



CIRCLE *of* LIFE 

CAREGIVER TRAINING GUIDE

Any question, day or night, call us at 479-750-6632
Be confident that we're here for you.

Caring for Your Loved One

IT IS OUR HONOR to serve you and your loved one and we are committed to providing compassionate end of life care for the body, mind, and spirit for our patients, their family members and caregivers. Your hospice team will do their utmost to preserve dignity and comfort. What is dignity? Dignity means many things to many different people. It is about self-respect, life history, family, friends, work, hobbies, feelings, hopes, dreams and life lessons—all the things that are most important to our patients; the things that make your loved one unique and special.

Comfort is easier to define. When making a visit, your care team will focus on the patient, noting pain and other symptoms (such as breathing trouble, nausea, weakness, constipation).

It is important to remember that you, the caregiver, are also part of the circle of care. Please keep your hospice care team informed of your own emotions and feelings. **Your team is here for you.**

Introduction

This caregiver training guide was created by a number of our staff members working as a team. Allow it to provide you with **an immediate source of information** and to answer many of the questions you might have as you and your loved ones go through this journey.

Medications and treatments are important, but the real work of hospice is being **physically and emotionally present**. Sharing the final stage of life's journey with someone who is dying is the most important thing you can do for them. Simply be there.

Confidence in your Caregiving

During this stressful time, your care team strives to help you feel more confident in providing care and support to your loved one. We will provide you with medication education, medical information, telephone guidance and ongoing discussions as the disease progresses.

We continually assess both our patient, and you, the caregiver. We want to hear what you feel, see and need throughout this time. Your care team will check in frequently asking, *"How can we help you feel more confident as a caregiver? What can we help you feel more comfortable doing for your loved one?"*

Whatever your questions or concerns, let us know. **We are here for you, too.**

Caregiving responsibilities can feel overwhelming. Please be aware of:

- ◆ Excessive Fatigue
- ◆ Fear of the unknown
- ◆ A loss of control
- ◆ A loss of "normal" activities
- ◆ Financial worries
- ◆ Social isolation
- ◆ Emotional challenges
- ◆ Feelings of obligation, guilt or resentment
- ◆ Difficulty making plans

In order to effectively care for another person, you need to care for yourself. Here are some valuable suggestions:

- ◆ Establish visiting hours so that you can have both support and privacy.
- ◆ Select a family member or friend to be in charge of relating updates by phone or email to others who are concerned.
- ◆ Educate yourself about the condition of the person receiving care. Talk to your physician. Information is empowering.
- ◆ Realize that no one can be all things to all people. You may not be able to live up to everyone's expectations. Try not to dwell on negative comments.

**Any question, day or night, call us 479-750-6632.
Be confident that we are here for you.**

On-Call Service

Often, questions, concerns, and problems occur during the night or on weekends. We encourage caregivers to use our on-call service when these needs arise. We want you to feel confident calling for support. A nurse is always available on-call.

The on-call number is 479-750-6632. Keep this booklet in an easily located area in the home to reference and document instructions from the team.

If you call for support after 4:30 in the evening, our answering service will promptly answer. The operator will request the patient's name and the reason for your call. Then the operator will ask you to hang up and to not use your telephone while awaiting the call back. The on-call nurse will be notified and he or she will return your call within 15-20 minutes. ***If your call is not returned in 15 to 20 minutes, please call again.***

If there is a change in the patient's condition or a medical emergency, call Circle of Life Hospice first. We request that you DO NOT call 911.

**AFTER 4:30PM, A
WEEKEND, OR HOLIDAY?
CONTACT CIRCLE OF LIFE'S
ON-CALL NURSE: 479-750-6632**

**Please have the following ready
and stay calm,
we are here to help:**

- ◆ This caregiver training booklet in case it is needed for reference during your call.
- ◆ The patient's **medication log** so that you can refer to the scheduled and as needed (prn) medications that the patient has most currently been given.
- ◆ A **pen and piece of paper (or call log)** to write down instructions from the nurse.

Be confident that we are here for you.

Call Log

Date: _____

Spoke with: _____

Instructions:

Date: _____

Spoke with: _____

Instructions:

Date: _____

Spoke with: _____

Instructions:

Date: _____

Spoke with: _____

Instructions:

For extra writing room, we encourage caregivers to utilize a spiral notebook to write down notes, questions for your hospice care team, and to document phone calls made to your hospice nurse.

The Role of Nutrition

It is normal for those who are seriously ill to have changes in appetite and in the way they eat and drink. Frequent oral care, small sips of fluid, ointment to the lips and light massage with lotion are all ways to comfort and support the patient at this stage. Try offering food frequently during the day; three to six light meals or smaller portions are usually better tolerated than traditional meal sizes. Offer fluids between meals, instead of with meals to prevent feelings of fullness. Arrange meal times when your loved one is most rested and active. *Do NOT force your loved one to eat.*

Helpful Hints to Improve Nutrition

- ◆ Your loved one should avoid eating when nauseated or in pain
- ◆ Invite others to share meal times—socializing makes everything taste better
- ◆ Set a pretty table—add candles or flowers, play music, garnish food to make it more pleasing to the eye
- ◆ Freshen up hands and face with a warm or cool, moist cloth before eating
- ◆ Have meal options for food choices available
- ◆ Vary food preparation techniques: grill, fry, broil, or roast
- ◆ Have favorite snacks readily available
- ◆ If nothing tastes good, hydrate with ice chips or popsicles
- ◆ Use herbs, spices and other seasonings to add flavor
- ◆ If your loved one complains of a metallic or bitter taste, or of dry mouth, give them lemon drops, mints or gum for relief
- ◆ Try serving foods cold or at room temperature, especially meat. This can decrease strong tastes and smells, making them easier to tolerate
- ◆ Avoid foods usually associated with a bitter taste such as red meat, tomatoes, coffee, tea, and chocolate
- ◆ Add sugar to make food more appealing
- ◆ Season foods with tart flavors such as lemon, lime, other citrus, vinegar, or sweet and sour sauce
- ◆ Do not use metallic containers or metal utensils because it can leave a residual flavor. Plastic, ceramic and glass is neutral
- ◆ Try frozen grapes, oranges, cantaloupe, watermelon, berries, and bananas for nutrition and hydration

Changes in Taste and Smell

Foods will often taste and smell differently as your loved one's illness progresses. This may be due to the illness itself, the medicine or treatments. Even favorite foods may have little or no taste or can taste "off". This can reduce appetite.

To combat a poor appetite, **have your loved one begin each meal or snack with a clean mouth.** Brush teeth and tongue with a soft toothbrush and use a mouth rinse. Frequently rinse mouth between meals with cool water, mint-flavored water, tea, or ginger ale.

If your loved one complains of foods such as soups, tomato sauces, casseroles, salad dressings, and gravy tasting salty, try adding sugar. If foods taste too sweet, add a pinch of salt and serve cold. If foods taste too bland, use additional herbs and seasonings and experiment with strong flavored foods. Have your loved one try alternate bites of different tasting foods within a meal. For example, a bite of something sweet like pineapple and then a bite of bland cottage cheese. A bite of grilled cheese; then a spoon of tomato soup.

Difficulty Swallowing

When a person has difficulty swallowing, there is increased risk of aspiration (taking food or fluids into the lungs) and choking. To decrease this risk, change the texture of foods and/or thickness of fluids. Foods that are mixed consistencies (liquid along with solid) may be difficult to manage in the mouth and therefore increase the risk of aspiration and choking. Examples of mixed consistency foods are vegetable soup and cold cereal and milk. Also avoid dry, hard, sticky and fibrous foods and any foods with seeds or skins. These types of foods are hard to chew and move around in the mouth, making them more difficult to swallow.

Give your loved one foods that are easy to chew, moist enough to slide down the throat, and evenly textured. Soft food is usually well tolerated but if not, it should be chopped/ground or pureed.

Foods to Avoid

- ☒ Foods that crumble and break into pieces (crackers, chips, pretzels, taco shells)
- ☒ Foods that consist of small pieces (rice, corn, peas, popcorn, granola, raisins, beans, nuts)

Foods to Avoid continued

- ❌ Foods that stick to the mouth and throat (peanut butter, cream cheese)
- ❌ Food that has fibrous parts or seeds (celery, fruits with peels, tough meat)
- ❌ Food that is hard to chew (tough meat, whole raw vegetables, hard fresh fruit, bagels)

Foods that are generally well tolerated

- ✅ **Starches:** bread, pancakes, waffles, hot cereals, well-cooked pasta, mashed potatoes, muffins, stuffing, lightly toasted bread
- ✅ **Fruits/vegetables:** soft, peeled or pureed fruits and well-cooked vegetables
- ✅ **Dairy:** milk shakes, pudding, custards, ice cream, yogurt, cottage cheese
- ✅ **Protein:** diced, well-cooked meats served with gravies, ground meats and scrambled eggs
- ✅ **Miscellaneous:** soft French fries, cheese pizza, cream soups

Thickening Liquids

To decrease the chance of choking, liquids can be thickened by adding a commercial food/liquid thickeners to all liquids, (including juices, soups, coffee, and milk) to bring them to the correct consistency. **Commercial food/liquid thickeners are available upon request.**

Helpful Hints

- ◆ Prepare milkshakes in a blender with milk, ice cream or instant breakfast mix
- ◆ Mix and thicken soups in a blender with potatoes and/or potato flakes or baby cereal flakes until smooth
- ◆ Combine pureed fruit and fruit juice to the consistency of syrup
- ◆ Thicken liquids with pureed fruits, yogurt, dried baby cereal, yogurt, or pudding
- ◆ Place a ripe banana into a blender and add to a milkshake, nutritional supplement or juice
- ◆ Add pudding or custard to milk or yogurt

CAREGIVER TRAINING

When Food and Water are No Longer a Priority

One of the most difficult but natural occurrences of the end-of-life journey is when the body no longer wants food or water. It is normal to want to feed and ensure that your loved one is adequately hydrated. However, the needs of a dying body are much different than that of a healthy body. Force feeding food and/or fluids can cause an increase in discomfort, cause fluid to build up in the lungs, increase chances of nausea and vomiting, and can hasten death.

We understand that food is a very emotional topic, and in many cultural traditions, we naturally feed the ill so that they can regain strength and vitality; however, ***during the final stages of life, eating and digesting food takes away more energy than what it gives.*** Even the patient's most favorite foods may cause nausea.

Best Practices for Caregivers

- ◆ Support the patient's decision not to eat or drink
- ◆ Encourage your loved one to rest
- ◆ Offer or perform mouth care to freshen mouth, *this is a great comfort measure (See page 12)*
- ◆ *Try not to worry.* Your loved one is not eating or drinking because they are dying. It is NORMAL for the body to slow down, taking with it the desire to eat and/or drink



Call your Hospice Care Team

- 📞 If choking or coughing occurs after eating or drinking fluids
- 📞 Any questions regarding nutritional needs and/or changes

"In the days before death they will not even take water. **This is normal.** This is how people die."

Barbara Karnes, RN

New Rules of End of Life Care
VIDEO AVAILABLE FOR VIEWING
IN THE COMFORT OF YOUR HOME.

Understanding the Role of Medications

Medications come in different forms including: pills, liquids, inhalants, patches, suppositories and ointments. Medications may be changed into different forms depending on the patient's needs, such as difficulty swallowing. **Let your hospice team know if you have less than a two-day supply of any current medications.**

Medication DO:

- ✓ Read the medication label first.
- ✓ Administer all medicine exactly as it is written on the prescription or as ordered by the physician, for example "with food".
- ✓ Administer routine medications on a regular schedule; timing is very important.
- ✓ Use break-through or as needed medicine as instructed by the hospice nurse and physician to prevent pain from escalating.
- ✓ Tell your hospice team before stopping or changing medications.
- ✓ Keep a written schedule and record when, and how often, medication is taken (See Appendix).
- ✓ Avoid alcoholic beverages while taking medicine.
- ✓ Tell your hospice nurse about any over-the-counter drugs, vitamins, mineral supplements or herbal remedies that your loved one is currently taking. Supplements can sometimes interfere with medication.

KEEP ALL MEDICINE OUT OF REACH OF CHILDREN AND PETS.

How to Make Medication Time Easier for Patient and Caregiver

- ◆ To make pill swallowing easier, moisten mouth with water or add pills to applesauce or pudding. Some pills may be cut in half.
- ◆ If giving a medication rectally, it is best to administer after a bowel movement, if possible. Using a glove, lubricate one finger and insert the medication at least 2/3 of the finger's length.
- ◆ When using liquid medicine, slightly tilt head upright and slowly pour the medicine down the side of the mouth.
- ◆ When administering medication under the tongue or between the cheek and gum, moisten the area with two to five drops of water and then place the pills in that area as directed by your hospice care nurse.

Medication DO NOT:

- ✗ Share medications with anyone else.
- ✗ Crush pills unless directed or instructed by your hospice nurse.
- ✗ Take more than the amount that is ordered.

Medication Record/Log

It is helpful to use a medication log to record all medications given or taken. If you wish, utilize the medication log found in the appendix, or notify your team members where to find your medication record so that they can make sure your loved one is receiving the correct medication(s) and doses at the right times.

Controlled Substances

Controlled substances are specific medications determined by legal authorities to have a greater need for careful and precise accountability. Examples of controlled substances include many pain medications like morphine and some anxiety medications like Ativan (lorazepam). The use of controlled substances at Circle of Life Hospice is based on a patient specific pharmaceutical plan of care, involving critical assessment, careful monitoring, and physician authorization. Any suspected diversion or misuse will be investigated.



In-Home medication LOCK BOXES are available as a FREE service for safe storage of medications.

If interested in this FREE service, please request a medication LOCK BOX from your nurse or hospice team.



CAREGIVER TRAINING

Comfort Kit Medications

For detailed instructions on giving comfort medications and medication log, go to pages 18-19.

Hospice patients condition can change dramatically at any time—our goal is to be prepared so suffering can be minimized and even prevented. **For optimal symptom control, it is best to use the comfort medication(s) at the first indication of increased pain and/or anxiety.**

Helpful Hints

- ◆ Always call when your comfort kit is going to be used for the **very first time**. (or for any questions thereafter)
- ◆ Call before a medication runs out

Medication	What's it For?	How to Take
Morphine Oral Solution	A concentrated liquid medication used for pain and/or shortness of breath.	Can be swallowed or given under the tongue. If swallowed, can be diluted in a small amount of fluid (water or juice) or given in soft food (pudding or applesauce)
Lorazepam (Ativan) Tablet	Commonly used for anxiety, agitation, insomnia, seizures, and shortness of breath	May be swallowed or given under the tongue

Common Myths regarding Comfort Medications

Myth: *Narcotic pain medications will cause loss of control or even hasten death.*

Truth: Adequate pain medication can actually give your loved one more life, providing better rest and therefore more energy and comfort to do things. Properly prescribed comfort medications do not hasten death. They keep your loved ones comfortable during the dying process.

PLEASE UTILIZE MEDICATION LOG FOUND ON PAGE 18 TO KEEP TRACK OF MEDICATIONS GIVEN. YOUR HOSPICE NURSE WILL REVIEW ON NEXT VISIT.

Medication Side Effects

Any medicine can have some side effects, but not all people experience them. People react in different ways to medications and combinations of medications. The doctor or hospice nurse can help your loved one work through any side effects to find the best way to manage symptoms.

Sleepiness

Patients tend to experience fatigue when first starting or increasing a pain medicine. Often after two to three days of following a pain treatment plan, the feeling will pass. The body adjusts to the change. Remember, pain is tiring and with relief of pain, the patient will sleep.

Constipation

(having no bowel movement or having small, hard stools)

Certain medication, especially pain medication, will cause constipation. If your loved one is able, drinking more water and fruit juices may help. The hospice nurse routinely starts a laxative when a patient is placed on pain medication. Taking laxatives and/or a stool softener **routinely EACH DAY** will prevent constipation. *DO NOT wait to start a stool softener while on pain medication, take at the start for ease of constipation symptoms!*



Call your Hospice Care Team

- ⌋ If there is no bowel movement in two days.
- ⌋ If the patient experiences abdominal pain or cramping, nausea and/or vomiting.
- ⌋ If there are black/tarry or coffee ground looking stools as these may indicate the presence of blood.

Diarrhea

Diarrhea is characterized by loose or watery stools. It may be accompanied by pain and stomach cramping. Diarrhea that does not stop can cause dehydration, weakness, electrolyte imbalances, and increased stomach pain.

Helpful hints

- ◆ Try a diet of clear liquids (water, broth, ginger ale), and keep rectal area clean and dry.
- ◆ Do not give the patient anti-diarrhea medication unless instructed by the hospice nurse.
- ◆ If diarrhea has stopped for 8 to 12 hours, try dry toast, dry crackers, bananas, rice and clear liquids.



Call your Hospice Care Team

- ⌋ If there is lightheadedness, fever, inability to urinate or continued diarrhea.



Pain

Managing pain is most important to us. Pain is whatever the person receiving care says it is, existing whenever he/she says it does. Please be confident that we will believe you and your loved one if you report pain. We will educate you about pain and pain relief measures. Your team will respond quickly to reports of pain.



Call Your Hospice Care Team if:

- 1 There is an increase in pain, new pain or discomfort
- 2 There is no relief from pain
- 3 There are side effects, which may include constipation, drowsiness, and/or nausea
- 4 You have questions regarding pain management
- 5 There is a rapid decline or change in your loved one
- 6 Questions arise regarding dosage and/or medication changes

Effective Pain Management

Pain can be physical, emotional or spiritual. Pain can be caused by many factors such as swelling, nerve damage, or progression of a disease. Your team will continually evaluate pain symptoms for your loved one.

Help your loved one try to describe the pain they are feeling. Use words like:

- ◆ Sharp
- ◆ Constant
- ◆ Shooting
- ◆ Squeezing
- ◆ Dull
- ◆ Aching
- ◆ Burning

Try to rate the pain, “0” (zero) is no pain, “10” is the worst pain.

Tell your team what makes the pain better or worse, and how well pain medications are working. We encourage you to write down any and all questions you have. Share them with your care team during visits, **or call anytime**.

Helpful Hints on Describing Pain

- ◆ Ask the team about what to expect regarding pain and pain management
- ◆ Work with your team to develop a pain management plan
- ◆ **Report pain when it first begins**
- ◆ Report any problems that you think the pain medications may be causing, as there may be other options
- ◆ Tell your team if you are having any difficulty getting medications or have concerns about them
- ◆ Report feelings of anxiety

If your loved one can’t communicate, look for the following signs of discomfort and speak for your loved one to your care team

- ◆ Moaning
- ◆ Frowning
- ◆ Restlessness
- ◆ Tenseness
- ◆ Tears

Helpful Hints for Managing Pain

- ◆ Try various relaxation techniques
- ◆ Distractions can help—watch a movie, visit with friends, play a game, listen to music
- ◆ Soak in a tub, if possible
- ◆ Hot or cold packs applied to painful areas
- ◆ Try guided imagery
- ◆ Apply light massage or touch

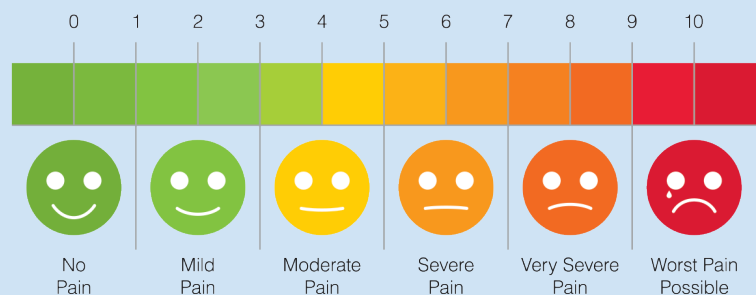
CAREGIVER TRAINING

Assessing Pain

By utilizing a pain scale, you and your hospice nurse will be able to gauge if the pain medication is effectively managing the patient’s discomfort. If unable to rate pain, use descriptors below to help best assess your loved one’s pain level prior to administering pain medications.

It is best to document your loved one’s level of pain prior to giving them pain medications and then again 30-45 minutes afterwards to gauge it’s effectiveness. Document the pain rating in your medication log.

PLEASE CALL IF THERE IS LITTLE OR NO RELIEF FROM PAIN.



No Pain (0): Feeling perfectly normal.

Mild Pain (1-3): Nagging, annoying, but doesn’t interfere with most daily living activities.

Moderate Pain (4-6): Interferes significantly with daily living activities. Requires lifestyle changes but patient remains independent.

Severe to Worst Pain Possible (7-10): Disabling; unable to perform daily living activities. Unable to engage in normal activities. Patient is disabled and unable to function independently.

Shortness of Breath

Oxygen therapy is not a treatment for all types of shortness of breath. Some suggestions for managing shortness of breath are below. Consult your hospice care team for other suggestions.

What Can Be Done if the Patient is Short of Breath

- ◆ Try to stay calm
- ◆ Open a window or use a fan directed at patient's face to create movement of air
- ◆ Prop head up in bed/chair
- ◆ Apply a cool cloth to face
- ◆ Massage
- ◆ Yoga breath - slow breathing in through nose, out through mouth
- ◆ Conserve patient's energy (sit whenever possible)
- ◆ Take medication as instructed
- ◆ Play soft music or keep room quiet, depending on patient's preference
- ◆ If oxygen has been ordered be sure that it is on

Seizures

Seizures look like twitches or tremors in the face and/or extremities. Seizures generally last less than a few minutes. Once a seizure has started, it cannot be stopped.

DO

- ✓ Stay Calm
- ✓ Protect patient from injury—pad bed rails, remove sharp or hard objects near patient
- ✓ Turn head to the side if mouth secretions are present
- ✓ Allow for rest after seizure has fully ended

DO NOT

- ✗ Force anything between the patient's teeth
- ✗ Put fingers in the mouth
- ✗ Hold down twitching extremities unless it is essential for personal safety



Call your Hospice Care Team

- ⌋ If the seizure is a new occurrence, is unusual, lasts longer than a few minutes, or results in injury

Nausea and Vomiting

Your loved one may experience nausea and vomiting for a number of reasons—starting a new pain medicine, an infection, anxiety or a change in their illness. **Call your hospice nurse if nausea or vomiting begins; there is medicine to help.** The patient should not stop taking the pain medicine without speaking to the hospice nurse first.

However, your loved one should avoid dairy products, heavy meals, fatty foods, strong odors, excessive activity and lying down after eating. These may help digestive issues.

Helpful Hints to Combat Nausea and Vomiting

- ◆ Rinse mouth thoroughly after vomiting
- ◆ Reduce anxiety with meditation, quiet, music or slow breathing techniques
- ◆ Administer anti-nausea medication as ordered
- ◆ Keep patient still and rested
- ◆ Offer small sips of ginger-ale or peppermint tea
- ◆ Take ice chips, popsicles or flavored ice for hydration
- ◆ Continue drinking clear liquids for 24 hours (ginger-ale, Jell-O, Gatorade) after vomiting
- ◆ Add bland foods (crackers, dry toast, dry cereal) after 24 hours following liquid diet

DO NOT

- ✗ Eat or drink 1-2 hours after vomiting
- ✗ Be around strong odors
- ✗ Eat any spicy or fatty foods



Call your Hospice Care Team

- ⌋ If vomiting returns after starting to drink clear liquids
- ⌋ If vomit is bright red or dark brown
- ⌋ If constipation persists
- ⌋ If the patient is unable to swallow
- ⌋ If you are concerned about medicating your loved one

Fatigue

Fatigue is one of the most commonly experienced symptoms in hospice and palliative care patients. Fatigue is a feeling of extreme exhaustion usually resulting from emotional distress, physical distress or an illness. Signs of fatigue include:

- ◆ Increased sleeping
- ◆ Lack of appetite
- ◆ Not participating in usual activities because of being “just too tired”

Helpful Hints

- ◆ Plan activities for the “most awake” times of the day
- ◆ Decrease the number of activities planned for one day
- ◆ Change position and location. Avoid staying in bed if able
- ◆ Routinely incorporate activities to restore energy such as music, meditation, and/or going outdoors
- ◆ Consider equipment to help with moving such as a walker, cane or wheelchair. Relying on equipment will help to conserve energy for other activities of choice
- ◆ Allow caregivers to assist with dressing, fixing meals, eating, shopping, cleaning, laundry, etc. to help conserve energy for other activities of choice
- ◆ Rest as needed. Listen to what the body needs
- ◆ Attempt to get uninterrupted hours of sleep and avoid interruptions of sleep routines
- ◆ Increase high protein foods
- ◆ Eat small, more frequent meals



Call your Hospice Care Team if:

- 】 You notice suggestions above aren’t working
- 】 Patient is unable to have a restful sleep
- 】 You are unable to administer medications as prescribed
- 】 The patient appears unsafe (concerns about falling from extreme fatigue)
- 】 If you would like increased emotional or spiritual support to help with emotional fatigue
- 】 You or other caregivers are having a hard time coping

Restlessness

A person may be described as restless if they are unable to rest, concentrate or focus. As restlessness becomes worse it can turn into agitation and the person is unable to relax given our best efforts. Nearly half of hospice patients become restless during the last 48 hours of life.

Signs of Restlessness

- ◆ Muscle twitching
- ◆ Sleeplessness
- ◆ Pulling on sheets or clothing
- ◆ Trying to get out of bed without a known reason
- ◆ Inability to get comfortable
- ◆ Repositioning or moving without a known reason
- ◆ Fidgeting

Helpful Hints

- ◆ Offer frequent reassurance to the person who is agitated
- ◆ Play soothing music
- ◆ Keep the environment calm (**consider decreasing visitors**)
- ◆ Calmly read a favorite story, poem or letter
- ◆ Give a gentle, soft touch massage, if desired
- ◆ Distract the person with something familiar such as photos or a task (folding laundry, art, or writing)
- ◆ Keep the person safe if they are wandering and check in frequently
- ◆ Understand that restlessness may be a sign that death is nearing



Call your Hospice Care Team if:

- 】 You notice behaviors or signs listed above
- 】 You are unable to administer medications as prescribed
- 】 The patient appears unsafe
- 】 You wish to consider spiritual support for the patient
- 】 You are having a hard time coping
- 】 To report what appears to make the restlessness worse

Needing Additional Care Support?

Circle of Life Hospice has two specialized Hospice Homes that offer 24/7 skilled nursing care.

Please check with your hospice team for more information on levels of care offered in our in-patient homes.

CAREGIVER TRAINING

What is Active Dying?

Active dying is the final phase of the dying process. While the pre-active stage lasts for about three weeks, the active stage of dying lasts roughly three days. By definition, actively dying patients are very close to death, and exhibit many signs and symptoms of near-death.

While a patient may not experience all of the signs below, this list will help you in recognizing and defining active dying.

Symptoms of Active Dying

- ◆ Long pauses in breathing; patients breathing patterns may also be very irregular
- ◆ Patient is in a coma, or semi-coma, or cannot be awoken
- ◆ Urinary and bowel incontinence and/or decrease in urine; urine may also be discolored
- ◆ Blood pressure drops significantly
- ◆ Patient's skin changes color (mottling) and their extremities may feel cold to the touch
- ◆ Hallucinations, delirium, and agitation
- ◆ Build-up of fluid in the lungs, which may cause unusual gurgling sounds

Helpful Hints

- ◆ Notice your loved one's facial expressions. Frowning, grimacing, and clenching teeth are expressions of discomfort.
- ◆ Use medication for comfort as directed by your hospice care team. Most of the medicines used for comfort can be given under the tongue or between the cheek and gums.
- ◆ Elevate your loved one's head by using extra pillows or raising the head of the bed by using extra pillows or raising the head of the bed. Turning them on one side, may help secretions drain out of the side of their mouth instead of collect in the back of the throat.
- ◆ In rare cases, gentle suction may relieve excess secretions. Your hospice care team will train you how to use correctly.
- ◆ Your loved one may feel cold, particularly in the legs and arms. You can help by covering your loved one with a warm blanket.



Call your Hospice Care Team

- ↳ When you first notice gurgling sounds
- ↳ To request in-home suctioning equipment and caregiver training
- ↳ If you need additional support

When Death has Occurred at Home

At the time of death, you will notice that your loved one's breathing and heartbeat have stopped, eyes are not moving and may be open or closed. Their mouth may fall or remain open as the jaw relaxes and their skin becomes pale and waxy looking. **It's important to try to stay calm and complete the following instructions, we will take care of everything:**

❌ DO NOT call 911

- ✅ **Call your Circle of Life Hospice Nurse**, or if the death has occurred after 4:30, on a weekend or holiday call our on-call team at **479-750-6632**.
- ✅ After hearing back from your Hospice Care Team, **call family members**, friends or your spiritual advisor if you would like someone to be with you. *Circle of Life Chaplains are also available for home visits during this time.*
- ✅ Spend as much time with the person who has died as you wish. **Remember there is no need to rush.** Take time to absorb the reality of death and to say goodbye.
- ✅ When you are ready, you or the Hospice Nurse who is present will call the funeral home. If you have not selected a funeral home, you will need to at this time.

In the moments immediately after death, family members can take the time they need to be with their loved one's body. Some families sit with their loved one. Some share stories. Some preform a religious ritual.

There is *no right or wrong* way to respond to the death of a loved one.

It is *okay* to cry.

It is ok if you *don't* cry.

Every culture, every family, every individual has a different way of processing the loss of a loved one.

Bereavement Support

Our Bereavement team is comprised of trained professionals who support those struggling with grief and loss. We offer a variety of support groups, grief classes, and workshops to assist those who have experienced a loss.

For more information and to find out when our next support group, grief class, and/or workshop is scheduled, please call 479-750-6632 or go to our website at www.nwacircleoflife.org.

Providing Physical Assistance to Your Loved One

Circle of Life Hospice has created 10 short, educational Caregiver Training Videos that demonstrate how to provide essential care during daily activities such as walking, bathing and toileting. These are not meant as a substitute for one-on-one education from your hospice care team but, may help you become more confident in your role as a caregiver. **For the full series of videos please visit www.nwacircleoflife.org and click on the “Our Care” tab.**

If you do not have access to the internet, or if you prefer in-person training, your Hospice Care Team would be happy to assist you.



Providing Mouth Care

1. Gather the following supplies for mouth care: soft toothbrush, toothpaste, cup of water, dish to spit into. Additional items such as K-Y Jelly or olive oil to moisturize lips (Vaseline should never be used with oxygen because it is flammable); 1 tsp of baking soda in 8 oz water can help with dry mouth.
2. Have the patient sit up if possible.
3. Check for redness or white patches.
4. Rinse mouth and dentures after meals.
5. Remove dentures before bed.
6. Notify the hospice team if you notice white patches on the person's gums, tongue or throat. Also notify the hospice team if the person is having difficulty swallowing.



Caring for the Bedbound Patient

1. When caring for a bedbound patient it is essential to prevent pressure sores or skin tears. Turning or repositioning every two hours is the most effective prevention.
2. A natural tendency is to raise someone's feet up; however, it can be harmful to a person's buttocks if their head is raised above 30 degrees and their feet are elevated at the same time. This position will cause skin breakdown to occur on the buttocks from the skin being pulled in opposite directions.
3. Another prevention strategy to consider when caring for a bedbound person is to keep the skin clean and dry.
4. If there are areas that promote sweating such as on the back, buttocks and under the breasts, clean and pat dry those areas daily. A common “hospice intervention” is to apply antiperspirant under the breasts to help prevent skin breakdown from sweating.



Positioning Your Loved One

1. Turning and repositioning of a bedbound person should occur every 2-3 hours to prevent skin breakdown and to maintain general comfort.
2. If using a hospital bed, start by raising the side rail on the side of the patient that they will be turning toward.
3. Raise the bed to the top of your hips to avoid bending over the person—bending over could cause back strain which you want to always avoid.
4. Lower the head of the bed so that the person is lying flat.
5. Remove all pillows.
6. If they are able, have the person bend their legs to help them roll to the side.
7. The person should always roll to their weaker side so that the strong arm is pulling their body over.
8. Ask the person to reach and grab the bed rail to their ability while you gently guide the person on to their side.
9. Consider placing a pillow, blanket or towel between the knees and ankles to offer additional comfort and prevent bone resting on bone while lying on their side.
10. Place a pillow behind the back for support and to hold the side-lying position.
11. There should not be any weight on the shoulder or knees. Be sure to keep bony prominence areas protected.
12. Slightly raise the head of the bed to about 20 degrees for comfort.



Pulling Up a Loved One in Bed

**This is a two-person task*

1. If using a hospital bed, start by lowering the side rails.
2. Raise the bed to the top of your hips to avoid bending over the person—bending over could cause back strain which you want to always avoid.
3. Lower the head of the bed so that the person is lying flat.
4. Remove the pillow from under their head.
5. Stand between the hip and shoulder of the person and role the draw sheet in towards the patient, grab the roll with palms facing down. Be sure the draw sheet is between the nipple line and mid-thigh of the person in bed.
6. Have the person bend their knees and dig their heels to help push with their legs to move up in bed. Remind them to do this on your count to three.
7. Further direct the person to hug themselves and lower their chin to avoid skin tears.
8. Both caregivers, turn their front foot forward toward the head of the bed.
9. Bend at the knees.
10. On the count of three, pull the person up in the bed.
11. Both people lift at the same time, using leg strength and not your backs, to move the person up in bed.
12. Gently replace the person in bed, straighten the sheets and flatten any wrinkles that could be uncomfortable for the person to lay on.
13. Replace pillow under patient's head.



Giving a Bed Bath

1. Gather the following supplies if giving a bed bath: Two wash basins, soap, lotion, washcloths and towels, gloves and clean clothes. *One basin will be used for soapy water, the other for non-soapy rinse water.*
2. Place warm water in the basins and add soap to the wet washcloth.
3. Wash, rinse then dry one area at a time using very little soap (to avoid drying of the skin). Cover each cleaned area with a towel or blanket before moving to the next area. A common strategy is to start with the extremities and wash the trunk last.
4. Consider changing the water half way through washing the patient so that it remains warm.
5. Check for dry skin and be sure to use moisturizing soap and lotion if you notice this.
6. Keep sheets dry and wrinkle free to prevent pressure sores.
7. Be sure to turn your loved one and reposition every 2-3 hours to prevent pressure sores.



Call your Nurse

If you notice any red areas that do not go away after several hours.

Skin Care

Keeping the skin moisturized and clean with frequent position changes (every 2-3 hours) is important during illness. Specific things to keep in mind about proper skin care:

- ◆ If the skin is very dry, use moisturizing soaps and lotions
- ◆ After bathing, make sure soap is rinsed off completely and the skin is thoroughly dried
- ◆ Avoid rubbing reddened areas
- ◆ Bathing may not be appropriate everyday for all patients

Changing Bed Sheets

1. If using a hospital bed, start by raising the side rails.
2. Raise the bed to the top of your hips to avoid bending over the person—bending over could cause back strain to your back which you want to always avoid.
3. Lower the head of the bed so that the person is lying flat.
4. Stand between the hip and shoulder of the person. This is where you will grab the draw sheet to move the person on to their side.
5. Ask the person to reach and grab the bed rail, if they are able, while you gently guide the person onto their side.
6. Place the pillow behind the back for support and to hold the side lying position. Position the person's arm out of the way to avoid shoulder discomfort while the person is lying on their side.
7. Begin to change the sheets by rolling the used sheets (including the fitted sheet) under the person along the length of the person's body.
8. Attach the top and bottom corners of the clean fitted sheet and flat sheet. Smooth the clean sheets under the patient.
9. At this time a **draw sheet** can also be placed under the patient and folded with the clean sheets under the patient. A draw sheet is necessary for someone who is bed bound.
10. To complete making the bed with clean sheets, roll the person to their opposite side, helping them to gently roll over the used sheets and newly placed clean sheets.
11. Ask the person to reach and grab the bed rail, if they are able, while you gently guide the person onto their side.
12. Once the person is re-positioned on their opposite side with pillows for stability, pull out the used sheets. Place used sheets into the laundry bin.
13. Pull the clean sheets tight and attach the final two corners, making sure any wrinkles are flattened.

What is a draw sheet?

Learn more at:

www.nwacircleoflife.org





Assistance Using a Bedpan

1. When assisting someone to use a bedpan, it is always recommended to use gloves.
2. First explain to the patient what you are planning to do.
3. Lower the bed into a flat position.
4. Help the person roll to one side in bed.

Helpful Hint

- ◆ To prevent skin from sticking to the plastic bedpan, sprinkle baby powder on the thick part of the plastic rim.
5. Place the bedpan squarely under the buttocks.
 6. Roll the person back over on top of the bedpan.
 7. Double check to be sure the bedpan is in the right position.
 8. If able, place the person into a sitting position. Place toilet paper or a warm wash cloth next to your loved one.
 9. Give the patient some privacy, but stay close to hear if help is needed.
 10. When they are done, lay their head down. To prevent spillage, with a gloved hand, hold onto the bedpan while the patient carefully rolls to one side. Remove the bedpan.
 11. Help cleanse the area if assistance is needed and pat dry.
 12. Dispose of waste in the toilet and clean out the bedpan.
 13. Remove gloves and wash hands.

Caring for a Catheter

A catheter is a tube inserted into the bladder to help drain urine. It has a small balloon that is blown-up to keep the tube from falling back out. A catheter may be needed due to increased weakness, loss of bladder control, etc. If a catheter becomes needed, the hospice nurse will place it and show the caregiver how to care for it.

Helpful Hints

- ◆ Wash your hands before and after handling the catheter.
- ◆ Check the tubing periodically to see if urine is draining.
- ◆ Be sure that the tubing is not kinked or bent.
- ◆ Empty the drainage bag 1-2 times per day; empty leg bags every 3-4 hours.
- ◆ Keep the drainage bag below the level of the bladder at all times.
- ◆ Do not pull or tug on the catheter or tubing.
- ◆ Cleanse the tubing with soap and water daily and when the tubing gets soiled.
- ◆ Be sure to begin where the tubing enters the body and work away.
- ◆ If the patient is pulling on the catheter, put on a pair of adult briefs to hold it more securely in place, keeping it from moving.
- ◆ When turning the patient from side-to-side, move the drainage bag from side-to-side.
- ◆ Irrigate the catheter if the nurse has instructed you to do so.



Call your Hospice Care Team

- ⌋ If the catheter is not draining
- ⌋ If the urine has an odor or change in color
- ⌋ If there is a leak in the catheter
- ⌋ If the patient spikes a fever



Assistance Out of a Bed to a Chair

1. Have the person scoot to the side of the bed that they will be sitting on.
2. Raise the head of the bed completely.
3. Allow the person to rest in the position of having their head elevated to avoid light headedness as their body gets used to sitting up.
4. Bring the person to a sitting position on the side of the bed.
5. Allow the person to dangle their legs on the side of the bed. Move slowly and allow time for the blood to circulate to avoid light headedness as someone changes position.
6. Place appropriate footwear on the person's feet to offer stability.
7. Face the person and place your right foot between the person's feet.
8. Bend your knees to ensure you are assisting the person **using your legs and not your back.**
9. Grab onto the person's pants or use the draw sheet to help pull the patient to a standing position.
10. The person should not grab you around your neck as this could injure you. The person can hold on to your waist or shoulders.
11. The person receiving help can push off the side of the bed or hold on to the walker, wheelchair or arms of the chair.
12. Once standing, pivot slowly, hold onto the person's pants or draw sheet until they feel the surface of the chair behind their knees.
13. Have the person reach both hands backwards to the arms of the chair or continue to hold the waist of the caregiver.
14. Bend your legs to help lower the person as they slowly sit.
15. Gently guide the person by their waist to sit.

Assistance from Sitting to Standing

1. Assist your loved one to the edge of the bed or chair.
2. Face the person with feet shoulder width apart.
3. Reach under the arms, with his/her arms on your waist, with your knees bent and back straight.
4. Hug your loved one gently while raising to a standing position.
5. Do NOT let go until you are sure the person is stable while standing.





Ambulating with Your Loved One

1. Always stand on the **person's weaker side** when assisting with ambulation.
2. Place your hands around their waist to guide the person gently and offer support. (may use a gait belt for more stability)
3. If the person should fall, guide them slowly to the ground and sit with them. Keep your hands around their waist to guide their center of gravity to the floor landing on their bottom.



Assistance Using a Commode

1. When moving with a person, it is essential to explain the purpose, goal and what you are going to do with the person prior to starting the task.
2. Ambulate with a person to the commode until the patient feels the surface of the commode behind their knees.
3. Lower their pants and make sure the lid is open to the commode.
4. Have the person reach both hands backwards to the arms of the commode, or continue to hold the waist of the caregiver.
5. Bend your legs when you help lower the person as they slowly sit. Be sure they are sitting squarely on the commode. Gently guide the person by their waist to sit.
6. Give them toilet paper and a warm wash cloth to clean themselves, if they are able.
7. Allow privacy if needed.
8. After using the commode, offer hand sanitizer and anything else needed to clean up.
9. Help to stand after using the commode by first placing their feet in a comfortable position in front of the commode. On a count of three help them to a standing position. Be sure the person gets their bearings prior to taking a step.

Helpful Hints for using a bedside commode

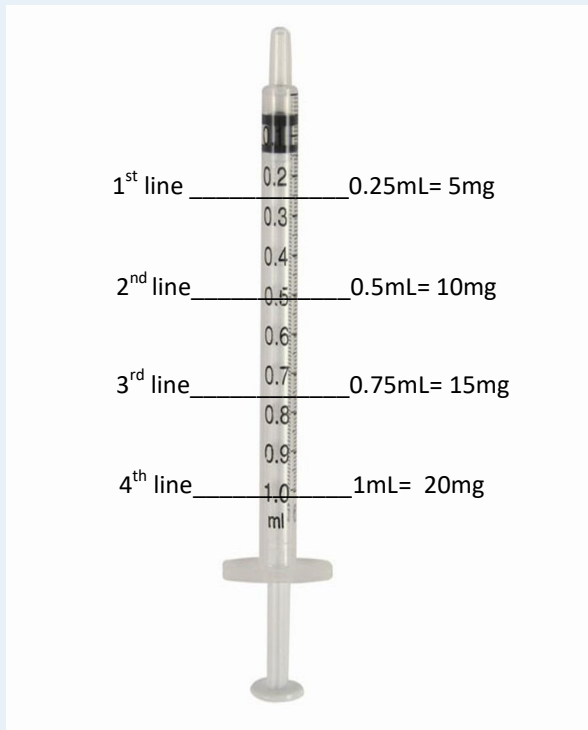
- ◆ If using a bedside commode, place 1 inch of water in the bottom of the pail. *Makes for easier cleaning.*
- ◆ Remove pail and discard waste in flushable commode.

CAREGIVER TRAINING

Comfort Kit Directions

Pain or Shortness of Breath

1. Medication: _____
2. Give _____ mg or to line _____ under tongue or between cheek and gum.
3. Wait 1 hour; call nurse if pain or shortness of breath continues.



Anxiety and Restlessness

1. Ativan (lorazepam) 0.5mg, take one tablet every 4 hours, as needed, for anxiety or restlessness.
2. Call hospice nurse after 1 hour if anxiety or restlessness is unrelieved.
3. If patient is unable to swallow, nurse will instruct on how to dissolve tablet in a few drops of warm water to give between the cheek and gum.

Terminal Lung Congestion

1. Call nurse when you hear "rattling in the chest" of an unresponsive patient.
2. Position the patient with the head of the bed raised or propped up with pillows. If able, position the patient on one side and support their back with pillows.

Common Myths regarding Comfort Medications

Myth: Opioids are addicting.

Fact: There is a difference between physical dependence and addiction. Physical dependence is a state in which physical withdrawal symptoms occur when a medication is stopped or decreased abruptly. This is expected. Addiction is a chronic disease in which people have a poor control over drug use and continue to use the drug despite physical and social harm. **Addiction is rare for patients who are terminally ill when the goal of care is comfort.**

Notes for your Nurse:

Date:

Date:

Date:

Date:

Date:

Date:

Date:

Comfort Kit Medication Log

Please date and note time when medications are given so that your nurse can review during the next visit.



Call Your Hospice Nurse (Circle of Life 479-750-6632)

- ⌋ BEFORE you give these medications for the **very first time**.
- ⌋ If you believe that there has been a change in your loved one's condition or if symptoms worsen.
- ⌋ If there has been little or no relief in symptoms after allowing 45 min to 1 hour for medications to take effect.
- ⌋ **For any questions or concerns when administering any medication, any time.**

Morphine liquid 20mg/ml

Instructions: Give under the tongue or between the cheek and gum for best absorption. If giving with pills; take the pills with water first, then the morphine for best absorption.

DOSE: Take 5-10 mg every hour AS NEEDED for pain or shortness of breath. *Use oral syringe guide on page 18.*

If your loved one has NO RELIEF after 45 min to 1 hour after medication given, please call your Hospice Care Team.

DATE: _____ TIME: _____ DOSE: _____ PAIN RATING: ____/10 <input type="checkbox"/> 5 mg = (0.25ml/line 1) <input type="checkbox"/> 10 mg = (0.5mg/line 2) RELIEF: <i>Circle one</i> Full Relief Partial NO RELIEF	DATE: _____ TIME: _____ DOSE: _____ PAIN RATING: ____/10 <input type="checkbox"/> 5 mg = (0.25ml/line 1) <input type="checkbox"/> 10 mg = (0.5mg/line 2) RELIEF: <i>Circle one</i> Full Relief Partial NO RELIEF	DATE: _____ TIME: _____ DOSE: _____ PAIN RATING: ____/10 <input type="checkbox"/> 5 mg = (0.25ml/line 1) <input type="checkbox"/> 10 mg = (0.5mg/line 2) RELIEF: <i>Circle one</i> Full Relief Partial NO RELIEF
DATE: _____ TIME: _____ DOSE: _____ PAIN RATING: ____/10 <input type="checkbox"/> 5 mg = (0.25ml/line 1) <input type="checkbox"/> 10 mg = (0.5mg/line 2) RELIEF: <i>Circle one</i> Full Relief Partial NO RELIEF	DATE: _____ TIME: _____ DOSE: _____ PAIN RATING: ____/10 <input type="checkbox"/> 5 mg = (0.25ml/line 1) <input type="checkbox"/> 10 mg = (0.5mg/line 2) RELIEF: <i>Circle one</i> Full Relief Partial NO RELIEF	DATE: _____ TIME: _____ DOSE: _____ PAIN RATING: ____/10 <input type="checkbox"/> 5 mg = (0.25ml/line 1) <input type="checkbox"/> 10 mg = (0.5mg/line 2) RELIEF: <i>Circle one</i> Full Relief Partial NO RELIEF

Lorazepam (Ativan) 0.5mg tablet

Instructions: Take 1 tablet every 4 hours AS NEEDED for anxiety.

WORKS WELL ALONG WITH MORPHINE (GIVEN AT THE SAME TIME) FOR SHORTNESS OF BREATH. Remember, if giving both medications, document both medications

DATE: _____ TIME: _____ RELIEF: <i>Circle one</i> Full Relief Partial NO RELIEF	DATE: _____ TIME: _____ RELIEF: <i>Circle one</i> Full Relief Partial NO RELIEF	DATE: _____ TIME: _____ RELIEF: <i>Circle one</i> Full Relief Partial NO RELIEF
DATE: _____ TIME: _____ RELIEF: <i>Circle one</i> Full Relief Partial NO RELIEF	DATE: _____ TIME: _____ RELIEF: <i>Circle one</i> Full Relief Partial NO RELIEF	DATE: _____ TIME: _____ RELIEF: <i>Circle one</i> Full Relief Partial NO RELIEF



901 Jones Road, Springdale, AR 72762
1201 NE Legacy Parkway, Bentonville, AR 72712

479-750-6632

nwacircleoflife.org

To access Caregiver Training Videos,
visit our website:

www.nwacircleoflife.org

"Our Care" tab
"Caregiver Training"