

Guiding You in Caring for Your Loved One at Home

Hospice Caregiver Guide



407-379-0311

24/7 PATIENT SERVICES LINE


Advent Health
Hospice Care
Central Florida

Dear Patient and Family,

We welcome you to AdventHealth Hospice Care. We are here to help you be as comfortable as possible, and to support you in the journey ahead.

Your hospice care team will assess your needs and provide the visits, supplies and equipment needed. They will teach you how to care for your loved one and support you in becoming a confident caregiver.

This guide has information about how to provide daily care, how to use the supplies and equipment, the expected changes that may occur, and other resources that you may find helpful. Use this guide like you would a dictionary...to look up something when you have a question or need guidance.

If at any time you have a concern, or want to ask a question, please call our Patient Services Line at 407-379-0311 — day or night. Remember, your hospice care team is only a phone call away.

The care of your loved one and your experience with us is of utmost importance; we may ask several times throughout our encounters for your feedback — with a phone call, check-ins by managers and surveys — so we can ensure that we are caring for your loved one in the best way he or she needs.

It is our privilege to serve you and your family during this special time.

Your Feedback to Us Is a Gift!

Call the 24/7 Patient Services Line
at 407-379-0311.



407-379-0311 — 24/7 Patient Services Line

Please call if you need anything, have questions or concerns.

When to Contact Hospice?

Call your AdventHealth Hospice Care team **FIRST** — day or night — at 407-379-0311, if you:

- Are considering calling 9-1-1. **PLEASE CALL US FIRST.** We can help.
- Feel that your loved one's pain or other symptom is not controlled.
- Notice a change like increased pain, agitation, trouble breathing, nausea, or vomiting.
- Have a question about medications, how to provide care, etc. We can help you 24/7.
- Think your loved one needs any medical tests or procedures ordered by a physician.
- Have questions or concerns that can't wait until your nurse visits.
- Have a change of address, or your loved one is leaving our service area of Orange, Seminole or Osceola counties.
- Your loved one dies.

When calling 407-379-0311, tell the nurse:

1. Your loved one's name
2. Team color
3. Your name and your phone number

If you leave a message, and don't receive a return call within 15 minutes, please call again.

Care Team Members

Team Color _____

Hospice care is provided by a team of highly skilled professionals who support your loved one and family through the end-of-life journey.

Nurse Case Manager _____

Hospice Aide _____

Hospice Physician _____

Attending Physician _____

Patient Care Manager _____

Social Worker _____

Chaplain _____

Volunteer Coordinator _____



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Pain Management

Medications

Your hospice physician will determine which medications are related to your hospice care during your initial assessment. **Your nurse will order all 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 your loved one 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.

Comfort Pack Medications have been ordered for you, depending on your loved one's needs. These can be administered by you when your loved one is having pain or showing symptoms. Dosage information and administration instructions are located on each medication package.

It is recommended to store all medications on the top shelf in the refrigerator.

DO NOT store medications in the bathroom, or in heat or light.

Keep all medications out of the reach of children and pets.

If you have any questions, call our Patient Services Line at 407-379-0311 (available 24/7) and tell them which Team (color) _____ you are on.

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 your loved one a double dose if a medication is forgotten.
- Medications that have been discontinued or changed should be destroyed. (See page 10.)
- 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. Do not keep them in the bathroom.
- 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 our Patient Services Line at 407-379-0311 (available 24/7) if you have any questions about your medications.

Notify your nurse 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.
- your loved one 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 your loved one'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 are opioid medicines?

Opioids are medicines used to control moderate to severe pain. They are usually used when other medicines have not been effective. Opioids work by blocking the pain and help to provide comfort and relief. The most common opioids are morphine and oxycodone.

4. Will my loved one become addicted to pain medication if he takes it regularly?

When the 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.

If medication is stopped abruptly, your loved one 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.

5. What if my loved one continues to have pain/side effects from the pain medication?

Please call our Patient Services Line at 407-379-0311 (available 24/7) if your loved one's pain worsens or if the current medication is no longer working. There is always a nurse available by phone to address any pain management problems. Informing the hospice team about your loved one's pain and other symptoms is critical when it comes to keeping him or her 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 opioids to prevent constipation. Ask your nurse for more information if you experience side effects such as nausea, rash, sedation, etc.

6. Will my loved one be drowsy all the time?

If an opioid pain medication is given for the first time, or if the dose is increased because of increased pain, he or she may be drowsy for the first two to three days. The body will adjust, and the drowsiness will subside.



7. If my loved one takes strong medication now, will it still work if the pain gets really bad? Shouldn't my loved one 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 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 as directed (known as PRN or breakthrough dose) if your loved one is having pain. You may give the short-acting dose at the same time as the long-acting dose if your loved one is having pain. If pain continues, call our Patient Services Line at 407-379-0311 (available 24/7).
- If activity causes pain, give your loved one a dose of short-acting medication about 15 to 30 minutes before doing the activity.
- Keep records of the pain medication given. This information is important to the doctor and nurse in making medication adjustments.
- Ask your nurse about other pain relief.

Notify your nurse 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).

Alternative Methods to Help with Pain

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 including:

- 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 or caress 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 your loved one feel better while showing that you care. Massage can reduce stress and anxiety, distract your loved one 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.

Your Feedback to Us Is a Gift!

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How to Assess Pain Level

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 your loved one 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 your loved one 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 also help them express the level of pain they are experiencing.

How to Use the Wong-Baker FACES® Pain Rating Scale

1. Explain to your loved one that each face represents a person with either no pain (HAPPY) or with pain (SAD).
2. Ask your loved one 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 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?



Disposing of Medications

During Course of Care or at the Time of Death

In accordance with Federal, State and Local guidelines, as well as the Medicare and Medicaid Programs, the hospice organization will educate patients and family in the disposal of medications that are no longer needed. Once dispensed to the patient, medications are the patient's personal property.

Medications may not be transported by a hospice staff member or volunteer for destruction.

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

Steps for Destruction of Pills and Liquids in the Home Setting

1. Remove medication from original container. To discard the container: eliminate all Protected Health Information (PHI) that can identify a your loved one including patient's name. This can be done with a black permanent marker or by scratching out.
2. Modify contents: 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, flour or spice to create a distasteful, pungent mixture in order to discourage consumption. Then place in a sealed container (such as a seal-able plastic bag or coffee can) and place in trash. Never mix medications with toxic chemicals or other products that may be harmful to humans if swallowed or ingested. Do not flush medications in toilet.

3. Discard the container: Place the sealed and concealed container into the household garbage for municipal pickup. Do not place into the recycling bin.
4. Liquid medications: Add directly to same items listed above to make slurry, and dispose.

Steps for Destruction of Fentanyl Patches in the Home Setting

For Fentanyl, or transdermal narcotic patches, fold in half (the adhesive sides together) and flush down the toilet.

Steps for Destruction of IV/SC Fluids in the Home Setting

Contents of infusion bags can be disposed of in the toilet. Hold bag over the toilet and cut the corner of the bag with scissors. Pour contents into the toilet and flush immediately.

Symptom Management

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. Sometimes an opioid medication may be needed.

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 28.)

How You Can Help

- Keep the room cool. Use a small fan blowing gently in your loved one'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 your loved one loose, light clothing to wear.
- Alternate short periods of activity with periods of rest to help your loved one 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 your nurse immediately if shortness of breath:

- is present for the first time.
- is worse despite medications and the above suggestions.



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 a Hospice Patient

- 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 him or her if they feel depressed.
- Make sure that he or she does not have access to firearms or other items that could cause harm.
- Administer anti-depressant medication, if ordered, as long as your loved one 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.
- if you feel there is an immediate concern, or you need additional support.
- does not gain relief from anti-depressant medication. The nurse will consult the physician about a dosage or medication change.

Confusion

Your loved one may become confused as the disease progresses, which can be distressing to you.

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 his or her distress. Instead, try asking questions such as “What is going on?” and “Tell me who is here.” Try to be supportive and accepting of his or her train of thought.
- Spend time sitting quietly with your loved one.
- Leave a small light on in the room at night.

Notify your nurse 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 your loved one 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 your nurse 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. He or she may also begin eating and drinking less. As a result, there is an increased risk for skin breakdown. With appropriate preventive measures, skin breakdown can be minimized or avoided.

However, at the end of life, skin breakdown may still occur even with preventative efforts. Skin is compromised due to decreased circulation and dryness. Your nurse will teach you about the use of special dressings which can often stay in place for up to one week; these can help to provide comfort and protect the wound.

How You Can Help

- Encourage your loved one to change positions every hour when sitting in a chair. Your loved one 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 positions every three to four hours while in bed. Help reposition him or her if they are too weak to turn themselves. (See page 23.)
- Our hospital beds have a pressure-relieving mattress which can provide comfort. 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.
- If a dressing is needed, follow directions as given by the nurse.

Notify your nurse 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.

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 your nurse 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.

Difficulty Swallowing

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 your loved one 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 your nurse 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 your loved one 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.

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 your nurse 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 both the patient and the caregiver. 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 your nurse 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.

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 your nurse 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.
- your loved one cannot take the anti-nausea/vomiting medication.
- the current anti-nausea/vomiting medication is not helping.
- your loved one 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 13.)
- 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 your nurse if your loved one:

- has difficulty swallowing.
- has changes in appetite.
- has a sore or painful mouth.
- complains of nausea.
- vomits.

Food and Hydration

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, your loved one 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.

When Your Loved One Says	What is Happening	What to Do
<p>“My family is afraid I’m starving to death.”</p>	<ul style="list-style-type: none"> • Weight loss, weakness and skin color changes may occur. • The body cannot process food in the final stages of terminal illness. • Decreased interest in food and water is one of nature’s way of allowing a person to pass away more comfortably. 	<ul style="list-style-type: none"> • Offer food and liquid, but do not force your loved one to eat or drink. • Focus on your loved one’s comfort. • Reassure your loved one that you support his or her decision.
<p>“I feel guilty because my family feels like I’m giving up.”</p>	<ul style="list-style-type: none"> • Sharing food is an important part of many cultures. Caregivers often feel helpless when their loved one cannot eat. • The body’s need for food decreases as the disease progresses. • Low food intake doesn’t cause hunger or discomfort. • Eating more than he or she wants may cause discomfort. • Not eating is a reminder that the disease is progressing. 	<ul style="list-style-type: none"> • Offer food and liquid, but do not force your loved one to eat or drink. • Focus on your loved one’s comfort. • Reassure your loved one that you support his or her decision.
<p>“I am eating, but still losing weight.”</p>	<ul style="list-style-type: none"> • Some chronic illnesses increase the body’s metabolism, using more calories. 	<ul style="list-style-type: none"> • Have a positive attitude about the amount of food your loved one eats. • Ask about ways to increase calories of food your loved one eats. • Focus on your loved one’s comfort instead of weight.
<p>“I have no appetite.”</p>	<ul style="list-style-type: none"> • Fewer calories are needed as some diseases progress. 	<ul style="list-style-type: none"> • Offer small amounts of food several times a day. • Don’t force your loved one eat. • Ask the nurse if any medications may be affecting appetite.
<p>“It hurts when I swallow or eat.”</p>	<ul style="list-style-type: none"> • Mouth and tongue may become dry because of medication or decreased fluid intake. 	<ul style="list-style-type: none"> • Notify nurse if you see white patches in the mouth or if your loved one 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 Your Loved One Says	What is Happening	What to Do
<p>“When I eat or smell food, I become nauseated.”</p>	<ul style="list-style-type: none"> • The body’s ability to digest food decreases. • Anxiety or pain may increase nausea. • Some medications may cause changes in taste or smell. 	<ul style="list-style-type: none"> • 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/spicy foods. Your loved one makes the final choice of what to eat.
<p>“I am hungry, but I fill up fast.”</p>	<ul style="list-style-type: none"> • Digestion slows and food may stay in the stomach longer. • Normal sized meals may increase feelings of fullness. 	<ul style="list-style-type: none"> • Offer small amounts of food several times a day. • Do not force your loved one to eat or drink.
<p>“What about tube feeding or IV fluids?”</p>	<ul style="list-style-type: none"> • The body’s need for food/fluid decreases as the disease progresses. • Giving IV fluids and tube feeding now may increase discomfort. • Dehydration is nature’s way of allowing a person to pass more comfortably. 	<ul style="list-style-type: none"> • Keep mouth and lips moist with crushed ice, sips of water or lip balm. • Fill small spray bottle with water, spray mouth and tongue as needed. • Provide frequent mouth care with toothettes or toothbrush.

Safety and Preventing Infection

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

(See Equipment and Supplies on page 25 to learn more.)

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 AdventHealth Hospice Care 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.

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:

Handwashing

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.



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

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 your loved one 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.

Sharps Container

- If your loved one'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 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.
- Hospice employees may not remove or transport full sharps containers.

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.

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. AdventHealth Hospice Care 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, and bath towels
- Soap or body wash

How to Give a Bed Bath

1. If you have a hospital bed, raise it to waist height.
2. Remove your loved one's upper-body clothing and cover them with the top sheet.
3. Place a towel under their head and shoulders to protect the sheets from getting wet.
4. Wash the face, neck, shoulders, arms and hands with a soapy washcloth. Rinse with a wet washcloth and dry with a towel.
5. Move the sheet down to the waist. Wash the chest, underarms and abdomen. Dry thoroughly, especially between folds of skin.
6. Cover the top half of your loved one's body with the top sheet and remove their lower-body clothing.
7. Wash and dry the legs and feet. If your loved one is able, allow them to wash their genital area with a separate washcloth.
8. Cover your loved one with the top sheet and change the water.
9. Help your loved one turn onto their side.
10. 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.
11. Dry thoroughly and help them put on clean clothes.



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 your loved one which include:

Helping Your Loved One Stand

This technique can be used for helping your loved one out of a chair or off a bed.

If he or she can bear weight, but are slightly unstable, a gait belt can help. (See page 25.)

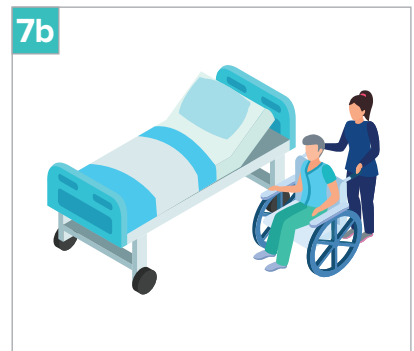
1. If you have a hospital bed, lower the bed to the lowest position.
2. Help your loved one move to the edge of the bed or chair.
3. Stand with your knees on either side of their knees and keep your back straight.
4. Bend your knees to get down to their level.
5. Ask your loved one to place their hands 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 your loved one up with you as you straighten your legs. Do not attempt to lift him or her by straightening your back as this can cause back strain.
7. Make sure your loved one is steady before releasing him or her.



Moving Your Loved One from Bed

Use this technique to move a your loved one 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 your loved one to a wheelchair, lock the wheels.
3. If your loved one is strong enough, have him or her put one hand on the chair arm and the other on the bed, pushing up to stand.
4. If your loved one is too weak, follow steps one through six of the “Helping Your Loved One Stand” procedure.
5. Support your loved one while he or she takes small steps, turning around slowly until the has reached the correct position to be seated.
6. Have your loved one back up until the chair is hitting the backs of the legs.
7. Your loved one should be holding you around the waist or shoulders with his or her head resting on your shoulder. Hold his or her waistband or put your hands behind their back and gently lower them 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 or the development of bedsores. Your nurse will advise you as to 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.

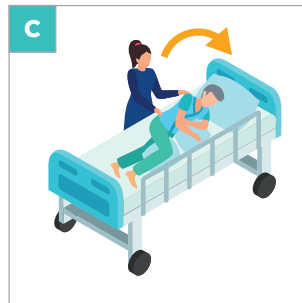
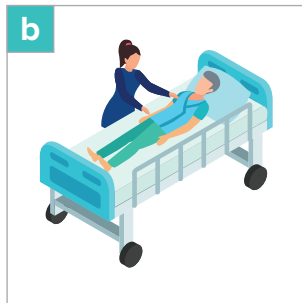
Flat on back — lying flat on the back with one or two pillows supporting the head.

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.



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 your loved one supporting their upper arm.



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 your loved one does not roll off the bed.
4. Roll your loved one 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 your loved one 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 your loved one at the head of the bed. Hold the sheet firmly with two hands, bend your knees and pull the sheet toward you. Your loved one 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 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 your loved one up in the bed.

Moving Your Loved One Sideways on the Bed

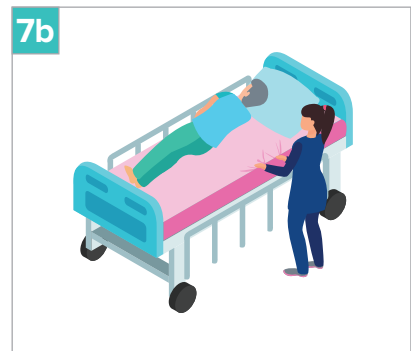
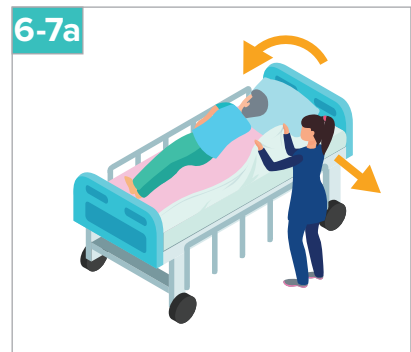
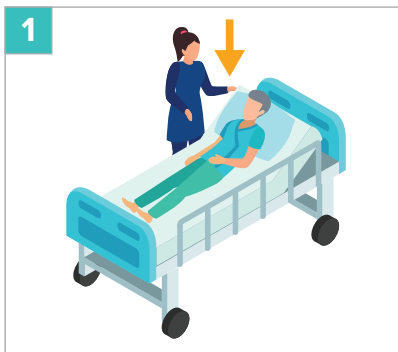
1. Follow steps one through six of the “Moving to the Head of the Bed” procedure.
2. Lower the head of the bed. From the side of the bed, hold the folded draw sheet firmly and pull toward you. Your loved one will move across the bed toward you. Place your loved one in a comfortable position.

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 your loved one 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 your loved one 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.

Changing the Sheets (Side-to-Side)

1. First, lower the head of the bed if it is raised. 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 your loved one 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 your loved one toward you over the two rolls of sheets. If you do not have a side rail, make sure your loved one does not roll off the bed.
7. Move to the opposite side of the bed and reach under the patient's back and pull out the used sheet, rolling it up to go in the laundry. In the same way, spread out the new sheet and tuck in the excess under the mattress.
8. Finally, position your loved one comfortably on his side or back.



Equipment and Supplies

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.
- Our beds provide a pressure-relieving mattress
- 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

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 multiple buttons. Use only one function at a time.

- A hand crank is provided in the event of a power outage. The crank is located at the foot of the bed and can be used to adjust the height of the bed only. If a power outage is anticipated, be sure to put the bed in a comfortable position before power is lost.
- 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. Our staff will demonstrate how to properly use the side rail bar.
- To avoid injury, do not attempt to disassemble or move the bed. Only our home medical equipment staff is authorized to do this.

Notify your nurse if the bed:

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

Gait Belts

A gait belt may be 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 your loved one 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 your loved one 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.

Adult Incontinence Briefs

If your loved one becomes weak, he or she 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 your loved one and the bed dry and clean. It may be difficult for both you and your loved one 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 your loved one on his or her 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 your loved one'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 his or her 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 his or her 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.

Urinary Catheters

Sometimes a catheter may be used for incontinence if there is skin breakdown or urinary retention. Catheters are not routinely changed, since this can increase the risk of infection.

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 your loved one's leg or to the bed.

How to Use a Urinary Catheter

- Clean the area where the catheter is inserted with soap and water. Always wipe from where the catheter is inserted outward, away from the patient. Rinse well. Do not use powder.
- If your loved one 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.
- Always keep the drainage bag below the bladder. The bag can be hooked onto the bed frame or onto your loved one's lower leg, if using a leg bag.
- Do not lay bag on bed.
- 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. Do not let the drainage spout touch surfaces.

Notify your nurse 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.

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.

Canes Use

- Canes must be used in the hand opposite the affected leg, regardless of which hand your loved one prefers to use.
- Your loved one 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.
- Your loved one should follow slightly behind the walker and should not step into the front of the walker. This may cause a loss of balance.
- Your loved one 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 your loved one to use the walker to pull up from a sitting position.
- Do not allow your loved one to go up or down steps.
- Remove rugs that are not tacked down.
- Assist your loved one when walking over uneven surfaces.
- Notify your nurse if the equipment is not working properly.

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 always be secure. 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 your loved one, family and friends of the location of tubing to avoid tripping and falls.

Notify your nurse if:

- the oxygen tank is at 25% 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 your loved one.

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 your loved one’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 your loved one’s 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.

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 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 with white vinegar. 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 your nurse if:

- your loved one is short of breath.
- there is no oxygen flow.
- there are any other problems with the concentrator.

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 your loved one'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.

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 your loved one's nose becomes sore.

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.
- 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.

Your Feedback to Us Is a Gift!

Call the 24/7 Patient Services Line
at 407-379-0311.

Volunteer Services

Volunteers are a dedicated group of individuals who share their time, talents and compassion with the patients and families served by AdventHealth Hospice Care. Our volunteers complete hours of specialized training and undergo extensive background checks.

Like staff, volunteers are required to uphold the organization's code of professional conduct which ensures that all visits are documented and in accordance with the patient's plan of care. Generally, volunteers are available for up to three hours of service per assignment.

Volunteers DO

- Provide companionship
- Prepare snacks, light meals
- Assist with clerical tasks
- Read to patients
- Write letters for patients
- Play cards, board or video games with patients
- Do light housework...laundry, dusting, vacuum.

Volunteers DON'T

- Administer medications
- Lift or move patients
- Provide hands-on physical care
- Feed patients

ALL volunteer requests are made through your Volunteer Coordinator. We ask that you make your request at least 48 hours in advance. Volunteers are based on availability and cannot be guaranteed.



If you find that you are unavoidably delayed from returning in time for the volunteer to leave at their scheduled time, please call the home directly, or contact our Patient Services Line at 407-379-0311 (available 24/7) so they may notify the volunteer of the delay, as the volunteer may have other appointments scheduled.

Since volunteers are providing a service on behalf of AdventHealth Hospice Care, they are not permitted to accept gifts, money or social invitations. However, each volunteer carries donation envelopes, should you like to donate to our Volunteer Department. They also are not permitted to give out their personal phone number.

To determine how a volunteer may help, contact your Volunteer Coordinator at 407-682-0808.

Respite Visits for Caregivers

Volunteers provide companionship to your loved one while the caregiver is away for up to three hours. Volunteers are unable to provide hands-on care, give medications, feed or provide personal hygiene care.

Befriending Visits for Patients

Volunteers visit your loved one 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, playing cards or games, 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

Complimentary volunteer services are based on availability:

- Licensed massage therapists provide comfort massage for your loved one. (The doctor must approve and order this service.)
- Music volunteers provide music with instruments, devices or voices.
- Pet therapy volunteers bring their trained, certified pets to visit your loved one.
- Licensed hair stylists provide a basic hair cut (no chemical treatment, manicure or styling).

Running Errands and Light Chores

Need an extra hand? We have volunteers that would be happy to run to the grocery store for you, pick up your laundry or take your Rover to the veterinarian. You'll need to provide a shopping list and cash.

Or maybe you haven't been able to rake the front yard or clean the ceiling fan blades...we have volunteers that can also do light housekeeping, cooking or yardwork to help you out. (Bathrooms not included...considered deep cleaning.)

Life Reflections Program

Create a legacy by telling your life story using video, audio and/or photographs. Volunteers will work with your loved one and family to create either a Life Reflections photo montage or video compilation DVD of your loved one's memories as a keepsake for the family (limit of two copies). This service is provided free of charge.

Memory Bears/Memory Pillows

Crafty volunteers create lasting memorials in the form of a bear, or a pillow made from your loved one's favorite apparel. These keepsakes may also offer comfort to family and friends in the future. These handcrafted treasures are provided at no cost, but we ask that you limit your request to two items.

Ask any member of your Hospice Care Team for an order form. He or she can take your request along with your garments to the Volunteer Services Department.

How to Be an Effective Caregiver

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?

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.

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?

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

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 AdventHealth Hospice Care 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 must 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

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 AdventHealth Hospice Care 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 with problem-solving a situation.

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.

Our AdventHealth Hospice Care team members are available by phone to help you work through any situation. You can reach them 24 hours a day at 407-379-0311.

Discuss your feelings of fear or anxiety with your social worker. They can teach you techniques to help lessen the intensity of these feelings. Sometimes talking it over with someone else may be all you need.

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 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

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.



End-of-Life Signs and Symptoms

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.

Increasing Weakness

This is often the earliest sign that 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 always be nearby. It helps to think ahead and plan for how you will provide this increased care.

How You Can Help

- Notify your nurse 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 your loved one 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 page 13.)

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 your nurse. 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 forgiveness for anything?”, “Do you need to forgive them for anything?” or “Is there someone they would like to see for the last time?”
- Express your love and appreciation for them.

When Death Is Near

Your Hospice Care Team members will review what may be expected to happen in your specific case.

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)*

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. The guide on the next two pages is provided to help with the understanding of the some of the changes that you may start to see.

Signs of Approaching Death

This guide helps to understand and anticipate the changes that may occur as a person nears death. Please remember these changes may not always occur, or may not occur in any certain order. Discuss any questions with your hospice nurse. Our goal is to keep your loved one as comfortable as possible.

Signs	Symptoms	Comfort Measures
Breathing	<ul style="list-style-type: none"> Your loved one may breathe with mouth open, (mouth may be very dry) Thick secretions may accumulate in back of the throat. A “rattling” sound in the back of the throat with each breath due to secretions in throat/chest. Your loved one can still get air, he or she may be too weak to clear their throat. Breathing rate become faster or slower, deeper or labored. There may be periods of no breathing for 5-15 seconds or a brief pause in breathing. This is known as apnea This is not painful to your loved one and is a normal part of the transition process. 	<ul style="list-style-type: none"> Use the mouth swabs your nurse will give you, dipped in ice water to swab the patient’s gums, teeth and tongue. Elevate 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 nurse if the rattling sound is not relieved. A medication may be given to decrease the accumulation of secretions (“wet” breathing). [Generally, suctioning the patient’s lungs is avoided as this procedure usually increases agitation, may interfere with the heart rhythm and is not effective in removing congestion.] It is helpful to recognize this breathing pattern. It will signal that death is very near. Anyone who has expressed the desire to be with your loved one at the time of death should stay near. Notify the nurse if your loved one is having rapid or difficult breathing so that medication may be given to ease the breathing. Oxygen may be used in special cases; however, it does not always make your loved one more comfortable. The mask may cause increased agitation.

Signs	Symptoms	Comfort Measures
Circulation	<p>Your loved one's arms/legs:</p> <ul style="list-style-type: none"> • Cool as circulation decreases • Look pale or mottled • Become blue or purple in color as do the lips and nail beds. 	<ul style="list-style-type: none"> • This is an indication of the circulation slowing down and is not painful. • Turn your loved one as instructed and massage the areas of the body on which your loved one was previously lying.
Confusion	<p>He/she may not:</p> <ul style="list-style-type: none"> • Be aware of time of day. • Be able to recognize people, places or objects once familiar. • Speak clearly – speech may be slurred or nonsensical. 	<ul style="list-style-type: none"> • Stand where your loved one can see you when you speak. • Gently remind your loved one what time of day it is, or who you or others are. • Try not to appear too distressed by his/her inability to remember familiar things. This may frustrate your loved one more. • Encourage your loved one to speak slowly.
Dreams	<ul style="list-style-type: none"> • It is not unusual for patients to talk about contact with loved ones who have died before them, or • Have “visualizations” about going on a long trip. 	<ul style="list-style-type: none"> • Recognize that this is quite a normal experience and encourage your loved one to share it with you.
Eyes	<ul style="list-style-type: none"> • The patient's eyes may become dry/crusty. • A comatose patient's eyes open partially or totally, and blinking is generally absent. • Tearing compensates for dryness. 	<ul style="list-style-type: none"> • With a warm moist washcloth, gently cleanse the eyes to remove any crusted matter. • You may try to close the patient's eyes; however, they will usually open again. • If the eyes remain wide open, you may want to purchase an artificial-tears preparation which can be dropped into the eyes periodically to soothe them.
Fatigue	<ul style="list-style-type: none"> • More tired. • Sleeping more • The deep sleep is called “coma.” 	<ul style="list-style-type: none"> • Often loved ones feel there is something they haven't had a chance to say to the patient. You can talk to the patient, even when in a coma and reassure your loved one by letting him/her know you are near. Your loved one probably hears and understands, even though he/she is unable to talk back. • Tell your loved one what you are going to do before you do it. For example, “Mom, I'm going to turn you now.”
Fever	<ul style="list-style-type: none"> • Your loved one can run a high fever as the temperature regulator in the brain fails prior to death. • Your loved one will probably perspire heavily when the fever breaks. • The chest/abdomen may be warm while the arms and legs are cool. 	<ul style="list-style-type: none"> • The nurse can instruct measures that can make your loved one more comfortable. • The gown, pajamas and sheets may need to be changed if they are damp. • Add blankets if your loved one is cold. • If your loved one is hot, gently sponge their skin with lukewarm water and let the water evaporate naturally. • Notify the nurse if your loved one's temperature is above 100.5 degrees orally so that appropriate medication can be given.
Perspiration	<ul style="list-style-type: none"> • Your loved one may have periods of extreme perspiration, even if body is cool. 	<ul style="list-style-type: none"> • Change the patient's nightclothes, and/or sheets if they become moist with perspiration. • A warm sponge bath may feel soothing along with a light application of baby powder.

Signs	Symptoms	Comfort Measures
Decreased Urination	<ul style="list-style-type: none"> Little or no urine present; the kidney function slows down 	<ul style="list-style-type: none"> 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.
Unresponsive	<ul style="list-style-type: none"> No response to touch or words. 	<ul style="list-style-type: none"> 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 23.) Let them know you are there through touch and a soft voice. Keep in mind that hearing remains until the end.
Muscles	<ul style="list-style-type: none"> Muscle twitching may occur from imbalances in the blood. 	<ul style="list-style-type: none"> The muscle twitches are usually not painful. If the twitching increases or becomes bothersome to your loved one, advise your nurse.
Restless	Your loved one may: <ul style="list-style-type: none"> Move about in bed Pull at the bed linens Reach out/pick at the air 	<ul style="list-style-type: none"> Elevate the side rails of the bed if there is a danger that your loved one may fall out of bed. Don't try to stop your loved one from picking at the air; it will only make him/her more agitated.

Death Notification — 407-379-0311

Remember, you are not alone. **If you think your loved one has passed away, please call our Patient Services Line at 407-379-0311 (available 24/7).** 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

The Hospice Care Staff Member Will:

- confirm that your loved one 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.
- review appropriate disposal of medications.

Members of the Hospice Care Team may call and visit to offer support to the family.

The home medical equipment company, Stateserv, will call to schedule a time to pick up equipment.

A member from our Horizons Bereavement Center 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 AdventHealth Hospice Care'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.

Final Arrangements

Planning for a Funeral

A funeral is to honor your loved one after they have passed. Planning a funeral or memorial service should include the wishes of 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. In 2017, the median cost* of a funeral with viewing, burial and vault is \$8,755. A cremation is \$2,500 to \$6,260 but can increase or decrease based on your choices. Life insurance or savings may be available to help pay for these expenses. 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.
 - Burials require caskets, clothing or personal items to be placed with the deceased. The location of the burial must be chosen.
 - 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 a price list.
- A memorial service may be held at the funeral home, a place of worship or another location. Some families choose not to have a service. This is perfectly acceptable if it is keeping within your loved one's wishes.
- 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.

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

**Statistics from the National Funeral Directors Association.*



Items to Address After a Death Occurs

Here is a checklist of things to consider in helping with your planning.

Immediately After Death

- Contact the funeral home, if hospice hasn't done so, to take your loved one into their care.
- Contact your clergy.
- Alert immediate family members and close friends.
- Notify agent under Power of Attorney (if applicable).
- Alert the executor of your loved one's Will.
- Notify religious, fraternal, and civic organizations with which your loved was involved.
- Arrange for the care of dependents or pets.
- Prepare an obituary for the newspaper.
- If the home will be unoccupied:
 - Dispose of perishables, such as food, and existing garbage.
 - Remove any valuables
 - Alert Post Office to forward mail
 - Stop delivery of newspaper
 - Make home appear to be occupied, such as using lamp timers
 - Secure residence
- Locate your loved one's important documents:
 - Will
 - Birth Certificate
 - Social Security Card
 - Marriage License
 - Military Discharge Papers
 - Deed to burial plot
 - Copy of funeral prearrangements
 - Life insurance policies
- Compile the following information for your loved one, which the funeral home will need in order to finalize the death certificate:
 - Date of death
 - Date of birth
 - First, middle and last name
 - Maiden name (if applicable)
 - Home address
 - Social Security Number
 - Age
 - Gender
 - Race/Ethnicity
 - Marital Status
 - Spouse's first and last name
 - Highest level of education attained
 - Occupation
 - Place of Birth (City and State)
 - Father's Name
 - Mother's Name
 - If your loved one was a Veteran:
 - Entered Service Date and Service Place
 - Service Number
 - Separated from Service Date and Service Place
 - Grade, Rank or Rating
 - Organization and Branch of Service
- Obtain certified copies of the death certificate. Five copies with the cause of death and five without.
- Notify your 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 acknowledgment cards for flowers, memorial donations, food or spiritual remembrances.
- Consult with an attorney about probate.
- Meet with an accountant to discuss estate taxes.
- Notify insurance companies or your insurance agent. File claims 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 and other government offices that may have been making payments to your loved one. Social Security Administration, 800-772-1213, ssa.gov
- 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.
- If the home is unoccupied, cancel services such as cable, phone, etc.
- Notify the Registrar of Voters.
- Cancel prescriptions.
- Contact the Department of Motor Vehicles to cancel the driver's license, and transfer titles of all registered vehicles.
- Notify your stockbroker or investment specialist to change ownership and tax identification number on accounts, physical stocks and bonds, book entry securities, IRA accounts and mutual funds.
- If your loved one was a Veteran, inquire about benefits that you may be entitled to through the VA. Department of Veteran Affairs, 800-827-1000, vba.va.gov/vba
- Notify all three credit reporting agencies in writing of your loved one's death, and obtain a current copy of his or her credit report:
 - Equifax, Equifax.com
PO Box 105139, Atlanta, GA 30348
 - TransUnion, TransUnion.com
PO Box 2000, Chester, PA, 19016
 - Experian, Experian.com
PO Box 2002, Allen, TX, 75013

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.
- Advise creditors in writing that a death has occurred.
- Change ownership of assets and lines of credit.
- Obtain copies of your loved one's outstanding bills.
- Organize and distribute your loved one's personal belongings.
- Remove loved one's name from marketing and mailing lists.
- Close any social media accounts, such as Facebook, Twitter, Instagram, etc.
- Have *your* will reviewed by an attorney.

After Your Loved One Is Gone

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.

Horizons Bereavement Center — 407-379-0490

We Are Here for You. For assistance, information or to request counseling services, please call the Horizons Bereavement Center at 407-379-0490 or visit our website at AdventHealthHospiceCentralFlorida.com.

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.

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, your loved one 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 your loved one 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, your loved one 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, your loved one begins to understand the certainty of death. Because of this, your loved one may become silent, refuse visitors and spend much of the time crying and grieving. This process allows your loved one to disconnect from things of love and affection. It is not recommended to attempt to cheer up a your loved one 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.

Bereavement Care — 407-379-0490

Grief is a unique experience for everyone. 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.
- Provide support groups, education, and resources about the grieving process, at no cost.
- Offer up to 6 sessions of individual bereavement counseling, at no cost.
- Offer ongoing social opportunities, such as breakfast and lunch groups, and potluck dinners.
- Provide community memorial services throughout the year to honor those who have passed away.

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

- Be honest — and use KISS (Keep It Simple & Short).
- Encourage them to ask questions — then provide age appropriate answers.
- Describe their loved one’s 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 Grief Support Educator can help adults learn how to talk to children about terminal illnesses and death; and provide individual support for children ages 5 to 17 at our Horizons Bereavement Center in Altamonte Springs or virtually. **For more information, call 407-379-0497.**

Grief Support Groups

With a support group, you choose your level of participation. This approach helps you cope in your own way as you develop your own emotional, spiritual and social resources. 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 to 12 participants. There are a variety of day and evening support group offerings available with virtual options.

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

Bereavement services are available to AdventHealth Hospice Care 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 AdventHealthHospiceCentralFlorida.com.

Your Feedback to Us Is a Gift!

Call the 24/7 Patient Services Line at 407-379-0311.

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 and 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. AdventHealth Hospice Care will respect that choice, offer information on alternative health care options consistent with their treatment choices, discharge the patient from AdventHealth Hospice Care, 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 decision 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
- if stipulated, make health care decisions for you without the determination of incapacity
- 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 your loved one 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 your loved one 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 your loved one delegates decision-making authority, a proxy is one to whom the responsibility falls by default when the incapacitated the 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 your loved one 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 your loved one 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 12/2004, 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 AdventHealth Hospice Care 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 and timely 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, personal property, cultural traditions and my religious and/or spiritual experiences.
23. Have a confidential clinical record; have a copy of the AdventHealth Hospice Care 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 AdventHealth Hospice Care when any Advance Directives are executed, changed or rescinded.
4. Providing AdventHealth Hospice Care 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 AdventHealth Hospice Care 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 secondhand 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 AdventHealth Hospice Care 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 AdventHealth Hospice Care 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 secondhand 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 AdventHealth Hospice Care with any questions about the use, administration or disposal of any medication.

R3 — Your Loved One and Caregiver Rights and Responsibilities, Created 9/26/02, Revised 6/17/11, 5/30/14

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.
- AdventHealth Hospice Care will be responsible for hospitalizations or other care and services that are preauthorized by AdventHealth Hospice Care and related to the terminal illness. AdventHealth Hospice Care 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 AdventHealth Hospice Care does not have a contract, or if I seek care and services related to my terminal illness without preauthorization from AdventHealth Hospice Care, I will be responsible for payment for those services unless and until I voluntarily revoke the Medicare Hospice Benefit in writing.
- AdventHealth Hospice Care 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 AdventHealth Hospice Care 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 AdventHealth Hospice Care covered by a payer other than Medicare, I will inform AdventHealth Hospice Care 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, AdventHealth Hospice Care will bill me or the responsible party/estate for those services.
- AdventHealth Hospice Care or the long-term care facility will bill me or the responsible party/estate for any your loved one 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

- AdventHealth Hospice Care 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 AdventHealth Hospice Care 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 AdventHealth Hospice Care.
- 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 AdventHealth Hospice Care Financial Assistance policy.
- AdventHealth Hospice Care staff will assist patients who are uninsured or underinsured in completing and submitting the necessary documentation to be

R7 - Your Loved One Financial Responsibility, Created 6/17/11, Revised 5/15/14

Comprehensive Emergency Management Plan Patient Information

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 AdventHealth Hospice Care (AHHC) 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 AHHC 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, etc.), current AH Hospice 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 several 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.

Emergency Management System
Special Needs Shelter

Orange County Residents

Emergency Management System 407-836-9140
Special Needs Shelter 407-836-9319

Osceola County Residents

Emergency Management System 407-742-9000
Special Needs Shelter 407-742-9000

Seminole County Residents

Emergency Management System 407-665-5102
Special Needs Shelter 407-665-5121

Special Needs Registry

AdventHealth Hospice Care is required to provide registration information to all Orange, Osceola and Seminole County patients who do not live in nursing homes or assisted living facilities for their county Emergency Management Services. This is done when you are admitted to AH Hospice services, or if you go home from a long-term care facility. You must call to register with your county. 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 AHHC 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 aids 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.

Important Phone Numbers

Hospice Patient Services Line — 407-379-0311

A nurse answers the phone 24 hours a day to address your care needs.

Horizons Bereavement Center — 407-379-0490

Horizons Student Grief Support — 407-379-0497

Privacy

For privacy (HIPAA) or compliance questions, or concerns, please contact the Privacy Officer at:

Phone: 800-906-1794/TTY: 407-200-1388

Email: patientrequest@adventhealth.com

Mail: AdventHealth, 900 Hope Way,
Altamonte Springs, FL 32714, Attn: Privacy Officer

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 **AdventHealth Hospice Care 407-682-0808**.

State Toll-Free Numbers

Florida Agency for Health Care Administration (AHCA)

To report a complaint about the services you receive

888-419-3456

Florida Abuse Hotline

To report abuse, neglect or exploitation

800-962-2873

Medicaid Fraud Hotline

To report suspected fraud

866-966-7226

Domestic Violence Hotline

800-500-1119



Caregiving Resources

Alzheimer's & Dementia Resource Center
407-843-1910 | ADRCcares.org

Assurance Wireless (free cell phones)
888-898-4888

Catholic Charities
407-658-0999

Charity & Love (energy bill for elders)
407-522-4473 | CharityLoveInc.com

Christian Service Center
407-425-2523

Christian Sharing Center
407-260-9155

Community Legal Services (Osceola County)
407-847-0053 | clsmf.org

Elder Helpline
407-514-0019

Disability Determination
407-897-2970

Family Caregiver Alliance
800-445-8106 | CareGiver.org

Florida Division of Consumer Services
800-435-7352 | FreshFromFlorida.com

Florida Division for Blind Services
407-245-0700

Florida Senior Legal Helpline
888-895-7873

Food Stamps/Vouchers (DCF)
866-762-2237 (24/7) | MyFLFamilies.com

Free Amplified Phone (hearing care)
407-623-1070

GriefShare
800-395-5755

Heart of Florida United Way Community Services
2-1-1 or 407-839-4357

Home Health Care - AdventHealth Home Care
407-691-8206

Jewish Family Center (JFS)
407-644-7593

Meals on Wheels – Seminole County
407-333-8877 | mealsetc.org

Medicare
800-633-2273 | medicare.gov

Medicare Beneficiary Helpline
800-844-0795

Mustard Seed (furniture)
407-875-2040

National Alliance for Caregiving
CareGiving.org

Orange County Bar Association
407-422-4551 | OrangeCountyBar.org

Orange County Crisis Assistance Pro.
407-836-6500

Orange County Senior Services
407-254-9277 | ocfl.net/seniors

Orlando Union Rescue Mission
407-841-7578

Osceola Council on Aging
407-846-8532 | OsceolaGenerations.org

Rebuilding Together Orlando
407-898-3777 | RTOrlando.org

Salvation Army - SalvationArmy.Orlando.org
407-423-8581 Orange County
407-465-0108 Osceola County
407-322-2642 Seminole County

Seminole County Bar Association
407-834-1660 | SeminoleCountyBar.com

Seminole County Community Assistance
407-665-2300

Seniors First
407-297-9980 | SeniorsFirstInc.org

Senior Resource Alliance
800-963-5337 | SeniorResourceAlliance.org

Social Security
800-772-1213 | ssa.gov

National Suicide Prevention Lifeline
800-273-8255 | SuicidePreventionLifeline.org

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

Transportation (ACCESSLYNX)
407-841-2279 | GoLynx.com

Veterans Administration
800-827-1000 | va.gov

Veteran Services
407-836-8990

Vision USA (free eye exam)
800-766-4466

Winter Park Christian Center
407-628-1692

Updated 4/30/2019

Our Health Equity Promise

Patient Protection and Affordable Care Act: Section 1557

AdventHealth complies with applicable federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability or sex. This facility does not exclude people or treat them differently because of race, color, national origin, age, disability or sex.

AdventHealth provides free aid and services to people with disabilities to communicate effectively with us, such as:

- Qualified sign language interpreters
- Written information in other formats (large print, audio, accessible electronic formats, other formats)

AdventHealth provides free language services to people whose primary language is not English, such as:

- Qualified interpreters
- Information written in other languages

If you need these services, please call 407-303-5600 x1106707.

If you believe that this facility has failed to provide these services or discriminated in another way on the basis of race, color, national origin, age, disability or sex, you can file a grievance or request that someone assist you with filing a grievance at 407-200-1324 or fh.risk.management@adventhealth.com.

You can also file a civil rights complaint with the U.S. Department of Health and Human Services, Office for Civil Rights, electronically, through the Office for Civil Rights Complaint Portal, available at ocrportal.hhs.gov/ocr/portal/lobby.jsf, or by mail or phone at:

U.S. Department of Health and Human Services
200 Independence Avenue, SW
Room 509F, HHH Building Washington, D.C. 20201
1-800-368-1019, 800-537-7697 (TDD)

Complaint forms are available at hhs.gov/ocr/office/file/index.html.

The statements below direct people whose primary language is not English to translation assistance.

ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al número siguiente.

CHÚ Ý: Nếu bạn nói Tiếng Việt, có các dịch vụ hỗ trợ ngôn ngữ miễn phí dành cho bạn. Gọi theo số điện thoại dưới đây.

注意: 如果您使用中文, 您可以免费获得语言协助服务。请拨打下面电话号码。

Atansyon: Si ou pale kreòl Ayisyen, gen sèvis asistans nan lang ou ki disponib gratis pou ou. Rele nimewo ki anba an.

주의: 한국어를 사용하시는 경우, 언어 지원 서비스를 무료로 이용하실 수 있습니다. 아래의 번호로 전화하십시오.

UWAGA: Jeżeli mówisz po polsku, możesz skorzystać z bezpłatnej pomocy językowej. Zadzwoń pod numer podany poniżej.

ملحوظة: اذا كنت لاتتحدث اللغة الانجليزية فان خدمات الترجمة متوفرة لك مجاناً. الرجاء الإتصال بالرقم أدناه.

ATTENTION: Si vous parlez français, des services d'aide linguistique vous sont proposés gratuitement. Appelez le numéro ci-dessous.

PAUNAWA: Kung nagsasalita ka ng Tagalog, maaari kang gumamit ng mga serbisyo ng tulong sa wika nang walang bayad. Tawagan ang numero sa ibaba.

ВНИМАНИЕ! Если вы говорите на русском языке, то вам доступны бесплатные услуги перевода. Для этого позвоните по нижеуказанному номеру.

ACHTUNG: Wenn Sie Deutsch sprechen, stehen Ihnen kostenlos sprachliche Hilfsdienstleistungen zur Verfügung. Rufen Sie die untere Nummer an.

સુચના: જો તમે ગુજરાતી બોલતા હો, તો નિ:શુલ્ક ભાષા સહાય સેવાઓ તમારા માટે ઉપલબ્ધ છે. નીચેના નંબર પર ફોન કરો.

ATENÇÃO: Se você fala português, disponibilizamos serviços lingüísticos gratuitos. Ligue para o número abaixo.

ध्यान दें: यदि आप हिंदी बोलते हैं तो आपके लिए मुफ्त में भाषा सहायता सेवाएं उपलब्ध हैं। नीचे लिखे नम्बर पर सम्पर्क करें।

اگر شما فارسی زبان هستید، خدمات کمکی زبان بطور مجانی در دسترس شما قرار دارد. تو شماره زیر زنگ بزنید.

توجہ فرمائیں۔ اگر آپ اردو بولتے/بولتی ہیں تو آپ کے لئے لسانی خدمات مفت میسر ہیں۔ ذیل میں دئیے گئے نمبر پر کال کریں۔

注意: 日本語でお話になりたい場合には、無料の通訳サービスをご利用いただけます。下記の番号にお電話してください。

ໄປດຊາຍ: ຖ້າວ່າ ທ່ານເວົ້າພາສາ ລາວ, ການບໍລິການຊ່ອຍເຫຼືອ ດ້ານພາສາ, ໄດ້ອະນຸຍາດ, ແມ່ນມີພ້ອມໃຫ້ທ່ານ. ກະລຸນາໃຫ້ມື້ເບິ່ງຂໍ້ມູນ

LUS CEEB TOOM: Yog tias koj hais lus Hmoob, cov kev pab txog lus, muaj kev pab dawb rau koj. Hu tus xojtooj hauv qab no.

ATTENZIONE: Se parlate italiano, sono disponibili dei servizi di assistenza linguistica gratuiti. Chiamare il numero sotto indicato.

407-303-5600 ☎ 407-303-3025

Frequently Asked Questions about Coverage of Hospice Care

1. If I have a Medicare Part D pharmacy provider, won't all my other medications be covered through this insurance?

There have been 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.

2. 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 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. You can speak to your social worker about other community resources.

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

At any time while 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.

4. 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:

- Patient moves out of the hospice's service area or chooses care from a non-contracted facility.
- 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 patient and caregiver prior to discharge. Upon discharge, patient loses the remaining days in the benefit period. General coverage under Medicare is reinstated at the time 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.




AdventHealth
Hospice Care
Central Florida

A compassionate, non-profit ministry since 1990.

480 West Central Parkway | Altamonte Springs, FL 32714
Phone: 407-682-0808 | AdventHealthHospiceCentralFlorida.com