Hospice Caregiver Guide
Hospice of the Comforter is a proud member of the Florida Hospital Connected Care family.
An important goal of hospice care is to keep your loved one as comfortable as possible and control their pain level. The nurse will ask the patient to rate his or her pain on a scale of zero to 10. If they are unable to verbalize their answer, the nurse may ask the caregiver to describe the patient’s actions, which may indicate if they are in pain.

If the patient is unable to speak, look for body language such as frowning, tension, anxiety, restlessness, moaning or movement, which may be signs of pain.

For children who cannot self-report their pain level, the illustration below may help them express the level of pain they are experiencing.

**How to use the Wong-Baker FACES® Pain Rating Scale**

1. Explain to the patient that each face represents a person with either no pain (HAPPY) or with pain (SAD).
2. Ask the patient to choose the face that best describes how he or she is feeling.

**Questions the Nurse May Ask**

- Where is the pain located?
- Does the pain hurt all of the time or some of the time?
- Does the pain feel sharp, dull, aching, throbbing, like pins and needles or another way?
- Does changing positions lessen the pain? Does it help to sit, stand, lie down or walk?
- Does eating, sleeping or taking medications help lessen the pain?
- What makes the pain worse? Is it worse when sitting, standing, lying down or eating?
- Does the pain stop you from doing things like bathing, dressing or eating?
Decreased interest in food and water is one of nature's ways of allowing a person to pass away more comfortably and peacefully. As the need for food and fluid decreases, the patient and caregiver may face difficult spiritual and emotional decisions. Your Hospice Care Team members are here to support you as you face these issues.

The following chart outlines the most common food and hydration issues you may encounter.

<table>
<thead>
<tr>
<th>When Patient Says</th>
<th>What is Happening</th>
<th>What to Do</th>
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</thead>
</table>
| “I am eating, but still losing weight.” | Some chronic illnesses increase the body’s metabolism, using more calories. | • Have a positive attitude about the amount of food the patient eats.  
• Ask about ways to increase calories of food the patient eats.  
• Focus on patient’s comfort instead of weight. |
| “I have no appetite.” | Fewer calories are needed as some diseases progress. | • Offer small amounts of food several times a day.  
• Don’t force the patient eat.  
• Ask the nurse if any medications may be affecting appetite. |
| “It hurts when I swallow or eat.” | Mouth and tongue may become dry because of medication or decreased fluid intake. | • Notify nurse if you see white patches in the mouth or if the patient complains of painful swallowing.  
• Keep mouth and lips moist with crushed ice, sips of water or lip balm.  
• Fill a small spray bottle with water, spray mouth and tongue as needed.  
• Provide frequent mouth care with toothettes or toothbrush. Avoid mouthwash with alcohol. |
| “When I eat or smell food, I become nauseated.” | • The body’s ability to digest food decreases.  
• Anxiety or pain may increase nausea.  
• Some medications may cause changes in taste or smell. | • Ask your nurse for medications to control nausea and vomiting.  
• Give pain and anxiety medications as ordered.  
• Reduce cooking smells.  
• Offer cool foods. Avoid greasy or spicy foods. The patient makes the final choice of what to eat. |
### Food and Hydration

<table>
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<th>When Patient Says</th>
<th>What is Happening</th>
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<tbody>
<tr>
<td>“I am hungry, but I fill up fast.”</td>
<td>• Digestion slows and food may stay in the stomach longer.</td>
<td>• Offer small amounts of food several times a day.</td>
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<td></td>
<td>• Normal sized meals may increase feelings of fullness.</td>
<td>• Do not force the patient to eat or drink.</td>
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<tr>
<td>“My family is afraid I’m starving to death.”</td>
<td>• Weight loss, weakness and skin color changes may occur.</td>
<td>• Offer food and liquid, but do not force the patient to eat or drink.</td>
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<td></td>
<td>• The body cannot process food in the final stages of terminal illness.</td>
<td>• Focus on patient’s comfort.</td>
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<td></td>
<td>• Decreased interest in food and water is one of nature’s ways of allowing a person to pass away more comfortably.</td>
<td>• Reassure patient that you support his or her decisions.</td>
</tr>
<tr>
<td>“I feel guilty because my family feels like I’m giving up.”</td>
<td>• Sharing food is an important part of many cultures. Caregivers often feel helpless when the patient cannot eat.</td>
<td>• Offer food and liquid, but do not force the patient to eat or drink.</td>
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<td></td>
<td>• The body’s need for food decreases as the disease progresses.</td>
<td>• Focus on patient’s comfort.</td>
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<td></td>
<td>• Low food intake doesn’t cause hunger or discomfort.</td>
<td>• Reassure patient that you support his or her decisions.</td>
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<td></td>
<td>• Eating more than he wants may cause discomfort.</td>
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<tr>
<td></td>
<td>• Not eating is a reminder that the disease is progressing.</td>
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</tr>
<tr>
<td>“What about tube feeding or IV fluids?”</td>
<td>• The body’s need for food and fluid decreases as the disease progresses.</td>
<td>• Keep mouth and lips moist with crushed ice, sips of water or lip balm.</td>
</tr>
<tr>
<td></td>
<td>• Giving IV fluids and tube feeding now may increase discomfort.</td>
<td>• Fill small spray bottle with water, spray mouth and tongue as needed.</td>
</tr>
<tr>
<td></td>
<td>• Dehydration is nature’s way of allowing a person to pass away comfortably.</td>
<td>• Provide frequent mouth care with toothettes or toothbrush.</td>
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</tbody>
</table>
Your hospice physician will determine which medications are related to your hospice care during your initial orientation. **Your nurse will order all of your hospice-covered medications.**

- Urgent medications will be ordered through a local pharmacy for you to pick up.
- Non-urgent medications will be ordered and delivered to the patient’s home.
- If the patient resides in a facility, the medications will be ordered through the contracted pharmacy.

If any of your loved one’s current medications are not related to his or her hospice diagnosis, your nurse will let you know. These medications can be obtained from your primary physician or specialist and picked up at your local pharmacy.

Your loved one’s medication supply will be checked by your nurse on each visit and be reordered as needed. If by Thursday, you notice there is not enough medication for the weekend, notify us immediately by calling (407) 379-0311.
Medication Safety Checklist

☐ Maintain a current list of medications.
☐ Advise your doctor and nurse of vitamins, herbal supplements and over-the-counter medications being taken.
☐ Notify your nurse if your loved one has any allergies.
☐ Do not stop, skip or change a dose without asking your nurse.
☐ Do not crush or break any medications without consulting your nurse. Some medications, such as sustained release medications, should never be crushed because this is dangerous.
☐ Do not give the patient a double dose if a medication is forgotten.
☐ Medications that have been discontinued or changed should be destroyed (See page 46).
☐ Consider setting up a daily log or using a weekly pillbox. Your nurse can provide a pillbox and set up a medication list for you.
☐ Keep medications out of the reach of children, pets and unauthorized or disoriented persons.
☐ Store medications away from heat or humidity.
☐ Limit or avoid alcohol use when taking prescription medications. There may be harmful effects from mixing alcohol and medications.
☐ Do not leave medication in bottles at the bedside at night. If necessary, leave the correct dose out in a small cup.
☐ Call Hospice of the Comforter if you have any questions about your medications.

Notify the nursing staff if:

• there are any new symptoms or side effects.
• the medication is not effective in managing symptoms.
• you become aware of a medication error.
• medication deliveries are damaged or have something missing.
• the patient visits another doctor and receives a new medication order.
Frequently Asked Questions

1. How is pain managed?
The nurse will assess your loved one to find where they are having pain, what type of pain they have and how intense the pain feels. If your loved one is having occasional pain, they will receive a short-acting medication that can be given as needed. You may hear this referred to as a PRN, an as needed medication or a breakthrough pain medication. Your Hospice Care Team will work to find the medication(s) that will keep your loved one most comfortable. Other relief measures can be tried to increase the patient’s comfort level as well.

2. What are the types of pain medication that may be used?
The doctor and nurse will consider the type and intensity of pain to decide on the right pain medication. Mild pain is usually treated with acetaminophen, aspirin or ibuprofen. Moderate to severe pain may need a stronger pain medication such as morphine or oxycodone. Pain that involves the nerves and bones may need additional medications.

3. What if the person continues to have pain or side effects from the pain medication?
Please notify Hospice of the Comforter any time, day or night, if your loved one’s pain worsens or if the current medication is no longer working. There is always a nurse available to address any pain management problems. Informing the hospice staff about your loved one’s pain and other symptoms is critical when it comes to keeping them comfortable.

There are several things that can be done to prevent side effects. For example, a doctor can prescribe laxatives or a stool softener for patients on opiates, to prevent constipation. Ask your nurse for more information if you experience side effects such as nausea, rash, sedation, etc.

4. What are opiate medicines?
Opiates are medicines used to control moderate to severe pain. They are usually used when other medicines have not been effective. Opiates work by blocking the pain and help to provide comfort and relief. The most common opiates are morphine and oxycodone.

5. Will the patient become addicted to pain medication if he takes it regularly?
When the patient’s body becomes accustomed to the pain medication, the dose of medication may be increased to keep the same effect. This is called tolerance. This is not an indication of addiction. Addiction occurs when a person craves a medication and takes it regardless of the harm it causes them.

If medication is stopped abruptly, the patient may show physical symptoms from withdrawal of the medication. This is called physical dependence. However, if the medication is slowly reduced, the person can come off the medication with few side effects.
6. Will the patient be drowsy all the time?
If an opiate pain medication is given for the first time or if the dose is increased because of increased pain, the person may be drowsy for the first two to three days. The body will then adjust and the drowsiness will subside.

7. If the patient takes strong medication now, will it still work if the pain gets really bad? Shouldn’t the patient save the strong pain medication for later?
There is no limit to the amount of strong pain medication that may be given. Your nurse will consult with your physician to obtain increases in pain medication when needed. The patient’s pain level and the frequency of the pain will determine the strength of medication needed.

What you can do:
- Give the medications as directed.
- Do not skip any long-acting dose of medication without permission from the nurse.
- Give the short-acting dose (PRN or breakthrough dose) if the patient is having pain. You may give the short-acting dose at the same time as the long-acting dose if the patient is having pain. If pain continues, call Hospice of the Comforter at (407) 379-0311 at any time, day or night.
- If activity causes pain, give the patient a dose of short-acting medication about 15 to 30 minutes before doing the activity.
- Keep records of the pain medication given to the patient. This information is important to the doctor and nurse in making medication adjustments.
- Ask your nurse about other pain relief methods such as hot or cold therapy.

Notify the nursing staff if your loved one:
- has an increase or change in the severity of pain.
- has needed more than three doses of breakthrough pain medication in a 24-hour period.
- regularly has pain before the next dose of medication is due.
- is having any unpleasant side effects, such as confusion, nausea, vomiting, restlessness, inability to urinate, rash or itchiness, allergic reaction (shortness of breath, hives).

8. Are there alternative methods to deal with pain?
Yes. Some of the most effective alternative methods used to alleviate pain include:

Distraction and Diversion
Changing thoughts or activities can help to lessen pain. By thinking or concentrating on something besides the pain, the pain loses some of its power. Things to try include:
- Change your activity. Move to a different room or place in the room.
- Listen to music. Concentrate on the sounds or words.
- Write in a diary or journal. Write letters, poems or stories.
- Watch television or movies.
- Read a newspaper, book or magazine.
- Take a walk, or sit outside and enjoy nature.
- Play with a pet.
- Play a game like cards or checkers.
Relaxation Breathing
- Sit or lie in a comfortable position with your feet uncrossed.
- Close your eyes.
- Take a deep breath and then breathe out slowly.
- Continue to breathe more deeply and slowly with each breath.
- While breathing out, think RELAX.
- Picture stress leaving your body with each breath out.

Relaxing Your Body
- Start with the relaxation breathing method.
- Feel your body becoming heavier with each breath.
- Think about your feet.
- Tighten your feet muscles as you breathe in.
- Relax your feet muscles as you breathe out.
- Repeat the tightening and relaxing.
- Think about your legs. Relax and tighten your leg muscles as you did your feet.
- Continue to tighten and relax each area of your body, moving up to your head. Start with your feet and move up to your legs, thighs, hips, stomach, chest, back, arms, hands and face.

Music Therapy
Turn on the radio, play a favorite CD or start singing or humming a song. Feel and listen to the rhythms. Breathe in and out with the music’s slower tempo. Music may help to:
- Distract attention away from pain.
- Relax your loved one so they may sleep better or more deeply.
- Release pent-up feelings.
- Energize the body, spirit or emotions.

Massage
Touch is a very powerful tool. Massage may help a person feel more relaxed. It is also a way to help the patient feel better while showing that you care. Massage can reduce stress and anxiety, distract the patient from thinking about pain, relax muscles and increase blood flow. To perform a light hand massage:
- Wash your hands.
- Remove your loved one’s rings, bracelets and watch.
- Cup their hand between both of your hands. Hold gently for a few minutes to warm the hand.
- Move your hand gently over their hand, as if you are petting a cat.
- Continue this motion while gently talking or listening to relaxing music.
- Gently stroke each finger.

Aromatherapy
Aromatherapy is the art of using fragrance from herbs, flowers, oils and trees to foster well-being. This can improve one’s emotional mood and state of mind.

Types of aromatherapy include:
- Massaging skin with a scented body oil or lotion.
- Placing potpourri in a bowl at the bedside.
- Using a light room fragrance.
- Placing fresh flowers at the bedside.
Shortness of Breath

Your loved one may say that they can’t get enough air or catch their breath. Their breathing rate may increase or become labored, causing anxiousness and restlessness. Shortness of breath can occur for a variety of reasons and can be treated with medication. Identify which, if any, activities or events increase the patient’s shortness of breath and notify the nurse. The nurse will assess the patient’s breathing during each visit and evaluate whether the medications are working. The nurse will speak with the physician who may change the dose or order a new medication. Oxygen may also be ordered by the nurse depending on the cause of the shortness of breath. If oxygen is ordered you will be taught how to administer it properly (See page 27).

How You Can Help

• Keep the room cool. Use a small fan blowing gently in the patient’s direction.
• Elevate the chest and head with pillows. A hospital bed may be ordered to help.
• Instruct your loved one to sit upright, leaning forward with arms on the side rails or elevated on pillows. This position helps the chest to expand.
• Remain calm, play relaxing music and minimize emotional upsets.
• Instruct your loved one to breathe in through the nose, and breathe out slowly through pursed lips so that the exhalation is extended.
• Ice chips, frequent sips of water, hard candy or artificial saliva may relieve a dry mouth.
• Frequent mini-meals may help. Full meals often make breathing harder.
• Give the patient loose, light clothing to wear.
• Alternate short periods of activity with periods of rest to help the patient conserve energy.

• Arrange the home so that your loved one does not have to exert a lot of energy. If possible, put a chair bedside or move the commode close to the bed.
• Administer medications as instructed by the nurse.

Notify the nursing staff immediately if shortness of breath:

• is present for the first time.
• is worse in spite of medications and the above suggestions.

Nausea and Vomiting

Possible Causes of Nausea, Vomiting and Dry Heaves

• Medications
• Uncontrolled severe pain
• Some foods and odors
• Moderate to severe anxiety
• Persistent coughing spells
• Radiation and chemotherapy
• Prolonged constipation

Nausea Prevention Tools

• Allow your loved one to eat whenever they feel like it. Give small amounts of dry food, such as toast or crackers, when they wake up.
• Eliminate foods, tastes and smells that nauseate them.
• Avoid serving fried, fatty, spicy or citrus foods.
• Experiment with sour foods such as sour hard candy, lemon sherbet or lemon pudding.
• Ask your nurse about the use of ginger capsules, tablets, candy, tea or ginger ale.
• Avoid giving pain medications on an empty stomach. Divide up medications and take at different times during the day.
• After eating, have them rest in a sitting or semi-reclined position.
• Keep a written record of when they need anti-nausea medication so you can keep your nurse updated.

What to do When Vomiting Has Occurred

• Prevent choking by turning your loved one on their side.
• Place damp, cool cloths on the forehead and neck.
• Help them rinse their mouth and brush their teeth.
• Have them avoid eating and drinking for one or two hours after vomiting.
• Give them small amounts of clear liquids such as broth, clear juices, popsicles, gelatin or sports drinks. Increase liquids as tolerated by the patient.
• Rest the digestive tract up to 24 hours, then try bland soft food like cereal or pudding.

Notify the nursing staff if:

• your loved one is vomiting repeatedly. The nurse may recommend anti-nausea/vomiting medication.
• the vomited material looks like coffee grounds or has blood in it.
• the patient cannot take the anti-nausea/vomiting medication.
• the current anti-nausea/vomiting medication is not helping.
• the patient is becoming weak, dizzy or thirsty.

Poor Appetite and Nutrition

Reasons for Decline in Appetite

• The disease process
• Nausea or vomiting
• Uncontrolled pain

• Loss or change in taste
• Lack of activity
• Drowsiness or long periods of sleep
• Difficulty swallowing
• Diarrhea or constipation

The patient’s appetite often decreases if they get weaker, and they may stop eating. It is important not to force your loved one to eat as this may lead to nausea and vomiting.

How You Can Help

• Offer small snacks four to six times a day.
• Give your loved one whatever food they want. Don’t worry about snacks being balanced or nutritious.
• Offer mouth care before snacks or meals (See page 15).
• If your loved one is complaining of nausea, give prescribed anti-nausea medication 30 minutes before snacks and meals.
• Suggest drinking liquids between meals and only sips of liquids with meals.
• Offer high calorie foods that are soft and easy to swallow such as pudding, ice cream and instant breakfast drinks or nutritional beverages.
• Provide companionship. Food tastes better when shared.

Notify the nursing staff if your loved one:

• has difficulty swallowing.
• has changes in appetite.
• has a sore or painful mouth.
• complains of nausea.
• vomits.
If your loved one becomes increasingly weak, they may have difficulty swallowing. This may occur when the nerves that coordinate swallowing aren’t working properly.

If they cough immediately after eating or drinking, or clear their throat several times, it may be an indication that some of the swallowed material has gone into the trachea or windpipe. In addition, infections of the mouth and throat can cause severe soreness that makes swallowing difficult.

### How You Can Help

- Use a straw to promote better swallowing.
- Instruct the patient to hold the fluid momentarily in the mouth and then swallow.
- Try thick liquids and semi-solid foods, which are easier to swallow.
- Try crushed ice, ice cream or sherbet at the beginning of a meal to stimulate the swallow reflex.
- Try putting pills in applesauce or pudding.
- Consult the nurse about which medications can be crushed to make them easier to swallow. Some long-acting, sustained release medications cannot be crushed.
- Offer easy to swallow foods such as:
  - nutrition shakes.
  - instant breakfast drinks.
  - yogurt.
  - soup.
  - ice cream.
  - pureed fruit.
  - pudding.
  - well-cooked veggies.

**Notify the nursing staff if your loved one:**

- is frequently choking or coughing after swallowing.

- is having difficulty swallowing medications. Changes in medication from pills to liquid may need to be made.
- can no longer swallow.
- complains of sore mouth or throat.
- has gray or white patches in their mouth or throat.

As the patient declines, they may eat and drink less, which may cause their mouth to become dry and sore. A dry or sore mouth also may be due to medications, infection, gum disease, decreased nutrition, decreased fluids or breathing through the mouth.

### Sore Mouth

Your loved one may develop a sore mouth that can be painful and make eating difficult.

### How You Can Help

- Check the tongue, sides of cheeks and the roof of the mouth for any white patches, sores, bruising or bright red pinpoint dots.
- Remove loose dentures that may be irritating the gums.
- Avoid hot foods, fluids and spicy foods.
- Avoid hard, coarse foods that can cause pain such as pretzels and potato chips.
- Avoid acidic juices like orange, pineapple and tomato.
- Try cold juices such as apple, pear, apricot or peach instead.
- Try foods that are cold and soft such as ice cream, yogurt or applesauce.
- Avoid mouthwash that contains alcohol. In its place, use a solution of ½ teaspoon baking soda and ¼ teaspoon of salt in a glass of warm water.
- Use a soft toothbrush or foam mouth swabs.
Notify the nursing staff if your loved one:

- has white patches, sores, bruising or bright red pinpoint dots in the mouth.
- is unable to eat or drink due to discomfort or soreness.

### Dry Mouth

Your loved one may develop a dry mouth, which can make swallowing foods difficult.

**How You Can Help**

- Try hard candies, ice chips or chewing gum. (Make ice chips by placing ice cubes in a plastic bag and crushing them with a blunt object.)
- Coat the inside of the mouth with milk before eating.
- Cut foods into small pieces to reduce the amount of chewing required. Add sauce or gravy.
- Apply lip balm to dry lips.
- Ask the nurse about a saliva substitute.

### Constipation

Constipation frequently occurs due to changes in diet, a decreased consumption of foods and liquids, a decrease in activity or medication side effects.

**How You Can Help**

- Try to include fruits in the patient’s diet. Offer a glass of prune juice daily.
- Increase fluids if possible. Warm fluids stimulate the bowel.
- Use stool softeners and/or laxatives as directed.
- Keep a written record of bowel movements and use of laxatives and/or stool softeners.

Notify the nursing staff if your loved one:

- has not had a bowel movement for two days.
- has any abdominal discomfort or runny stools.
- is having difficulty taking their laxatives.

### Diarrhea

Diarrhea can be very distressing for patients and their caregivers. Many factors can cause diarrhea including medication (especially antibiotics) and food.

**How You Can Help**

- Use gloves when cleaning the skin around the rectal area after each loose stool.
- Apply a moisture barrier protective cream to the skin to protect it from irritation.
- Increase the amount of fluids your loved one is drinking to keep them hydrated. Use room temperature liquids such as broth, sports drinks and clear fruit juices.
- Avoid dairy products, solid foods, sugar and stimulants such as caffeine or nicotine.

• Try “The Big Four” – bananas, white rice, unsweetened applesauce and plain, dry toast.
• Try using an adult brief to avoid accidents (See page 26).
• Keep a record for the nurse of the frequency and type of stools.

Notify the nursing staff if your loved one:
• has more than three loose bowel movements in a day.
• has blood in the bowel movement.
• has severe cramping or a fever.
• begins passing small amounts of liquid stool after being constipated.

Confusion
Patients often become confused as their disease progresses, which can be distressing to caregivers.

How You Can Help
• Speak quietly and in short, simple sentences.
• Keep the noise level down. Limit the number of people present in the room.
• When entering the room, always say who you are and what you are going to do.
• Do not try to correct your loved one as this may lead to an argument and increase their distress. Instead, try asking them questions such as “What is going on?” and “Tell me who is here.” Try to be supportive and accepting of their train of thought.
• Spend time sitting quietly with your loved one.
• Leave a small light on in the room at night.

Notify the nursing staff if:
• confusion has appeared for the first time or confusion has increased.
• your loved one is becoming restless with repetitive movements such as trying to get in and out of a bed or chair or picking at the air.
• confusion has placed your loved one at risk for falls or injury.

Difficulty Sleeping
There are many reasons patients have difficulty sleeping such as pain, general discomfort, depression, fear and anxiety, too much daytime napping, and frequent trips to the bathroom at night.

How You Can Help
• Have your loved one avoid caffeinated drinks, heavy foods or liquids in the evening.
• Give the patient a light bedtime snack such as a small amount of cereal and milk, cheese and crackers, ice cream or cottage cheese.
• Limit naps to an hour at a time during the day.
• Administer pain medication as directed to ensure comfort at bedtime.
• Establish a bedtime ritual that is followed each night.
• In chronic cases, sleeping medication can be administered as directed to promote sleep.

Notify the nursing staff if your loved one:
• is not sleeping at night.
• has difficulty falling asleep or staying asleep.

Skin Breakdown
Your loved one may begin to spend more time in bed due to increased fatigue. They may also begin eating and drinking less. As a result, they are at increased risk for skin breakdown. With appropriate preventive measures, skin breakdown can be minimized or avoided.

How You Can Help
• Encourage your loved one to change positions every hour when sitting in a chair. The patient can shift from one hip to the other, or alternate a pillow under each buttock to relieve pressure.
• Use a cushion in a chair or wheelchair.
• Encourage your loved one to change position every three to four hours while in bed. Help reposition them if they are too weak to turn themselves (See page 21).
• Use an alternating air pressure mattress on top of the regular mattress as directed by the nurse. Your nurse will arrange delivery.
• When your loved one is laying on their back, place pillows under the lower legs to lift the heels off the bed.
• When your loved one is lying on their side, place pillows between the knees and ankles.
• Apply lotion to elbows, knees and hips as long as the skin is not red.
• Keep urine and feces off the skin by applying a moisture barrier protective cream available from your nurse. Your nurse can also contact the physician if further treatment is needed.

Notify the nursing staff if your loved one:
• has any red or discolored areas that don’t go away in 15 to 20 minutes once the pressure is off the area.
• has any cracked, blistered or broken areas of skin.
• has any rashes that don’t respond to moisture barrier protective cream.
• if you need instruction on repositioning or you need assistance.

Depression
Depression is difficult to identify because the symptoms can overlap with disease symptoms. There is a tendency to assume that a terminally ill patient should be depressed by his or her situation, but there is a difference between feeling sad and being depressed.

Signs and Symptoms of Depression in Hospice Patients
• Sleep interruption (not related to pain or discomfort)
• Persistent pattern of too little or too much sleep
• Feelings of hopelessness, helplessness or desperation
• Recurring thoughts of suicide
• Anxiety and irritability
• Difficulty concentrating or making decisions
• Sadness or crying more easily than usual

How You Can Help
• Listen, without judging, when your loved one talks of feeling discouraged, hopeless, sad or suicidal.
• Ask them if they feel depressed.
• Make sure that they do not have access to firearms or other items that could cause harm.
• Administer anti-depressant medication, if ordered, as long as the patient is able to swallow.

Notify the nurse, social worker or chaplain if your loved one:
• develops mood, sleep or outlook changes.
• begins talking about not being able to cope with things, making statements like, “I wish I could end it all,” or asking you to give them enough medication to end things sooner.
• does not gain relief from anti-depressant medication. The nurse will consult the physician about a dosage or medication change.
Preventing Infection

One of the most important duties a caregiver has is infection prevention. Infections are caused by germs (bacteria or viruses) and can be dangerous for patients and caregivers alike. Contagious infections can be spread to many other people including caregivers, family members and visitors. Several steps can be taken to prevent the spread of infection including:

Hand-washing

Hand washing is a vital part of preventing the spread of infection. Wash your hands thoroughly with anti-bacterial soap, rubbing your hands together for at least 20 seconds. Rub between fingers and under fingernails. Dry hands with a clean paper towel.

Always wash your hands:
• before and after preparing or eating food.
• before and after giving personal care.
• after gloves are removed.
• after covering your mouth with your hand during a cough or sneeze.
• after going to the bathroom.
• after touching any open wounds and/or bodily fluids such as blood, saliva, pus, vomit, urine or feces.

Gloves

Disposable gloves should be worn whenever you expect to touch bodily fluids. Some common situations requiring gloves include:
• Changing a disposable brief
• Bathing the rectal or genital area
• Mouth care
• Urinary catheter care
• Colostomy or ileostomy care
• Dressing changes or wound care
• Using a home glucose meter to test blood sugars
• Touching tissue paper used to cough or blow nose
• Bathroom assistance when contact with urine or feces is likely
• Bathing the patient if there are open wounds

Waste Disposal

• Feces, urine, blood, vomit and liquid waste should be flushed down the toilet.
• Soiled disposable items like disposable bed pads, adult briefs, dressings, bandages and catheters should be double-bagged and tied securely before being put in household trash containers.

Bio Hazardous Waste

• Items soiled with large amounts of blood are placed in red bags supplied by Hospice of the Comforter. Your nurse will arrange for a bio-hazardous disposal service to pick up the filled red bags. Do not dispose of red bags in the regular trash.

Sharps Container

• If the patient’s care requires needles and syringes, your nurse will provide you with a red plastic sharps container. Keep the sharps container out of the reach of children and pets. When the container is full or no longer in use, seal it and give it to your nurse or take the sealed container to the nearest fire station. They are authorized to dispose of sharps containers.
• DO NOT dispose of needles or the red sharps container in your household trash or recycle bin. Never reach inside of the sharps container for any reason.
Linen and Clothing Care
• Remove blood by soaking material in cold water, applying stain remover or hydrogen peroxide, and rubbing until the blood comes out.
• Disinfect linens or laundry by washing in hot, soapy water with one cup of bleach for large loads. Dry at the highest temperature available. If the item is not color fast, use non-chlorine bleach.

Disinfectants
• Use a household disinfectant spray or solution on surfaces touched by blood, urine or feces. Certain infections may require special cleaning procedures. If this is the case, your nurse will give you the proper instruction.

Personal Care Supplies
Your nurse will provide the following supplies to help you fight the spread of infection.
• Disposable gloves
• No-rinse foam
• Disposable bed pads
• Wash basin
• Skin protectant cream

How to Give a Bed Bath
• If you have a hospital bed, raise it to waist height.
• Remove your loved one's upper-body clothing and cover them with the top sheet.
• Place a towel under their head and shoulders to protect the sheets from getting wet.
• Wash the face, neck, shoulders, arms and hands with a soapy washcloth. Rinse with a wet washcloth and dry with a towel.
• Move the sheet down to the waist. Wash the chest, underarms and abdomen. Dry thoroughly, especially between folds of skin.
• Cover the top half of your loved one's body with the top sheet and remove their lower-body clothing.
• Wash and dry the legs and feet. If the patient is able, allow them to wash their genital area with a separate washcloth.
• Cover the patient with the top sheet and change the water.
• Help your loved one turn onto their side.
• Use the original soapy washcloth and wash their back and buttocks. If it is uncomfortable for them to lie on their side, they can sit up while you wash their back.
• Dry thoroughly and help them put on clean clothes.

Bathing the Patient
If your loved one is well enough to shower, they should be encouraged to do so. A shower chair can be provided for safety and to conserve the patient's energy. If your loved one is too weak to shower, a bed bath may be given. Hospice of the Comforter can provide a hospice aide to assist with bathing and to teach the family proper bed bathing techniques.

What You Need for a Bed Bath
• A basin of warm water
• Two or three washcloths
• Two or three bath towels
• Soap or body wash

Caring for a Bed-bound Patient
Caring for someone who is confined to a bed can be physically challenging. It's important as a caregiver to determine your limits and ask others for help. Your hospice aide can be scheduled to assist you if needed. There are several methods for moving a bed bound patient which include:
Changing the Sheets (Side to Side):

1. If you have a hospital bed, raise it to waist height. Make sure the wheels are locked.

2. Raise the side rail on the opposite side of the bed. If someone is helping, have him or her stand on the other side of the bed.

3. Turn the patient onto his side facing away from you. Make sure he can’t roll off the bed.

4. Pull out the edge of the used bottom sheet from under the mattress. Roll it toward the patient’s back and tuck it under the back and buttocks.

5. Place the new bottom sheet on the bare mattress. Center the sheet. Tuck the excess on your side under the mattress. Gather the part of the sheet that will cover the other half of the bed into a roll along the patient’s back and buttocks. Press this roll under his back and buttocks next to the roll of the used sheet.

6. Raise the side rail on your side of the bed. Turn the patient toward you over the two rolls of sheets. If you do not have a side rail, make sure the patient does not roll off the bed.

7. Move to the opposite side of the bed and reach under the patient’s back and buttocks. Pull the used sheet downward and off. Now pull the new sheet downward under the buttocks and legs toward the bottom of the bed, tucking it in.

Changing the Sheets (Top to Bottom):

1. If you have a hospital bed, raise it to waist height. Make sure the wheels are locked.

2. Sit the patient up and roll the used bottom sheet down to the base of his back, tucking it under the buttocks.

3. Tuck the new bottom sheet under the head of the bed and extend it down to the base of the back and buttocks, rolling it up and pressing it next to the used sheet.

4. Lie the patient down and lower the head of the bed. Lift his buttocks off the bed.

5. Pull the used sheet downward and off. Now pull the new sheet downward under the buttocks and legs toward the bottom of the bed, tucking it in.

Moving Your Loved One to the Head of the Bed

1. If you have a hospital bed, raise it to waist height. Make sure the wheels are locked.

2. Fold a flat sheet in half.

3. Stand at the side of the bed. If using a hospital bed, raise the side rail on the opposite side to ensure the patient does not roll off the bed.

4. Roll the patient away from you and place the flat sheet lengthwise so that it extends from mid-thigh to above the head. Center the sheet in the middle of the bed. Roll up the excess along the length of the body.

5. Raise the side rail on your side of the bed. Move to the opposite side of the bed.

6. Roll the patient away from you over the sheet. While holding him, reach under the buttocks and back, and pull the draw sheet through. Extend it to the edge of the bed.

7. If you have a hospital bed, lower the head and raise the foot of the bed slightly.

8. Stand behind the patient at the head of the bed. Hold the sheet firmly with two hands, bend your knees and pull the sheet toward you. The patient will move on the sheet toward the head of the bed. You may remove the sheet or leave it on the bed.
Moving Your Loved One Sideways on the Bed

1. Follow steps one through six of the “Moving to the Head of the Bed” procedure.

2. Lower the head of the bed. From the side of the bed, hold the folded draw sheet firmly and pull toward you. The patient will move across the bed toward you. Place the patient in a comfortable position.

Moving Your Loved One to the Head of the Bed With Two People

1. Follow steps one through seven of the “Moving to the Head of the Bed” procedure.

2. After placing the sheet under the patient, have one person stand on each side of the bed. Roll the folded sheet up and hold firmly. Both people will lift the sheet at the same time, moving the patient up in the bed.

Helping Your Loved One Stand

This technique can be used for helping a patient out of a chair or off of a bed. For more help, use a gait belt (see page 25).

1. If you have a hospital bed, lower the bed to the lowest position.

2. Help the patient move to the edge of the bed or chair.

3. Stand with your knees on either side of their knees and keep your back straight.

4. Bend your knees to get down to their level.

5. Ask the patient to place their hands around your waist or loosely around your shoulders and rest his head on your shoulder. Grab around his waist.

6. Begin with a rocking motion and, on the count of three, pull the patient up with you as you straighten your legs. Do not attempt to lift him by straightening your back as this can cause back strain.

7. Make sure the patient is steady before releasing him.

Moving Your Loved One from Bed

Use this technique to move a patient from a bed into a chair, bedside commode or wheelchair.

1. If you have a hospital bed, lower the bed to the lowest position.

2. Position the chair at the head of the bed. Angle the chair 45 degrees, toward the bed. Make sure the closest side of the chair touches the bed. If moving the patient to a wheelchair, lock the wheels.

3. If the patient is strong enough, have him put one hand on the chair arm and the other on the bed, pushing up to stand.

4. If the patient is too weak, follow steps one through six of the “Helping Your Loved One Stand” procedure.

5. Support the patient while he takes small steps, turning around slowly until he has reached the correct position to be seated.

6. Have the patient back up until the chair is hitting the backs of his legs.

7. The patient should be holding you around the waist or shoulders with his head resting on your shoulder. Hold his waistband, or put your hands behind his back and gently lower him into the chair, keeping your back straight and bending your knees if necessary.

Re-positioning Your Loved One in Bed

It is important to turn a bed-bound patient frequently to prevent skin breakdown and the development of bedsores. Your nurse will advise you which positions are best for your loved one.
Some of the most common positions include:

- **45-degree angle**  
  Sitting up in bed with the head at a 45-degree angle.

- **Flat on back**  
  Lying flat on the back with one or two pillows supporting the head.

- **Side with pillows**  
  Lying on the side with a pillow under the head. A pillow is also supporting the upper leg that is slightly flexed. Another pillow is in front of the patient supporting their upper arm.

- **Flat on stomach**  
  Lying on the stomach with the head turned to the side and arms flexed at the elbow. Pillows support the head, chest and lower legs.

- **Flat on the stomach with one side bent**  
  Lying on the abdomen with one leg and arm bent. The leg and arm that are bent are both supported by a pillow.

### Safety in the Home

There are a host of measures you can take to make your home safer during the care process.

**Tips to Prevent Falls**

- Remove loose rugs.
- Keep halls and pathways clear of furniture, toys, etc.
- Help your loved one rise slowly after sitting or sleeping.
- Always lock the wheels of a wheelchair or hospital bed before your loved one gets in or out.
- Use a night light in rooms, halls and bathrooms.
- Give your loved one a bell, baby monitor or noise maker to call you.
- Notify the nurse if your loved one experiences dizziness or confusion from medications.
- Bowel or bladder incontinence may cause your loved one to rush to the bathroom, increasing the risk of a fall. Discuss using a bedside commode with your nurse to alleviate such a risk.
- Oxygen tubing, catheters and IV tubing can increase the risk of a fall. Ask your loved one to request help when getting out of bed or walking to avoid tripping.

**If your loved one becomes weak or unsteady, ask the nurse about helpful equipment such as:**

- Elevated toilet seats
- Bedside commodes
- Walkers
- Wheelchairs
- Non-slip shower booties
- Bed alarms
- Hospital beds
- Non-skid slippers
- Shower chairs
- Gait belts

### Additional Safety Concerns

- Keep electrical cords in good repair.
- Do not overload outlets or extension cords.
- Keep a fire extinguisher in your kitchen.
- Keep emergency numbers by the phone.
- Plug equipment from Hospice of the Comforter into separate electrical outlets.
- NEVER SMOKE IN BED OR AROUND OXYGEN.
- Have a planned escape route in the event of a fire.
- Utilize smoke detectors and change the battery twice a year.
- Use non-slip strips or a rubber mat in the tub.
- Keep a flashlight handy.
Hospital Beds

There are times when a hospital bed can be extremely useful to help keep your loved one more comfortable. If there is room, a hospital bed may be setup next to the spouse’s bed. If more space is needed, it often works well to put the bed in a den or living room. Your nurse will advise you where to set-up the hospital bed in your home.

Advantages of Using a Hospital Bed

- Adjusting the height of the bed helps your loved one get in and out easily.
- Adjusting the bed to waist height can help caregivers avoid back strain.
- Your loved one can hold on to the side rails when turning from side to side.
- The head of the bed can be raised, making eating and breathing easier.

Tips For Using the Hospital Bed

There are two types of hospital beds: a fully electric bed and a semi-electric bed. The hospital beds must be plugged into a grounded electrical wall outlet. Do not use extension cords or an outlet that is being used to power other major appliances. If you don’t have a three-prong outlet, we can provide an adapter.

Fully Electric Hospital Beds

The fully electric bed has a hand control with six buttons. Use only one function at a time.

- The upper set of buttons raise and lower the head of the bed.
- The middle set of buttons raise and lower the height of the bed.
- The lower set of buttons adjusts the foot of the bed.
- A hand crank is provided in the event of a power outage. The crank is located under the springs of the bed and can be used to adjust only the height of the bed. If a power outage is anticipated, be sure to put the bed in a comfortable position before power is lost.

Semi-electric Hospital Beds

The semi-electric bed has a hand control with four buttons. Use only one function at a time.

- The top set of buttons moves the head of the bed.
- The bottom set of buttons moves the foot of the bed.
- To raise the height of the bed, extend the hand crank at the bottom of the bed and crank it either clockwise or counter-clockwise. Be sure to put the hand crank back in the flush position against the bottom of the bed to avoid bumping your leg on it.
- Always make sure the wheels on each end of the bed are locked. This can be accomplished by stepping on the small extensions protruding from each wheel.
- The bed has partial side rails, which have been proven to be safer than full rails. A locking button on the rail must be pulled out to change the position. Our staff will demonstrate how to properly use the side rails.
- To avoid injury, do not attempt to disassemble or move the bed. Only our home medical equipment staff is authorized to do this.

Notify the nursing staff if the bed:

- makes unusual sounds or malfunctions.
- needs to be moved.
Gait Belts

A gait belt is used to help move your loved one from one place to another and to hold them up while they walk. The belt fits around their waist, giving you something to hold onto to keep them from falling. It also decreases the chance of you hurting your back while helping your loved one move or walk.

How to Use a Gait Belt

- Put the belt around the waist of your loved one. It should go over clothing with the buckle in front. If your loved one is female, be sure the belt is not over her breasts.
- Thread the belt through the teeth of the buckle and then through the other two openings to lock it.
- Be sure the belt is snug with just enough room to get your fingers under it.
- Prevent injuring your back by adhering to the following procedures:
  - Bend your knees and keep your back straight.
  - Lift using your arm and leg muscles.
  - Do not use your back muscles.
  - Do not twist your body while moving or lifting a person.

Shower Chairs

If your loved one is weak or unsteady on their feet, a shower chair is a helpful tool when it comes to showering. There are a variety of shower chair styles. Your nurse can help you determine which style is best for your loved one.

Bedside Commodes

To limit the risk of falling, place a bedside commode at the head of the bed if your loved one is weak or unsteady on their feet.

Tips for Using a Bedside Commode

- Adjust the height of the commode by pushing the buttons on the sides of the legs. Your loved one’s feet should rest squarely on the floor once seated.
- Place a small amount of water in the bucket before each use.
- When transferring the patient to the commode, put both hands on the arm rests and push straight down to prevent tipping.
- After each use, empty the removable bucket into the toilet using gloves and clean with a disinfectant spray or disposable wipes.

Over-toilet Commodes

A low toilet can be difficult for your loved one to use if they are weak. An over-toilet commode raises the height and can include handles for ease of use. It is possible to order an over-toilet commode for use in the bathroom as well as a bedside commode if needed.

Tips for Using an Over-toilet Commode

- When transferring the patient to the commode, put both hands on the arm rests and push straight down to prevent tipping.
- After each use, put gloves on and clean with a disinfectant spray or disposable wipes.

Canes and Walkers

Canes and walkers help your loved one maintain independence. Your nurse will determine the correct equipment for their needs and provide instruction for safe use.

Cane Use

- Canes must be used in the hand opposite the affected leg, regardless of which hand your loved one prefers to use.
• The patient should move the cane and the affected leg forward at the same time, bearing weight on the stronger leg.
• Once the cane is firmly placed, move the stronger leg forward.
• Quad canes (canes with four short feet extending from a flat base) have one flat side and one side that extends. The flat side must always be held closest to the body of the patient. Make sure the locking mechanism is secured.

**Walker Use**
• Instruct your loved one to lift the walker and place it forward so the rear legs of the walker are a few inches ahead of their feet.
• Take one step forward so the affected leg is even with the rear leg of the walker. The other leg is then brought forward and placed beside the extended foot.
• The patient should follow slightly behind the walker and should not step into the front of the walker. This may cause a loss of balance.
• The patient should not raise the walker off the ground and take multiple steps.
• Before using the seat of a four-wheel walker, make sure the brakes are in the locked position.
• When using the rollator in a stationary position, the hand brakes must be locked on the four-wheel walker.

**General Safety for Canes and Walkers**
• The height of the handgrip should be above the wrist when standing straight, providing a slight bend in the elbow.
• Do not allow the patient to use the walker to pull up from a sitting position.
• Do not allow the patient to go up or down steps.
• Remove rugs that are not tacked down.

• Assist your loved one when walking over uneven surfaces.
• Notify the nursing staff if the equipment is not working properly.

**Adult Incontinence Briefs**
If your loved one becomes weak, they may lose control of their bladder and bowel. It may be appropriate to use a disposable adult incontinence brief at this time. The brief provides a way to keep the patient and the bed dry and clean. It may be difficult for both the patient and caregiver to start using the briefs since it represents a loss of independence. However, briefs help minimize work for the caregiver and the spread of infection.

**Supplies You Will Need**
• Disposable gloves
• Incontinence brief
• Washcloth or disposable incontinence wipes
• Waste disposal container
• Towel
• Mild soap and water
• Moisture barrier protective cream
• Disposable bed protector

**How to Put on an Adult Incontinence Brief**
• Put on gloves.
• Explain to your loved one what you plan to do and give them instructions throughout the process.
• If using a hospital bed, raise the bed to waist height. Raise the side rail on the opposite side of the bed. Turn the patient on their side, away from you, making sure they do not roll out of bed.
• If necessary, cleanse the rectal and buttocks area thoroughly from front to back. Remove all stool, urine or skin care products from the skin using a wet washcloth or disposable incontinence wipes.

• Apply moisture barrier protective cream to the area.

• Remove gloves if soiled and put on new ones.

• Open the brief and position the end with the tabs at the patient’s lower back. Extend it over the buttocks with the brief centered. Pull the front of the brief between the legs.

• Turn your loved one back toward you onto their other side.

• Find the end of the brief under the buttocks and pull it through firmly so that the brief is extended.

• Position your loved one on their back and pull up the front of the brief and smooth over the stomach. Open the tabs so the adhesive is exposed and pull the side tabs across the stomach toward the center. Fasten the adhesive tabs to the plastic surface on both sides.

• Remove gloves and wash your hands.

• The brief has a line in the front that changes color when urine contacts it. Check every two hours and change as necessary.

• If the patient is mobile, the catheter can be secured to the upper thigh with a Velcro leg band that your nurse can provide.

• Make sure the tubing to the drainage bag doesn’t get kinked.

• Keep the drainage bag below the bladder at all times. The bag can be hooked onto the bed frame or onto the patient’s lower leg if using a leg bag.

• At least twice a day, empty the drainage bag through the spout on the bottom into a container that can be taken to the toilet to pour out. Remember to use gloves and to recap the drainage bag.

Notify the nursing staff if:

• there is cramping or pain in the bladder area.

• there is leaking around the catheter.

• no urine is draining into the bag.

• there is a significant change in the appearance or amount of urine in the bag.

• the catheter comes out for any reason. Accidental pulling on the catheter may cause pain. If pulled hard enough, the catheter may come out, causing bleeding.

Urinary Catheters

If your loved one prefers not to use an adult incontinence brief, it may be appropriate to consider a urinary catheter. A catheter drains urine from the bladder through a tube to a drainage bag. Your nurse can explain the pros and cons of using a urinary catheter and help you determine the best plan of action. Catheters are available that attach to the patient’s leg or to the bed.

How to Use a Urinary Catheter

• Clean the area where the catheter is inserted with soap and water. Rinse well. Do not use powder.

Oxygen Equipment

Oxygen Safety Tips

DO NOT ALLOW ANYONE TO SMOKE IN THE SAME ROOM WHERE AN OXYGEN TANK OR CONCENTRATOR IS USED. FIRES HAVE OCCURRED AND PATIENTS HAVE BEEN BURNED.

• Place a “No Smoking” sign on the front door of your home.

• If you are traveling in a car with an oxygen tank, do not allow anyone to smoke in the car.

• Oxygen must be secure at all times. Keep it in a place where it will not get knocked over. When traveling in a car, wrap the tank in a blanket so it will not roll.
• Before storing an oxygen tank, make sure the tank is shut off with the plastic key.
• Do not use electric razors, hair dryers or any electrical equipment when the oxygen is on.
• Do not use flammable products such as aerosol sprays, rubbing alcohol, paint thinners or other oil-based lubricants near oxygen.
• Do not use petroleum jelly to moisten your loved one’s lips or nose when using oxygen. If needed, use a water-based lubricant.
• Do not place the tubing under furniture, bed covers, carpets, clothing or other items that can kink the tubing and prevent oxygen flow.
• Remind the patient, family and friends of the location of tubing to avoid tripping and falls.

Notify the nursing staff if:
• the oxygen tank is at 25 percent or less.
• there are any concerns about the equipment working correctly.

Oxygen Concentrators
This electric machine concentrates oxygen from the air in the room and delivers it to the patient.

How to Use the Oxygen Concentrator
• Plug the concentrator into a grounded electrical outlet. Do not use an extension cord or a multi-plug adapter.
• The concentrator should be placed at least 12 to 24 inches away from walls, furniture, curtains, etc. It can be placed outside the patient’s room.
• A short alarm will sound when you turn on the concentrator letting you know the oxygen is flowing properly. You should notice bubbling in the bottle if a humidifier is present.
• Check the flow rate on the concentrator and make sure the metal ball rises to the correct level. Turn the dial until the metal ball is at the correct rate. Do not change the flow rate unless you have talked to the doctor or nurse.
• Our home medical equipment technician will provide the correct amount of tubing to accommodate patient independence. Observe safety precautions to avoid tripping and falls.
• If the oxygen flow is greater than 2 liters, your nurse may recommend using a humidifier bottle to moisten the air.

Nasal Cannula
If a nasal cannula is provided, the two prongs are placed in a curved downward position in your loved one’s nostrils. The tubing is looped behind the ears and then the small ring at the base of the tubing is slid up toward the throat to secure it. The cannula may be taken off for short periods of time if the patient’s nose becomes sore.

Oxygen Mask
If a mask is provided, it should be placed over the nose and mouth with the elastic straps put over the back of the head. Be careful not to allow the elastic straps to cut into the skin. If the tubing irritates the patient’s skin, use cotton balls or gauze to pad the tubing. The home medical equipment department can also provide “Oxy-Ears,” which is padding behind the ears.

Caring for the Oxygen Concentrator Equipment
• To fill the humidifier bottle, turn the concentrator off. Unscrew the bottle from the humidifier lid. Pour in distilled water to the fill line. Distilled water can be purchased at the drug or grocery store in gallon jugs.
• Clean the bottle daily. Turn the concentrator off and unscrew the humidifier bottle from the lid. Discard any remaining water. Wash the bottle with liquid soap and tap water. Rinse well. Refill the bottle with distilled
water to the fill line. Screw the bottle on tightly and turn the concentrator on. Make sure the water is bubbling.

- The bottle should be changed at least once a month if oxygen is used continuously.
- The nasal cannula should be changed once a week if it is used continuously.
- The oxygen tubing should be changed once a month.

**Troubleshooting**
- To check the oxygen flow, feel the ends of the cannula or place the nasal cannula in a glass of water. If bubbles come from the cannula, oxygen is flowing.
- If it appears the oxygen is not flowing
  - check the tubing for kinks.
  - make sure the tubing is not disconnected from the concentrator.
  - remove the humidifier bottle and re-screw it on.

**Notify the nursing staff if:**
- the patient is short of breath.
- there is no oxygen flow.
- there are any other problems with the concentrator.

**Tank Oxygen**
Most home patients use concentrators. In case of a power outage, a back-up oxygen tank is provided.

**Tank Oxygen Equipment**
- Oxygen tank
- Rolling cart
- Flow regulator
- Plastic “key” or wrench
- Round gauge on top that shows how much oxygen is left in the tank
- Tubing connected to a mask or nasal cannula

**Using the Tank**
- Be sure the flow regulator knob is at zero.
- Attach the tubing to the small metal projection or nipple at the bottom of the regulator.
- Open the tank with the plastic wrench by turning it counterclockwise.
- The needle on the oxygen gauge dial will now move and show how much oxygen is currently in the tank. Ask your nurse to order a new tank when the gauge reads between 1000 to 1500 psi.
- Turn the knob of the flow regulator to set the flow rate prescribed by the doctor.
- Place the nasal cannula in your loved one’s nose or the mask over their nose and mouth.

**How to Shut Off the Tank**
- Turn the flow regulator knob back to zero.
- Close the tank with the plastic wrench by turning it clockwise until tight.
Caring for someone at the end of their life can be a privilege, a blessing and an honor. This is a selfless time, and caregiving is a gift that rewards both the caregiver and the patient. There is a sense of intimacy when serving your loved one at their most vulnerable time. These experiences, although difficult at times, can be meaningful in unexpected ways.

The caregiving role may be something you’ve done most of your life or it may be a new experience. Regardless of your experience level, caring for a loved one with an incurable illness brings responsibilities and demands that may seem overwhelming at times.

Remember, you are not alone. Your Hospice Care Team is here to support you in your role as caregiver. We are here to help you learn how to care for your loved one, support you with information and resources, and help you work through any caregiving challenges. There are times when difficult decisions need to be made, and our team members are always available to help.

Ask For Help

Look at your situation to determine if you need help and what kind of help you may need.

Answering the following questions can help guide you:

- List all the demands on your time. What obligations do you have in your life such as work, children, pets, clubs, committees, etc.?
- How much time do you have to dedicate to the care of your loved one?
- If the patient’s condition worsens, can you adjust your time accordingly?
- Which family members, friends or church members are available to help you?
- Can you afford to hire additional help?

List Persons Who Can Help

- What can they do?
- What is their availability?
- Are they good at organizing things?
- Can they take care of the lawn or clean the house?
- Can they provide financial assistance?
- Can they pick up medicine or run errands?
- Can they listen to you when you need to talk?
- Can they make phone calls?
- Can they bring over a meal?

Self Care

The most important aspect of caregiving is self care. Taking care of yourself gives you the patience, energy and strength needed to take care of your loved one. It is normal for your stress level to rise, so it helps to find ways to manage the stress.

Exercise

Even a few minutes of stretching can make a difference. If you have a normal exercise routine, try to stick to it. You may have to adapt to a new schedule, but don’t put it aside.

Nutrition

We receive strength and energy from food. Try to eat three balanced meals or six small meals per day. Eat foods high in fiber such as fruits and vegetables.

Take Breaks

Plan activities with other people outside the home such as lunch with a friend. Participate in activities that you enjoy and make you feel
relaxed. Request a volunteer for a scheduled respite visit to stay with your loved one while you take a needed break.

Humor
Laughter can reduce stress. Put on a funny movie and watch it with your loved one. Read the jokes in Reader’s Digest or the comics in your newspaper.

Journaling
Each day, take some time alone to record your feelings, concerns and ideas in a journal.

Spirituality
Spirituality can be an important part of caregiving. It may help you rise above daily challenges and rebuild your strength. Set aside time for spiritual nourishment in any form that is meaningful to you. The hospice chaplain is available to help you realize your spiritual goals.

Take Care of Your Health
Get regular checkups and practice good preventive health care. By taking good care of yourself, you are indirectly taking care of your loved one. Discuss your needs, feelings, fears and concerns with your social worker. He or she is knowledgeable about the services offered by Hospice of the Comforter and community resources; and, can help you consider all your options so you can make informed decisions. Your social worker is also a skilled listener, counselor and may be able to help you problem solve a situation.

Understand Your Feelings
It is normal to experience strong feelings during this time. The following are some feelings that you may experience and ways to deal with them. You are not alone. A member of the Hospice of the Comforter team is always available at any time to talk with you.

Feeling Overwhelmed
As a caregiver, it is normal to find yourself facing situations over which you have no control. This can be frightening and stressful. Plan as best you can and trust that things will be resolved.

• Try not to make important decisions when you are upset. Give yourself time to calm down, even if you have to leave the room. Take deep, calming breaths and then reconsider the decision.
• Prioritize your time. Make a list and check things off as you complete them. This can help give you a feeling of accomplishment and control.
• Learn to say ‘no’. Determine what your limits are, and don’t hesitate to let others know what you can and cannot do. This is not a form of selfishness, but an expression of self love.

• Talk to someone you can trust to give you unbiased feedback. Your hospice social worker can be helpful.

Feeling Anger
You may be angry that your loved one is ill and can’t participate in activities. You may resent their dependence on you or the lack of understanding or assistance from others. You may feel angry over lack of personal time to do things for yourself. It is important to express your anger in an appropriate way before it gets worse.

Denying or repressing feelings of anger can result in resentment or being short-tempered. Discuss your feelings from your perspective. (For example: “When you say you’re going to help me and don’t show up, I feel like you don’t care.”) If your anger is based on frustration, beat a pillow, scream in your car, work in the garden, exercise or write down your feelings in a journal.

Feeling Fear
Your loved one may have symptoms you are not familiar with, or you may have questions about what to do or what to expect as the disease progresses. This may be frightening. Identify your fears and write them down. When you have the opportunity, address these with your nurse or other team members.

Feeling Guilt
Guilt can come unexpectedly. It may result from conflicts in relationships or second guessing decisions made about health care. Something innocently said by your loved one may trigger guilt. You may overreact to a situation and feel guilty about your reaction. If you’ve made a mistake or overreacted, apologize and forgive yourself.

Caregiver Burnout
It is common for people to feel overwhelmed when caring for a loved one. Below are some warning signs that may indicate that you need extra help or support. If you begin to experience some of the following symptoms, please discuss them with your social worker.

• Withdrawal from friends and family
• Loss of interest in activities you once enjoyed
• Feeling blue, irritable, hopeless or helpless
• Changes in appetite, weight or both
• Changes in sleep patterns
• Getting sick more often
• Feelings of wanting to hurt yourself or your loved one
• Emotional and physical exhaustion

Anticipatory Grief
Anticipatory grief is knowing a loss will come and mourning before it happens. When a loved one is dying, you have time to prepare, but you may experience symptoms of grief before the death has occurred. The intensity of the symptoms may vary, and they may come and go. Not everyone experiences anticipatory grief or all of its symptoms.
Symptoms can include:
• Depression
• Extreme concern for the dying person
• Crying
• Sense of helplessness
• Fearing continued uncertainty
• Denial
• Health issues such as fatigue, sleep loss and weight loss or gain

What You Can Do
• Acknowledge the joys and pleasures still available.
• Talk with a trusted friend or your social worker or chaplain.
• Give yourself permission to cry.
• Spend time on a hobby.
• Write your thoughts in a journal

Volunteer Services
Volunteers can be an invaluable resource for practical assistance and emotional support. Our volunteers complete many hours of special training and undergo extensive background checks. Volunteer Coordinators contact patients to determine if and how a volunteer may help.

Respite Visits for Caregivers
Volunteers provide companionship to the patient and give assistance if needed while the caregiver is away. Volunteers do not give medications or provide personal hygiene care.

Befriending Visits to Patients
Volunteers visit the patient on a regular basis to provide a caring presence, compassionate listening and support. When possible, the volunteer is matched to the patient’s interests. Volunteers can do special projects with patients such as reading, doing puzzles, knitting, baking and more. A patient who is a military veteran can request a volunteer military veteran to visit with them.

Complimentary Therapies
A host of complimentary volunteer services are available for your loved one including:
• Licensed massage therapists provide comfort massage for your loved one. (The doctor must approve and order this service.)
• Music volunteers provide music at the bedside.
• Pet therapy volunteers bring their trained, certified pets to visit your loved one.

Spiritual Care
Hospice chaplains are emotional and spiritual guides. They strive to fulfill the spiritual needs and desires of patients, caregivers and families. This is facilitated through intimate, confidential support, grief and pastoral counseling and crisis care.

Some patients and caregivers may find comfort in religious faith, language, rituals and symbols while others seek a more individualized spiritual perspective. Hospice chaplains can help individuals reconnect or maintain relationships with the religious communities of their choosing. Chaplains facilitate a deeper experience with the spiritual essence of being, meaning and purpose. They affirm the ultimate value of each and every life and assist with any unresolved issues.

Our chaplains provide support by creating a spirit of loving care and inner peace. Dealing with spirituality at the end of life may include finding strength to face one’s death or the death of a loved one, or making meaning out of the life remaining. Hospice chaplains go on this journey with patients and caregivers, regardless of religious affiliation and without imposing any particular religious perspective.
Life Reflections Program
Volunteers help your family create a legacy DVD of your loved one’s life story and personal memories or a photo montage compilation DVD.

Support for Bereaved Family and Caregivers
Volunteers are available to call or visit bereaved family and caregivers to provide support. Memory Bear Program volunteers sew teddy bears or pillows from clothing or other materials that belonged to your loved one. These items serve as a special gift of remembrance for family and friends.
Advance Directives
It is important for patients to discuss their values and wishes with their caregiver, loved ones and health care providers. An advanced directive is a legal document that makes these wishes known on paper, in advance, to direct others on how to make decisions for the patient if they cannot communicate. Your social worker can review any questions you may have concerning the legal documents associated with advance directives. An attorney should be consulted if in-depth questions or concerns arise.

Living Will
This is a written set of directions to your health care providers. It specifies what kinds of life sustaining treatment you wish to receive and circumstances under which you might want that treatment withheld or withdrawn.

Health Care Surrogate Designation
Appoints a person you trust to make health care decisions for you. Their authority begins when one or more physicians determine that you lack the capacity to make health care decisions for yourself.

Durable Power of Attorney
Allows you to designate who you want to handle your financial and legal affairs if you cannot. You may appoint more than one person.

Final Arrangements
Here is a checklist of things to take in to consideration to help with your planning.

Now:
- Basic Will (Non-taxable estate) – Distribution of assets to surviving spouse and, if none, then to children or specific beneficiaries outright.
- Will with Testamentary Trust (Non-taxable estate) – Everything to the surviving spouse and, if none, then to children as specific beneficiaries over a period of time.

Florida Hospital Foundation has a free Online Wills Planner designed to help you gather the information your attorney will need to plan for your future as well as a free Wills Guide they can send you. Learn more at fhf.giftlegacy.com

Immediately After Death:
- Obtain certified copies of the death certificate. Five copies with the cause of death and five without.
- Locate the will. You may also need to contact an attorney. A valid will must be filed for safekeeping with the probate court in the county of residence within 10 days following the date of death.
Within 30 Days

- Organize, prepare and send acknowledgement cards for flowers, memorial donations, food or spiritual remembrances.
- Notify insurance companies or your insurance agent. Request and file forms for life, medical, health, disability, travel accident, retirement benefits, homeowners and automobile. Note: You may need to change beneficiaries on your own policies.
- Notify the Social Security Administration of the death. For an appointment or to apply for benefits, call 1-800-772-1213.
- Cancel any direct deposits.
- Ask your pension plans, previous employers, workers’ compensation, and Veterans Affairs about burial and survivor benefits.
- Be careful paying bills. Verify what the expense is for and that services were actually rendered. Unscrupulous people prey on survivors by sending fraudulent bills.
- Notify your stock broker or investment specialist to change ownership and tax identification number on accounts, physical stocks and bonds, book entry securities, IRA accounts and mutual funds.
- Cancel the deceased’s driver’s license.

Within 60 Days

- Notify your bank(s) to change ownership and tax identification number if necessary. Savings, checking, money market and certificate of deposit accounts should be reviewed. Remember to leave one checking account open in joint names for at least one year to handle any payments or checks that may come payable to both of you.
- Inquire about mortgage loans, installment loans and credit card accounts. Each lending institution may have a different policy regarding changes due to death. Also check these accounts for any possible credit life insurance policy that may exist that would pay off the unpaid balance.
- Review who is authorized to access safe deposit boxes and make appropriate changes.
- Contact an attorney to review the estate and begin probate proceedings, if required.
- Have YOUR will reviewed by an attorney.
Funeral Arrangements

A funeral honors your loved one after they have passed. Planning a funeral or memorial service should include the wishes of the your loved one (which may be documented in their advance directives), as well as those of the family. Try to accomplish one task at a time, and ask for help from family and friends.

• Discuss the budget. The average cost* of a funeral with burial is $6,600 and a cremation is $3,200, but can increase or decrease based on your choices. Life insurance or savings may be available to help pay for the funeral. Funeral costs are expected to be paid at the time of the service, or billed to the deceased's family.

• Determine if there will be a burial or cremation.
  o Burials require caskets, clothing or personal items to be placed with the deceased. The location of the burial must be chosen.
  o Cremations can include a special vase or urn to be kept by loved ones or buried. Some may choose to have their ashes scattered in a special place.

• Choose a funeral home or cremation service. Ask for references and a price list.

• Choose a location. A memorial service may be held at the funeral home, a place of worship or another location.

• Decide on the program for the service. This may include music, photos, a video and a person to deliver the eulogy.

• Depending on your family’s customs, you may want to coordinate an after-service reception. This might be held at a restaurant, a family member’s home, the funeral home or place of worship.

• Some families choose not to have a service. This is perfectly acceptable if it is keeping within your family’s wishes.

Your social worker or chaplain can answer other questions you may have about funeral planning.

*Foxbusinessnews.com, Terry Sheridan, April 11, 2013
Common Signs and Symptoms that the End of Life is Near

Each person’s journey through the end-of-life process is unique. However, there are some common signs that usually appear to prepare the body for this transition. This process can take days to weeks, unless death comes suddenly from an event such as a heart attack or stroke. Now is a good time to spend extra time with your loved one, sharing your memories, thoughts and love. It is important to have time to say goodbye.

Your Hospice Care Team members will review what may be expected to happen in your specific case. It is important to call with any questions and report any changes in your loved one’s condition. If your loved one is no longer able to communicate, review their advance directive to familiarize yourself with how they would like to be cared for at the end of life.

Increasing Weakness

This is often the earliest sign your loved one is nearing the dying process. Their legs will become weak, and they may be unable to rise from a chair, get out of bed or walk to the toilet or bedside commode. Someone should be nearby at all times. It helps to think ahead and plan for how you will provide this increased care.

How You Can Help

• Notify the nursing staff when you notice this change. Equipment such as a hospital bed, wheelchair or bedside commode can be ordered. Hospice Aide visits may be started or increased.
• Ask for help from your family and friends if they are available.
• Discuss the changing situation with the social worker to review options for care when the patient is bed-bound.

Increasing Sleep

Sleeping increases until the person sleeps more than they are awake. They are usually capable of being aroused and may have short periods of being alert.

How You Can Help

• Let your loved one sleep as much as they want.
• Make the most of the time when they are awake, and give personal care and medications at this time.
• Make sure to wake your loved one to give them their regularly scheduled pain medications so pain control is maintained.

Decreasing Appetite

When your loved one no longer feels hungry, food and fluid intake will decrease. This is nature’s way of allowing a person to pass away more comfortably and peacefully.

How You Can Help

• Take cues from your loved one. Offer soft food and liquids, but do not force them to eat.
• Focus on comfort, not on the amount of food that is eaten.
• Keep their mouth clean and moist. Give mouth care several times a day (See page 15).

Difficulty Swallowing

Your loved one may begin to hold food or liquid in their mouth before swallowing. Gradually, it will become more difficult for them to swallow.
How You Can Help
• Let the nurse know when your loved one is having difficulty swallowing. Their medications will need to be changed from pills to liquid.
• Place liquid medication inside the cheek pocket and gently massage.

Change in Bowel and Bladder Function
Bowel movements become less frequent and the amount of urine decreases. Darker urine is expected as your loved one drinks less. They may become unable to control their bladder or bowels at this time.

How You Can Help
• Use disposable bed pads and disposable briefs.
• As long as your loved one can swallow, it is important to continue medications to prevent constipation.
• Clean the skin thoroughly after each passage of urine or stool and apply a moisture barrier to protect the skin.
• Discuss a urinary catheter with the nurse.

Confusion
Your loved one may have periods of confusion. Confusion is often pronounced at night and upon awakening.

How You Can Help
• Gently remind your loved one who you are and where they are.
• Speak in a calm, reassuring manner.
• Keep the lights on and the surroundings quiet.
• Stay with your loved one during bouts of confusion.

Restlessness
Restlessness may occur. It may be due to the changes in the body, lower oxygen levels to the brain, emotional issues or spiritual concerns. Your loved one may toss and turn, try to get out of bed, talk rapidly or pull at the bed covers.

How You Can Help
• Speak quietly.
• Keep the lights dim.
• Try soft music, giving a back rub or reading aloud.
• Notify the nursing staff. Medications can be administered to calm and relax your loved one.

Emotional and Spiritual Signs
When your loved one gets close to the final stage of dying, they may give hints in behavior or words that the time is close. Your loved one may:
• become less interested in what is going on around them.
• use expressions of speech that indicate they realize the end is close, such as “I am not going to win this ball game” or “I am going home soon.”
• “see” or “talk” with people who have already died.
• reach out for things that cannot be seen.

How You Can Help
• Be accepting of what your loved one says or does. Do not try to correct them. Ask gently what they are doing or seeing, and listen carefully.
• Listen for unspoken needs, such as, “Do they need to be reassured that you will be okay without them?”, “Are they needing your
• Express your love and appreciation for them.

The Five Stages of Grief

Elizabeth Kubler-Ross, a psychiatrist, pioneer in near-death studies and the author of the groundbreaking book, *On Death and Dying*, originally applied five stages to people suffering from terminal illness. They describe a process by which people cope and deal with grief and tragedy, especially when diagnosed with a terminal illness or after experiencing a catastrophic loss. Everyone experiences these stages at different times, different intensities and not necessarily in this order.

1. Denial

“I feel fine.”

“This can’t be happening, not to me.”

Denial is usually only a temporary defense for the patient. This feeling is generally replaced with heightened awareness of possessions and individuals that will be left behind after death.

2. Anger

“Why me? It’s not fair!”

“How can this happen to me?”

“Who is to blame?”

Once in the second stage, the patient recognizes that denial cannot continue. Because of anger, the person is very difficult to care for due to misplaced feelings of rage and envy.

3. Bargaining

“Just let me live to see my children graduate.”

“I’ll do anything for a few more years.”

“I will give my life savings if...”

The third stage involves the hope that the patient can somehow postpone or delay death. Usually, the negotiation for an extended life is made with a higher power in exchange for a reformed lifestyle. Psychologically, the patient is saying, “I understand I will die, but if I could just have more time...”

4. Depression

“I’m so sad, why bother with anything?”

“I’m going to die... What’s the point?”

During the fourth stage, the patient begins to understand the certainty of death. Because of this, the patient may become silent, refuse visitors and spend much of the time crying and grieving. This process allows the patient to disconnect from things of love and affection. It is not recommended to attempt to cheer up a patient who is in this stage. It is an important time for grieving that must be processed.

5. Acceptance

“It’s going to be okay.”

“I can’t fight it, I may as well prepare for it.”

In this last stage, the person comes to terms with his mortality or that of a loved one.

At this stage, the patient’s body begins to make its final transition. The following physical changes may occur in the last days and hours.
Unresponsiveness
Your loved one may not respond to touch or words.

What You Can Do
• Take turns with family and friends at the bedside.
• Turn your loved one every 3 or 4 hours and position them with pillows for comfort (See page 20).
• Let them know you are there through touch and a soft voice. Keep in mind that hearing remains until the end.

Breathing Changes
Your loved one's breathing rate may become rapid and labored. There may be periods of no breathing or a brief pause in breathing known as apnea. This is a normal part of the transition process.

Noisy Secretions in the Throat and Chest
Sometimes a rattling sound may occur in the back of the patient's throat with each breath. This is caused by the throat relaxing and the patient being too weak to clear their throat. Secretions may also accumulate in the airways of the upper chest. This rattling sound may be stressful for caregivers to hear, but it does not prevent your loved one from getting air.

What You Can Do
• Raise the head of the bed or prop your loved one up with pillows.
• Try positioning your loved one on their side. It may decrease some of the rattling sound.
• Notify the nursing staff if your loved one is having rapid or difficult breathing so that medication may be given to ease the breathing.

• Notify the nursing staff if the rattling sound is not relieved. Different medications may be given to decrease the accumulation of these secretions.

Decreased Urination
Little or no urine may be present as the kidney function slows down.

What You Can Do
• Use disposable bed pads and disposable briefs (See page 26).
• Clean the skin thoroughly after each passage of urine or stool, and apply a moisture barrier to protect the skin.

Poor Circulation
The toes and fingers may become pale or bluish, and areas on the legs and arms may have a blotchy purplish discoloration. This is a normal part of the transition process.

Temperature Changes
Because the body loses its ability to maintain an even temperature, your loved one’s temperature may vary. High fevers may occur or they may feel chilled. The chest and abdomen may be warm, while the arms and legs are cool to the touch.

What You Can Do
• Add blankets if your loved one is cold.
• If your love one is hot, gently sponge their skin with lukewarm water and let the water evaporate naturally.
• Notify the nursing staff if your loved one’s temperature is above 100.5 degrees orally so that appropriate medication can be given.
**Saying Goodbye and Giving Permission**

Giving permission to your loved one to let go can be hard. They may try to hold on, waiting to be sure loved ones will be all right. Your ability to release them from this concern and give them assurance that it is okay to let go is a gift you can give to your loved one.

Saying goodbye can be done in many ways. Touching your loved one can be comforting to you both. Tell your loved one that you love them. If they are unable to respond, answer for them, “And I believe you love me, too.” Forgive your loved one or apologize for past acts or words. If they are unable to respond, answer for them, “I believe you forgive me, too.” Recall favorite memories, say “thank you for...”, and tell them goodbye. Crying is a normal and natural response to saying goodbye. (From HospiceNet.org)

**What Does Hospice Do at the Time of Death?**

Remember, you are not alone. If you think your loved one has passed away, please call Hospice of the Comforter any time, day or night at (407) 379-0311. The nurse will ask you your name, the patient’s name and the time of death. If your loved one passes away at home, a team member will be sent to the home.

Signs that your loved one has passed away include:

- no breathing
- no heartbeat
- total loss of bowel or bladder control
- no response to stimulation
- eyelids slightly open
- eyes fixed
- mouth slightly open and jaw is relaxed

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**The Hospice of the Comforter staff member will:**

- confirm that the patient has passed away.
- advise the Hospice Care Team and the patient’s physician of the patient’s death.
- provide emotional support to the family and caregivers.
- assist in calling the funeral home as needed.

Members of the Hospice Care Team may call and visit to offer support to the caregiver(s). The Home Medical Equipment staff will call to schedule a time to pick up equipment.

A bereavement staff member will call to see how you are coping with your loss and let you know about the services that are provided to support you. If you need immediate assistance, please call Hospice of the Comforter’s Horizons Bereavement Center at (407) 379-0490. If there are children in the family under the age of 18 who need support, our Horizons Children’s Loss Program can provide support and advice.
Bereavement Care

Grief is a unique experience for each individual. One may be presented with an array of feelings such as sadness, anger, relief, guilt, and loneliness. These feelings are a normal part of grieving.

Our compassionate counselors at Horizons Bereavement Center offer support and resources to help you cope with your loss. The bereavement counselors will guide you and your family through the grieving process.

The Horizons Grief Support Program helps you rebuild your life by providing grief education, emotional and social support and community resource referrals. By creating a comfortable environment to share emotions and normalizing the grief process, our counselors help grieving persons achieve personal growth and adjust to the new reality of their lives without their loved ones.

The bereavement staff will:
- Keep in touch with the family by phone or by letter for up to 13 months.
- Offer support groups, education, and resources about the grieving process.
- Offer up to 6 sessions of individual bereavement counseling.
- Offer ongoing social opportunities, such as breakfast and lunch groups and potluck dinners.
- Provide bi-annual community memorial services throughout the year to honor those who have passed away.

How can I help my child through the illness and grieving process?

- Be honest – and use a KISS (Keep It Simple & Short)
- Encourage them to ask questions – then provide age appropriate answers.
- Describe their loved ones illness/diagnosis in age appropriate terms
- Use simple words – death and dying, no euphemisms.
- Minimize change and disruption, and keep up discipline and structure.
- Give them choices about their participation – to see their loved one or not, to attend the funeral or not.
- Provide opportunities for play – be prepared for children to return to playing or doing something familiar after asking a difficult question.

If you would like information about how to help a grieving child, please let your social worker know. Our Children’s Loss Educator can help adults learn how to talk to students about terminal illnesses and death; and provide individual support for students at our Horizons Bereavement Center.

How do I find out more about the Horizons Bereavement Program?

Bereavement services are available to Hospice of the Comforter families and the community at no charge. To learn more about our services, speak with your social worker or call the bereavement staff at (407) 379-0490. More information is also available on our website at HospiceOfTheComforter.org.
How to Respond to a Grieaver

Sometimes it is hard for others to know how to respond to the news of your loved one’s passing. The following is a list of suggestions of how your friends may offer their support to you.

- Be the first to call.
- Be a flexible and sensitive communicator.
- Be authentic and honest.
- Realize more help may be needed over time.
- Offer help in practical tasks.
- Understand community resources.
- Be there.

What not to say:  What to say:

“You must move on”  “Take all the time you need”

“I know what you’re going through”  “I am sorry for your loss. How are you feeling?”

“It’s God’s will”  “This must be hard for you”

“Why didn’t you call me?”  “Let us schedule a time to see each other”

“You are lucky to have had them for so long.”  “You must miss your loved one and the time you had together”

Understanding Grief

Grief is a normal and natural response to loss. Reactions to loss can vary depending upon many factors, such as whom we lost, the nature of the relationship, our support system and our own coping skills. Grief is painful and at times can seem unbearable. It is a combination of emotions that come and go, often without warning.

Grief can also cause physical reactions such as head and stomach aches, difficulty sleeping, increased anxiety or appetite changes. For some, making decisions and adjusting to changes can be difficult after a loss. Others may experience sadness, anger, guilt, loneliness or loss of faith.

Understanding grief and the feelings attached to grief are important steps in healing and in helping others who may be grieving. Horizons Bereavement Center understands that there is no “right” way to grieve or “right” amount of time to grieve. It can help to talk about grief with someone outside of your network of family and friends.

We Are Here For You.

For more information or to request counseling services, please call the Horizons Bereavement Center at (407) 379-0490 or visit our website at HospiceOfTheComforter.org.
Grief Support Groups

Though our group offerings change based on community and client needs, these are a sampling of the types of grief support groups available to you. Our support groups provide a safe place for grieving persons to express emotions, learn about normal symptoms of grief, and connect with other bereaved individuals. Groups are offered at no cost and typically consist of 4-12 participants.

General Grief Groups
These six-week sessions provide structure while learning about the grief process.

Young Widows and Widowers
For men and women age 62 and under who have lost their spouse or life partner.

Women’s Lunch Bunch
A Bereavement Counselor guides lunch outings at a restaurant in Altamonte Springs. Attendees pay for their own meals.

Men’s Breakfast Group
A Hospice Chaplain and Volunteer guide breakfast outings at a restaurant in Altamonte Springs. Attendees pay for their own meals.

Comfort Foods Potluck
These gatherings are facilitated by Bereavement Counselors and are held after an educational presentation. Attendees bring a dish to share.

Special Workshops
Throughout the year, grief education workshops are offered to address special topics such as stress relief, helping children cope with grief, and grieving as a family.

Memorial Services
Twice a year, community members and family members of patients are invited to attend a nondenominational memorial service in the spring and the fall to honor their loved one.
Disposing of Medications

During Course of Care or at the Time of Death

Following the death of a patient under the care of hospice, the nurse often offers to assist the family with the disposal of medicine associated with the deceased. Drugs once dispensed to the patient are the patient’s personal property.

In accordance with Federal, State and Local guidelines, as well as the Medicare and Medicaid Programs, the hospice organization will assist/educate patients and family in the disposal of medications that are no longer needed.

The Standard Operating procedure at Hospice of the Comforter outlines the necessary steps to dispose of medication in order to be environmentally safe, prevent accidental ingestion and unauthorized usage (diversion).

Steps for Destruction in the Home Setting

1. Remove medication from original container (to discard the container: eliminate all Protected Health Information (PHI) that can identify a patient including patient’s name. This can be done by black permanent marker or by scratching out).

2. Place pills in container and add a small amount of water to pills or capsules in order to partially dissolve them into a slurry. Mix slurry into cat litter, detergent, vinegar, used coffee grounds, charcoal, or non-toxic or spice to create a distasteful, pungent mixture in order to discourage consumption, then place in a sealed container (such as a sealable plastic bag or coffee can) and place in trash. Never mix drugs with toxic chemical other products that may be harmful to humans if swallowed or ingested.

3. For liquid medications, add directly to same items listed above to make slurry.
Frequently Asked Questions about Coverage of Hospice Care
Frequently Asked Questions about Coverage of Hospice Care

1. How does care for my illness change when I receive hospice?
When you choose hospice, it’s after the doctors and you have decided that efforts to cure your illness are not working, and there is now a limited life expectancy. Care that had been primarily focused on curative treatments or life prolonging measures now changes to care to maintain quality of life and comfort. The hospice team will develop a plan of care with you to meet these goals.

2. How can I use my Medicare insurance for hospice care?
Medicare has a special hospice benefit for Medicare Part A recipients. When you access your Medicare Hospice Benefit, you sign a form that tells Medicare that you want the chosen hospice to manage your care related to your terminal illness. This form states that you are aware that the care will be comfort focused and not curative. You are also aware that you will be giving up the use of your Medicare insurance for curative care and other standard Medicare services for your terminal illness and related conditions. By signing the form, you are agreeing to this plan.

It is very important that you keep the hospice team well informed of your needs and desires as all treatment measures related to your illness must be evaluated by the hospice to determine coverage. When your goals of care are no longer just comfort focused and you want treatments beyond the hospice plan of care, you have the right to stop hospice care by signing a revocation form. Your standard Medicare coverage would then go back into effect.

3. Will hospice cover the nurse and other needed health care visits in the home?
When you receive hospice services, you will be assigned an RN case manager who will set up the needed frequency of nursing visits with you. She will also determine your needs for a nursing assistant for personal care. You can also expect contacts from the hospice social worker and chaplain within the first 5 days of care. They, too, will arrange an agreed upon visit schedule with you based upon your needs. The hospice doctor may schedule visits when medical assessments are needed. All of these health provider visits are covered services.

4. Will hospice cover any medication or treatment measure that I want?
Hospice will cover medications and treatments for pain and symptom management for the terminal illness and related conditions. The hospice nurse will confer with the hospice doctor to determine relatedness and will clarify this with you. The hospice doctor may decide that a medication is not necessary at this time or may make a substitution from a medication list. This will be discussed with you. Medications and treatments that are not covered by hospice will be your responsibility.
5. If I have a Medicare Part D pharmacy provider, won’t all of my other medications be covered through this insurance?

There have been some recent changes for hospice recipients who also have Medicare Part D coverage for the cost of medications. If you attempt to obtain a medication for anxiety, constipation, pain, or nausea management through your Medicare Part D insurance provider, a hold will be placed on this medication. This is because the Medicare Part D provider assumes that these medications will be covered by your hospice. Therefore, it is very important that you keep the hospice nurse informed of any prescriptions that you have prior to taking them to a pharmacy.

6. Can my doctor visits still be covered when I am receiving hospice care?

You can still continue to see the doctor that you name as your attending physician on the Hospice Medicare Benefit election form. This will be the doctor with whom we will confer about your care and who will be responsible for signing your eligibility certification. No other doctor besides your named attending doctor and the hospice doctor can bill Medicare for your care for your terminal illness and any related conditions. You may change your attending doctor at any time by signing a form notifying Medicare of this change.

You can still see other consulting doctors for any care that is not related to your terminal illness. However, it is very important that you keep your hospice team aware of any planned doctor visits. We need to determine if the purpose of the visit is related to the terminal illness or any related condition. Hospice would then need to coordinate coverage of this visit if it is deemed medically necessary within the hospice plan of care. Otherwise, we would discuss your options if you continue to want care for your terminal illness that is not within the hospice plan of care.

7. What kind of care is covered if I need more care at home?

If you feel that your condition is worsening, you are expected to call the hospice 24 hours a day. The hospice nurse will assess your needs and contact either your doctor or the hospice doctor for additional medications or treatments that may be needed. There are times when supplemental nursing services may be required for additional hours in the home to help relieve symptoms of distress. In addition, a transfer can be arranged to our inpatient hospice unit if the level of care for pain or symptom management cannot be provided in the home. These services are covered by hospice for short periods of time.

If the care that is needed is primarily for assistive care needs, the hospice nurse and/or social worker can discuss options for a limited period of additional nursing assistant hours in the home. In addition, placement for respite care in a skilled nursing facility for up to 5 days can be arranged.
8. Can I go to the hospital at any time and expect for this to be covered?

When you have chosen the Hospice Medicare Benefit, you have given up standard care for your terminal illness and related conditions. Therefore, care in an emergency room or hospital and any related ambulance transportation would not be covered by Medicare unless it is arranged by hospice. It is important that you notify hospice prior to or immediately upon any hospitalization so we can help to assure appropriate provision and coverage of needed services. The hospice nurse can help to evaluate the goals of care with you in the hospital setting and arrange for care in the hospital or our own inpatient unit if the needs warrant. If you want treatments in the hospital for your terminal illnesses that are not within the hospice plan of care, your options can be discussed with you.

9. What happens to my health care coverage if I choose to stop hospice services?

At any time in the course of receiving hospice care, the regulations specify that you can choose to revoke the hospice benefit which means that you want to stop services. To revoke the election of hospice care, the individual must file a document with the hospice that includes a signed statement that the individual revokes the election for Medicare coverage of hospice care for the remainder of that election period and the effective date of that revocation. An individual may not designate an effective date earlier than the date that the revocation is made.

Upon revoking the election of Medicare coverage of hospice care for a particular election period, an individual resumes Medicare coverage of the benefits waived when hospice care was elected. This is usually the case with other insurances as well. Hospice care may be restarted at a later date if eligibility requirements are met.

10. What happens to my health care coverage if a hospice discharges me from services?

Regulations permit hospice programs to discharge patients under only three circumstances:

• The patient moves out of the hospice’s service area or transfers to another hospice.

• The patient’s condition improves and he/she no longer considered terminally ill with a six-month or less prognosis.

• Discharge for cause: There may be extraordinary circumstances in which a hospice would be unable to continue to provide hospice care to a patient. These situations would include issues where patient safety or hospice staff safety is compromised.

When a patient is to be discharged due to no longer being terminally ill, he/she may ask the Quality Improvement Organization (QIO) for an expedited review of the discharge. Hospice services will continue during this short appeals process.

The hospice team members will engage in a discharge planning process with the patient and caregiver prior to discharge. Upon discharge, the patient loses the remaining days in the benefit period. General coverage under Medicare is reinstated at the time the patient is discharged. This is usually the case with other insurances as well. Hospice care may be restarted at a later date if eligibility requirements are met.
Your Generosity Heals.

Hospice of the Comforter is compassionate people providing compassionate care.

The Florida Hospital Foundation is committed to the current needs and future sustainability of the mission and ministry of Hospice of the Comforter. Your generosity changes lives for Hospice of the Comforter patients and their families.

Your gift changes lives.

• Celebrate life with a memorial gift
• Suggest gifts in lieu of flowers
• Name a room, garden or plaque in honor of someone special
• Designate your gift to support a program or people
• Pledge an annual or monthly gift in remembrance
• Honor someone for an anniversary, birthday or special holiday
• Donate items, equipment or supplies from the Hospice Wish List
• Leave a legacy gift in your will

In Partnership with:

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Florida Hospital Foundation is deeply grateful for the support of our friends in the community. THE REGISTRATION NUMBER ISSUED BY THE FLORIDA DEPARTMENT OF AGRICULTURE AND CONSUMER SERVICES (“DEPARTMENT”) FOR SUNSYSTEM DEVELOPMENT CORPORATION IS CH4118. A COPY OF THE OFFICIAL REGISTRATION AND FINANCIAL INFORMATION MAY BE OBTAINED FROM THE DIVISION OF CONSUMER SERVICES BY CALLING TOLL-FREE WITHIN THE STATE. REGISTRATION DOES NOT IMPLY ENDORSEMENT, APPROVAL, OR RECOMMENDATION BY THE STATE. THE TOLL FREE NUMBER IS 1 (800) 435-7352.

In Partnership with:

Florida Hospital Foundation
The skill to heal. The spirit to care.

Hospice of the Comforter
FLORIDA HOSPITAL CONNECTED CARE

550 East Rollins Street, Sixth Floor | Orlando, FL 32803
FloridaHospitalFoundation.org
Patient Resources
ADVANCE DIRECTIVES

According to Florida Statutes Chapter 765, every competent adult in the State of Florida has the right to control decisions relating to his/her own care, including the right to choose or refuse medical or surgical treatment. This right is subject to certain interests of society such as the protection of human life and preservation of ethical standards in the medical profession. Artificial prolongation of life for a person with no reasonable medical expectation of recovery may only serve to secure a precarious and burdensome existence, while providing nothing medically beneficial to the patient.

Advance Directives are intended to:

1. Preserve individual rights and intentions in the event the individual is no longer able to participate in his/her health care decisions.

2. Encourage communication between the patient and his/her family, physician and health care providers regarding the patient's intentions.

3. Provide an opportunity for verbal or written declarations instructing the physician to provide, withhold or withdraw life-prolonging procedures.

4. Allow each individual to designate another person to make treatment decisions in the event that he/she is unable to make his/her own decisions.

PHILOSOPHY & POLICY ON ADVANCE DIRECTIVES

Hospice care neither hastens death nor prolongs life. When patients with life-limiting diseases and their caregivers choose hospice care, this means that aggressive, lifesaving or curative medical interventions are no longer their choice or option. At that point, they have chosen to receive comfort care that relieves pain or other symptoms in order to experience quality time at the end of life.

Hospice provides an interdisciplinary team of healthcare professionals who make regular visits and are available on call 24-hours every day to support, encourage, guide and teach palliative caregiving to families taking care of the terminally ill person in their place of residence.

Hospice respects patients' and caregivers' rights to make decisions about all medical interventions. If the patient/caregiver should choose lifesaving, aggressive measures outside the hospice plan of care, they accept responsibility for these choices. Hospice of the Comforter will respect that choice, offer information on alternative health care options consistent with their treatment choices, discharge the patient from Hospice of the Comforter, and encourage readmission when palliative end of life care is their choice.

TYPES OF ADVANCE DIRECTIVES

Under Florida Law, advance directives take several forms. You may exercise your right of self-determination through a Living Will (LW), a Health Care Surrogate (HCS), Health Care Durable Power of Attorney (DPOA), and in conjunction with your physician, a Do Not Resuscitate Order (DNRO). Please read this information carefully. Do not sign any documents unless you fully understand the information. You may wish to discuss this material in more detail with your physician, family or legal advisor.

*NOTE: The legal basis for these rights can be found in the Florida Statutes Chapter 765 and Federal law 42-CFR.-489.*
LIVING WILL

The State of Florida recognizes the legal right of any adult to make a written declaration to withhold or withdraw life-sustaining procedures.

- A “living will” may be signed by a competent adult at any time.
- Before exercising the incompetent patient’s right to forego treatment, the surrogate must be satisfied that:
  a. the patient has a medical condition from which there is no reasonable probability of recovery and which without treatment, can be expected to cause death, or
  b. a persistent vegetative state characterized by a permanent and irreversible condition of unconsciousness in which:
      1. the patient does not have a reasonable medical probability of recovering capacity so that the right could be exercised by the patient.
      2. the patient has an end-stage condition, the patient is in a persistent vegetative state, or the patient’s physical condition is terminal.

HEALTH CARE SURROGATE

A person may designate a Health Care Surrogate (HCS), delegating this individual to make healthcare decisions if/when a person lacks the capacity to do so, unless authority has been expressly limited by the individual, to:

- make health care decisions which they believe you would have made
- to provide informed consent if you are incapable of doing this for yourself
- provide written consent not to resuscitate
- have access to appropriate medical records
- authorize release of information and medical records

Any competent adult may designate a person to serve as his/her health care surrogate. It is wise to notify the person designated as the surrogate of this designation to make certain he/she is willing to serve as your surrogate. Even if named in a Living Will, a person named as a health care surrogate has the right to refuse to serve. You should consider naming a backup in the event your first choice is unable or unwilling to serve. It is also your responsibility to notify the physician that you have signed a Living Will and provide him or her with a copy.

A health care surrogate cannot consent to:

- abortion
- sterilization
- electroshock therapy
- psychosurgery
- experimental treatment or therapy with those exceptions provided by Florida law
- voluntary admission to a mental facility
- withholding or withdrawing life-prolonging procedures from a pregnant patient prior to viability

Once you have designated a health care surrogate, this designation revokes any prior designations. The law requires that your physician and your health care surrogate review your capacity to consent every 30 days or at any time you request this to be done. If you ask to revoke the designation of your health care surrogate, your physician and one other physician who is not employed by the entity or associated with your physician will evaluate your capacity to make this decision.
HEALTH CARE DURABLE POWER OF ATTORNEY

This document appoints an individual to act on behalf of the person executing the document. The person appointed performs the same function as would a court-appointed guardian. Under Florida law, the person appointed may be given broad powers to make health care decisions for you.

These powers include:

• the right to require, consent to or withdraw any type of personal care or medical treatment for any physical or medical condition;
• the right to admit you to or discharge you from any hospital, other institution, or to home; and
• the right to arrange for consent to medical, therapeutic and surgical procedures.

Your agent must use due care to act for your benefit. The court may take away the powers of your agent if it finds that he/she is not acting properly. An individual granted a “Health Care Durable Power of Attorney” may not consent to any of the following without review by two physicians and review by a bioethics committee as appropriate unless specific direction is contained in the document:

• abortion
• sterilization
• electroshock therapy
• psychosurgery
• experimental treatment or therapy with those exceptions provided by Florida law
• voluntary admission to a mental facility
• withholding or withdrawing life-prolonging procedures from a pregnant patient prior to viability

Unless you expressly limit the duration of your agent’s power, or until you revoke this power or a court acting on your behalf revokes it, your agent may exercise the powers given by this document throughout your lifetime.

Proxy Decision-Makers. While a surrogate is someone to whom the patient delegates decision-making authority, a proxy is one to whom the responsibility falls by default when the incapacitated patient has not executed an advance directive. Unless a court has previously appointed a legal guardian for the patient, family and friends should be approached in the following order:

• Patient’s spouse
• Adult children
• Patient’s parent
• Adult siblings of patient
• Adult relative who is familiar with the patient’s values and beliefs
• Close friend of the patient

This order, dictated by common sense and standard practice, has been codified in the Florida statutes. Proxies (and surrogates) are tasked with directing care for the incapacitated patient in accordance with the principle of substituted judgment. That is to say, they are to make the decision they believe the patient would make if he or she could speak for himself or herself, based on their knowledge of the patient and his or her value system. When there is more than one adult child or sibling and they disagree about what the patient would want, care should be provided according to the directions of the majority of those available to participate in the decision-making process.
**FLORIDA DO NOT RESUSCITATE ORDER (DNRO)**

This informed consent, signed order directs the withholding or withdrawing of cardiopulmonary resuscitation (artificial ventilation, cardiac compression, endotracheal intubation and defibrillation). A patient with a DNRO shall still receive comforting pain relieving care.

This document (DH Form 1896, revised 2/2000, pursuant to Florida Statute Chapter 765), a copy or original may be honored by hospital emergency services, nursing homes, assisted living facilities, home health agencies, hospices, adult family care and emergency medical services. It is signed by a Florida licensed physician (458 or 459 FS), and the patient or his/her health care surrogate, proxy, court appointed guardian or Durable Power of Attorney.

Any advance directive (which includes the Living Will, Health Care Durable Power of Attorney, Health Care Surrogate and DNRO) may be revoked at any time by:

- another signed and dated document
- physically destroying the document
- verbally expressing the desire to rescind it.

**PATIENT BILL OF RIGHTS**

**PATIENT AND CAREGIVER RIGHTS AND RESPONSIBILITIES**

As a patient of Hospice of the Comforter I have the right to:

1. Be treated with courtesy and respect including appreciation of my individual dignity and protection of my privacy.

2. Complete life with peace, dignity, and the presence of supportive persons.

3. Receive information about services covered under the hospice benefit and information about the scope of services that hospice will provide, including specific limitations on those services.

4. Know who is providing my medical services and who is responsible for my care and what support services are available, including provision of an interpreter if necessary.

5. Choose my attending physician.

6. Give my informed consent for care and participation in decisions concerning my care, including who is providing and will be responsible for my care.

7. Receive information and counseling regarding financial resources for hospice care; upon request, receive a copy of any bills and charges sent to my insurance company.

8. Receive answers to questions and requests in a timely manner concerning diagnosis and plan of care, and not be deceived regarding diagnosis, treatments, risks and options.

9. Continue receiving medical and nursing services even if “curative” goals change to “comfort” goals.

10. Voice grievances regarding treatment or care that is (or fails to be) furnished and the lack of respect for property by anyone who is furnishing services on behalf of hospice.

11. Not be subjected to discrimination or reprisal for exercising my rights.
12. Be involved in developing my hospice plan of care.

13. Receive information on Advance Directives in accordance with Florida statutes.

14. Execute a Do Not Resuscitate Order (DNRO) at any time; rescind the DNRO at any time.

15. Receive hospice care and services with or without an Advance Directive and/or DNRO, understanding that life-prolonging measures are not part of the hospice plan of care.

16. Receive effective pain management and symptom control, including emotional or spiritual symptoms to the best of my physician’s and team’s ability.

17. Be free from mistreatment, neglect or verbal, mental, sexual or physical abuse including injuries of unknown source, and misappropriation of property.

18. Express my feelings and emotions in my own way, however changing that may be.

19. Refuse any treatment, except otherwise provided by law.

20. Request in writing discontinuation of hospice services at any time, for any reason.

21. Respect for the sanctity of my body, including honoring my wishes for arrangements after my death.

22. Respect for my value system, home environment, cultural traditions and my religious and/or spiritual experiences.

23. Have a confidential clinical record; have a copy of the Hospice of the Comforter Notice of Privacy Practices.

**PATIENT RESPONSIBILITIES**

As a patient I am responsible for:

1. Providing hospice, to the best of my ability, accurate and complete information about present complaints, past illnesses, hospitalizations, medications and other matters relating to my health.

2. Notifying hospice when I have unexpected changes in my condition and/or changes in my address or phone number.

3. Notifying Hospice of the Comforter when any Advance Directives are executed, changed or rescinded.

4. Providing Hospice of the Comforter with a copy of any Advance Directives including DNRO.

5. Informing hospice of my understanding or lack of understanding of what is expected of me.

6. Participating in developing and following the plan of care recommended by my physician and hospice, and accepting responsibility for any treatment not included in the hospice plan of care.

7. Keeping appointments and, when I am unable to do so for any reason, notifying the appropriate healthcare provider and/or hospice.

8. Understanding that Hospice of the Comforter will follow all applicable local, state or federal hospice laws and regulations in its provision of hospice care and services.
9. Providing a safe environment for hospice staff including refraining from smoking when hospice staff is present. (This requirement is due to documented risks associated with exposure to second hand smoke.)

10. Ensuring that any firearms are safely secured.

11. Ensuring that pets/animals are secured to prevent injury to staff.

**CAREGIVER BILL OF RIGHTS**

As the caregiver you have the right to:

1. Accurate information.
2. Have your own needs met.
3. Regular sleep and rest.
4. Ask and receive answers to your questions related to caregiving.
5. Participate in making decisions that affect your future.

**CAREGIVER RESPONSIBILITIES**

As the caregiver you are responsible for:

1. Providing or arranging for basic 24 hour care, including working with Hospice of the Comforter to arrange additional caregiver support as the patient’s care needs increase.

2. Providing a copy of the patient’s Advance Directives and/or DNRO if available, with the understanding that Hospice of the Comforter cannot honor an Advance Directive without seeing the information in writing.

3. Working with the patient and hospice team to develop and follow the plan of care and meet state and federal eligibility criteria; accepting responsibility for care and services outside the plan of care.

4. Calling hospice to report problems the patient and/or you are experiencing.

5. Being patient with yourself in this sometimes exhausting role.

6. Providing accurate and complete information necessary for hospice to bill Medicare, Medicaid or any other third party payer.

7. Asking questions when you do not understand how to provide care for the patient.

8. Following home safety precautions including those taught by hospice staff in order to provide a safe environment for the patient and avoid injury of the patient/caregiver.

9. Assisting to provide a safe environment for hospice staff while they are in patient's home, including refraining from smoking and not allowing others to smoke when staff are present. (This requirement is due to documented risks associated with exposure to second hand smoke.)

10. Ensuring that any firearms or other weapons are secured.

11. Ensuring that pets/animals are secured to prevent injury to staff.
PATIENT AND CAREGIVER MEDICATION RESPONSIBILITIES

The patient and/or responsible caregivers agree to:

1. Store all patient medications in a safe place, separate from other toxic drugs or chemicals, and out of the reach of children, pets, unauthorized or confused/disoriented persons.

2. Administer the patient’s medications as prescribed and stated in the patient’s hospice plan of care.

3. Dispose of the patient’s medications when no longer needed, as instructed by the hospice nurse.

4. Document dates and times when specific medications are given, if requested to do so by the hospice nurse.

5. Assist the hospice nurse in tracking the use of prescribed, controlled substances.

6. Read the patient education materials that accompany hospice-provided medications in order to be aware of the purposes and potential risks of certain types of medications.

7. Contact Hospice of the Comforter with any questions about the use, administration or disposal of any medication.

PATIENT FINANCIAL RESPONSIBILITY

Medicare

- Services not related to my terminal illness will continue to be covered under the Part A and Part B Medicare benefit.

- Hospice of the Comforter will be responsible for hospitalizations or other care and services that are preauthorized by Hospice of the Comforter and related to the terminal illness. Hospice of the Comforter must have a contract with the hospital or other provider for approval to be given.

- I understand that if I enter a hospital or utilize any provider with which Hospice of the Comforter does not have a contract, or if I seek care and services related to my terminal illness without preauthorization from Hospice of the Comforter, I will be responsible for payment for those services unless and until I voluntarily revoke the Medicare Hospice Benefit in writing.

- Hospice of the Comforter will provide equipment and supplies necessary for palliation of symptoms of my terminal illness. If I choose to obtain equipment or supplies from another provider, I will be responsible for the associated costs and Hospice of the Comforter will not be financially responsible.

- I understand that I will be responsible for any Medicare deductibles and/or copayments, if applicable.

Newly-Eligible for Medicare

- If I am receiving services from Hospice of the Comforter covered by a payer other than Medicare, I will inform Hospice of the Comforter if I become eligible for Medicare Part A before the effective date of the Medicare Part A coverage.
• I understand that I will be responsible for any Medicare deductibles and/or copayments.

**Medicaid or Medicaid Pending**

• I will not withhold information regarding income or assets that would result in ineligibility for the Hospice Medicaid Benefit.

• I agree to provide accurate and complete information and to cooperate fully in the Medicaid application process.

• If I am denied the Hospice Medicaid Benefit for any reason and am admitted to a long term care facility, I will assume total financial responsibility for room and board costs from the date of admission to that facility.

• If I am denied the Hospice Medicaid Benefit for any reason, or for any period of time during which I have received hospice care and services, Hospice of the Comforter will bill me or the responsible party/estate for those services.

• Hospice of the Comforter or the long term care facility will bill me or the responsible party/estate for any patient responsibility expenses as computed by the Department of Children and Family Services (CFS) office from the effective date of my Medicaid approval.

**Other Insurance Plans**

• Hospice of the Comforter works with many insurance carriers to provide end-of-life care and services.

• I will be responsible for knowing the coverage and limitations of my insurance plan, and for copayments or deductible costs.

• I will work with Hospice of the Comforter representatives and provide complete and accurate information necessary for payment for hospice care and services.

• I understand that I will be responsible for any deductibles and/or copayments not covered by insurance.

**Financial Assistance**

• The decision to provide hospice care and services is not based on a patient’s ability to pay.

• I will be responsible for providing complete and accurate information necessary to determine my financial responsibility and ability to pay for care and services received from Hospice of the Comforter.

• Financial assistance may be available to patients who demonstrate their eligibility based on income, assets and family size and who meet the financial criteria specified in the Hospice of the Comforter Financial Assistance policy.

• Hospice of the Comforter staff will assist patients who are uninsured or underinsured in completing and submitting the necessary documentation to be considered for financial assistance.

R7-Patient Financial Responsibility Created 6/17/11, Revised 5/15/14
General Emergency Preparedness

In Florida, when we think of emergency plans, we most often think of hurricanes. However, an emergency could be any event that interferes with your ability to stay in your home or interferes with your access to necessary care.

Your Hospice of the Comforter (HOTC) team will help you develop an emergency plan so you are prepared. Some measures can be planned in advance while in other situations, you will follow instructions from your local emergency management authority. Your HOTC team will assist with specific emergency measures depending on the circumstances. These might include (but not limited to) the following:

• Help you assemble necessary documents such as advance directives, DNR order (if applicable), identification, medication lists, essential telephone numbers (physicians, pharmacy, HOTC, etc.), current HOTC Plan of Care

• Help with arranging non-electric equipment alternatives (for example a regular mattress instead of an electric air mattress, gravity tube feedings instead of feeding pumps, portable oxygen instead of electric concentrators) and/or adequate supplies of batteries for back-up power

• Help you make sure you have enough medications

Considerations for different kinds of emergencies are listed below.

Hurricanes
Hurricane season is June 1st through November 30th. There are a number of published guidelines for pre-storm preparations, emergency supply lists and general hurricane preparedness.

Severe Thunderstorms
Storms resulting in power outages or possible structural damage are common in Florida. If you are dependent on electricity for essential medical equipment, notify your local power company. You will be put on a priority list to restore power after an outage. Have portable oxygen and other backup plans in place.

Building Fires
Follow basic fire safety guidelines.

Tornadoes
In the event of a tornado warning, be prepared to go to an interior room away from windows, on the lowest level of your home.

Other Emergency Situations
For other disaster or emergency situations such as wildfires, sinkholes, floods, conditions of extreme heat, disruption of public utility services, destruction of public utility infrastructure,
bomb threats, acts of terrorism, exposure to hazardous materials or nuclear disasters, listen to emergency instructions on television or radio, or contact the Emergency Management Services office in your county. If local authorities provide a specific Hotline number (on radio or television), use that number first.

<table>
<thead>
<tr>
<th>Emergency Management System</th>
<th>Special Needs Shelter</th>
</tr>
</thead>
<tbody>
<tr>
<td>Orange County Residents</td>
<td>407-836-9140</td>
</tr>
<tr>
<td>Osceola County Residents</td>
<td>407-742-9000</td>
</tr>
<tr>
<td>Seminole County Residents</td>
<td>407-665-5102</td>
</tr>
</tbody>
</table>

**Special Needs Registry**

Hospice of the Comforter is required to register all Orange, Osceola and Seminole County patients who do not live in nursing homes or assisted living facilities with their county Emergency Management Services. This is done when you are admitted to HOTC services, or if you go home from a long term care facility. If it is necessary for you to evacuate your home, the following guidelines may be helpful in creating your emergency plan.

If you are leaving your home to go to another location, please call Hospice of the Comforter at (407) 379-0311 with your new location/address and telephone number.

**Stay at home if you . . .**
- live in a sturdy, safe structure
- are not in a mandatory evacuation zone and feel safe in your own home
- are not dependent on electricity for essential medical equipment
- have someone who can assist you with activities of daily living as needed

**Stay with relatives, friends or in a hotel/motel if you . . .**
- are sure the destination is in a safe location
- are able to take necessary equipment, supplies, medications and documents with you

**Go to a general public shelter if you . . .**
- must leave your home and have no alternative than a shelter and
- are able to walk without assistance
- do not need outside assistance with activities of daily living
- can provide your own care

**Go to a special needs shelter if you . . .**
- have been preregistered with your county Emergency Management Services
- have received instructions regarding which facility you may go to
- do have an accompanying caregiver to assist
- are not dependent on electricity for essential medical equipment
- are not confined to bed

A special needs shelter is a place of last refuge.
AHCA INFORMATION FOR HOSPICE PATIENTS REGISTERED WITH SPECIAL NEEDS REGISTRY

The following information shall be supplied by the hospice to those patients registered with the special needs registry, so they will be prepared prior to an evacuation to a special needs shelter.

Please note: The special needs shelter is intended to be a place of last refuge. The evacuee may not receive the same level of skilled care received from staff in the home, and the conditions in a shelter might be stressful.

1) It is recommended that if the special needs registrant has a caregiver, the caregiver accompany the special needs registrant and remain with the registrant at the special needs shelter.

2) The following is a recommended list of what special needs registrants need to bring with them to the special needs shelter during an evacuation:

• Bed sheets, blankets, pillow, folding lawn chair, air mattress;

• The special needs registrant’s medication, supplies and equipment list supplied by the hospice, including the phone, beeper and emergency numbers for the special needs registrant’s physician, pharmacy and, if applicable, oxygen supplier; supplies and medical equipment for the special needs registrant’s care; advance directives including the Do Not Resuscitate Order (DNRO) form, if applicable;

• Name and phone number of the special needs registrant’s hospice;

• Prescription and non-prescription medication needed for at least 72 hours; oxygen for 72 hours, if needed;

• A copy of the special needs registrant’s plan of care;

• Identification & current address;

• Special diet items, non-perishable food for 72 hours & 1 gallon of water per person per day;

• Glasses, hearing aides and batteries, prosthetics and any other assistive devices;

• Personal hygiene items for 72 hours;

• Extra clothing for 72 hours;

• Flashlight and batteries; and

• Self-entertainment and recreational items, i.e., books, magazines, quiet games.

3) Special needs registrants need to know the following:

• It is recommended that if the registrant has a caregiver, the caregiver accompany the special needs registrant. A special needs shelter can accommodate one caregiver at a time, and other family members, friends, etc. should go to a general population shelter.

• The special needs registrant’s caregiver will have floor space provided. The caregiver must provide his or her own bedding.
• Check with the local emergency management agency regarding service dogs in the shelter. However, check with your local emergency management agency to see if other pets are permitted.

• Bring personal snacks, drinks, and any special dietary foods for 72 hours. It is possible only sparse meals will be provided.

• Caregivers who regularly assist the special needs registrant in the home are expected to continue to do the same care in the shelter.

MEDICARE HOSPICE BENEFITS
CENTERS FOR MEDICARE & MEDICAID SERVICES

Welcome
Choosing hospice care is a difficult decision. The information in this booklet and support from a doctor and trained hospice care team can help you choose the most appropriate health care options for someone who’s terminally ill.

Whenever possible, include the person who may need hospice care in all health care decisions.

“Medicare Hospice Benefits” isn’t a legal document. Official Medicare Program legal guidance is contained in the relevant statutes, regulations, and rulings.

The information in this section was correct when it was printed. Changes may occur after printing. Visit Medicare.gov, or call 1-800-MEDICARE (1-800-633-4227) to get the most current information. TTY users should call 1-877-486-2048.

Hospice care
Hospice is a program of care and support for people who are terminally ill. Here are some important facts about hospice:

• Hospice helps people who are terminally ill live comfortably.
• Hospice isn’t only for people with cancer.
• The focus is on comfort, not on curing an illness.
• A specially trained team of professionals and caregivers provide care for the “whole person,” including his or her physical, emotional, social, and spiritual needs.
• Services may include physical care, counseling, drugs, equipment, and supplies for the terminal illness and related condition(s).
• Care is generally provided in the home.
• Family caregivers can get support.

Medicare hospice benefits
You can get Medicare hospice benefits when you meet all of these conditions:

• You’re eligible for Medicare Part A (Hospital Insurance).
• Your doctor and the hospice medical director certify that you’re terminally ill and have 6 months or less to live if your illness runs its normal course.
• You sign a statement choosing hospice care instead of other Medicare-covered benefits to treat your terminal illness. (Medicare will still pay for covered benefits for any health problems that aren’t related to your terminal illness.)

You get care from a Medicare-approved hospice program.

**How hospice works**

Your doctor and the hospice team will work with you and your family to set up a plan of care that meets your needs. Your plan of care includes hospice services that Medicare covers. For more specific information on a hospice plan of care, call your area hospice organization (see pages 12 and 14–15).

If you qualify for hospice care, you’ll have a specially trained team and support staff available to help you and your family cope with your illness.

You and your family members are the most important part of the team. Other people on the team may include:

• Doctors
• Nurses or nurse practitioners
• Counselors
• Social workers
• Physical and occupational therapists
• Speech-language pathologists
• Hospice aides
• Homemakers
• Volunteers

In addition, a hospice nurse and doctor are on-call 24 hours a day, 7 days a week to give you and your family support and care when you need it.

A hospice doctor is part of your medical team. Your regular doctor or a nurse practitioner can also be part of this team as the attending medical professional to supervise your care. However, only your regular doctor (not a nurse practitioner that you’ve chosen to serve as your attending medical professional) and the hospice medical director can certify that you’re terminally ill and have 6 months or less to live.

The hospice benefit allows you and your family to stay together in the comfort of your home unless you need care in an inpatient facility. If the hospice team determines that you need inpatient care, the hospice team will make the arrangements for your stay.

**What Medicare covers**

You can get a one-time only hospice consultation with a hospice medical director or hospice doctor to discuss your care options, pain, and management of your symptoms. You can get this one-time consultation if you decide not to get hospice care.

Medicare will cover the hospice care you get for your terminal illness, but the care you get must be from a Medicare-approved hospice program.
Important: Medicare will still pay for covered benefits for any health problems that aren’t related to your terminal illness, like care for an injury.

Medicare covers these hospice services when they’re needed to care for your terminal illness and related condition(s):

- Doctor services
- Nursing care
- Medical equipment (like wheelchairs or walkers)
- Medical supplies (like bandages and catheters)
- Drugs for symptom control or pain relief (may need to pay a small copayment)
- Hospice aide and homemaker services
- Physical and occupational therapy
- Speech-language pathology services
- Social worker services
- Dietary counseling
- Grief and loss counseling for you and your family
- Short-term inpatient care (for pain and symptom management)
- Short-term respite care (may need to pay a small copayment)
- Any other Medicare-covered services needed to manage your pain and other symptoms related to your terminal illness, as recommended by your hospice team

Respite care
If your usual caregiver (like a family member) needs a rest, you can get inpatient respite care in a Medicare-approved facility (like a hospice inpatient facility, hospital, or nursing home). Your hospice provider will arrange this for you. You can stay up to 5 days each time you get respite care. You can get respite care more than once, but it can only be provided on an occasional basis.

What Medicare won’t cover
When you choose hospice care, you’ve decided that you no longer want care to cure your terminal illness and/or your doctor has determined that efforts to cure your illness aren’t working. Medicare won’t cover any of these once you choose hospice care:

- Treatment intended to cure your terminal illness
  Talk with your doctor if you’re thinking about getting treatment to cure your illness. As a hospice patient, you always have the right to stop hospice care at any time.

- Prescription drugs to cure your illness (rather than for symptom control or pain relief)

- Care from any hospice provider that wasn’t set up by the hospice medical team
  You must get hospice care from the hospice provider you chose. All care that you get for your terminal illness must be given by or arranged by the hospice team. You can’t get the same type of hospice care from a different provider, unless you change your hospice provider.
However, you can still see your regular doctor if you've chosen him or her to be the attending medical professional who helps supervise your hospice care.

**Room and board**
Medicare doesn't cover room and board if you get hospice care in your home or if you live in a nursing home or a hospice inpatient facility. However, if the hospice team determines that you need short-term inpatient or respite care services that they arrange, Medicare will cover your stay in the facility. You may have to pay a small copayment for the respite stay.

**Care in an emergency room, inpatient facility care, or ambulance transportation, unless it’s either arranged by your hospice team or is unrelated to your terminal illness.**

*Note:* Contact your hospice team before you get any of these services or you might have to pay the entire cost.

**What you pay for hospice care**
Medicare pays the hospice provider for your hospice care. There's no deductible. You'll pay:

- **No more than $5 for each prescription drug and other similar products for pain relief and symptom control.**
- **5% of the Medicare-approved amount for inpatient respite care.**

For example, if Medicare pays $100 per day for inpatient respite care, you'll pay $5 per day. The amount you pay for respite care can change each year.

**Hospice care if you’re in a Medicare Advantage Plan (like an HMO or PPO) or other Medicare health plan**
All Medicare-covered services you get while in hospice care are covered under Original Medicare, even if you're in a Medicare Advantage Plan (like an HMO or PPO) or other Medicare health plan. That includes any Medicare-covered services for conditions unrelated to your terminal illness or provided by your attending doctor. A Medicare Advantage Plan is a type of Medicare health plan offered by a private company that contracts with Medicare to provide you with all your Medicare Part A and Medicare Part B benefits. However, if your plan covers extra services not covered by Original Medicare (like dental and vision benefits), your plan will continue to cover these extra services.

**Care for a condition other than your terminal illness**
You should continue to use Original Medicare to get care for any health care needs that aren’t related to your terminal illness. You may be able to get this care from the hospice team doctor or your own doctor. The hospice team determines whether any other medical care you need is or isn’t related to your terminal illness so it won’t affect your care under the hospice benefit.

You must pay the deductible and coinsurance amounts for all Medicare-covered services. You must also continue to pay Medicare premiums, if necessary.

For more information about Original Medicare, Medicare Advantage Plans, and other Medicare health plans, visit Medicare.gov, or call 1-800-MEDICARE (1-800-633-4227). TTY users should call 1-877-486-2048.
Information about Medicare Supplement Insurance (Medigap) policies

If you have Original Medicare, you might have a Medigap policy. Your Medigap policy covers your hospice costs for drugs and respite care and still helps cover health care costs for problems that aren’t related to your terminal illness. Call your Medigap plan for more information.

To get more information about Medigap policies, visit Medicare.gov. You can also call 1-800-MEDICARE.

How long you can get hospice care

Hospice care is intended for people with 6 months or less to live if the disease runs its normal course. If you live longer than 6 months, you can still get hospice care, as long as the hospice medical director or other hospice doctor recertifies that you’re terminally ill.

Important: Hospice care is given in benefit periods. You can get hospice care for two 90-day periods followed by an unlimited number of 60-day periods. At the start of each period, the hospice medical director or other hospice doctor must recertify that you’re terminally ill, so you can continue to get hospice care. A benefit period starts the day you begin to get hospice care and it ends when your 90-day or 60 day period ends.

Stopping hospice care

If your health improves or your illness goes into remission, you no longer need hospice care. Also, you always have the right to stop hospice care at any time for any reason. If you stop your hospice care, you’ll get the type of Medicare coverage you had before you chose a hospice program (like treatment to cure the terminal illness). If you’re eligible, you can go back to hospice care at any time.

Example: Mrs. Jones has terminal cancer and got hospice care for two 90-day benefit periods. Her cancer went into remission. At the start of her 60-day period, Mrs. Jones and her doctor decided that, due to her remission, she wouldn’t need to return to hospice care at that time. Mrs. Jones’ doctor told her that if she becomes eligible for hospice services in the future, she may be recertified and can return to hospice care.

Your Medicare rights

As a person with Medicare, you have certain guaranteed rights. If your hospice program or doctor believes that you’re no longer eligible for hospice care because your condition has improved and you don’t agree, you have the right to ask for a review of your case. Your hospice should give you a notice that explains your right to an expedited (fast) review by an independent reviewer hired by Medicare, called a Quality Improvement Organization (QIO). If you don’t get this notice, ask for one.

Note: If you pay out-of-pocket for an item or service your doctor ordered, but the hospice refuses to give you, you can file a claim with Medicare. If your claim is denied, you can file an appeal.

For more information about your Medicare rights, visit Medicare.gov/appeals or call 1-800-MEDICARE (1 800 633 4227). TTY users should call 1-877-486-2048.

If you have a complaint about the hospice that’s providing your care, contact your State Survey Agency. To get the phone number of your State Survey Agency or learn more about how to file a complaint, visit Medicare.gov, or call 1-800-MEDICARE.
Changing your hospice provider

You have the right to change providers only once during each benefit period. You can get hospice care for two 90-day periods followed by an unlimited number of 60-day periods.

Finding a hospice program

To find a hospice program, talk to your doctor, or call your state hospice organization. See pages 14–15 for the phone number in your area. The hospice program you choose must be Medicare-approved to get Medicare payment. To find out if a certain hospice program is Medicare-approved, ask your doctor, the hospice program, your state hospice organization, or your state health department.

For more information

1. Call National Hospice Associations, or visit their Web sites.

   **National Hospice & Palliative Care Organization (NHPCO)**
   nhpc.org
   1731 King Street Suite 100 Alexandria, Virginia 22314 1-800-646-6460

   **Hospice Association of America**
   nahc.org/haa
   228 7th Street, SE Washington, DC 20003 1-202-546-4759


2. Call 1-800-MEDICARE (1-800-633-4227). TTY users should call 1 877 486 2048.

Note: At the time of printing, these phone numbers and websites were correct. This information sometimes changes. To get the most updated phone numbers and websites, visit Medicare.gov/contacts or call 1-800-MEDICARE.

Definitions

**Coinsurance** — An amount you may be required to pay as your share of the cost for services after you pay any deductibles. Coinsurance is usually a percentage (for example, 20%).

**Copayment** — An amount you may be required to pay as your share of the cost for a medical service or supply, like a doctor’s visit, hospital outpatient visit, or prescription. A copayment is usually a set amount, rather than a percentage. For example, you might pay $10 or $20 for a doctor’s visit or prescription.

**Deductible** — The amount you must pay for health care or prescriptions before Original Medicare, your prescription drug plan, or your other insurance begins to pay.

**Medicare approved amount** — In Original Medicare, this is the amount a doctor or supplier that accepts assignment can be paid. It may be less than the actual amount a doctor or supplier charges. Medicare pays part of this amount and you’re responsible for the difference.

**Medicare health plan** — A plan offered by a private company that contracts with Medicare to provide Part A and Part B benefits to people with Medicare who enroll in the plan. Medicare health plans include all Medicare Advantage Plans, Medicare Cost Plans, Demonstration/Pilot Programs, and Programs of All-inclusive Care for the Elderly (PACE).
Medigap policy — Medicare Supplement Insurance sold by private insurance companies to fill “gaps” in Original Medicare coverage.

Original Medicare — Original Medicare is fee-for-service coverage under which the government pays your health care providers directly for your Part A and/or Part B benefits.

Quality Improvement Organization (QIO) — A group of practicing doctors and other health care experts paid by the federal government to check and improve the care given to people with Medicare.

Respite care — Temporary care provided in a nursing home, hospice inpatient facility, or hospital so that a family member or friend who is the patient’s caregiver can rest or take some time off.

This booklet is available in Spanish. To get a free copy, call 1-800-MEDICARE (1-800-633-4227). TTY users should call 1-877-486-2048.

¿Necesita usted una copia en español? Para obtener su copia GRATIS, llame al 1-800-MEDICARE (1-800-633-4227).

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Centers for Medicare & Medicaid Services 7500 Security Boulevard Baltimore, Maryland 21244-1850

Official Business Penalty for Private Use, $300
CMS Product No. 02154 Revised August 2013

NOTICE OF PRIVACY PRACTICES

This Notice is effective September 20, 2013

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

WE ARE REQUIRED BY LAW TO PROTECT MEDICAL INFORMATION ABOUT YOU

We are required by law to protect the privacy of medical information about you and that identifies you. This medical information may be information about healthcare we provide to you or payment for healthcare provided to you. It may also be information about your past, present, or future medical condition.

We are also required by law to provide you with this Notice of Privacy Practices explaining our legal duties and privacy practices with respect to medical information. We are legally required to follow the terms of this Notice. In other words, we are only allowed to use and disclose medical information in the manner that we have described in this Notice.
We may change the terms of this Notice in the future. We reserve the right to make changes and to make the new Notice effective for all medical information that we maintain. If we make changes to the Notice, we will:

- Post the new Notice in our waiting area.
- Have copies of the new Notice available upon request. (Please contact our Privacy Officer at 407-682-0808 to obtain a copy of our current Notice).

The rest of this Notice will:

- Discuss how we may use and disclose medical information about you.
- Explain your rights with respect to medical information about you.
- Describe how and where you may file a privacy-related complaint.

If, at any time, you have questions about information in this Notice or about our privacy policies, procedures or practices, you can contact our Privacy Officer at 407-682-0808.

WE MAY USE AND DISCLOSE MEDICAL INFORMATION ABOUT YOU IN SEVERAL CIRCUMSTANCES

We use and disclose medical information about patients every day. This section of our Notice explains in some detail how we may use and disclose medical information about you in order to provide healthcare, obtain payment for that healthcare, and operate our business efficiently. This section then briefly mentions several other circumstances in which we may use or disclose medical information about you. For more information about any of these uses or disclosures, or about any of our privacy policies, procedures or practices, contact our Privacy Officer at 407-682-0808.

1. Treatment
We may use and disclose medical information about you to provide healthcare treatment to you. In other words, we may use and disclose medical information about you to provide, coordinate or manage your healthcare and related services. This may include communicating with other healthcare providers regarding your treatment and coordinating and managing your healthcare with others.

Example: Jane is a patient at the health department. The receptionist may use medical information about Jane when setting up an appointment. The nurse practitioner will likely use medical information about Jane when reviewing Jane's condition and ordering a blood test. The laboratory technician will likely use medical information about Jane when processing or reviewing her blood test results. If, after reviewing the results of the blood test, the nurse practitioner concludes that Jane should be referred to a specialist, the nurse may disclose medical information about Jane to the specialist to assist the specialist in providing appropriate care to Jane.

2. Payment
We may use and disclose medical information about you to obtain payment for healthcare services that you received. This means that, within the health department, we may use medical information about you to arrange for payment (such as preparing bills and managing accounts). We also may disclose medical information about you to others (such as insurers, collection agencies, and consumer reporting agencies). In some instances, we may disclose medical
information about you to an insurance plan before you receive certain healthcare services because, for example, we may need to know whether the insurance plan will pay for a particular service.

**Example:** Jane is a patient at the health department and she has private insurance. During an appointment with a nurse practitioner, the nurse practitioner ordered a blood test. The health department billing clerk will use medical information about Jane when he prepares a bill for the services provided at the appointment and the blood test. Medical information about Jane will be disclosed to her insurance company when the billing clerk sends in the bill.

**Example:** The nurse practitioner referred Jane to a specialist. The specialist recommended several complicated and expensive tests. The specialist’s billing clerk may contact Jane’s insurance company before the specialist runs the tests to determine whether the plan will pay for the test.

3. **Healthcare Operations**

We may use and disclose medical information about you in performing a variety of business activities that we call “healthcare operations.” These “healthcare operations” activities allow us to, for example, improve the quality of care we provide and reduce healthcare costs. For example, we may use or disclose medical information about you in performing the following activities:

- Reviewing and evaluating the skills, qualifications, and performance of healthcare providers taking care of you.
- Providing training programs for students, trainees, healthcare providers or non-healthcare professionals to help them practice or improve their skills.
- Cooperating with outside organizations that evaluate, certify or license healthcare providers, staff or facilities in a particular field or specialty.
- Reviewing and improving the quality, efficiency and cost of care that we provide to you and our other patients.
- Improving healthcare and lowering costs for groups of people who have similar health problems and helping manage and coordinate the care for these groups of people.
- Cooperating with outside organizations that assess the quality of the care others and we provide, including government agencies and private organizations.
- Planning for our organization’s future operations.
- Resolving grievances within our organization.
- Reviewing our activities and using or disclosing medical information in the event that control of our organization significantly changes.
- Working with others (such as lawyers, accountants and other providers) who assist us to comply with this Notice and other applicable laws.

**Example:** Jane was diagnosed with diabetes. The health department used Jane’s medical information — as well as medical information from all of the other health department patients diagnosed with diabetes — to develop an educational program to help patients recognize the early symptoms of diabetes. (Note: The educational program would not identify any specific patients without their permission).
Example: Jane complained that she did not receive appropriate healthcare. The health department reviewed Jane’s record to evaluate the quality of the care provided to Jane. The health department also discussed Jane’s care with an attorney.

4. Persons Involved in Your Care
We may disclose medical information about you to a relative, close personal friend or any other person you identify if that person is involved in your care and the information is relevant to your care. If the patient is a minor, we may disclose medical information about the minor to a parent, guardian or other person responsible for the minor except in limited circumstances. For more information on the privacy of minors’ information, contact our Privacy Officer at 407-682-0808.

We may also use or disclose medical information about you to a relative, another person involved in your care or possibly a disaster relief organization (such as the Red Cross) if we need to notify someone about your location or condition.

You may ask us at any time not to disclose medical information about you to persons involved in your care. We will agree to your request and not disclose the information except in certain limited circumstances (such as emergencies) or if the patient is a minor. If the patient is a minor, we may or may not be able to agree to your request.

Example: Jane’s husband regularly comes to the health department with Jane for her appointments and he helps her with her medication. When the nurse practitioner is discussing a new medication with Jane, Jane invites her husband to come into the private room. The nurse practitioner discusses the new medication with Jane and Jane’s husband.

5. Required by Law
We will use and disclose medical information about you whenever we are required by law to do so. There are many state and federal laws that require us to use and disclose medical information. For example, state law requires us to report gunshot wounds and other injuries to the police and to report known or suspected child abuse or neglect to the Department of Social Services. We will comply with those state laws and with all other applicable laws.

6. National Priority Uses and Disclosures
When permitted by law, we may use or disclose medical information about you without your permission for various activities that are recognized as “national priorities.” In other words, the government has determined that under certain circumstances (described below), it is so important to disclose medical information that it is acceptable to disclose medical information without the individual’s permission. We will only disclose medical information about you in the following circumstances when we are permitted to do so by law. Below are brief descriptions of the “national priority” activities recognized by law. For more information on these types of disclosures, contact our Privacy Officer at 407-682-0808.

• Threat to health or safety: We may use or disclose medical information about you if we believe it is necessary to prevent or lessen a serious threat to health or safety.

• Public health activities: We may use or disclose medical information about you for public health activities. Public health activities require the use of medical information for various activities, including, but not limited to, activities related to investigating diseases, reporting child abuse and neglect, monitoring drugs or devices regulated by the Food and Drug
Administration, and monitoring work-related illnesses or injuries. For example, if you have been exposed to a communicable disease (such as a sexually transmitted disease), we may report it to the State and take other actions to prevent the spread of the disease.

- **Abuse, neglect or domestic violence:** We may disclose medical information about you to a government authority (such as the Department of Social Services) if you are an adult and we reasonably believe that you may be a victim of abuse, neglect or domestic violence.

- **Health oversight activities:** We may disclose medical information about you to a health oversight agency – which is basically an agency responsible for overseeing the healthcare system or certain government programs. For example, a government agency may request information from us while they are investigating possible insurance fraud.

- **Court proceedings:** We may disclose medical information about you to a court or an officer of the court (such as an attorney). For example, we would disclose medical information about you to a court if a judge orders us to do so.

- **Law enforcement:** We may disclose medical information about you to a law enforcement official for specific law enforcement purposes. For example, we may disclose limited medical information about you to a police officer if the officer needs the information to help find or identify a missing person.

- **Coroners and others:** We may disclose medical information about you to a coroner, medical examiner, or funeral director or to organizations that help with organ, eye and tissue transplants.

- **Workers’ compensation:** We may disclose medical information about you in order to comply with workers’ compensation laws.

- **Research organizations:** We may use or disclose medical information about you to research organizations if the organization has satisfied certain conditions about protecting the privacy of medical information.

- **Certain government functions:** We may use or disclose medical information about you for certain government functions, including but not limited to military and veterans’ activities and national security and intelligence activities. We may also use or disclose medical information about you to a correctional institution in some circumstances.

### 7. Authorizations

Other than the uses and disclosures described above (#1-6), we will not use or disclose medical information about you without the “authorization” – or signed permission – of you or your personal representative. In some instances, we may wish to use or disclose medical information about you and we may contact you to ask you to sign an authorization form. In other instances, you may contact us to ask us to disclose medical information and we will ask you to sign an authorization form.

If you sign a written authorization allowing us to disclose medical information about you, you may later revoke (or cancel) your authorization in writing (except in very limited circumstances related to obtaining insurance coverage). If you would like to revoke your authorization, you may write us a letter revoking your authorization or fill out an Authorization Revocation Form. Authorization Revocation Forms are available from our Privacy Officer. If you revoke your authorization, we will follow your instructions except to the extent that we have already relied upon your authorization and taken some action.
The following uses and disclosures of medical information about you will only be made with your authorization (signed permission):  
- Uses and disclosures for marketing purposes.  
- Uses and disclosures that constitute the sales of medical information about you.  
- Most uses and disclosures of psychotherapy notes, if we maintain psychotherapy notes.  
- Any other uses and disclosures not described in this Notice.  

YOU HAVE RIGHTS WITH RESPECT TO MEDICAL INFORMATION ABOUT YOU  
You have several rights with respect to medical information about you. This section of the Notice will briefly mention each of these rights. If you would like to know more about your rights, please contact our Privacy Officer.  

1. Right to a Copy of This Notice  
You have a right to have a paper copy of our Notice of Privacy Practices at any time. In addition, a copy of this Notice will always be posted in our waiting area. If you would like to have a copy of our Notice, ask the receptionist for a copy or contact our Privacy Officer.  

2. Right of Access to Inspect and Copy  
You have the right to inspect (which means see or review) and receive a copy of medical information about you that we maintain in certain groups of records. If we maintain your medical records in an Electronic Health Record (EHR) system, you may obtain an electronic copy of your medical records. You may also instruct us in writing to send an electronic copy of your medical records to a third party. If you would like to inspect or receive a copy of medical information about you, you must provide us with a request in writing. You may write us a letter requesting access or fill out an Access Request Form. Access Request Forms are available from our Privacy Officer.  

We may deny your request in certain circumstances. If we deny your request, we will explain our reason for doing so in writing. We will also inform you in writing if you have the right to have our decision reviewed by another person.  

If you would like a copy of the medical information about you, we will charge you a fee to cover the costs of the copy. Our fees for electronic copies of your medical records will be limited to the direct labor costs associated with fulfilling your request.  

We may be able to provide you with a summary or explanation of the information. Contact our Privacy Officer for more information on these services and any possible additional fees.  

3. Right to Have Medical Information Amended  
You have the right to have us amend (which means correct or supplement) medical information about you that we maintain in certain groups of records. If you believe that we have information that is either inaccurate or incomplete, we may amend the information to indicate the problem and notify others who have copies of the inaccurate or incomplete information. If you would like us to amend information, you must provide us with a request in writing and explain why you would like us to amend the information. You may either write us a letter requesting an amendment or fill out an Amendment Request Form. Amendment Request Forms are available from our Privacy Officer.
We may deny your request in certain circumstances. If we deny your request, we will explain our reason for doing so in writing. You will have the opportunity to send us a statement explaining why you disagree with our decision to deny your amendment request and we will share your statement whenever we disclose the information in the future.

4. Right to an Accounting of Disclosures We Have Made
You have the right to receive an accounting (which means a detailed listing) of disclosures that we have made for the previous six (6) years. If you would like to receive an accounting, you may send us a letter requesting an accounting, fill out an Accounting Request Form, or contact our Privacy Officer. Accounting Request Forms are available from our Privacy Officer.

The accounting will not include several types of disclosures, including disclosures for treatment, payment or healthcare operations. If we maintain your medical records in an Electronic Health Record (EHR) system, you may request that we include disclosures for treatment, payment or healthcare operations. The accounting will also not include disclosures made prior to April 14, 2003.

If you request an accounting more than once every twelve (12) months, we may charge you a fee to cover the costs of preparing the accounting.

5. Right to Request Restrictions on Uses and Disclosures
You have the right to request that we limit the use and disclosure of medical information about you for treatment, payment and healthcare operations. Under federal law, we must agree to your request and comply with your requested restriction(s) if:

1. Except as otherwise required by law, the disclosure is to a health plan for purpose of carrying out payment of healthcare operations (and is not for purposes of carrying out treatment); and,

2. The medical information pertains solely to a healthcare item or service for which the healthcare provided involved has been paid out-of-pocket in full.

Once we agree to your request, we must follow your restrictions (except if the information is necessary for emergency treatment). You may cancel the restrictions at any time. In addition, we may cancel a restriction at any time as long as we notify you of the cancellation and continue to apply the restriction to information collected before the cancellation.

You also have the right to request that we restrict disclosures of your medical information and healthcare treatment(s) to a health plan (health insurer) or other party, when that information relates solely to a healthcare item or service for which you, or another person on your behalf (other than a health plan), has paid us for in full. Once you have requested such restriction(s), and your payment in full has been received, we must follow your restriction(s).

6. Right to Request an Alternative Method of Contact
You have the right to request to be contacted at a different location or by a different method. For example, you may prefer to have all written information mailed to your work address rather than to your home address.

We will agree to any reasonable request for alternative methods of contact. If you would like to request an alternative method of contact, you must provide us with a request in writing. You may write us a letter or fill out an Alternative Contact Request Form. Alternative Contact Request Forms are available from our Privacy Officer.
7. Right to Notification if a Breach of Your Medical Information Occurs
You also have the right to be notified in the event of a breach of medical information about you. If a breach of your medical information occurs, and if that information is unsecured (not encrypted), we will notify you promptly with the following information:

- A brief description of what happened;
- A description of the health information that was involved;
- Recommended steps you can take to protect yourself from harm;
- What steps we are taking in response to the breach; and,
- Contact procedures so you can obtain further information.

8. Right to Opt-Out of Fundraising Communications
We may use demographic information about you including your name, address, phone numbers, and the dates you received care in order to contact you or your family to raise money for the agency. If we conduct fundraising and we use communications like the U.S. Postal Service or electronic email for fundraising, you have the right to opt-out of receiving such communications from us. Please contact our Privacy Officer at 407-682-0808 or Attn: Privacy Officer, 480 W. Central Parkway, Altamonte springs, FL 32714 to opt-out of fundraising communications if you chose to do so.

YOU MAY FILE A COMPLAINT ABOUT OUR PRIVACY PRACTICES
If you believe that your privacy rights have been violated or if you are dissatisfied with our privacy policies or procedures, you may file a written complaint either with us or with the federal government.

We will not take any action against you or change our treatment of you in any way if you file a complaint.

To file a written complaint with us, you may bring your complaint directly to our Privacy Officer, or you may mail it to the following address:

Privacy Officer
Hospice of the Comforter
480 W. Central Parkway
Altamonte Springs, FL 32714

To file a written complaint with the federal government, please use the following contact information:

Office for Civil Rights
U.S. Department of Health and Human Services
200 Independence Avenue, S.W.
Room 509F, HHH Building
Washington, D.C. 20201

Toll-Free Phone: 1-(877) 696-6775
Website: http://www.hhs.gov/ocr/privacy/hipaa/complaints/index.html
Email: OCRComplaint@hhs.gov
**HELP RESOURCES AND REGULATORY TELEPHONE NUMBERS**

**Patient Help Line**
A Nurse is available by phone 24 hours a day to address your care needs. For any questions or concerns, call Hospice of the Comforter’s Patient Help Line at (407) 379-0311

**Privacy**
For privacy (HIPAA) or compliance questions or concerns the confidential Hospice of the Comforter voicemail number is (407) 682-0808, voicemail number 2226

**Problem Resolution**
It is our goal to resolve any problems that may occur with our services. Problems may be reported to any team member, any Patient Care Manager, the Chief Clinical Officer or the Administrator by calling Hospice of the Comforter (407) 682-0808

**State Toll-Free Numbers**

<table>
<thead>
<tr>
<th>Service</th>
<th>Number</th>
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<tbody>
<tr>
<td><strong>Florida Agency for Health Care Administration (AHCA)</strong></td>
<td>To report a complaint about the services you receive, please call toll-free: 1-888-419-3456</td>
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<tr>
<th>Service</th>
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<tbody>
<tr>
<td><strong>Florida Abuse Hotline</strong></td>
<td>To report abuse, neglect or exploitation, please call toll-free: 1-800-962-2873</td>
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<tbody>
<tr>
<td><strong>Medicaid Fraud Hotline</strong></td>
<td>To report suspected Medicaid Fraud, please call toll-free: 1-866-966-7226</td>
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<tbody>
<tr>
<td><strong>Florida Hospice &amp; Palliative Care State Hotline</strong></td>
<td>For questions or concerns about the Hospice Medicare Benefit, please call toll-free: 1-800-282-6560</td>
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<tbody>
<tr>
<td><strong>Domestic Violence Hotline</strong></td>
<td>1-800-500-1119</td>
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**CAREGIVING RESOURCES**

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<tr>
<th>Service</th>
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<tbody>
<tr>
<td><strong>Alzheimer’s &amp; Dementia Resource Center</strong></td>
<td>407-843-1910</td>
</tr>
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<td></td>
<td><a href="http://www.ADRCareshape.org">www.ADRCareshape.org</a></td>
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<th>Service</th>
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<tbody>
<tr>
<td><strong>The Cameron Group</strong></td>
<td>407-896-2010</td>
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<td></td>
<td><a href="http://www.thecamerongroup.us">www.thecamerongroup.us</a></td>
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<tr>
<td><strong>Charity &amp; Love</strong></td>
<td>407-522-4473</td>
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<tr>
<td></td>
<td><a href="http://www.charityloveinc.com">www.charityloveinc.com</a></td>
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<th>Service</th>
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<tr>
<td><strong>Community Legal Services of Mid-Florida (Orange County)</strong></td>
<td>407-841-7777</td>
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<tr>
<td><strong>Council for Caregivers Monthly Seminars</strong></td>
<td>407-836-6563</td>
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<td><a href="http://www.ocfl.net/seniors">www.ocfl.net/seniors</a></td>
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<tr>
<td><strong>Department of Health (Family HealthLine)</strong></td>
<td>800-451-2229</td>
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<tr>
<td><strong>Elder Helpline</strong></td>
<td>800-963-5337</td>
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<tr>
<td><strong>Family Caregiver Alliance</strong></td>
<td><a href="http://www.caregiver.org">www.caregiver.org</a></td>
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<td><strong>Florida Division of Consumer Services</strong></td>
<td>800-435-7352</td>
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<td><a href="http://www.freshfromflorida.com">www.freshfromflorida.com</a></td>
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<tr>
<td><strong>Florida Senior Legal Helpline</strong></td>
<td>888-895-7873</td>
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<td><strong>Food Stamps/Vouchers (DCF)</strong></td>
<td>866-762-2237 24/7</td>
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<td><strong>Hospice Journey</strong></td>
<td>Keep family and friends updated on your own private website, free.</td>
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<td><a href="http://www.HospiceJourney.org">www.HospiceJourney.org</a></td>
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<td><strong>Jewish Pavilion</strong></td>
<td>407-678-9363</td>
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<td><a href="http://www.JewishPavilion.org">www.JewishPavilion.org</a></td>
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Meals on Wheels – Seminole County
407-333-8877
www.mealsetc.org

Medicare
800-MEDICARE (800-633-2273)

Medicare Beneficiary Helpline
800-844-0795

National Alliance for Caregiving
www.caregiving.org

Orange County Bar Association
407-422-4551

Osceola Council on Aging
407-483-1498
www.OsceolaGenerations.org

Rebuilding Together Orlando
321-385-7823
www.rtorlando.org

Salvation Army
Orange County: 407-423-8581
Osceola County: 407-518-9111
Seminole County: 407-322-2642

Seminole County Bar Association
407-834-1660

Seminole County Community Assistance
407-665-2300

Seniors First
407-297-9980
www.SeniorsFirstInc.org

Social Security
800-772-1213

National Suicide Prevention Lifeline
800-273-8255

Transportation (ITNOrlando)
407-228-7761
www.ITNOrlando.org

Transportation (ACCESSLYNX)
407-423-8747

Triad – Seminole County
407-265-0534
www.SeminoleCountyTriad.org

Veterans Administration
800-827-1000

R8-Help Resources Created 5/19/14
Florida Hospital, Private Duty Care and Home Care Services

There may be times when your loved one requires additional care at home. For more than 25 years, Florida Hospital has been providing a specialized continuum of care for patients in their home with Private Duty and Home Care Services.

You may consider arranging hourly home health aides and companion services with Florida Hospital Private Duty. Their professional team provides personalized attention for patients—working hand-in-hand with your Hospice Care Team. They provide assistance and hands-on care needed to maintain a safe and comfortable daily life. The full spectrum of services is tailored to the needs of every patient and caregiver.

**Private Duty Home Care**
- Skilled nurses
- Physical, occupational and speech therapists
- Home health aides
- Certified nursing assistants

**Services Offered**
- Assistance with daily activities, such as bathing, grooming, and dressing
- Companion service
- Light housekeeping
- Meal planning and preparation

Florida Hospital Private Duty may be covered by your insurance, but is not covered by Medicare or Medicaid. For more information, call Florida Hospital Private Duty Care at (407) 691-8206.

**Home Care Services**

For patients who no longer need Hospice of the Comforter services, you may want to consider Florida Hospital Home Care Services. They are the leading provider of home health nursing, rehabilitation and personal care services in Central Florida. All employees meet and exceed the health care needs of our patients by offering dependable, compassionate care every day and in every way.

Home Care Services provides professionals trained to meet your home health care needs, such as:
- Skilled Nurses
- Wound Care and Ostomy Continence Management
- Pain Management
- Chronic Disease Management
- Neurological Rehabilitation
- LANA Certified Lymphedema therapist
- Alzheimer and related Dementia Management
- Medical Social Worker
- Chaplain services

Florida Hospital Home Care accepts Medicare, private insurance and self-pay. For more information or a referral, call Florida Hospital Home Care Services at (407) 691-8202.
Hospice of the Comforter
FLORIDA HOSPITAL CONNECTED CARE

A compassionate, non-profit ministry since 1990.

480 West Central Parkway | Altamonte Springs, FL 32714
(407) 682-0808 | HospiceoftheComforter.org