

No. That is not true. Some newspaper and magazine articles have suggested that heroin is the only way to relieve severe pain, but the reported success with heroin was due more to how the drug was given (in a preventive way) than to the effects of the drug itself. Strong narcotics such as morphine and Dilaudid usually can relieve very severe pain. In fact the body converts heroin into morphine. Heroin is available in England and has been used there to treat pain in cancer patients. However, even in England, morphine is now being used routinely because it has been shown to be just as effective as heroin. In the United States, heroin is not legally available.

### **What Other Prescription Medicines Are Used To Relieve Cancer Pain?**

Several different classes of drugs can be used along with (or instead of) narcotics to relieve cancer pain. They may have their own pain relieving action or they may increase the pain relieving activity of narcotics. Others lessen the side effects of narcotic pain relievers. The following classes of non-narcotic drugs might be prescribed by your doctor to help you get the best pain relief:

- Antidepressants such as Elavil, Tofranil, or Sinequan are used to treat the pain that results from surgery, radiation therapy, or chemotherapy.
- Antihistamines such as Vistaril or Atarax relieve pain, help control nausea, and help patients sleep.
- Antianxiety drugs such as Xanax or Ativan may be used to treat muscle spasms that often go along with severe pain. In addition they are helpful for treating the anxiety that some cancer patients feel.
- Dextroamphetamine (Dexadrine) increases the pain relieving action of narcotic pain relievers and also reduces the drowsiness they cause.
- Anticonvulsants such as Tegretol or Klonopin are helpful for pain from nerve injury caused by the cancer or cancer therapy.
- Steroids such as prednisone or Decadron are useful for some kinds of both chronic and acute cancer pain.
- NSAIDs such as Motrin decrease inflammation and lessen post-surgical pain and the pain from bone metastases.

Dealing with Pain, sponsored by the Connecticut Division, Inc., of the American Cancer Society and the Yale Comprehensive Cancer Center, New Haven, Connecticut, was the basis of the first edition of Questions and Answers about Pain Control: A Guide for People with Cancer and Their Families. Since that time, new advances in pain control have taken place. This guide reflects many of those advances. We wish to thank the many



reviewers, people who work with cancer patients daily, for their helpful comments and their assistance in revising Questions and Answers about Pain Control.

## **RESPONSIBILITIES OF PATIENT/CAREGIVER DURING A DISASTER/ EMERGENCY:**

Provide agency with requests for assistance with 211 registration if needed.

Notify agency of any immediate or anticipated problems if able.

Have an evacuation plan, notify agency if evacuating and give location.

- Know where the shelter is located that can meet your special needs
- Plan for alternate locations
- Plan for transportation to a shelter or other location.
- "Have an emergency kit or emergency supplies prepared ("grab bag")
- Arrange for assistance if you are unable to evacuate by yourself

### **Prepare for Shelter-in-Place**

- Maintain a supply of non-perishable foods for seven days
- Maintain a supply of bottled water; one gallon per person
- Be prepared to close, lock and board/seal windows and doors if necessary
- Have an emergency supply kit prepared

### **Pets**

- Have a care plan for your pet
- Locate a shelter for your pet (hotel, local animal shelter etc.) Emergency shelters will not accept animals.
- Keep extra food and/or medications, leashes, carriers, bowls, ID tags and immunizations records, etc.

### **Special Needs Considerations**

#### **Speech or communication Issues**

- If you use a laptop computer for communication, consider getting a power converter that plugs into the cigarette lighter

#### **Hearing Issues**

- Have a pre-printed copy of key phrase messages handy, such as "I use American Sign Language (ASL)," "I do not write or read English well, "If you make announcements, I will need to have them written simply or signed"
- Consider getting a weather radio, with a visual display that warns of weather emergencies

#### **Vision Issues**

- Mark your disaster supplies with fluorescent tape, large print, or Braille
- Have high-powered flashlights with wide beams and extra batteries

#### **Assistive Device Users**

- Label equipment with simple operation/instruction cards and attach to equipment
- Keep a Spare cane in emergency kit.

## **RESPONSIBILITIES OF JOURNEYS HOSPICE OF TEXAS DURING A DISASTER/EMERGENCY:**

Educate patient and provide materials (resources and tips) to assist patients prepare for emergencies.

Inform patients of local/state evacuation plan if applicable.

Instruct patients on the agencies Emergency Preparedness plan.

Keep list of vendors who supply each patient's medical supplies in the patient's chart.

Contact family or friends that the patient may request and make arrangements for patient's transportation if needed.

Make arrangements to be made through the county emergency planners for transportation to an alternate care facility, hospital/emergency room/ triage site depending on needs if appropriate.

Maintain a list of special needs to be reported to county emergency planners if needed.

Inform patients of the potential for care to be deferred in an emergency.

Assist patients with assistance for **211 registration** if requested.

**YOUR EMERGENCY PREPAREDNESS TRIAGE CODE IS: \_\_\_\_\_**

**CLASS 1:** Life threatening (or potential) requiring ongoing medical treatment to prevent a life threatening episode. Patient is unable to withstand any interruption in power supply. Patient is unable to evacuate/transport self. No readily available caregiver or caregiver is unable to provide needed care. Appropriate arrangements to transfer to an acute care facility will be made by the agency in collaboration with the local county or city authorities (fire department, police, and sheriff), the Patient/family and the physician.

**CLASS 2:** Not immediately life threatening but Patient may suffer adverse effect without service (i.e. new insulin-dependent diabetic unable to self-inject insulin, IV medications, or sterile wound care with large amounts of drainage). Visits may be postponed 24-48 hours with minimal adverse effect. Patient is unable to transfer/transport self or no transportation available from caregiver. Appropriate arrangements may be made if necessary, to send Patient to a facility that can meet their needs. This will be done in collaboration with the Patient/family, physician, and local or city authorities.

**CLASS 3:** Services may be postponed 48-72 hours without adverse effect on the Patient (i.e. new insulin-dependent diabetic able to self-inject, cardiovascular and/or respiratory assessments, or sterile wound care to a wound with minimal to no drainage). Transportation is available from family, friends, volunteers or caregiver.

**CLASS 4:** Services may be postponed 48-72 hours without adverse effect on the Patient (i.e. new insulin-dependent diabetic able to self inject, cardiovascular and/or respiratory assessments, or sterile wound care to a wound with minimal to no drainage). Transportation is available from family, friends, volunteers or caregiver.

## SAFETY/FALL PREVENTION PATIENT SELF QUESTIONNAIRE

1. Do I have throw rugs that are not adhered to the floor?  YES  NO
2. Does my walkway have obstacles that may trip me?  YES  NO
3. Am I dizzy when I first stand or turn/change position?  YES  NO
4. Am I unsteady when I walk?  YES  NO
5. Do I have a walker or cane? If so, do I use it consistently?  YES  NO
6. Do I have trouble getting up from the toilet?  YES  NO
7. Do I need hand rails/grab bars in the bathroom?  YES  NO
8. Do I hesitate to ask for assistance, if needed?  YES  NO
9. Do I have poor vision especially at night?  YES  NO
10. Do I need a night light in some areas?  YES  NO
11. Are my exits cluttered or obstructed?  YES  NO

**\*\*\*\*\*ANY YES ANSWERS MAKES YOU A HIGH RISK FOR FALLS\*\*\*\*\***

**Take Precautions-Speak with your Nurse on how to stay safe!**

## OXYGEN SAFETY RULES

Oxygen does not explode. Oxygen does not burn by itself, but it is one (1) of the three (3) ingredients necessary for a fire to occur. The other two (2) ingredients are a combustible or flammable material and a source of ignition. To prevent the chance of fire, follow these rules:

### **DO NOTs:**

Do not permit the use of open flames or burning tobacco in the room where oxygen is being used or stored.

Do not use any household electric equipment in an oxygen enriched atmosphere (i.e., electric razors, heaters and blankets). Keep these type items at least five (5) feet from your oxygen.

Do not use heavy coating of oily lotions, face creams or hair dressings while receiving oxygen. This includes any paraffin- or petroleum-based products.

Do not use aerosol sprays in the vicinity of oxygen equipment.

Do not oil or grease oxygen equipment.

Do not allow oxygen tubing to be covered by any objects.

Do not have oxygen "on" when equipment is not in use.

Do not use or handle oxygen containers roughly.

Do not store oxygen in a confined area.

Do not allow untrained persons to use or adjust any oxygen equipment.

Do not attempt to fix or repair oxygen equipment.

Do not store oxygen containers near radiators, heat ducts, steam pipes or other sources of heat.

Do not open cylinder valves quickly.

Do not remove oxygen tanks from stand.

Do not transport oxygen in an enclosed area or the trunk of your car.

Do not alter the liter flow from what your physician prescribes.

### **Do's:**

It is advisable to have "NO SMOKING" signs visible throughout the home.

Have a smoke detector(s) in your home

Consider having fire extinguishers available.

Store oxygen tanks in a clean, dry location away from direct sunlight and heat.

Do transport portable oxygen tanks in the back seat of your car and secure it properly.

## Patient Information - Advance Directive - Bill of Rights

### **Points to remember:**

- Anyone can use an **Out-of-Hospital DNR Order**
- To show that you have an **Out-of-Hospital DNR Order**, you must have your original form or copy of the completed form with you or wear an approved ID necklace or bracelet.
- The **Out-of-Hospital DNR Order** pertains to health care decisions-not to financial matters.

### **Medical Power of Attorney**

#### **What is it?**

A form that allows you to appoint someone to make health care decisions for you if you are no longer able to make them for yourself.

#### **Why do I need one?**

So that someone you choose can speak for you when you cannot. If you have no named someone, a guardian may be appointed for you by the court.

#### **What do I do?**

- Choose your **Medical Power of Attorney**. Discuss your health care requests with this person.
- Complete the form.

### **Points to remember:**

- You can change your Medical Power of Attorney at any time for any reason.
- Anyone 18 years or older can choose a Medical Power of Attorney. Don't wait until you are sick.
- The person you choose makes decisions for you only if you cannot make decisions for yourself.

#### **What is a Declaration for Mental Health?**

Under Texas law, a competent adult may declare their preference for mental health treatment should they become incapacitated in the future. The mental health treatment to be covered by the directive includes psychoactive medications, electroconvulsive or other convulsive treatment, emergency care and other preferences. The declaration only becomes effective should the person be declared to be incapacitated at a time later by a court of law. The form must be signed by two witnesses who will not benefit from the person's will, and who are not related to or caring for the person completing the form. The witness must affirm that the person signing the declaration appeared to be of sound mind. The declaration remains in effect for 3 years unless the person becomes incapacitated, then the declaration stays in effect until the person is no longer incapacitated.

**If you have not executed Advanced Directives and would like to, please ask your health care provider or your physician for the appropriate forms.**

### **Hospice Scope of Services**

Nursing Services	*Medical Equipment/Supplies
Hospice Aide	Physician Service
Nutritional Counseling	Medical Social Worker
Patient/Family Counseling	Bereavement
Volunteers	Spiritual Counseling
Inpatient Respite	Routine Home Care
*Therapy	* Pharmacy
*Continuous Home Care	* General Inpatient Care

\*For non-Medicare/Medicaid patients, these services will be coordinated with your insurance carrier and/or other third party payers

## **Patient Information - Advance Directive - Bill of Rights**

### **Non-Discrimination**

Agency does not discriminate:

- In admissions or treatment on the basis of age, race, color, religion, military status, gender preference, sex, marital status, national origin, disability, or source of payment;
- On the basis of age in the provision of services (except when age is a factor necessary to normal operation or achievement of statutory objectives).

### **Patient Responsibilities**

1. To provide medical and personal information necessary to plan and carry out care, including information on advanced directives.
2. To follow instructions agreed upon by you and the Agency and to inform when instructions are not followed.
3. To provide information and releases when required for billing purposes.
4. To allow the Agency to act on your behalf in filling appeals of denied payments of service and to the fullest extent possible in such appeals.
5. To be available to the staff for home visits at reasonable times.
6. To notify the Agency if you are going to be unavailable for a visit.
7. To provide a safe working environment for the hospice staff.
8. To notify the Agency of any changes in physician orders.
9. To inform the Agency of any dissatisfaction with care or service.
10. To participate with the Agency staff in developing a patient/family Emergency Preparedness and Response Plan.

### **Agency Responsibilities**

1. To be available to respond to the physician and Patient in a timely manner.
2. To provide hospice care utilizing a team approach.
3. To submit written documentation and medical information to the physician, in a timely manner.  
To include:
  - Interdisciplinary Plan of Care
  - IDT Updates
  - Discharge Summary
4. To follow the IDT Plan of Care as ordered by the physician and IDT.
5. To notify the physician of changes in the patient's status.
6. To promote and protect the Patient's rights.
7. To ensure that the Patient understands their rights and how to exercise their rights.
8. To provide supplies, drugs, and biological as needed and per plan of care for palliation and management of the terminal illness.



## **Journeys Hospice of Texas**

### **Patient Bill of Rights**

The law provides certain rights. As a hospice patient, these include the right:

1. To formulate, and have assistance formulating, Advanced Directives, including a description of applicable state law.
  - In the case of a patient adjudged incompetent, the rights of the Patient are exercised by the person appointed by law to act on the Patient's behalf.
  - In the case of a Patient who has not been judged incompetent, any legal representative may exercise the patient's rights to the extent permitted by law. The Patient has the right to have assistance in understanding and exercising his or her rights.
2. To have his or her person and property treated with consideration, respect, and full recognition of his individuality and personal needs.
3. To be informed prior to election of the hospice benefit about the agency's requirements and the primary caregivers rights and responsibilities, including availability of and/or absence of a primary or alternate caregiver.
4. To voice grievances regarding treatment or care that is or fails to be furnished, or regarding the lack of respect for property by anyone who is furnishing services on behalf of the hospice and shall not be subjected to discrimination or reprisal for doing so.
  - The hospice shall investigate complaints made by a client or the client's family or guardian regarding treatment or care that is or fails to be furnished, or regarding the lack of respect for the client's property by anyone furnishing services on behalf of the hospice, and must document both the existence of the complaint, and the steps taken to resolve the complaint.
  - The investigation and documentation must be initiated within 10 calendar days and completed within 30 calendar days after the hospice receives the complaint unless the hospice has and documents reasonable cause for delay.
5. To be free from mistreatment, neglect, or verbal, mental, sexual, and physical abuse, including injuries of unknown source, and misappropriation of Patient property.
6. To be informed, in advance about the services covered under the hospice benefit, scope of services and care to be furnished, the plan of care, expected outcomes, barriers to treatment and of any changes to the care to be furnished.
  - The hospice shall advise or consult with the Patient or legal representative in advance of any change in the plan of care.
7. To participate in the planning of care.
  - The hospice shall advise the patient in advance of the right to participate in the planning of care or treatment and in planning changes in the care or treatment.
8. To elect or revoke the Medicare Hospice Benefit, refuse care and services, or to terminate medical care.
9. To be informed of the availability of short term inpatient care for pain control, management and respite services and the names of the facilities with which the hospice has a contract agreement.
10. To be informed, before care is initiated, of the extent to which payment and payment options may be expected from the Patient, third party payers, and any other source of funding known to the hospice. To be informed of costs related to services provided and method of payment is applicable.
11. To receive effective pain management and symptom control from hospice for conditions related to the terminal illness.

12. To choose his or her attending physician.
13. To unlimited contact with visitors and others.
14. To an environment that preserves dignity and contributes to a positive self-image.
15. To assistance in understanding and exercising these rights.
16. To receive information addressing any beneficial relationship between the Agency and referring entities.
17. To receive information addressing organizational ownership and control.
18. To have personal health information kept confidential.

## **ABUSE, NEGLECT AND EXPLOITATION**

### **DEFINITIONS (Human Resources Code, §48.401 and §48.002) (Texas Family Code, §261.401)**

- A. "Agency" means an entity licensed under Chapter 142, Health and Safety Code.
- B. "Employee" means an individual who:
  - 1. Is directly employed by the Agency, a contractor, or a volunteer;
  - 2. Provides personal care services, active treatment, or any other personal services to an individual receiving agency services; and
  - 3. Is not licensed by the state to perform the services the person performs for the agency.
- C. "Employee misconduct registry" means the employee misconduct registry established under Chapter 253, Health and Safety Code.
- D. "Executive director" means the executive director of the Department of Family and Protective Services.
- E. "Adult Abuse" means:
  - 1. The negligent or willful infliction of injury, unreasonable confinement, intimidation, or cruel punishment with resulting physical or emotional harm or pain to an elderly or disabled person by the person's caretaker, family member, or other individual who has an ongoing relationship with the person; or
  - 2. Sexual abuse of an elderly or disabled person, including any involuntary or nonconsensual sexual conduct that would constitute an offense under Section 21.08, Penal Code (indecent exposure) or Chapter 22, Penal Code (assaultive offenses), committed by the person's caretaker, family member, or other individual who has an ongoing relationship with the person.
- F. "Adult Exploitation" means the illegal or improper act or process of a caretaker, family member, or other individual who has an ongoing relationship with the elderly or disabled person using the resources of an elderly or disabled person for monetary or personal benefit, profit, or gain without the informed consent of the elderly or disabled person.
- G. "Adult Neglect" means the failure to provide the one's self the goods or services, including medical services, which are necessary to avoid physical or emotional harm or pain or the failure of a caretaker to provide such goods or services.
- H. "Child Abuse" means an intentional, knowing, or reckless act or omission by an employee, volunteer, or other individual working under the auspices of a facility or program that causes or may cause emotional harm or physical injury to, or the death of, a child served by the facility or program as further described by rule or policy. This includes the following acts or omissions by a person:
  - 1. Mental or emotional injury to a child that results in an observable and material impairment in the child's growth, development, or psychological functioning;

2. Causing or permitting the child to be in a situation in which the child sustains a mental or emotional injury that results in an observable and material impairment in the child's growth, development, or psychological functioning;
  3. Physical injury that results in substantial harm to the child, or the genuine threat of substantial harm from physical injury to the child, including an injury that is at variance with the history or explanation given and excluding an accident or reasonable discipline by a parent, guardian, or managing or possessory conservator that does not expose the child to a substantial risk of harm.
  4. Failure to make a reasonable effort to prevent an action by another person that results in substantial harm to the child;
  5. Sexual conduct harmful to the child's mental, emotional, or physical welfare; including conduct that constitutes the offense of continuous sexual abuse of a young child or children under Section 21.02, Penal Code; indecency with a child under Section 21.11, Penal Code; sexual Assault under Section 22.01 I, Penal Code; or aggravated sexual assault under Section 22.021, Penal Code;
  6. Failure to make a reasonable effort to prevent sexual conduct harmful to a child;
  7. Compelling or encouraging the child to engage ill sexual conduct as defined by Section 43.01, Penal Code;
  8. Causing, permitting, encouraging, engaging in, or allowing the photographing, filming, or depicting of the child if the person knew or should have known that the resulting photograph, film, or depiction of the child is obscene as defined by, Section 43.21, Penal Code, or pornographic:
  9. The current use by a person of a controlled substance as defined by Chapter 481. Health and Safety Code, in a manner or to the extent that the use results in physical, mental, or emotional injury to a child;
  10. Causing, expressly permitting, or encouraging a child to use a controlled substance as defined by Chapter 481. Health and Safety Code; or,
  11. Causing, permitting, encouraging, engaging in, or allowing a sexual performance by a child as defined by Section 43.25, Penal Code.
- I. "Child Neglect" means a negligent act or omission by an employee, volunteer, or other individual working under the auspices of a facility or program. including failure to comply with an individual treatment plan, plan of care, or individualized service plan that causes or may cause substantial emotional harm or physical injury to, or the death of, a child served by the facility or program as further described by rule or policy. This includes the following acts or omissions by a person:
1. Leaving a child in a situation where the child would be exposed to substantial risk of physical or mental harm, without arranging for necessary care for the child, and the demonstration of an intent not to return by a parent, guardian, or managing or possessory conservator of the child:
  2. Placing a child in or failing to remove a child from a situation that a reasonable person would realize requires judgment or actions beyond the child's level or

maturity, physical condition, or mental abilities and that results in bodily injury or a substantial risk of immediate harm to the child;

3. Failing to seek, obtain, or follow through with medical care for a child, with the failure resulting in or presenting a substantial risk of death, disfigurement, or bodily injury or with the failure resulting in an observable and material impairment to the growth, development, or functioning of the child;
  4. The failure to provide a child with food, clothing, or shelter necessary to sustain the life or health of the child excluding failure caused primarily by financial inability unless relief services had been offered and refused;
  5. Placing a child in or failing to remove the child from a situation in which the child would be exposed to a substantial risk of sexual conduct harmful to the child;
  6. Placing a child in or failing to remove the child from a situation in which the child would be exposed to acts or omissions that constitute abuse under subdivision (1). (E), (F), (G) or (K) of Family Code, Chapter 261 committed against another child.
  7. The failure by the person responsible for a child's care, custody, or welfare to permit the child to return to the child's home without arranging for the necessary care for the child after the child has been absent from the home for any reason, including having been in residential placement or having run away.
- J. "Cause to believe" means that an individual knows, suspects or receives an allegation regarding abuse, neglect, or exploitation.
- K. "Child Exploitation" means the illegal or improper use of a child or of the resources of a child for monetary or personal benefit, profit, or gain by an employee, volunteer, or other individual working under the auspices of the agency or program

## **POLICY**

Agency employees/contractors will be aware of signs and symptoms indicating possible abuse, neglect and/or exploitation and will sign (upon hire) an acknowledgment affirming compliance with agency policy and obligation to report.

If agency has "cause to believe" abuse, neglect or exploitation of the client has occurred by an Agency employee, representative, volunteer or contractor, information will be reported immediately, meaning within 24 hours, upon witnessing the act or upon receipt of the allegation to: Department of Family and Protective Services (DFPS) at 1-800-252-5400, or through the DFPS secure website at [www.txabusehotline.org](http://www.txabusehotline.org); and DADS at 1400-458-9858. Agency or staff members will not implement retaliatory action against any individual who in good faith reports suspected client abuse, neglect and/or exploitation as specified per Family Code, Chapter 261.110, (b). Clients will be informed of this policy, verbally and in writing, during the admission process.

## **PROCEDURE**

- A. Agency staff/contractor/representative will: Immediately report assessment of client's condition which might indicate abuse/neglect to Agency supervisor. Symptoms that may indicate a need for further investigation may include the following:
  1. Criteria to identify child neglect or abuse, physical assault and domestic abuse include but not limited to:

- a. Injuries to the trunk of the body that could be intentional;
  - b. Femoral fractures or retinal hemorrhages in children under two years old;
  - c. Fractures that do not correlate with the child's gross motor ability or rib fractures in infants and children:
  - d. An imprint from a hot object on the back, buttocks or back of the hands;
  - e. CNIS signs/symptoms that may indicate a head injury from violent shaking;
  - f. Inadequate supervision with resulting effect on ADL provisions, e.g. bathing, toileting, food, etc.:
  - g. Unexplained injuries, frequent falls or multiple hematomas of various colors;
  - h. Delinquent or run-away behavior; and
  - i. Child's clothing inappropriate in relation to weather condition.
2. Criteria to identify elder neglect or abuse, physical assault and domestic abuse include but not limited to:
- a. injuries to the trunk of the body that could be intentional:
  - b. An imprint from a hot object on the back, buttocks or hack of hands:
  - c. Inadequate supervision with resulting effect on ADM, provisions, e.g., bathing, toileting, food, etc.:
  - d. Unexplained injuries, frequent fails or multiple hematomas of various colors:
  - e. Withdrawal and/or crying: and
  - f. Any client who reports an abusive incident.
3. Criteria to identify victims of exploitation include but not limited to:
- a. Abuse and/or misuse of client's money;
  - b. An inability of caregiver/family to account for client's money or property;
  - c. Discrepancies between client's resources and living situations: and
  - d. Reports of demands for goods in exchange for services.
4. Criteria to identify victims of rape or sexual molestation include but not limited to:
- a. Feelings of humiliation, degradation, shame, guilt, embarrassment, self-blame, anger and revenge;
  - b. Fear of injury, mutilation and death:
  - c. Complete disruption of client's normal activities of daily living and life-style:
  - d. Presence of abrasions, bruises, swelling, lacerations and/or teeth marks:
  - e. Tearful, trembling, sobbing, hyperventilation and/or withdrawal:
  - f. Long periods of silence;

- g. Sudden marked irritability, avoidance of relationships and/or marked change in sexual behavior: and
      - h. Phobic reactions to being alone, going outside and/or staying inside.
- B. When appropriate, staff will acquire input from other disciplines providing client care regarding concerns and findings.
- C. Agency Management will initiate an investigation immediately for any known or alleged acts of abuse, neglect and/or exploitation by agency employees, including volunteers, or contractors, immediately upon witnessing the act or upon receipt of the allegation. Immediately, meaning within **24 hours**, Agency will contact: **at 1.800-458-9858 to make an oral report of abuse, neglect and/or exploitation and, Department of Family and Protective Services (DFPS) at 1-800-252-5400 or through the DFPS secure website at [www.txabusehotline.org](http://www.txabusehotline.org).**
- D. A written report of the investigation will be sent to DADS Complaint Intake Unit no later than 10 days after reporting the act or receipt of the allegation to DADS and D1-PS. A complete written report will be completed on 3613, Provider Investigation Report and include the following:
  - 1. Incident date;
  - 2. Alleged victim;
  - 3. Alleged perpetrator;
  - 4. Any witnesses;
  - 5. Allegation;
  - 6. Any injury or adverse effect;
  - 7. Any assessments made;
  - 8. Any treatment required;
  - 9. Investigation summary; and
  - 10. Any action taken.

Website for obtaining reporting form 3613 is: [www.dads.state.tx.us/forms/3613/](http://www.dads.state.tx.us/forms/3613/)

- E. Agency will complete the investigation and documentation within 30 days after the agency receives a complaint or report of abuse, neglect, and exploitation, unless the agency has and documents reasonable cause for a delay.
- F. Agency will not retaliate against any person or terminate an employee for filing a complaint, presenting a grievance, or providing in good faith, information relating to home health services provided by the agency.
- G. Agency employees, representative, volunteer or contractor suspected of abuse, neglect or exploitation, will be suspended immediately. Appropriate actions will be taken by the Agency as indicated by investigation.

- H. Report findings and intentions to report the suspected abuse to the client's attending physician. Medical Social Services may be ordered by the physician, as appropriate.
- I. Report findings to an appropriate agency according to state law/regulations.
- J. Copies of reports filed with the state or local law enforcement will be tracked and kept by the Agency.
- K. Incidents of Family Violence shall be reported to a local law enforcement agency.
- L. Reports of child abuse, neglect or exploitation will be filed immediately with DFPS, local law or state law enforcement agency. The state agency that operates, licenses, certifies, or registers the Agency in which alleged abuse occurs or other state agency as appropriate, but no later than 24th hour after the hour of discovery or suspicion,
- M. The Child Abuse report will identify the following if known:
  - 1. Name and address of the child:
  - 2. The name and address of person responsible for the care, custody, or welfare of the child:
  - 3. Any other pertinent information concerning the alleged suspected abuse or neglect;
- N. If any Agency employee, volunteer or contractor is suspected of abuse, neglect or exploitation, the employee will be suspended immediately and an investigation will be conducted by the Agency/State agency. If the investigation validated the claim, the employee or contractor will be terminated and the incident(s) reported to appropriate state department, state licensing board or law enforcement official.



## **Rights of the Elderly**

### **Section 102.001 Definition**

1. "Convalescent and nursing home" means an institution licensed by the Department of Aging and Disability Services under Chapter 242, Health and Safety Code.
2. "Home health services" means the provision of health service for pay or other consideration in a patient's residence regulated under Chapter 142, Health and Safety Code.
3. "Alternate care" means services provided within an elderly individual's own home, neighborhood, or community, including:
  - A. Day care,
  - B. Foster care,
  - C. Alternative living plans, including personal care services, and
  - D. Supportive living services, including attendant care, residential repair, or emergency response services.
4. "Person providing services" means an individual, corporation, association, partnership, or other private or public entity providing convalescent and nursing home services, home health services, or alternate care services.
5. "Elderly individual" means an individual 60 years of age or older.

### **Section 102.002 Prohibition**

A person providing services to the elderly may not deny an elderly individual a right guaranteed by this chapter.

1. Each agency that licenses, registers, or certifies a person providing services shall require the person to implement and enforce this chapter. A violation of this chapter is grounds for suspension or revocation of the license, registration, or certification of a person providing services.

### **Section 102.003 Rights of the Elderly**

1. An elderly individual has all the rights, benefits, responsibilities and privileges granted by the constitution and laws of this state and the United States, except where lawfully restricted. The elderly individual has the right to be free of interference, coercion, discrimination and reprisal in exercising these civil rights.
2. An elderly individual has the right to be treated with dignity and respect for the personal integrity of the individual, without regard to race, religion, national origin, sex, age, disability, marital status, or source of payment. This means that the elderly individual:
  - A. Has the right to make his/her own choices regarding the individual's personal affairs, care, benefits and services.
  - B. Has the right to be free from abuse, neglect, and exploitation, and
  - C. If protective measures are required, has the right to designate a guardian or representative to ensure the right to quality stewardship of the individual's affairs.

An elderly individual has the right to be free from physical and mental abuse, including corporal punishment or physical or chemical restraints that are administered for the purpose of discipline or convenience and not required to treat the individual's medical symptoms. A person providing services may use physical or chemical restraints only if the use is authorized in writing by a physician or the use is necessary in an emergency to protect the elderly individual or others from injury. A physician's written authorization for the use of restraints must specify the circumstances under which the restraints may be used and the duration for which the restraints may be used. Except in an emergency, restraints may only be administered by qualified medical personnel.

4. A mentally retarded elderly individual with a court-appointed guardian may participate in a behavior modification program involving use of restraints or adverse stimuli only with the informed consent of the guardian.
5. An elderly individual may not be prohibited from communicating in his/her native language with other individuals or employees for the purpose of acquiring or participating in any type of treatment, care, or services.
6. An elderly individual is entitled to privacy while attending to personal needs and a private place for receiving visitors or associating with other individuals, unless providing privacy would infringe on the rights of other individuals. This right applies to medical treatment, written communications, telephone conversations, meeting with family, and access to resident councils. An elderly person has the right to send and receive unopened mail, and the person providing services shall ensure that the individual's mail is sent and delivered promptly. If an elderly individual is married and the spouse is receiving similar services, the couple may share a room.
7. An elderly individual may participate in activities of social, religious or community groups unless the participation interferes with the rights of other persons.
8. An elderly individual may manage his/her personal financial affairs. The elderly individual may authorize, in writing, another person to manage his/her money. The elderly individual may choose, without restriction, the manner in which their money is managed, including a money management program, a representative payee program, a financial power of attorney, a trust, or similar method. A person designated to manage an elderly individual's money shall do so in accordance with each applicable program policy, law, or rule. In request of the elderly individual or the individual's representative, the person designated to record and provide an accounting of the money. An elderly individual's designation of another person to manage his/her money does not affect the individual's ability to exercise another right described by this chapter. If an elderly individual is unable to designate another person to manage his/her affairs and a guardian is designated by a court, the guardian shall manage the individual's money in accordance with the Probate Code and other applicable laws.
9. An elderly individual is entitled access to his/her personal and clinical records. These records are confidential and may not be released without the elderly individual's consent, except in the following circumstances:
  - A. To another person providing services at the time the elderly individual transferred, or
  - B. If the release is required by another law.

10. A person providing services shall fully inform an elderly individual, in a language that the individual can understand, of his/her complete medical condition and shall notify the individual whenever there is a significant change in their medical condition.
11. An elderly individual may choose and retain a personal physician and is entitled to be fully informed in advance about treatment or care that may affect his/her well-being.
12. An elderly individual may participate in an individual plan of care that describes his/her medical, nursing and psychological needs and how the needs will be met
13. An elderly individual may refuse medical treatment after the elderly individual:
  - A. Is advised by the person providing the services of the possible consequences of refusing treatment.
  - B. Acknowledges that the individual clearly understands the consequences of refusing treatment.
14. An elderly individual may retain and use personal possessions, including clothing and furnishings, as space permits. The number of personal possessions may be limited for the health and safety of other individuals.
15. An elderly individual may refuse to participate in services required by the person providing services.
16. Within 30 days following the date the elderly individual is admitted for service, a person providing services shall inform the individual:
  - A. Whether the individual is entitled to benefits under Medicare or Medicaid, and
  - B. Which items and services are covered by these benefits, including items or services for which the elderly individual may not be charged.
17. A person providing services may not transfer or discharge an elderly individual unless:
  - A. The transfer is for the elderly individual's welfare, and the individual's needs cannot be met by the person providing services,
  - B. The elderly individual's health is improved sufficiently so that services are no longer needed,
  - C. The elderly individual's health and safety or the health and safety of another individual would be endangered if the transfer or discharge was not made.
  - D. The person providing services ceases to operate or to participate in the program that reimburses them for the elderly individual's treatment or care, or
  - E. The elderly individual fails, after reasonable and appropriate notices, to pay for service.
18. Except in an emergency, a person providing services may not transfer or discharge an elderly individual from a residential facility until the 30th day after the date the person providing services provides written notice to the elderly individual, the individual's legal representative, or a member of the individual's family stating:
  - A. That the person providing services intends to transfer or discharge the individual,

- B. The reason for the transfer or discharge (as stated above),
  - C. The effective date of the transfer or discharge,
  - D. If the individual is to be transferred, the location to which the individual will be transferred, and
  - E. The individual's right to appeal the action and the person to who the appeal should be directed.
19. An elderly individual may:
- A. Make a living will by executing a directive under the Natural Death Act (Chapter 672, Health and Safety Code),
  - B. Execute a durable power of attorney for health care under Chapter 135, Civil Practice and Remedies Code, or Designate a guardian in advance of need to make decisions regarding the individual's health care should the individual become incapacitated
20. An elderly individual may complain about his/her care or treatment. The complaint may be made anonymously or communicated by a person designated by the elderly individual. The person providing the service shall promptly respond to resolve the complaint. The person providing services may not discriminate or take other punitive action against an elderly individual who makes a complaint.

#### **Section 102.004 List of Rights**

1. A person providing services shall provide each elderly individual with a written list of the individual's rights and responsibilities, including each provision of Section 102.003, before providing services or as soon after providing services as possible, and shall post the list in a conspicuous location.
2. A person providing services must inform an elderly individual of changes or revisions in the list.

#### **Section 102.005 Rights Cumulative**

The rights described in this chapter are cumulative of other rights or remedies to which an elderly individual may be entitled under law.

## Journeys Hospice of Texas

### HC Policy 585

### Disposal of Medication

#### **Purpose:**

To establish a process for appropriately handling medication disposal, to ensure client, family, staff, and community safety.

#### **Policy:**

When medications are first ordered, the hospice Nurse will instruct the client/caregiver in the proper technique for disposal of discontinued medication. Agency recognizes and respects that the medications utilized in the home are the property of the client or the client's household after death. Accordingly, after death, a member of the hospice patient's household may dispose of the patient's pharmaceutical controlled substances, but the home hospice or home care provider cannot do so unless otherwise authorized by law to dispose of the decedent's personal property.

#### **Procedure:**

- A. Agency will provide and instruct the client/caregiver on the policy concerning discontinued medication.
- B. Agency will notify the client/caregiver of the medication discontinuation order and will instruct the client/caregiver on specific disposal techniques as indicated.
- C. If assistance is requested a staff member, with client's/caregiver's approval, participates in the disposal of medication, the method of disposal and amount disposed is documented and witnessed in the medical record.
- D. When disposing of medications in the home, the caregiver will be reminded of the following preferred procedure:
  1. Take unused, unneeded, or expired drugs out of their original containers. (Patches should be cut up or aspirated, injectables should be drawn from the bottle.)
  2. Mix the drugs with an undesirable substance, like used coffee grounds or cat litter, and put them in impermeable, nondescript containers, such as empty cans or sealable bags, further ensuring that the drugs are not diverted or accidentally ingested by children or pets. For added security, the container may be taped closed.
  3. Throw these containers in the outside trash.
  4. Drugs may be flushed down the toilet only if the accompanying client information specifically instructs it is safe to do so.
- E. Agency will notify the client's Physician and/or Pharmacist if a client/caregiver refuses to dispose of a medication and it is suspected that the client/caregiver and/or home environment indicates one of the following:
  1. Medication misuse;
  2. Medication Abuse; or

- 3. Potential improper disposal of a hazardous waste material.
- F. Upon the client's death, medication disposal instructions will be given to caregivers again. Documentation of disposal or family refusal will appear on the last visit note. Signature of a witness to the disposal will be obtained on the visit note.
- G. Any unused medications will not be returned, or removed from the home.
- H. When the agency has provided medication to hospice patients in contracted facilities, such as hospitals or nursing facilities, the agency will abide by that contracted facilities policy on disposal of medications.

## Journeys Hospice of Texas

### R&E Policy 406 Advance Directives

#### **Purpose:**

To ensure that adult clients/legal guardians are informed of client rights under federal and state law to make and direct decisions concerning medical care; including the right to accept or refuse medical or surgical treatment and the right to formulate advance directives such as a "Living Will"/ Directive to Physician, "Medical Power of Attorney", "Out-Of-Hospital DNR", or "Declaration of Mental Health Statement"

To guide agency staff in implementing the provisions of the Client Self-Determination Act and Texas' Advance Directives Act

To provide for education of staff and the community on issues concerning advance directives and related advance care documents

#### **Definitions:**

**Artificial Nutrition and Hydration-** The provision of nutrients or fluids by a tube inserted in a vein, under the skin in the subcutaneous tissues, or in the stomach (gastrointestinal tract).

**Cardiopulmonary Resuscitation (CPR)** - Any medical intervention used to restore circulatory or respiratory function that has ceased.

**Declarant** - Person who has executed or issued a directive.

**Health Care or Treatment Decision** - Consent, refusal to consent, or withdrawal of consent to health care, treatment, service, or a procedure to maintain, diagnose, or treat an individual's physical or mental condition, including such a decision on behalf of a minor.

**Irreversible Condition** - Condition, injury or illness that may be treated but is never cured or eliminated; that leaves the person unable to care for or make decisions for person's own self; and that without life sustaining treatment, is fatal.

**Life Sustaining Treatment** - Treatment that, based on reasonable medical judgment, sustains life of a client and without which the client will die. The term includes life sustaining medications and artificial life support; it does not include pain management medication or a medical procedure that provides comfort care, or palliative care.

**Living Will/Directive to Physician** - Type of advance directive in which an individual puts in writing their wishes about medical treatment should they be unable to communicate at the end of life. The Texas Directive permits the withholding or withdrawing of life-sustaining medical treatment in the event of a terminal or an irreversible condition that would result in death without life-support.

**Medical Power of Attorney** - A document that enables the client to appoint someone they trust to make decisions about their medical care if they cannot make those decisions them self. This type of advance directive may also be called a "health care proxy" or "appointment of a health care agent." The person appointed may be called the health care agent, surrogate, attorney-in-fact, or proxy.

**Terminal Condition** - Incurable condition that according to reasonable medical judgment will produce death within 6 months, even with available life-sustaining treatment.

**Witnesses** - Two competent adult witnesses must sign the form acknowledging the signature of the client or the person acting on the client's behalf except when signed by two (2) physicians in Section C of OOHDR.

A. Witness 1 MAY NOT BE:

1. Related to the client by blood or marriage;
2. Entitled to any part of the estate;
3. Be a person who has claim against the estate of the client;
4. The attending physician
5. An employee of attending physician;
6. An employee of a health care facility in which that client is being cared for, if involved in providing direct client care to the client
7. An officer, director, partner, or business office employee of a health care facility in which the client is being cared for or any parent organization of the health care facility;
8. Person designated to make treatment decision for the client

B. Witness 2: May be any competent adult

**Policy:**

A. Agency recognizes an adult client's/legal guardian's right under federal and state law to make decisions regarding medical care, including the right to formulate advance directives. The agency will not withhold care based on whether or not the individual has an advance directive. However, if at any time agency staff is unable to honor an advance directive elected by the client, the client will be notified and will be transferred to another appropriate agency/organization.

B. Agency does not participate in the withdrawal of life sustaining care. C. Life sustaining procedures agency is unable and /or unwilling to withhold in: D. Accordance with a client's advance directive/ and or E. As discussed with client (or designated representative), family, physician, and /or agency's governing body are:

1. Artificial Nutrition
2. Artificial Hydration,
3. Mechanical Breathing Machines- (oxygen, ventilator, etc.)
4. Total Parenteral Nutrition,
5. Life Sustaining Medications- (All routes),
6. Dialysis (Agency will not withdraw follow-up support services such as assessments and coordination of care because client is at end of life),
7. Any other methods recognized as artificial life support,8. Surgical procedures (discussed on an individual basis with client (or designated representative), family, physician, and /or hospice's Governing Body.
8. CPR (unless client has a standing DNR or meets other legal criteria for no CPR)



**R&E Policy 406**  
**Advance Directives (Cont.)**

**Procedure:**

- A. Agency staff will distribute to and review with the client/legal guardian written information relating to the client's right to refuse medical or surgical treatment and the right to formulate advance directives, as well as agency policies relating to advance directives at the time of the initial assessment, prior to the provision of care to the client.
- B. Agency staff will inquire whether the client has an advance directive at the time of the initial assessment. If an advance directive is not in place and the client expresses the desire to establish an advanced directive, then a medical social services referral may be initiated to facilitate the proper execution of documents.
  - 1. If an advance directive is in place, agency staff will request a copy for the client's medical record and the medical record will be "flagged" appropriately.
  - 2. Hospice staff will make every effort to obtain a copy of any client's advance directive and file this copy in the medical record. If the client does not provide agency with a copy, this will be documented in the client's medical record.
  - 3. If at the time of notice, the client is incompetent or otherwise incapacitated and unable to receive the notice, agency will provide the required written notice in the following order of preference, to:
    - a. The individual's legal guardian;
    - b. A person responsible for the health care decisions of the client;
    - c. The individual's spouse;
    - d. The individual's adult child;
    - e. The individual's parent; or
    - f. The person admitting the client.
  - 4. If the hospice is unable, after a diligent search, to locate an individual listed above, agency is not required to provide notice. The hospice will provide notice if at any time the client becomes able to receive the notice.
- C. The client's Advance Directive status will be communicated to all staff involved in the client's care in one of the following ways:
  - 1. Identifying the chart(s).
  - 2. List in the on call book.
  - 3. Verbal and written communication
- D. Hospice staff will document in the medical record (i.e. the Consent Form, Plan of Care form), information about any type of advance care directive the client may have. Hospice staff will encourage the client to forward a copy to his/her physician if the physician does not have a copy.

- E. Agency staff will direct the client/caregiver to the client's physician, lawyer, MSW or other community resource if the client requests additional information or wishes to develop an advance directive.
- F. Agency staff may complete or witness an advance care document or participate in the decision-making process relating to whether to have an advance care document.
- G. If, at any time, a client refuses medical treatment, agency staff will discuss the refusal with the physician and document both the refusal and the physician notification in the client's medical record and complete a verbal order.
- H. Agency staff will not provide any medical treatment that the client has not consented to receive
- I. Agency staff will not withhold treatment or otherwise discriminate against clients based on whether or not the client has an advance directive.
- J. Agency staff will recognize and honor properly executed advance directives as evidence of the client's desire to have medical treatment withheld or discontinued as specified.
- K. Agency will provide functions relating to advance directives such as, but not limited to, educating agency personnel and the community served on advance directives and other bioethical issues, assisting the client and family as needed, and aiding in the development of guidelines on advance directives and other bioethical issues.

**Journeys Hospice of Texas**  
**Drug Free Work Place Policy**

**Purpose:**

To establish procedures for a "drug-free" workplace.

**Policy:**

Agency conducts:

"On Hire" and "Random/for Cause" drug testing of its employees.

X "Random/for Cause"

- A. Agency will provide a copy of the policy to anyone applying for services from the agency, employees on hire and any person who requests the information.
- B. All employees are prohibited from the unlawful or unauthorized manufacture, distribution, dispensing, possession or use of a controlled substance or any alcoholic beverages while in the workplace or on agency paid time. Violation of this policy can result in disciplinary action, up to and including termination of employment.
- C. Employees who have direct contact with clients will be subject to testing on a "random/for cause" (reasonable-suspicion testing) basis when the agency or its client has reason to believe that drug or alcohol problem exists or violation of the policy has occurred, or post-accident/near-miss accident or an incident where an injury or property damage did or might occur. Agency further reserves the right to perform random/for cause drug testing on any employee upon written notice.
- D. Employee refusal to comply with request for "random for cause drug testing" will be cause for immediate termination.
- E. In order to implement both the agency policy and to be in compliance with the Federal Law, employees are notified that:
- F. All employees are prohibited from the unlawful or unauthorized manufacture, distribution, dispensing, possession or use of a controlled substance or any alcoholic beverages while in the workplace or on agency paid time. Violation of this policy can result in disciplinary action, up to and including termination of employment.

**Rationale**

The agency and its employees must be alert, responsive and able to perform work in a safe and productive manner. Working "under the influence of drugs or alcohol" creates a risk to the safety and well-being of the individual and client.

**Procedure:**

- A. The agency educates all employees during orientation and clients upon admission regarding the drug testing policy.
- B. Employees must sign acknowledgment of receipt of policy. A signed statement will be maintained in the employee personnel file.

- C. All employees are responsible to report instances of possible abuse. Reported instances of abuse will be thoroughly and confidentially investigated. Management personnel will terminate the employee, if results of the investigation indicate alcohol/drug use or abuse.
- D. The employees are notified of the following:

## **Drug Free Work Place Policy**

1. There are substantial dangers of drug and alcohol abuse in the workplace;
  2. It is the agency policy to maintain a workplace free of illegally used drugs and abuse of alcohol;
  3. Management and the human resources department are prepared to advise what counseling and rehabilitation programs are available;
  4. The agency may at its sole discretion, require an employee to participate in an appropriate counseling and rehabilitation program as the result of substance abuse violations. Refusal to participate in such program and to periodically submit to "random/for cause" testing during the course of treatment for a reasonable period of time, will be grounds for termination;
  5. Employees taking legally prescribed or over-the-counter drugs that might impair mental or physical functions must notify management prior to reporting to work and/or prior to taking after the start of work. A doctor's note may be required;
  6. Employees must notify management of drug convictions within five days of such conviction. Management will notify human resources immediately; and
  7. If the employee is performing services under a government contract, the agency will notify the government-contracting officer within ten days of the agency's receipt of a notice of conviction.
- E. The agency may require an employee to submit to drug and/or alcohol screening under the following circumstances:
1. The agency will comply with the reasonable contractual requirements of alcohol and/or drug testing of employees;
  2. Employees will be subject to on hire and "random/for cause" post-accident testing if involved in an on-the-job accident, near-miss accident, or an incident where injury or property damage did occur or might have occurred;
  3. Employees will be subject to "random/for cause" (reasonable-suspicion testing) when the problem exists or a violation of the policy has occurred; or
  4. Employees may be required to submit to drug testing when required by state or federal law, regulation or contractual obligation not otherwise anticipated by this policy.
- F. Method of drug testing: Witnessed Urine Testing

## **Journeys Hospice of Texas**

### **R&E Policy 412 Non-Discrimination**

#### **Purpose:**

To ensure that there is understanding that discrimination is prohibited.

Title VI of the Civil Rights Act of 1964, Section 504 of the Rehabilitation Act of 1973, the Age Discrimination Act of 1975, and Regulations of the U.S. Department of Health and Human Services issued pursuant to the Acts, Title 45 Code of Federal Regulations Part 80, 84, and 91. (Other Federal Laws and Regulations provide similar protection against discrimination on grounds of sex and creed.)

#### **Policy:**

Hospice agency does not does not exclude, deny benefits to, or otherwise discriminate against any person on the ground of race, color, or national origin, or on the basis of disability or age in admission to, participation in, or receipt of the services and benefits of any of its programs and activities or in employment .

**Journeys Hospice of Texas**  
**Written Informational Materials Policy**

**Purpose:**

To ensure accuracy of written informational materials to clients and the general public

**Policy:**

Agency will distribute accurate written informational materials that address the care agency is capable of providing either directly or through written agreement.

The agency's advertising accurately reflects the scope of facilities and services.

Agency will include a non-discrimination policy to referral sources, community organizations, employees, clients, and potential clients.

Agency will provide public disclosure information to client on admission.

**Procedure:**

- A. All written informational materials to be distributed to clients and/or the general public will be submitted to agency leaders for approval prior to distribution for confirmation of accuracy of content.
- B. A non-discrimination clause will be included in, but not limited to, the following written documents:
  - 1. Agency brochures;
  - 2. Contracts;
  - 3. Client admission packets; and
  - 4. Employee orientation manual.
- C. Public disclosure information will be provided to client at time of admission and in the Business Profile to include the following:
  - 1. Ownership information;
  - 2. Statement of organization's mission statement; and
  - 3. Licensure and accreditation status as applicable.

## HIPAA Notice Privacy Practices

### HIPAA Notification of Privacy Practices

**THIS NOTICE DESCRIBES HOW MEDICAL INFORMATION ABOUT YOU MAY BE USED AND DISCLOSED AND HOW YOU CAN GET ACCESS TO THIS INFORMATION. PLEASE REVIEW IT CAREFULLY.**

#### **USE AND DISCLOSURE OF HEALTH INFORMATION**

The Agency may use your health information, information that constitutes protected health information as defined in the Privacy Rule of the Administrative Simplification provisions of the Health Insurance Portability and Accountability Act of 1996, for purposes of providing you treatment, obtaining payment for your care and conducting health care operations. The Agency has established policies to guard against unnecessary disclosure of your health information.

**THE FOLLOWING IS A SUMMARY OF THE CIRCUMSTANCES UNDER WHICH AND PURPOSES FOR WHICH YOUR HEALTH INFORMATION MAY BE USED AND DISCLOSED:**

**To Provide Treatment.** The Agency may use your health information to coordinate care within the Agency and with others involved in your care, such as you attending physician and other health care professionals who have agreed to assist the Agency in coordinating care. For example, physicians involved in your care will need information about your symptoms in order to prescribe appropriate medications. The Agency also may disclose your health care information to individuals outside of the Agency involved in your care including family members, pharmacists, suppliers of medical equipment or other health care professionals.

**To Obtain Payment.** The Agency may include your health information in invoices to collect payment from third parties for the care you receive from the Agency. For example, the Agency may be required by your health insurer to provide information regarding your health care status so that the insurer will reimburse you or the Agency. The Agency also may need to obtain prior approval from your insurer and may need to explain to the insurer your need for home care and the services that will be provided to you.

**To Conduct Health Care Operations.** The Agency may use and disclose health information for its own operations in order to facilitate the function of the Agency and as necessary to provide quality care to all of the Agency's patients. Health care operations includes such activities as:

- Quality assessment and improvement activities.
- Activities designed to improve health or reduce health care costs.
- Protocol development, case management and care coordination.
- Contacting health care providers and patients with information about treatment alternatives and other related function that do not include treatment.
- Professional review and performance evaluation.
- Training programs including those in which students, trainees or practitioners in health care learn under supervision.
- Training on non-health care professionals.
- Accreditation, certification, licensing or credentialing activities.
- Review and auditing, including compliance reviews, medical review, legal services and compliance programs.
- Business planning and development including cost management and planning related analyses and formulary development.



- Business management and general administrative activities of the Agency.
- Fundraising for the benefit of the Agency.

For example the Agency may use your health information to evaluate its staff performance, combine your health information with other Agency patients in evaluating how to more effectively serve all Agency patients, disclose your health information to Agency staff and contracted personnel for training purposes, use your health information to contact you as a reminder regarding a visit to you, or contact you as part of general fundraising and community information mailings (unless you tell us you do not want to be contacted).

**For Fundraising Activities.** The Agency may use information about you including your name, address, phone number and the dates you received care in order to contact you to raise money for the Agency. The Agency may also release this information to a related Agency foundation. If you do not want the Agency to contact you, notify Privacy Officer and indicate that you do not wish to be contacted.

**For Appointment Reminders.** The Agency may use and disclose your health information to contact you as a reminder that you have an appointment for a home visit.

**For Treatment Alternatives.** The Agency may use and disclose your health information to tell you about or recommend possible treatment options or alternatives that may be of interest to you.

THE FOLLOWING IS A SUMMARY OF THE CIRCUMSTANCES UNDER WHICH AND PURPOSES FOR WHICH YOUR HEALTH INFORMATION MAY ALSO BE USED AND DISCLOSED (check your State laws to ensure consistency with State law requirements).

**When Legally Required.** The Agency will disclose your health information when it is required to do so by any Federal, State or local law.

**When There Are Risks to Public Health.** The Agency may disclose your health information for public activities and purposes in order to:

- Prevent or control disease, injury or disability, report disease, injury, vital events such as birth or death and the conduct of public health surveillance, investigations and interventions.
- Report adverse events, product defects, to track products or enable product recalls, repairs and replacements and to conduct post-marketing surveillance and compliance with requirements of the Food and Drug Administration.
- Notify a person who has been exposed to a communicable disease or who may be at risk of contracting or spreading a disease.
- Notify and employer about an individual who is a member of the workforce as legally required.

**To Report Abuse, Neglect Or Domestic Violence.** The Agency is allowed to notify government authorities if the Agency believes a patient is the victim of abuse, neglect or domestic violence. The Agency will make this disclosure only when specifically required or authorized by law or when the patient agrees to the disclosure.

**To Conduct Health Oversight Activities.** The Agency may disclose your health information to a health oversight agency for activities including audits, civil administrative or criminal investigations, inspections, licensure or disciplinary action. The Agency, however, may not disclose your health

information if you are the subject of an investigation is not directly related to your receipt of health care or public benefits.

### **HIPAA Notice Privacy Practices**

**In Connection With Judicial And Administrative Proceedings.** The Agency may disclose your health information in the course of any judicial or administrative proceeding in response to an order of a court or administrative tribunal as expressly authorized by such order or in response to a subpoena, discovery request or other lawful process, but only when the Agency makes reasonable efforts to either notify you about the request or to obtain an order protecting your health information.

**For Law Enforcement Purposes.** As permitted or required by State law, the Agency may disclose your health information to a law enforcement official for certain law enforcement purposes as follows:

- As required by law for reporting of certain types of wounds or other physical injuries pursuant to the court order, warrant, subpoena or summons or similar process.
- For the purpose of identifying or locating a suspect, fugitive, material witness or missing person.
- Under certain limited circumstances, when you are the victim of a crime.
- To a law enforcement official if the Agency has a suspicion that your death was the result of criminal conduct including criminal conduct at the Agency.
- In an emergency in order to report a crime.

**To Coroners and Medical Examiners.** The Agency may disclose your health information to coroners and medical examiners for purposes of determining your cause of death or for other duties, as authorized by law.

**To Funeral Directors.** The Agency may disclose your health information to funeral directors consistent with applicable law and if necessary, to carry out their duties with respect to your funeral arrangements. If necessary to carry out their duties, the Agency may disclose your health information prior to and in reasonable anticipation of your death.

**For Organ, Eye or Tissue Donation.** The Agency may use or disclose your health information to organ procurement organizations or other entities engaged in the procurement, banking or transplantation of organs, eyes or tissue for the purpose of facilitating the donation and transplantation.

**For Research Purposes.** The Agency may, under very select circumstances, use your health information for research. Before the Agency discloses any of your health information for such research purposes, the project will be subject to an extensive approval process. (If the Agency intends to routinely conduct research it is important to carefully review the authorization requirements for research exceptions and revise the Notice provisions as needed.)

**In the Event of A Serious Threat To Health Or Safety.** The Agency may, consistent with applicable law and ethical standards of conduct, disclose your health information if the Agency, in good faith, believes that such disclosure is necessary to prevent or lessen a serious and imminent threat to your health or safety or to the health and safety of the public.

**For Specified Government Functions.** In certain circumstances, the Federal regulations authorize the Agency to use or disclose your health information to facilitate specified government functions relating to military and veterans, national security and intelligence activities, protective services for the President and others, medical suitability determinations and inmates and law enforcement custody.

**For Worker's Compensation.** The Agency may release your health information for worker's compensation or similar programs.

### **AUTHORIZATION TO USE OR DISCLOSE HEALTH INFORMATION**

Other than is stated above, the Agency will not disclose your health information other than with your written authorization. If you or your representative authorizes the Agency to use or disclose your health information, you may revoke that authorization in writing at any time.

### **YOUR RIGHTS WITH RESPECT TO YOUR HEALTH INFORMATION**

You have the following rights regarding your health information that the Agency maintains:

- **Right to request restrictions.** You may request restrictions on certain uses and disclosures of your health information. You have the right to request a limit on the Agency's disclosure of your health information to someone who is involved in your care or the payment of your care. However, the Agency is not required to agree to your request. If you wish to make a request for restrictions, please contact the Privacy Officer.
- **Right to receive confidential communications.** You have the right to request that the Agency communicate with you in a certain way. For example, you may ask that the Agency only conduct communications pertaining to your health information with you privately with no other family members present. If you wish to receive confidential communications, please contact Privacy Officer. The Agency will not request that you provide any reasons for your request and will attempt to honor your reasonable requests for confidential communications.
- **Right to inspect and copy your health information.** You have the right to inspect and copy your health information, including billing records. A request to inspect and copy records containing your health information may be made to the Privacy Officer. If you request a copy of your health information, the Agency may charge a reasonable fee for copying and assembling costs associated with your request.
- **Right to amend health care information.** You or your representative have the right to request that the Agency amend your records, if you believe that your health information is incorrect or incomplete. That request may be made as long as the information is maintained by the Agency. A request for an amendment of records must be made in writing to Privacy Officer. The Agency may deny the request if it is not in writing or does not include a reason for the amendment. The request also may be denied if your health information records were not created by the Agency, if the records you are requesting are not part of the Agency's records, if the health information you wish to amend is not part of the health information you or your representative are permitted to inspect and copy, or if, in the opinion of the Agency, the records containing your health information are accurate and complete.
- **Right to an accounting.** You or your representative have the right to request and accounting of disclosures of your health information made by the Agency for certain reasons, including reasons related to public purposes authorized by law and certain research. The request for an accounting must be made in writing to Privacy Officer. The request should specify the

time period for the accounting starting on or after April 14, 2003. Accounting requests may not be made for periods of time in excess of six (6) years. The Agency would provide the first accounting you request during any 12-month period without charge. Subsequent accounting requests may be subject to a reasonable cost-based fee.

- **Right to a paper copy of this notice.** You or your representative have a right to a separate paper copy of this Notice at any time even if you or your representative have received this Notice previously. To obtain a separate paper copy, please contact Privacy Officer.

## **HIPAA Notice Privacy Practices**

### **DUTIES OF THE AGENCY**

The Agency is required by law to maintain the privacy of your health information and to provide to you and your representative this Notice of its duties and privacy practices. The Agency is required to abide by the terms of this Notice of its duties and privacy practices. The Agency is required to abide by the terms of this Notice as may be amended from time to time. The Agency reserves the right to change the terms of its Notice and to make the new Notice provisions effective for all health information that it maintains. If the Agency changes its Notice, the Agency will provide a copy of the revised Notice to you or your appointed representative. You or your personal representative have the right to express complaints to the Agency and to the Secretary of DADS if you or your representative believe that your privacy rights have been violated. Any complaints to the Agency should be made in writing to Privacy Officer. The Agency encourages you to express any concerns you may have regarding the privacy of your information. You will not be retaliated against in any way for filing a complaint.

### **CONTACT PERSON**

The Agency has designated the Privacy Officer as its contact person for all issues regarding patient privacy and your rights under the Federal privacy standards. You may contact this person or the administrator at:

AGENCY NAME: Journeys Hospice of Texas

AGENCY ADDRESS: Mailing: 4830 Whirlwind Dr

San Antonio, YX 78217

AGENCY PHONE # **(833) 467-5468**

### **EFFECTIVE DATE**

This Notice is effective January 1, 2017

# **FAMILY EMERGENCY PREPAREDNESS and RESPONSE PLAN**

This booklet is a plan template and is intended to give you a format and possible suggestions about information you might want to include in a family disaster plan. It is not all inclusive and should be modified as needed. You should adapt this plan to your own specific needs or requirements.

Keep this plan updated with current and correct information.

**NOTE:** It is important to store this document in a secure location to reduce the risk of losing personal information that could lead to possible ID theft and fraud.

In addition, this document should be stored in a water tight container and on a computer disk.

## Household Members

Household Members	Relation / Birthdate	Social Security

Pets	Pet Rabies Vaccination #	Vet Name and Number

## Household Information

Home Address:					
Phone 1:		Phone 2:			
E-mail 1:					
E-mail 2:					
<b>Car Information:</b>					
Car 1:	Make	Model	Year	License #	
Car 2:	Make	Model	Year	License #	
Car 3:	Make	Model	Year	License #	
<b>Emergency Numbers:</b>					
<b>CALL 911 EMERGENCY</b>					
Doctor #1:					
Doctor #2:					
Doctor #3:					
Fire Number:					
Police Number:					
Ambulance Number:					
Poison Control Number:					
Hospital Emergency Room Number:					
Name/Number:					
Name/Number:					

*Note: After a disaster, 911 may not be working. Use these numbers as you listed above.*

## Contacts

<b>Utility and Service Contacts</b>		
Organization Name Water / Sewer	Address	Contact
		Phone
Organization Name Electric	Address	Contact
		Phone
Organization Name Gas	Address	Contact
		Phone
Organization Name Phone / Cable	Address	Contact
		Phone
Organization Name Home Medical	Address	Contact
		Phone

<b>Insurance / Other Information (Health, Auto, Home and Life)</b>		
Name	Policy # / Other Information	Phone



## Contacts

Name	Address/Physical Location to Home	Phone	E-mail Address	Cell Phone Number

*Note: Identify two neighbors. Agree to check on each other.*

Out- of-Area Contact #1			
Name	Home Address	Home Phone	E-mail Address
	Work Address	Work Phone	Cell Phone Number

*Important: During disasters, use phone for emergencies only. Local phone lines may be tied up. Make one call out-of area to report in. Let this person contact others.*

Out- of-Area Contact #2			
Name	Home Address	Home Phone	E-mail Address
	Work Address	Work Phone	Cell Phone Number

## Procedures

Reunion Procedures	
In or Around House / Apartment	Inside House / Apartment
	Outside House / Apartment
When Family is Not Home	Priority Location  (Leave note in a designated place where you will be: i.e., neighbor, relative, park, school, shelter, etc.)

*Note: Identify and discuss with household members the reunion places for a disaster prevents anyone from entering the home. Also, reunion and evacuation procedures need to include children at school and house members with disabilities. Talk to school officials. Write down procedures.*

Important Notes and Procedures

*Note: People with disabilities are advised to identify two or three people at work school, neighborhood, etc., who will assist them in the event of a disaster. In addition, please contact your local department of social services, local office on aging and local office of disabilities to discuss registering your specific need (DIAL 211).*

## Medication List

User's Name	Medication Name	Dosage / Frequency	Reason for Taking
Doctor	Prescription #	Date Started / Ending	Location of Medicine
User's Name	Medication Name	Dosage [Frequency	Reason for Taking
Doctor	Prescription #	Date Started / Ending	Location of Medicine
User's Name	Medication Name	Dosage / Frequency	Reason for Taking
Doctor	Prescription #	Date Started / Ending	Location of Medicine
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Doctor	Prescription #	Date Started / Ending	Location of Medicine
User's Name	Medication Name	Dosage / Frequency	Reason for Taking
Doctor	Prescription #	Date Started / Ending	Location of Medicine

*Note: Keep on hand at least seven days of vital medications and supplies. Talk to doctor before storing medication or if use two or more medications. Take them with you if you have to evacuate to a shelter, friend's house, or other family members.*

### Pharmacy / Doctors / Specialists

Pharmacist Name(s)	Pharmacy Name	Phone / Address
	Pharmacy Name	Phone / Address
Specialist Name	Area of Concern	Phone
	Organization	Address
Specialist Name	Area of Concern	Phone
	Organization	Address

Allergies to Medications	Person's Name	Person's Name
	Medication	Medication
Health / Disability Information		
Special Needs, Equipment, and Supplies		

Note: Fill this and all sections out in pencil. Update regularly.

## Utility Control

### Electricity:

In the event that you need to turn off the electricity in your house, go to the breaker box and do the following:

1. Turn off smaller breakers one by one.
2. Flip the "main" breaker last.

To re-energize your home, reverse the steps above.

### Water:

In the event you need to shut water off inside your home, find the main water valve and turn it to your right. To open the flow of water back into the house, turn it to your left.

### Gas:

#### **IMPORTANT - Only turn off your gas at the meter if you smell gas!**

To turn off natural gas in your house, take a wrench and tighten it on to the quarter turn valve that is on the pipe that feeds into the gas meter. Turn it one quarter turn to make the indicator parallel to the ground. In most locations, once you do this you cannot turn the gas back on to the house without the utility company.

### Propane:

If you live in an area that uses outdoor propane or LPT you will find this outside the home. Open the top of the tank and you will see either a regular turn knob or a quarter turn valve. Turn the knob to your right to shut off the flow of propane into your house. For quarter turn valve see above.

**Never run a generator inside; doing so may cause carbon monoxide poisoning and possibly death!**

## **Other Sources of Information**

### **FEMA**

1-806-621-FEMA (3362)

<http://www.fema.gov/>

### **Red Cross**

<http://www.redcross.org/services/prepare/>

### **Department of Aging and Disability**

[www.dads.state.tx.us/dem/hurricane.htm](http://www.dads.state.tx.us/dem/hurricane.htm)

### **Texas Evacuation Routes**

[www.txdps.state.tx.us/dem/hurricane.htm](http://www.txdps.state.tx.us/dem/hurricane.htm)

### **Assistance with evacuation - 211**

[www.211texas.org/211/](http://www.211texas.org/211/)

### **Important Number to Contact after a Disaster:**

#### **Local Department of Social Services:**

(Emergency food stamps, emergency Medicaid emergency financial assistance)

#### **FEMA:**

(Apply for disaster funds)

## HOME SAFETY CHECKLIST

Prevention is the best approach to safety. The National Safety Council states that four million serious accidents happen in the home each year. Periodic room-by-room checks are recommended. Agency staff will assess the home and inform the patient/family on recommendations to increase safety.

***Check appropriate areas of need.***

### Fire Prevention Checklist

#### Prevention

Check smoke alarms, make sure batteries are changed regularly and that the alarm is working.

Keep a fire extinguisher handy and make sure that all family members know how to use it.

Make sure any curtains near the stove or a furnace are firmly tied back and cannot come in contact with a burner or flame.

Check appliances for frayed electrical cords. Unplug all appliances when they are not in use. Avoid using long extension cords.

Don't wear long-sleeved or loose clothing that can come in contact with a burner or flame.

### Fall Prevention Checklist

#### Prevention of Falls and Other Injuries

Keep stairways and passageways free of clutter.

Don't wear loose or long clothing that can cause tripping when standing on a ladder or step stool.

Let the toaster cool and unplug it before reaching into it with a fork or other utensil.

Avoid slippery scatter rugs. Use nonskid pad or backing. Wipe up spills promptly.

Never run electrical cords under a rug.

Store hazardous materials (including bleaches and cleaning products) in a safe place and away from food.

Don't use pesticides or other poisonous substances in areas where food is prepared.

## **BATHROOM SAFETY CHECKLIST**

Make sure that electrical appliances (such as hair dryers, radios, shavers, heaters, etc.) are not placed where they can fall into the bathtub or come in contact with water.

Install grab bars on the side of the bathtub.

Use a skid-resistant bath mat by the tub or shower.

If the bathtub doesn't have a skid resistant bottom use a suction-type mat in the tub.

Have a special container for used razor blades and other sharp objects. Don't toss them into the wastebasket.

Don't store medicines in the bathroom. Instead, keep them in a closet or another dry, cool place that can be locked.

Leave a night light on in the bathroom and in dark hall ways.

## **SAFETY CHECKLIST FOR WEATHER PRECAUTIONS**

### **Tornado**

Go to closet or bathroom.

Wrap in a blanket.

Cover head with pillow.

### **Cold Weather**

Have available blankets.

Wear layered clothes.

Have hot food and drinks several times a day.

Cover head - up to 20% of body heat can be lost through the scalp

### **Hot Weather**

Wear loose cool clothing.

Drink liquids several times a day.

Use fans if air conditioning is not available.

Avoid direct exposure to the sun.



## **Poison Prevention Checklist**

Label all poisons.

Keep all substances in their original containers.

Store cleaning agents away from food and medications.

**Poison Control phone # 1-800-222-1222**

## **Hazardous Waste Disposal**

Place all needles and syringes in a hard plastic or metal container with a screw top or re-enforce top with heavy duty tape.

Place soiled bandages, disposable pads/sheets and medical gloves, masks and gowns in securely fastened plastic bags before placing them in the garbage can with other trash.

## **Oxygen (O<sub>2</sub>) Safety/Medical Gases**

Store medical gas cylinders on their sides in a stable protected area (i.e. protected from heat extremes).

Utilize O<sub>2</sub> in a area free from open flames and cigarettes.