

HOSPICE OF THE WESTERN RESERVE



Caregiver Guide

Any question, day or night, call us 800.707.8922.
Be confident that we're here for you.

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William E. Finn, CEO

Welcome

On behalf of the entire staff of Hospice of the Western Reserve, I would like to thank you for choosing us as a caregiving partner. We are honored to be entrusted by you, and assure you that we are committed to providing compassionate, exceptional care, focusing on the priorities and values of you and the person receiving care.

Our teams will work to assist you in reaching your goals, ensuring that your wishes are realized, and to provide physical, emotional, and spiritual care of the very highest quality. Hospice of the Western Reserve has served patients in Northern Ohio for over 30 years. We are Ohio's largest independent, non-profit, community-based hospice program.

This guide provides you with the information and resources needed to supplement the services that we provide. It is not meant to be a substitute for care, as we are available 24 hours a day to answer your questions, alleviate your concerns, and ease your burdens.

We consider it a privilege to play a significant role in your life during this time. You and your loved ones can count on Hospice of the Western Reserve's support and compassionate expertise every step of the way.

Sincerely,

A handwritten signature in black ink that reads "William E. Finn". The signature is written in a cursive, flowing style.

William E. Finn, CEO
Hospice of the Western Reserve

"You matter because you are you. You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but also to live until you die."

—Dame Cicely Saunders, founder of the modern hospice movement

Our Mission

Hospice of the Western Reserve provides palliative and end-of-life care, caregiver support, and bereavement services throughout Northern Ohio.

In celebration of the individual worth of each life, we strive to relieve suffering, enhance comfort, promote quality of life, foster choice in end-of-life care, and support effective grieving.

INTRODUCTION

Hospice of the Western Reserve provides people who are dealing with a serious illness the unique experience to celebrate life, to enjoy the time they have, and to live out their lives with dignity. The focus of hospice care is comfort for the person receiving care, and support for you—the caregiver. Our staff works to manage pain and symptoms, provide emotional support, and explore spiritual needs, but you and the person receiving care are in control of the care plan.

How do you help someone who is dying? This question is often asked of hospice workers. The answer is not found in the techniques, but in one's own experience of sharing the final stage of life's journey with those who are dying. Medications and treatments are important, but we know that something more is needed. The real work of hospice is being physically and emotionally present through the trials and joys.

The staff at Hospice of the Western Reserve created this guide to provide you with an immediate source of information to answer many of the questions you might have as you go through the end-of-life process.

Confidence in Your Caregiving

During this stressful time, your Hospice of the Western Reserve team strives to help you feel more confident in providing care and support. To this end, we will provide you with medication education, medical information, telephone guidance, and ongoing discussions as the disease progresses.

We continually assess our patients and you the caregiver. We want to hear what you are seeing and feeling through this process. Team members will ask, "How can we help you feel more confident in providing care?" Whatever your questions or concerns, let us know. We are here for you too.

Frequently Asked Questions about Hospice

Where can hospice care be provided?

- In a private home
- Group home
- Nursing facility
- One of our Hospice Care Settings (refer to page 5)
- Hospital
- Assisted living facility
- Anywhere the person calls “home”

Does the patient keep his/her own doctor?

Yes. Hospice of the Western Reserve works directly with the patient’s doctor. If you would like to change physicians or do not have your own, Hospice of the Western Reserve has its own practice of certified, experienced hospice physicians.

What happens if the patient moves away?

A transfer to another Medicare-certified hospice can be arranged by your hospice team.

What if the patient no longer wants or needs hospice services?

We will always honor the wishes of the patient or his/her designated representative for treatment. If services are no longer needed or desired, the patient will need to sign a discharge form. There are times when a patient’s condition stabilizes, and the team will discuss the need to be discharged. After this time, the patient may join our Navigator Program (see Other Programs on page 7) and a team member will call periodically to check on the patient’s condition. If you notice changes in the patient’s physical health, call us. Hospice services will always be available when needed.

Hospice Team Members

Specially qualified and trained team members provide hospice services. **The person receiving care and caregivers are vital members of this team.** Together we decide on an ideal plan to maintain dignity and ensure that physical, emotional, and spiritual needs are met. Comfort and confidence are our priority.

Other members of the Hospice team include:

The **Primary Physician** for the person receiving care is responsible for continued medical management. The **Hospice Physician** acts as a resource for hospice medical care, and reviews the plan of care on a regular basis.

A **Hospice Nurse** visits on a regular basis to perform physical assessments, provides education on medications, physical care needs, and updates the doctor. Your nurse is valuable source of knowledge.

Your **Social Worker** helps explore care options, understand legal and financial issues, find emotional support and is available for counseling. Social workers are dedicated to helping the patient and family with the many areas of life impacted by an illness.

Nursing Assistants often have the most frequent interactions with patients, and can be a great source of helpful information. Our nursing assistants are experienced in hospice and palliative care. They care for patients not only in the traditional duties of bathing, dressing and personal care, but in being present for emotional support.

Spiritual Care Coordinators explore ways to find joy, meaning and purpose in life. For those who have a religious faith, this may include working closely with your clergy person and faith community. Everyone can benefit from their listening ear, guidance and

willingness to explore questions, forgiveness and hope.

Art and Music Therapists provide opportunities for life review and the creation of legacies through art and music experiences. They work with patients and caregivers to relieve symptoms and express feelings.

A **Massage Therapist** integrates massage therapy into the plan of care as needed to promote comfort, relaxation and relief from physical symptoms.

Pharmacists strive to relieve pain and manage symptoms with minimal side effects and maximum benefit.

A **Dietician** provides suggestions on nutrition and symptom management.

Overnight and Weekend Team Members assure access to care 24 hours a day, 7 days a week. Your confidence and comfort are our priority.

A **Bereavement Coordinator**, trained in supporting those who are grieving, offers supportive services to family members and significant others during the 13 months following a death.

Coordinators of Volunteers help identify areas in your life where a volunteer may offer assistance. They discuss the role of a volunteer with the patient and caregiver before asking a volunteer to join the team.

Volunteers are valuable members of your team and may be a great source of support. Volunteers receive extensive education and are dedicated to maintaining the privacy and dignity of the person receiving care. They share their unique skills and talents in many ways.

Volunteers may:

- Provide a friendly visit or respite for a caregiver
- Offer spiritual care support
- Preserve life experiences through audio or video recording
- Bring a pet to visit
- Assist with occasional housekeeping and meal preparation
- Provide simple legal assistance
- Provide support to Veterans through our Peaceful & Proud Program (see Other Programs on page 7)
- Assist patients through the health care system with the Navigator Program (see Other Programs on page 7)
- Provide support and presence in the time surrounding death
- Help fill a special request to bring fulfillment and comfort
- Plus many more options

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 through our on-call service.

The on-call number is on the card that looks like the one in the back of the guide. We have placed the card near the telephone or other easily located area in the home.

Our answering service will promptly answer your call requesting the patient's name and the reason for your call. The on-call nurse will be notified and will return your call within 15 to 20 minutes. **Please do not use your telephone while awaiting this return call.** 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 Hospice of the Western Reserve first**. We request that you **do not** call 911.

Hospice Services in Long-Term Care Settings

People living in long-term care settings, including nursing homes, assisted living facilities or group homes, may receive hospice care. A team of specialized hospice workers, who are familiar with the staff at these facilities, provide the same support and care for a resident as they would for a person living in a private home. Hospice of the Western Reserve works collaboratively with many long-term care settings in the Northeast Ohio area, enhancing the care provided by nursing facility staff.

If the patient is eligible for a hospice benefit through private insurance, then supplies, equipment, and medications needed as a result of the serious illness will be covered.

The charge for room and board is not covered under the Medicare Hospice Benefit. If the patient is living at home, but expects to enter a long-term care facility, the hospice social worker will help locate a facility that works in collaboration with Hospice of the Western Reserve.

Our Hospice Care Settings Other than Your Home

Hospice of the Western Reserve offers choices in our home-like Hospice Care Settings. Each setting has its own array of services, which we tailor to meet the needs of our patients and their caregivers. Your participation in care is welcome in making the best choice to meet your needs.



General Inpatient Care/Symptom Management

If a patient has pain, nausea, shortness of breath or other symptoms that cannot be managed in the current residence, the hospice team may suggest an admission under the General Inpatient level of care. Usually the patient will be admitted to one of our Hospice Care Settings for symptom management. However, if the patient or the patient's physician prefers, an admission may be arranged at a local hospital. Many local hospitals contract with Hospice of the Western Reserve to provide this service.

Residential Care

Patients at a Hospice Care Setting for General Inpatient care who need to stay once pain and symptoms are managed, may be eligible to transition to the Hospice Residential level of care at one of our Hospice Care Settings, based upon bed availability. Daily room and board charges will be billed automatically.

Respite Care

There are times when caregivers may need a short interval of rest or relief from their caregiving duties. A patient may be admitted to one of our Hospice Care Settings for Respite Care, based upon bed availability, or to a facility with which Hospice of the Western Reserve has a contract. A Medicare or Medicaid patient may be admitted for up to five days for Respite Care with no room and board charges.

Preparing for Transfer to one of our Hospice Care Settings

Please refer to the *Patient and Family Admission Guide to the Hospice Care Settings* for further details including billing information, room and board charges (where applicable), transportation, and what to bring.

Extended Care

If a patient has pain, nausea, shortness of breath, or other symptoms but desires to remain in the place of residence, the hospice team may suggest Extended Care, also known as Continuous Care. During this time, hospice services will be provided in blocks of time of two to four hours or more. Occasionally, care may be needed around-the-clock for very severe symptoms, but this is not the usual case. The patient's regular hospice team will continue to oversee the care; however, other hospice team members may come and go to provide care as well. This type of care is meant only to be short term. The patient's condition will be re-evaluated frequently while receiving Extended Care.

Once symptoms are controlled, the patient will return to routine hospice care. Extended Care is not meant to take the place of the patient's regular caregivers in providing for general daily care and safety of the patient, rather it is geared toward managing active symptoms.

What can you expect of us while receiving Extended Care?

- We will reposition bedbound patients and bathe/change incontinent patients frequently for comfort and to prevent skin breakdown.
- Our staff will bring their own food and beverages and will not smoke while in your home. Staff members are allowed a 30-minute meal break and up to two, 10-minute breaks during an 8–12 hour shift.

- Our staff will remain awake and alert at all times, will conduct themselves as guests in your home, and will be courteous and respectful at all times.
- In addition to regular visits by your primary team, you may encounter different staff members while you are receiving this service, including volunteers.
- Our staff will document on a laptop computer while in your home to record care given and keep other staff members updated on the patient's response to the plan of care.

What can you do to maximize the benefits of Extended Care?

- Stay involved in the patient's care. Please be available for visits from your primary team and assist in planning for the patient's care when the current symptoms are managed. Ask questions freely and as often as needed.
- You are always welcome to make decisions that you feel are in the best interest of the patient, such as not turning in bed, refusing medications, etc. Please discuss these decisions with your primary team.
- If at any time you are not satisfied with a particular staff member in your home, please call your primary team or our On-Call service to request a replacement.

Other Programs and Information

Palliative Care

Palliative care extends the principles of hospice care to a broader population of patients who are not ready for hospice or do not choose it but could benefit from disease management earlier in their illness. Considering the physical and emotional toll symptoms can take, palliative care aims to ease pain, insomnia and shortness of breath, as well as anxiety, depression and other intense emotions.

Navigator Program

While under the compassionate care of hospice, some patients improve to the point where they no longer fit into hospice or palliative care guidelines. We stay connected with them through our Navigator Program. Social workers, advance care nurses and educated volunteers provide assistance with community resources, caregiver support, pain and symptom management and supportive social visits.



WE HONOR VETERANS

Peaceful & Proud: Personalized Care for Veterans

Through the Peaceful & Proud program, Hospice of the Western Reserve paid and unpaid staff receive training in post-traumatic stress disorder and other emotional issues for Veterans, such as remorse or regret, anxiety, and substance abuse. Veterans are assisted

with ethical wills, storytelling, expressive therapies using music and art, Veteran-to-Veteran-volunteer pairing, spiritual care and counseling, resources and benefits for Veterans and dependents. We recognize Veterans for their military service with our Honored Veteran pin.

Research Opportunities

The Hospice Institute supports research projects and studies that will further the science of hospice and palliative care. For more information or to participate, please contact us at 216.383.3740.

Patient Travel Information

Hospice of the Western Reserve understands that there are occasions when the person receiving care will need to travel to a destination that is out of our service area. Many of the hospices in the United States are willing to collaborate with Hospice of the Western Reserve. Please notify your hospice team as soon as possible, **preferably at least five business days prior to traveling**, so we may contact a hospice and make arrangements for your access to hospice care.

Our policy supports travel outside of our service area for 14 consecutive days. If staying longer than 14 days, please inform the hospice team and alternate arrangements can be made for these situations. The team will provide appropriate forms to be completed.

If the patient's status changes during travel and requires inpatient care, we will assist with the transfer of hospice care to the hospice provider in the area. If you have any questions regarding traveling, please consult your hospice team.

Patient Care

Dignity and Comfort

The members of your hospice team strive to preserve dignity and comfort. What is dignity? Dignity means many things to many different people. For Hospice of the Western Reserve, dignity is 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 him/her unique and special.

Tell your hospice team what they need to know about the person receiving care noting pain and other symptoms (such as breathing trouble, nausea, weakness, constipation). In addition, keep your team informed of your emotions and feelings. Your hospice team is here for *you* too.

Pain Education

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:

- Reports of pain will be believed
- We will educate you about pain and pain relief measures
- Your team responds quickly to reports of pain

Helpful Hints

- 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

When to Call Hospice

- Increase in pain, new pain or discomfort
- No relief in pain
- Side effects, which may include constipation, drowsiness and/or nausea
- Questions regarding pain management
- A rapid decline or change in patient
- Questions 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 hospice team will continually evaluate pain symptoms for each patient.

What Can Be Done

Help the person receiving care try to describe the pain. 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 hospice team, or call us anytime.

Helpful Hints

- Relaxation techniques
- Distractions (watch a movie, visit with friends, play a game, listen to music)
- Soak in a tub, if able
- Hot or cold packs
- Guided imagery
- Light massage or touch

Look for and communicate to your team signs of discomfort for patients who cannot speak.

- Moaning
- Restlessness
- Tears
- Frowning
- Tenseness

Medications

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

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 medication on a regular schedule, timing is very important.
- Use *break-through* or *in-between* 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 of when and how often medication is taken.
- Avoid alcoholic beverages while taking medicine.
- Tell the hospice nurse about any over the counter drugs, vitamins, mineral supplements or herbal remedies that are currently being taken.
- **Keep all medicine out of reach of children and pets.**

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

Helpful Hints

- To ease swallowing pills, 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 applicable. 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 the hospice nurse.

Medication Record and Schedule

Place medication record and schedule in a place where hospice team members can find it, so they can make sure the patient is receiving the correct medication(s) and doses. Keep the DNR card with the medication schedule.

Medication Disposal

First, remove any personal information from the medicine label (peel label off, crossing off with a permanent black marker). Disposal can occur in the original container or place all medications in a sealable bag, empty can, or empty plastic container depending on the amount of medication.

- Add water to dissolve pill or tablet dosage forms. Allow some time for the dissolving process to begin.
- Suppository form – cut up suppositories.
- Ointments or creams – eject remainder into the container.
- Patches – put on gloves and cut up and place in opaque bag.
- Injectables – withdraw remainder and inject into the container.
- Syringes – eject remainder into the container
- Liquid – pour into the container

Add used coffee grounds, kitty litter, or flour to the container to make the mixture undesirable and unusable. Place in a trash receptacle, preferably inside a non-clear bag, if able, to further discourage identification. Do not flush medications down a toilet unless specifically instructed to do so on the drug label or by a hospice team member. If you have questions or need instruction, please call your hospice team.

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 Hospice of the Western Reserve is based on a patient specific pharmaceutical plan of care, involving critical assessment, careful monitoring, and physician authorization.

Side Effects of Pain Medication

All medicines can have some side effects, but not all people experience them. People react in different ways. Your doctor or hospice nurse can help work through any side effects.

Sleepiness

Patients tend to experience fatigue when first starting or recently 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 small, hard stools*)

Certain medication, especially pain medication, will cause constipation. If able, drink more water and fruit juices. The nurse will talk with the patient about a laxative. Taking laxatives and/or a stool softener

routinely each day will prevent constipation. Call the hospice nurse if there is no bowel movement in two days, patient experiences abdominal pain or cramping, nausea and/or vomiting, or blood in stools.

Nausea and Vomiting

When starting a new pain medicine, or as the result of infection, anxiety or disease change, the patient may experience nausea and vomiting. Call the hospice nurse who will arrange for some medicine to help. Do not stop taking the pain medicine without speaking to the hospice nurse first. Avoid dairy products, heavy meals, fatty foods, strong odors, excessive activity and lying down after eating.

Helpful Hints

- 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
- Rinse mouth thoroughly after vomiting
- Take ice chips, popsicles or flavored ice for hydration
- Continue taking 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

When to Call Hospice

- Vomiting recurs after starting to drink
- Vomit is bright red or dark brown
- Continued constipation
- Unable to swallow
- You have concerns about medicating the person receiving care

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. 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 the hospice team if there is light-headedness, fever, inability to urinate or continued diarrhea.

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
- Change the drainage bag weekly, as the nurse demonstrated
- Empty the drainage bag 1–2 times per day, 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 an adult diaper to hold it more securely in place and keep it from moving
- When turning from side to side, move the drainage bag from side to side
- Irrigate the catheter if the nurse has instructed

When to Call Hospice

- Catheter is not draining
- Urine has an odor or change in color
- Patient spikes a fever

Nutrition

It is normal for seriously ill patients to have changes 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 support the patient at this stage. Try offering food often during the day; three to six light meals or smaller portions are usually better tolerated. Offer fluids between meals, instead of with meals, to keep from feeling full, and arrange meal times when he/she is less tired. Do not force the patient to eat.

Helpful Hints

- Avoid eating when nauseated or in pain
- Share meal times with others
- Set a nice table, add candles or flowers play music, garnish food to make it more pleasing to the eye
- Use a warm/cool moist cloth prior to eating to freshen face and hands
- Have options or choices available ahead of time
- Vary food preparation techniques: grill, fry, broil, roast
- Have good tasting snacks readily available
- Try ice chips or Popsicles
- Use herbs, spices, and other seasonings

Changes in Taste and Smell

Due to the progression of an illness, or medications and treatments, foods may taste and smell differently, or have little or no taste at all. This can reduce appetite. Begin each meal or snack with a clean mouth. Brush teeth and use a mouth rinse. Try brushing tongue lightly with a soft toothbrush. Frequently rinse mouth between meals with cool water, mint-flavored water, tea, or ginger ale.

If foods such as soups, tomato sauces, casseroles, salad dressings, and gravy taste too salty, try adding sugar. If foods taste too sweet, add a pinch of salt and serve cold to decrease their sweet taste. If foods taste too bland, experiment with strong flavored foods, use herbs and seasonings, and alternate bites of different tasting foods within a meal. For example, pineapple and cottage cheese, grilled cheese with tomato soup.

Helpful Hints

- Offer lemon drops, mints or gum to help eliminate a metallic or bitter taste, and to relieve dry mouth
- Try foods cold or at room temperature, especially meats. This can decrease strong tastes and smells, making them easier to tolerate
- Avoid foods usually associated with a bitter taste such as red meats, tomatoes, coffee, tea, and chocolate
- Add sugar
- Season foods with tart flavors such as lemon, lime, other citrus, vinegar, or sweet and sour sauce
- Avoid serving foods in metallic containers or with metal utensils; use plastic or glass
- Try frozen grapes, oranges, cantaloupe, watermelon, berries, and bananas

Difficulty Swallowing

When a person has difficulty swallowing, there is increased risk for 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 of mixed consistency (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, 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 in the mouth and therefore can be difficult to swallow. In general, foods that are easy to chew, moist enough that they slide down the throat, and are evenly textured are better tolerated and are usually easier to swallow. The consistency needed is usually soft, but if not tolerated should be chopped/ground or pureed.

Avoid Foods That

- Crumble and form pieces (crackers, chips, pretzels, taco shells)
- Consist of small pieces (rice, corn, peas, popcorn, granola, raisins, beans, nuts)
- Can stick to the mouth (peanut butter or cream cheese)
- Have fibrous parts or seeds (celery, fruits with peels, some whole meats)
- Are hard to chew (tough meats, whole raw vegetables, hard fresh fruit, bagels)

Foods 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
- Meat/meat substitutes: diced, well-cooked meats served with gravies, ground meats, scrambled eggs
- Miscellaneous: soft French fries, cheese pizza, cream soups

Helpful Hints

- Eat in a pleasant and relaxing environment; minimize distractions such as TV
- Do not leave the patient alone
- Allow sufficient time for eating, but avoid long mealtimes which may cause fatigue
- Position the patient straight up (hips at a 90 degree angle) with the head slightly forward and the chin down to prevent food from going down the airway
- Serve only one bite at a time and allow time to chew food thoroughly
- If one side of the mouth is stronger, he or she should chew on that side
- Keep lips closed during chewing and swallowing
- Concentrate on swallowing; patients should not breathe or try to talk until food is completely swallowed
- Cough as often as needed to prevent food from going down the airway
- Avoid using liquids to clear the mouth of food
- If pocketing of food (food collecting in side of mouth) is a problem, apply external pressure to the affected side of the mouth
- After eating, remain in an upright position for 20 to 30 minutes
- Rinse mouth after eating
- Use pureed baby foods for convenience and season to enhance flavor
- Use garnishes to make the pureed food look more attractive.

Thickening Liquids

To decrease the chance of choking, liquids can be thickened by adding a commercial thickening agent (powder) to all liquids, including juices, soups, coffee, and milk) to bring them to the correct consistency.

- 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 nectar
- 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

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

When to Call Hospice

- Seizure is unusual or a new occurrence, lasts beyond a few minutes, or results in injury

Prevention of Bleeding

Patients may be more likely to bleed because of the effects of their illness. Talk with a hospice nurse if any unusual bleeding occurs.

Helpful Hints

- Avoid using sharp objects (knives, scissors, razors)

- Make sure sufficient light is available when moving around the patient to keep from bumping into patient
- Use an electric shaver not a manual razor
- Drink warm fluids and/or eat fruit to help reduce the likelihood of constipation, which can cause bleeding. (See Constipation pg. 10)
- Use soft toothbrush, sponge, or “toothette” to prevent gums from bleeding; avoid flossing
- Blow nose gently

When to Call Hospice

- Blood in urine, stool, sputum or vomit
- Bloody nose (several episodes or one that is not easy to control)
- Multiple bruises
- Many small, reddish-purple spots under the skin

If bleeding occurs, apply moderate pressure to the area if possible and call Hospice.

Oxygen

Use of oxygen is determined by the doctor and hospice nurse and must be used as instructed. Oxygen is most commonly supplied in the home through an oxygen tank which provides 5-6 hours of oxygen. To safely use oxygen, keep room well ventilated and free of candles or other lit objects. The patient should stay at least 10 feet from any source of sparks (radios, TVs, or other electrical equipment), and have a fire extinguisher near.

Post “No Smoking” signs that are visible to all visitors

Important Safety Reminders

- **Do Not smoke while oxygen is in use**
 - Smoking while using oxygen can cause facial burns, property damage and fatalities
 - People who smoke on oxygen put more than themselves at risk. They pose a threat to public safety: to family members, caregivers, neighbors and pets.
 - Many items that would not normally burn in normal air will ignite more easily when increased oxygen levels are present.

- When oxygen is used, it creates an oxygen-enriched environment and lowers the temperature at which everyday household items burn such as bedding, furniture, clothes and person’s hair.

Oxygen use can be safe if the following rules are followed:

- Keep all ignition sources away from oxygen. Sources of ignition include: matches, lighters, candles, hair dryers, electric razors, grinders, gas stoves and appliances. Avoid use of oil-based lotions, lip balms, petroleum jelly or aerosol sprays.
- The safest policy is to not allow the oxygen user or occupants to smoke where oxygen is being used.

When Using an Oxygen Tank DO

- Keep tank secured in carrying cart in upright position
- Store tanks not currently being used on their side and away from heat sources
- Keep valve protection cap in place when tank is not being used
- Store in a well ventilated area

DO NOT

- Grab the tank by its valve
- Drop the tank or allow tanks to hit each other
- Store in the trunk of a vehicle

Oxygen Concentrator

An oxygen concentrator is an electrical device that takes the oxygen from the room air and concentrates it so that you are receiving higher oxygen levels. It provides nearly pure oxygen through a nose tube (cannula) or mask. It may use a humidifier bottle attached to a concentrator to filter the room air. An alarm will sound when not operating properly and when initially turned on.

When Using an Oxygen Concentrator DO

- Store in an open area
- Always keep sides of the unit three inches away from walls, curtains or furniture

- Make sure oxygen tubing is not kinked or bent
- Use only distilled water in the humidifier bottle
- Keep water level in bottle between water lines at all times
- Empty humidifier bottle when water level reaches bottom line
- Connect oxygen tubing to humidifier lid
- Change water in bottle every 24 hours to prevent bacterial growth
- Check to make sure water is not building up in tubing

DO NOT

- Plug into outlets that have other appliances plugged into them
- Use an extension cord
- Place unit in a closet or enclosed space
- Add fresh distilled water on top of old water

Nasal Cannula (nose tube) and Tubing

The nasal cannula has two prongs that go gently into the nose. Make sure prongs are curved downwards and bring tubing around each ear to help hold the prongs securely. Replace nasal cannula or mask if it becomes discolored or cracked. Irritation may occur when using nasal cannula, but can usually be relieved by putting water-based lubricants, such as K-Y Jelly (**not Vaseline** as it is flammable) around nasal passages. If tubing causes ear soreness, pad tubing with cotton or gauze around ear area.

Helpful Hints

- Clear tubing attached to oxygen tank/concentrator which provides the way for oxygen to travel from equipment to the patient, either through a cannula, or facial mask
- Tubing is routinely changed every three months, along with humidifier bottle, cannula and/or mask or as needed
- Replace tubing if it becomes blocked or kinked

When to Call the Oxygen Provider (number is printed on oxygen equipment)

- When oxygen level meter reads “1”
- When equipment is not working properly

What to do if Electricity Goes Out

- Stay calm
- Since oxygen concentrators use electricity, the oxygen company provides at least two tanks for security and in case of power outage
- Take oxygen tubing that is attached to the concentrator and attach to the oxygen tank, then adjust and set flow rate
- Call Hospice to report any problems or concerns

Managing Shortness of Breath

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

What Can Be Done

- Try to stay calm
- Open a window or use fan directed at patient’s face to create movement of air
- Prop head up in bed/chair
- Apply a cool cloth to face
- Massage
- Encourage 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

When to Call Hospice

- Distress caused by shortness of breath
- Fever or moist productive cough
- Bluish discoloration of face, nose, fingers, or toes

Relaxation

Everyone has his or her own way to relax. By following these simple steps for relaxation, the ability to manage stress and improve breathing will increase.

- Find a place free of distraction and interruptions
- Dim the lights and turn off the television
- Turn off the phone ringer
- Turn on soothing music (optional)
- Lie in bed or sit in a comfortable chair

Lie or sit quietly, begin to focus on breathing. Naturally, breathing will slow down as you begin to focus on exhaling. As breathing slows, let the weight of the body sink into the chair or bed. Imagine a favorite place. Imagine moving around in this place and notice all the colors, sounds and smells of the surroundings. Enjoy this place and the feeling of relaxation it brings. Movement is free and breathing is easy in this place. Continue to relax and enjoy the music for a time. It is okay to fall asleep. When ready to return from this place, slowly move fingers and toes and slowly return to an upright position.

Bed Bound Patients

Due to physical decline and/or weakness a patient may not be able to do everyday tasks and are only comfortable when in bed. They will need help with personal care, moving and transferring in the bed, eating and drinking and will need added skin protection due to decreased mobility. A hospital bed, which may be obtained through your hospice team, can be useful in providing comfort as the head and the feet of the bed are adjustable. Its height is also adjustable making caregiving easier.

Using a Hospital Bed

- Make sure the brakes are locked at all times, except when moving the bed
- Raise the bed to waist height when providing care to prevent back injuries

- Always put the bed in the lowest position when patient is getting out of bed
- Do not allow children to play on or with the bed

Protecting the Skin

When the body is no longer moving as usual, (walking, getting up and down frequently, adjusting positions) and is staying in a still position most of the day, the skin becomes fragile, gets little circulation in some areas and can develop sores. It is important to take care of skin when being bed bound (see Skin Care on page 18).

Positioning in Bed

Before turning the patient on his/her side, explain how and what is going to be done before starting. If using a hospital bed, start by raising the side rail on the side the patient is turning toward. The patient may be able to assist in turning by grabbing onto this side rail.



Move the patient closer to you if possible, so there is no extended reaching. Gently turn the patient away from you, using your hand to push on the patients shoulder closest to you. Place a pillow behind the back for support and to hold side position. Consider placing a pillow between the knees for comfort. Several pillows may be needed to hold the position. Adjust the shoulders, pulling the bottom slightly out and toward you.

It is not unusual for a bed bound patient to moan during the turning, and it may be necessary to give a dose of pain medication first. If a patient can no longer help in turning,

use a “lift sheet” (flat sheet or extra large towel) under the patient. Your hospice nurse and/or hospice nursing assistant will instruct on using of a lift sheet, if needed.



Changing Bed Sheets

Your hospice nurse and/or hospice nursing assistant can show in detail how to complete this task.

- If using a hospital bed, raise the opposite side rail from the side you are working on
- Turn the patient to one side, position with pillows for stability, and work from opposite side
- Roll used sheet under patient
- Attach the top and bottom corners of a clean sheet to the mattress



- Smooth the clean sheet and fold and tuck the sheet and the dirty sheet under the patient
- Roll the patient to the opposite side over the clean and soiled or used sheet
- Pull out the soiled or used sheets
- Pull the clean sheet tight and attach the corners
- A lift sheet and/or bed pan can be added at this time while the patient is still on their side.
- Reposition the patient comfortably in bed

Using a Bedpan

- The use of gloves is recommended when assisting the patient on and off a bedpan
- Roll the patient to one side
- Place bedpan squarely under the buttocks
- Roll the patient back over on top of the bedpan
- Check to make sure the bedpan is in the right position
- If able, place the patient in sitting position; Stay nearby for safety
- When the patient is done, lay head down and carefully roll the patient to one side
- Remove bedpan and roll the patient back
- Help cleanse the area if assistance is needed and pat dry
- Dispose of waste in toilet, clean out bedpan
- Remove gloves and wash hands



Assistance Out of Bed to Chair

When moving the patient from the bed to a chair, remember to bend your knees and keep your back straight to prevent straining. Have chair placed in position at the head of bed, facing the foot of the bed before beginning. If transferring to a wheelchair, be sure brakes are locked.

- Bring the patient to sitting position on the bed
- Turn patient toward the edge of the bed by swinging legs to the side and down to the floor
- Wait a few moments to allow for adjusting to new position

- Face patient and place your right foot between the patient's feet
- Reach under the arms with his/her arms on your shoulders
- Hug the patient gently while raising off the bed and gently pivot from bed toward chair
- Lower patient to the chair, keeping knees bent and back straight



Assistance from Sitting to Standing

- Assist the patient to edge of bed or chair
- Face the patient with feet shoulder width apart
- Reach under the arms with his/her arms on your shoulders, with your knees bent and back straight
- Hug the patient gently while raising to standing position; allow them to pull on your shoulders for stability
- **Do Not** let go until you are sure the patient is stable in standing

Assistance with Walking

If oxygen is in use, tubing should be held to the side away from feet. Allow the patient to stand for a few seconds to get good balance and reduce dizziness. Support by placing one arm around the patient's waist or holding his/her clothes at the waist. Move at the pace the patient does and look for signs for needed rest such as shortness of breath or moving unsteadily.

If you find while walking you can no longer assist, ease the patient to the floor slowly and get help.

Using Assistive Equipment (Walkers, Canes, Wheelchairs, Shower Chairs and Bath Benches)

Assistive equipment should not be used alone until the patient is shown how to use them properly. If patient is unsteady, a walker or cane should not be used without some assistance during walking. Clean equipment with soap and water and make sure it is towel dried before using again. A pad or pillowcase on the wheelchair seat will help keep it clean. Remove all throw rugs to reduce slipping. Make sure chair or bench are secured in the tub and dry before getting onto equipment.

Call Hospice

- The patient has fallen
- Equipment is broken or cracked
- Questions regarding proper usage of equipment

Skin Care

Keeping the skin clean and moisturized, with frequent position changes is important during illness. Bathe patient two to three times per week, or once a week if skin is very dry, and use moisturizing soaps. After bathing make sure all soap is rinsed off completely and the skin is dried thoroughly. Apply lotion to the skin to soften and decrease the possibility of cracking. Avoid rubbing reddened areas, instead apply lotion. Inspect the skin regularly for any areas that might be at risk.

Every two to three hours, turn and reposition the patient to prevent skin breakdown, and check for moisture on the skin. Add extra pillows to support the body or use cushions. Keep sheets dry and wrinkle free.

Giving a Sponge Bath

Before starting a sponge bath, gather all the supplies you'll need:

- Basin(s) • Washcloths, towels
- Soap • Gloves
- Lotion • Clean gown or pajamas and sheets

Continued on the next page.

Warm the room and keep it free of drafts. Fill basin(s) with warm water about 2/3 high. Wash, rinse, and dry one area at a time, using very little soap. Cover each cleaned area with a towel or blanket before moving to the next area. Change the water halfway through washing the patient.

When to Call Hospice

- Reddened areas don't go away after several hours, or are open or bleeding.

Mouth Care

Regular mouth care helps maintain comfort and prevents mouth sores and infections. It may also improve appetite by providing a fresh tasting mouth. Mouth care is needed even if the patient is not eating or drinking. Brush teeth with toothpaste and soft tooth brush or toothette moistened with mouthwash two or more times per day, with patient sitting up if possible. Check mouth for redness or white patches. Keep lips moist with water based lubricant such as K-Y Jelly—**not Vaseline**.

Dentures

- Rinse mouth and dentures after every meal
- Remove dentures daily and check mouth for sores
- Remove dentures at night if it is more comfortable; clean mouth and dentures before reinserting

Dry mouth

- Suck on candy, ice chips or popsicle
- Take small sips of water
- Keep lips moist
- Rinse mouth with baking soda solution (1 teaspoon of baking soda in 8 oz. of water)

When to Call Hospice

- Pain or discomfort
- Difficulty swallowing
- White patches on gums, tongue or in throat
- Fever

Preventing Infection

Hand washing is the single most important step in the prevention of any infection. Wash your hands with liquid soap and warm water for a full count of 15–20 seconds. Be sure to wash entire hand to above the wrist, between fingers and under fingernails. Rinse well with warm water. Dry hands with a paper towel.

Alcohol-based hand sanitizers may be used when hands are not visibly soiled. Sanitizers may be kept at the bedside for use when a sink isn't close to the patient care area. Apply a small amount to palm of hand and rub hands together, covering all surfaces of hands and fingers until dry.

Wash your hands before and after:

- Giving care to the patient
- Using gloves
- Using the bathroom
- Eating or smoking
- Before preparing meals
- Having contact with any body fluids
- Playing with pets, doing yard work and/or housework
- Returning home from being out
- Having contact with someone who is ill
- Coughing or sneezing

Influenza (Flu)

This is a highly contagious viral disease that infects the nose, throat and lungs. It is spread from person to person by droplets in the air when the infected person coughs, sneezes or talks. Symptoms develop one to four days after exposure. Symptoms include fever, headache, dry cough, sore throat, extreme fatigue, runny or stuffy nose and muscle aches. The peak flu season is from late December through March.

Preventing Flu

It is important that caregivers and family members get a flu shot in October or November. Some patients have weak immune systems and are unable to respond to the flu vaccine. The flu vaccine is a “dead” virus and does not give the flu. It takes two–three weeks for the body to build antibodies to the vaccine and protect you from the flu. The flu shot lasts approximately 12 months and must be repeated every year.

Shingles

Shingles is caused by the same virus that causes chicken pox. After recovering from chicken pox, the virus lives on in the body and remains inactive until a patient has a serious illness or trauma that affects the immune system. The virus, when reactivated, causes shingles.

Symptoms of shingles include a tingling feeling on one side of the body which starts itching and then becomes a rash. Fluid filled blisters then develop from the rash. These fluid filled blisters are contagious to caregivers or family members who have not had chicken pox. When these blisters dry and crust over (in about three to five weeks) they are no longer contagious. Visitors and anyone caring for the patient who has not had chicken pox should wait until the patient is no longer contagious before visiting. Check with your doctor immediately.

Bloodborne Pathogens

There are diseases that cause a risk to caregivers such as Hepatitis B and C and AIDS. Hepatitis B and C are viruses that cause serious liver disease and are spread through exposure to blood and other body fluids. AIDS (Human Immunodeficiency Virus) affects the immune system. It is spread through blood and semen. There is no vaccine for AIDS. Use precautions and use latex condoms to prevent the spread through sexual contact.

Helpful Hints

- Use disposable gloves when in contact with the patient’s body fluids (blood, urine, stool, wound drainage)
- Remove gloves and dispose of in trash immediately after use. Place trash soiled with blood or body fluids in a leak-proof plastic bag and place in garbage/trash container
- Clean any body fluid spills as soon as possible
- Use a 10% bleach and water solution to clean up body fluid spills (1 oz bleach and 10 oz water). This solution is good for 24 hours only. A fresh solution needs to be made daily. Use household disinfectants appropriate to surface
- Air out room when possible
- Place needles, syringes, razors and other sharp objects in a plastic red container. Keep these sharp items and the red container out of the reach of children
- Do not share personal care items
- Instruct visitors to wash hands before and after visiting with patient. Request “no visiting” if visitor has a cold or does not feel well
- If the primary caregiver or other family member is ill, the best choice would be to relieve the caregiver of duties until well again. If this isn’t possible, use good handwashing, gloves, and a disposable surgical mask to protect the patient until well again
- Request advice from your hospice team about vaccines and further precautions to take

Cardiopulmonary Care

Chronic Obstructive Pulmonary Disease

COPD is the result of lung problems that have developed over a period of many years. It is often associated with severe asthma, chronic bronchitis, or emphysema. Airflow through the lungs has been hindered by inflammation and/or excess mucus, tightening of muscles around the airways, or by collapse of the airways.

Heart Failure (HF)

When the heart's pumping ability has become too weak to completely empty its chambers, fluid may back up in the lungs making it very difficult to breathe. Fluid can collect in other body parts as well, causing swelling and discomfort.

Fatigue

A common symptom of COPD and HF is fatigue. It can be difficult for patients to perform everyday tasks such as walking short distances (i.e. down your driveway or around the house) or sitting up at the dinner table. Your Hospice Team will suggest ways to help conserve energy.

Though rest is helpful, so is exercise. Research shows that the use of large muscle groups in low intensity exercise can increase energy. Patients who are able should take short walks several times a day when it best suits him/her. If unable to walk, enjoy other physical activities like knitting or painting. Your Hospice team can suggest ideas for physical activities for those who cannot get out of bed.

Breathing Techniques

There are two breathing techniques that help patients in end-stage cardiopulmonary disease take in more oxygen-rich air. In the first technique, inhale slowly through the nose for two counts, then pucker lips as if blowing out a candle and exhale slowly through the mouth.

In the second technique, sit in a comfortable position with hands resting on the abdomen. Inhale slowly through the nose, feeling the stomach muscles relax. The chest does not rise. Then, tighten the stomach muscles and exhale slowly through pursed lips.

Managing Shortness of Breath with Medication

Sometimes it might be suggested by the hospice team that medicine be used to help relieve shortness of breath. Research studies show that the use of an opioid (i.e. morphine) can help reduce exhaustion and relieve a feeling of breathlessness. The hospice team will help explain the use of any medications.

When to Call Hospice

- Increased shortness of breath
- Increased use of an inhaler or nebulizer
- Excessive fatigue
- Increased mucus secretions
- Change in color of secretions
- Fever
- Weight gain of two or more pounds in one day
- Waking during the night unable to breathe
- Pain in chest, arms, neck, jaw, or back, not relieved by current medications

Relaxation

Relaxation may be useful to cope with the physical and mental stress of COPD and HF. The hospice team can provide assistance in relaxation techniques. Some general examples can be found on page 16.

Spirituality and Patients with COPD/HF

Exploring spirituality can be helpful emotionally and further enhance relaxation. A Spiritual Care Coordinator from your hospice Team will contact you to offer to visit. Patients are encouraged to meet the Spiritual Care Coordinator. He or she may be helpful in discussing fears, regrets, and hopes.

Consider the following:

- What gives you hope?
- What gives you peace?
- What provides meaning and purpose in your life?

Suggestions:

- Talk about accomplishments or regrets
- Think about past coping skills
- Utilize support systems of friends, family, church, or synagogue
- Engage in complementary / integrative therapies, such as art, music, massage
- Meditate or use guided imagery
- Identify sources of inspiration and personal growth/satisfaction
- Keep a journal
- Arrange for Pastoral care/supportive presence
- Pray, read scripture or sacred texts

Phone Support: A Call to Connect

Hospice of the Western Reserve's cardiopulmonary phone support team is comprised of volunteers who make weekend phone calls to cardiopulmonary patients or their caregivers who reside in a private residence. Caregivers of patients living in nursing facilities, and interested in receiving weekend phone calls from a volunteer, should let the hospice team know. Calls are made once during the weekend and accommodate the patient's schedule. We encourage patients and caregivers to use these calls to discuss any difficulties they may be experiencing.

Benefits:

- Keeps the patient and caregiver connected with the hospice team
- Provides support and monitoring of symptoms
- As a reminder that the hospice team is available

Dementia Care

Caring for someone with dementia can be both rewarding and challenging. It can be particularly difficult if you feel you've lost a connection with the person. Hospice of the Western Reserve is experienced in managing dementia. The following section is information designed to assist caregivers in creative caregiving, communication, typical behaviors, safety, medication and other common concerns.

Caring for Yourself

Studies have shown that many caregivers who are taking care of someone with dementia experience feelings of depression as the disease nears the end (see Caregiver Needs on page 30).

Disease Progression

The course of dementia and its progression depend on many factors including the type of dementia and the overall health of the person. The loss of abilities, the symptoms and behaviors below may indicate late stages of dementia.

Cognitive

- Progressive decline in the ability to remember
- Profound confusion and disorientation
- Impaired ability to communicate
- Behavioral changes

Functional

- Loss of ability to walk or get out of bed independently
- Loss of ability to care for oneself (i.e. dressing, bathing)

Nutritional

- Progressive loss of appetite
- Loss of ability to feed oneself
- Weakened capacity to swallow, increasing

the risk of choking or aspiration (taking fluid and food into the lungs) and resulting in pneumonia

Complications

- Frequent infections, such as pneumonia, urinary tract infections
- Bowel and bladder incontinence
- Skin breakdown related to immobility and incontinence

Communication

Of all the complications of dementia, the struggle to communicate may be the most troublesome. Memory loss and confusion can create barriers in a once close relationship. In addition, it is harder to understand the patient's want and needs. Avoid quizzing, such as, "Don't you remember?" Instead, offer reminders. A firm or loud tone and rapid pace of your words may unintentionally express negative attitudes. A relaxed, lower tone of voice conveys patience. Getting a clear response from the patient is not the goal. Communicating to the patient is what is important—not what you get back.

Non-verbal means of communication become increasingly important as the ability to use and convey words diminishes. Body language, gentle touch and eye contact promote on-going, sensitive communication. Adopting new ways of communication will help maintain the personal relationship and dignity for the person with dementia.

What Can Be Done

- Look directly at the patient, approaching him/her from the front
- Use a gentle touch to get attention and provide a physical connection
- Avoid sudden movement as the patient may startle easily
- Greet the patient using his/her first name
- Use short, simple words and sentences, or try gestures to help explain

- Speak slowly, clearly and deliberately, but do not talk to him/her like a child
- Give one-step directions
- Ask questions one at a time. Patiently wait for a response, give extra time to respond
- Accept silence. He/she may not talk as much as before
- Eliminate background noise and distractions
- Maintain eye contact at eye level, for example when he/she is sitting, sit also
- Smiling helps to gain and keep attention

Behavior Challenges

Each person with dementia experiences unique changes in behavior. It is important to note that while the changes can be upsetting, the person is not acting this way on purpose. There are underlying reasons such as: pain or illness, noisy environment or over-stimulation, unfamiliar or unrecognizable surroundings, or frustration due to difficulty communicating or completing activities. Any changes in behavior should be discussed with your hospice team so that a comprehensive pain assessment can be done.

People with dementia sometimes become anxious or agitated, and may even scream, hit, or push. Try not to take the aggressive behavior personally. Instead, stay calm and use a soft, reassuring tone. Redirect by engaging in a relaxing activity, such as art, music, or massage. Contact your Hospice team for more individualized suggestions.

Wandering may not be as much of an issue in late stage dementia. You may notice the person pacing or walking aimlessly as a result of confusion, restlessness or boredom. For some, it is a way of communicating fears or needs. Make sure the person is getting the right amount of rest, food and drink. Provide reassurance that he/she is safe. Allow to wander in areas that are well lit and secure, and walk with him/her.

What Can Be Done

- Keep the area quiet with few distractions
- Make note of what “triggers” the behavior and try to avoid it
- Remove throw rugs and electrical cords that could cause tripping
- Install childproof latches or doorknobs
- Post signs for rooms (ex. “Bathroom”, “Kitchen”) to help patient recognize location
- Keep car keys out of sight
- Keep identification on him/her at all times (name, contact phone numbers, address)
- Do not rearrange furniture as this may add to the patient’s confusion

Connecting with Music

Music is very effective in easing the stresses of dementia. The rhythm, pitch and melody can stimulate different parts of the brain. It can soothe an agitated person, relieve anxiety and decrease pain. It provides a means of reminiscence and can bring a sense of belonging and spirituality. Furthermore, music helps a person with dementia express himself/herself. By singing or playing a familiar song, you may notice changes in facial expression, increased eye contact, vocal activity and movement.

Suggestions:

- Sing or hum a familiar song, such as Take Me Out to the Ball Game, while completing personal care like bathing or changing the sheets
- During meal times, play familiar recorded music with a relaxed tempo
- Rock or move gently to his favorite music, for example, big band or classical music
- Listen to music from concerts he attended and tell stories about it
- Play quiet music at bedtime

NOTE: Listening to music may conjure both positive and negative memories and feelings. If certain types of music cause agitation, try another song or stop the music altogether.

The Importance of Touch

For a person with dementia, touch can be a way of connecting and avoiding a feeling of isolation. A gentle touch provides a feeling of acceptance and a sense of well-being. This improved emotional experience reduces fatigue, anxiety, depression and tension. Use gentle touch when you need to get his/her attention.

Suggestions:

- Be clear about your intention, telling him/her exactly what you are going to do
- Massage over clothing, which may be more comfortable for people with neuropathy
- Do not require him/her to move positions
- Avoid areas of skin with irritation or inflammation
- Keep in mind that skin may be fragile and sensitive

Creative Caregiving

Before beginning any personal care for the person, such as bathing, consider any sensitivity he/she may have and how to accommodate it. Think about how and when the person with dementia prefers to wash. For instance, *Is he a late-riser? Does she prefer to wash before bed?* Have the room ready, warm and free of drafts. Begin in the least sensitive area of the body, such as hands and arms. Wash hair last or at a separate time. Give him/her something to hold like a sponge ball, and play soothing music or sing familiar songs.

Sleeping

Sleep problems are part of normal aging and can be more severe with dementia. Some people with dementia experience “sundowning”, which is characterized by increased agitation, restlessness and confusion at dusk and through the night. This can make it difficult for them to get the sleep needed to function well during the day.

Suggestions:

- Limit intake of alcohol and caffeine

- Plan days with interesting activities and increased exposure to daylight
- Establish consistently scheduled times for getting up and going to bed
- Limit daytime napping
- Establish a bedtime routine
- Avoid activities that might be upsetting or cause agitation near bedtime
- Stay calm if they awaken in the middle of the night

Eating

Often a person with dementia experiences changes in appetite or ability to eat. While these new eating habits can be distressing for the caregiver, there is a reason, or several reasons, for these changes: loss of interest, inability to chew or swallow, inability to recognize the need to eat, depression, or forgetting how to feed oneself can affect his eating. Talk to your hospice team about well-balanced meals. You may be able replace meals with high calorie snacks.

Suggestions:

- Reduce the size of helpings or offer finger foods
- Alter the flavor of foods since tastes may have changed
- Chop or puree food to ease chewing and swallowing
- Avoid exposure to large groups of people during mealtime
- Offer one food at a time with the correct utensil to avoid confusion

Overeating

In some instances, the person cannot sense fullness or differentiate nutritious foods from foods that are less healthy. He/she may not understand the timing of meals, or the differences between breakfast, lunch, dinner and snacks, or is unable to recall when he last ate. In this case, it is better to limit access to snacks, especially sugary ones, which has a negative effect on the individual’s mobility.

Suggestions:

- Provide alternatives that satisfy the sweet tooth but are lower in calories, such as sugar-free Jell-O and pudding, cookies containing dried fruit and/or nuts, low sugar candies
- Introduce stimulating activities throughout the day that help keep focus away from food and eating
- Maintain a consistent meal schedule
- Look for snacks the individual may have hidden

Swallowing

Difficulties in eating can be the result of physical conditions and an indication that dementia is in late stage. Dysphagia (trouble managing oral secretions or drooling), weakness of a voluntary cough or swallow, and involuntary tongue thrusts are common. Changes may also occur in voice quality/ tone (hoarseness/moist sound), frequent throat clearing, poor oral hygiene, and weight loss or dehydration.

During mealtimes, the person may experience uncoordinated chewing or swallowing, multiple swallows for each mouthful, pocketing of food in the cheeks, or coughing or sneezing during/following eating. If the patient experiences pain or discomfort in the throat or chest when swallowing, or has a sensation of food/liquid “sticking” in the throat, it may require that something special is done with the head or neck to ease swallowing. In such cases, eating may be so strenuous as to cause fatigue, changes in respiratory patterns, hoarseness or reflux. Talk with your hospice team if you feel swallowing has become challenging.

Suggestions:

- Keep eating and speaking separate to avoid choking
- Avoid lengthy mealtimes which contribute to fatigue
- Do not leave the person alone while eating

Refer to the Nutrition section on page 11 for more tips and suggestions.

Feeding Tube

Sometimes the placement of a feeding tube is considered. Studies have shown that artificial nutrition and hydration do not improve the comfort, functional status or quality of life for people with dementia. This is an individual choice for each family, and your hospice team will respect your wishes.

Not surprisingly, caregivers are often concerned the person on a feeding tube is experiencing hunger; however, other patients at the end of life who are able to communicate say they experience little or no hunger or thirst. Mouth swabs or ice chips can alleviate what little discomfort they might feel.

Pain and Discomfort

Pain can go unrecognized and untreated if the person is not able to express degrees of pain or other symptoms. Part of the comprehensive pain assessment is the PAINAD tool. A member of your Hospice Team will use it during each visit to determine his/her level of pain. Simple measures such as repositioning or applying a warm compress can help alleviate discomfort. Medications may be required to improve the level of comfort.

Medications

Upon enrolling with Hospice of the Western Reserve, your hospice nurse and pharmacist reviewed all current medications with the primary physician. Medications are evaluated for effectiveness and appropriateness. New medicines may be ordered depending on the stage of dementia. In general, medications meant to slow the advancement of Alzheimer’s dementia are no longer appropriate during the end stages of the illness when the focus of care is on comfort. All medications will be discussed with the caregiver(s) by the hospice team.

Refer to the Medication section for more information or ask your hospice team.

Spirituality and People with Dementia

Spirituality is a connection to a higher sense of self and purpose in life. It is expressed in our beliefs, actions, faith and relationships with God or a higher power, self, others and creation. For persons with end stage dementia,

the emotional aspects of spirituality are more meaningful, as they connect with the heart rather than the intellect. Re-affirm that life is precious, love is available and joy in the present moment is possible.

Suggestions:

- Stimulate the senses especially through scents, visuals and textures
- Play videos of scenes of nature with soft calming sounds
- Read familiar prayers, poems, stories, Scripture passages and blessings
- View TV programs of religious/spiritual nature
- Listen to music or sing religious hymns
- Make religious or cultural rituals or services available
- Give the patient a spiritual symbol to hold
- Provide an exercise in guided imagery or meditation
- Get help from your local religious figure of your faith
- Celebrate religious/cultural holidays that are a family tradition

Unique Grief and Loss for Dementia Caregivers

Feelings of grief and loss can occur at any time when caring for a person with dementia – not just in the final stages. You may feel angry about the disease, saddened that you struggle to communicate, or depressed that he/she is no longer the person you knew. Focusing on the person he/she is, versus the loss of memory or abilities, may help lessen the grief that you are experiencing.

When the end is near, caregivers deal with what is referred to as *anticipatory grief* – the reality that death is inevitable. Previously, the end seemed to be far in the future, but changes in the last few months have made the end of the journey closer. There is no right or wrong way to grieve, no calendar and no magic solutions. Feelings of grief are very powerful and often misunderstood. It is physically and emotionally draining, and operates on a timeline all its own. You may experience physical, emotional, intellectual, behavioral and spiritual reactions.

Talking about the grief you are experiencing sometimes requires help from a professional. Hospice of the Western Reserve offers bereavement services that provide support, encouragement, education and resources during thirteen months after the death of your loved one.

About You

Name: _____ Like to be called: _____

Hometown: _____ Other towns lived in: _____

Schools attended: _____ Occupation: _____

Favorite food: _____ Least favorite food: _____

Favorite music or songs: _____

Hobbies and interests: _____

Bowling Cards Faith community Cooking Crosswords Fishing

Gardening Movies Painting Puzzles Reading Sewing

Sports Walking Other: _____

Spouse's Name: _____ Married _____ Years

Significant other: _____

Brothers and Sisters: _____ Closest friends: _____

Regular visitors: _____

Children and Grandchildren: _____

About Your Life

Favorite trip: _____

Languages spoken other than English: _____

Special achievements: _____

Things that are upsetting: _____

Good topics for conversation: _____

Home Safety

Electrical

Place electrical cords from equipment (bed, oxygen concentrator, etc.) and extension cords out of walkways to prevent tripping or falling. Check extension cords often to make sure they are in good repair. Extension cords should not be overloaded; power strips (surge protectors) or outlet adapters are a safer choice. Keep unused electrical equipment unplugged and place safety covers in unused electrical outlets. Store and use electrical appliances away from water.

Walkways

Remove as many rugs, runners and mats as possible from areas used by the patient. Secure all loose rugs with double sided tape or rubber matting to prevent falling. Replace or repair torn or frayed rugs. Keep carpets tacked down. Keep stairs and halls clear and well lit, with well-secured rails on both sides. Patients should avoid using the stairs wearing only socks, loose slippers, or smooth-sole shoes.

Outdoor entry ways should be well lit and clear of debris, ice, leaves and snow. Provide secure outside step and porch railings. The house address should be clearly visible from the street during the day and night for Hospice staff.

Bathroom

Install grab bars and non-skid mats in showers, tubs and toilet areas to help with transferring the patient. Always check the water temperature for the patient before a bath or shower.

Telephone

Be certain that all cell and cordless phones are charged and place hospice and emergency phone numbers in easy to find places near phones. Keep a phone near

the patient's bed or chair so they may use it without standing or walking. If the patient is alone for all or part of the day, ask a friend, neighbor or other family member to call and check on the patient throughout the day, or consider an emergency monitoring device.

Fire safety

There should be at least one smoke detector for each level of the home. Develop an evacuation plan that includes those who are dependent on help to walk or who may be bedbound, and secondary escape plans in case primary plan cannot be carried out. Include family members, neighbors and/or friends to assist in evacuation if necessary. Be certain to communicate evacuation plan to all involved.

Clear all pathways and keep all exits open and unblocked. Keep the deadbolt key near the door with its place known to all household members. Fireplaces and space heaters **should not** be left unattended while in use. Fireplaces should have screens or doors which are kept closed. Heaters should have screens or an automatic shutoff device. Kerosene heaters require good room ventilation. Do not smoke or have open flames in the home where oxygen is being used or stored. Keep fire extinguishers within reach at home and check the expiration date.

Tornado safety

Tornado Watch means that local weather conditions exist for a tornado to develop. For Tornado Warnings, remain calm. Move the patient to the lowest level or basement of the home. If there is no basement then go to an interior room or hallway that does not have windows, or move toward an inner wall and cover up with blankets. Close all blinds and drapes in the room to aide in reducing flying glass if the window(s) break. If crisis occurs, call 911.

Power Outage

In the event of a power outage, report the problem to the electric company. If the patient

is using an oxygen concentrator, switch to the back-up oxygen tanks (see Oxygen on page 14) and call a member of your hospice team to alert the supplier to provide additional oxygen as needed. If a crisis occurs, call 911.

Gas Leak

Should there be a gas leak in the home, report the problem to the gas company. Open the windows, and if able, turn off the main gas valve. Do not smoke or use an open flame (including a candle, fire in fireplace, or cooking). Inform the police and fire department, and be prepared to leave. Do not return home until the gas company has given you approval. If a crisis occurs, call 911.

Water Outage

If there is a water outage or shortage, report it to the water company, and to a member of your hospice team. Consider moving the patient. Restrict use of available water. Use bottled-water for drinking or boil water for 20 minutes before use. If a crisis occurs, call 911.

Evacuation

Have an evacuation plan ready should there be a natural disaster. Determine where the patient may be moved to, such as a neighbor's home or friend. Have a backup plan and communicate plan to everyone involved. Call a member or your Hospice Team before evacuating the home.

For situations where travel may be prohibited due to weather or other conditions, prepare ahead of time by having a three to five day supply of water (one gallon per person, per day in home), ready to eat foods that do not need to be refrigerated, medications, first aid kit and patient care supplies in the home. In addition, have a battery-operated radio or TV, flashlight, extra batteries, etc. Follow the directions of the community emergency response system from the radio or TV.

Caregiver Needs

WE ARE HERE FOR YOU TOO

Although you may not consider yourself a caregiver, you are. A caregiver is anyone who cares for a seriously ill person. A caregiver is most often a family member or close friend.

Caring for someone can be both rewarding and stressful. It is not unusual to experience a variety of feelings at this time. These feelings are neither good nor bad. They are your feelings and they may affect your life and well-being during the time you are providing care..

Over the years, we have learned from caregivers that caring for someone with a serious illness is a life-changing process. They have taught us that even in the midst of hurt and sadness, there are chances to learn and grow and heal.

Being a caregiving can be a valuable time to create lasting and positive memories together. Other rewards of caregiving include:

- Sense of inner peace
- Times of laughter and joy
- Feelings of intimacy
- Completing unfinished business
- Stronger sense of self-worth

We understand that it is easy to become tired and overwhelmed as your caregiving responsibilities are many. 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.
- Maintaining good health is a priority: Get enough rest, eat properly, and exercise.

Identifying your needs as a caregiver is the first step toward taking care of yourself and the person receiving care. Here’s a worksheet with some ideas to help you get started. Please talk these over with your Hospice Team.

What would you like to have help with?

- Household chores
- Shopping
- Getting through the night
- Personal care
- _____

What questions do you have about providing care?

- How do I administer medication?
- If the person receiving care is not eating, will he/she starve?
- Can we take outings?
- _____

What worries you?

- Being alone and missing my loved one
- My loved one suffering and being in pain
- What is Hospice of the Western Reserve paying for?
- _____

We are committed to answering your questions, supporting your needs and helping you feel more at peace and confident in caring for your loved one. Please know that your hospice team is *always* here for you throughout this time... we're just a phone call away.

Final Days

Everyone's life is unique, and so is everyone's journey toward death. This is a difficult time because you may not know what to expect during the patient's final days. Your Hospice Team will do everything they can to help you feel more confident and less anxious. Your Team can provide bedside education on things you can do or say to help the person receiving care. We want you to be more informed and prepared, but it is natural to feel confused and upset. Be kind and gentle to yourself.

From one to three months before death, it is common for a person's world to focus inward. There is a shift away from the outer more social world. This is not a withdrawal of love from you, but a need to focus energy inward. Your presence is very important.

There may be differences in how family members and friends respond. Some may wish to have private time with their loved one. Some may wish to provide personal care. The Hospice Team will support you in your wishes and help you do what feels right for you.

Signs and symptoms of approaching death

As the patient prepares for the final stage of life, you may notice physical changes taking place. Not all of these signs will appear at the same time and some may never appear at all. Please let us know what you see and experience. Your Hospice Team will help you identify these changes and support you through this difficult time. You have undertaken the most precious service by caring for a loved one.

When to Call Hospice

- **Decreased need for food and drink, and difficulty swallowing** because the body functions are gradually slowing down. There may be difficulty in swallowing. The mouth may become dry and will need to be kept moist. The patient will not experience hunger.
- **Sleeping/difficult to arouse** is a result of a change in the body's metabolism. Try to spend more time with the patient during those times of greatest awareness.
- **Restlessness or confusion** is common. The patient may become increasingly confused about time, place and identity of close and familiar people. Reminders as to what day it is, what time it is, and who is in the room will be comforting. Soft music and dim lights may be calming. Keep side rails up for safety.
- **Visions** of people and things you cannot see are common and not necessarily frightening, but comforting to the patient.
- **Seizure-like movements** with arms, chest or face in the last few minutes of death are a part of the body's shutdown process. These are not to be considered seizures or seizure activity.
- **Unusual eye movement** such as side to side.
- **Incontinence/decrease in the amount of urine/darker urine color** may become a problem. The nurse or hospice nursing assistant can help you obtain pads to place under the patient for more comfort and cleanliness. You may notice a decrease in the amount of urine and it will be darker in color.
- **Moist-sounding breathing** is caused by relaxed vocal cords and a small amount of oral secretions collecting in the back of the throat. The patient does not feel any discomfort from this and may not even be aware of it. Elevating the head of the bed or turning the patient on their side will usually quiet the breathing sounds.

- **Hearing and vision** may change. Keep some soft light on in the room. Assume that the person receiving care can hear, since hearing is thought to be the last of the senses to diminish. Explain to the patient what you are doing.
- **Cooler body temperature** may cause the arms and legs to become cool to the touch and bluish in color. You may notice that the underside of the body is much darker in color. These symptoms are a result of blood circulation slowing down and do not necessarily indicate that the person is too cold. Fevers are common as well.
- **Change in breathing patterns**, including 10–30 second periods of no breathing (called apnea), may occur in the final stages of life.
- **Unable to respond to touch or voice.** Assume that the sense of hearing remains and speak in a comforting voice.
- **Pain and discomfort may diminish** as death approaches but continue to give medications as directed by the nurse.

Please let your hospice team know of any special or unique practice/ritual you would like to incorporate at this time. Hospice of the Western Reserve will notify your physician and funeral home at the time of death. Try not be alone during this time. Include family and friends. Ask for assistance with caregiving needs. Use your hospice team for support.

Important Things to Attend to When Someone Dies

Often when death occurs, even expected death, the sadness can be overwhelming and interfere with the ability to take care of important matters that must be attended to in a timely manner. You may think, “Where do I begin?” and feel at a loss to start the process. Having a checklist may help you be more efficient and thorough. Although this

list is not exhaustive, it highlights important tasks that need to be taken care of and when.

Immediately

Notify necessary parties. Your Hospice Team is available to help make these phone calls.

- Hospice of the Western Reserve
- Family
- Funeral Home
- Physician
- Attorney

Determine whether or not a home needs to be secured if it is now empty. If homeowner is deceased, check with the insurance company regarding any changes in coverage.

After the Funeral

Obtain the following documents:

- 10–15 copies of the death certificate
- Social Security card
- Marriage Certificate
- Birth Certificate
- Insurance policies
- Deed and titles to property
- Stocks, bonds and/or IRAs
- Bank books
- Honorable discharge papers for Veterans and/or VA claim number
- Automobile title and registration papers
- Loan and installment payment books and contracts

Contact the following:

- Government agencies or benefits program, including alliances or unions that may be making payments to the deceased
- Creditors owed money by the decedent (credit cards, mortgage company, automobile loan agency)
- Social Security Administration to determine if you are eligible for benefits

- The deceased's bank and handle financial matters (roll over joint accounts; determine if deceased had a safe deposit box or a bank security box and follow appropriate procedures)
- Human Resources at the deceased's place of employment (if he/she was working) to discover whether there are monies you are entitled to such as vacation pay, death benefits, final wages, retirement plans, or other types of compensation.
- Your attorney to discuss estate matters. Do not pay any of the deceased's debts until after meeting with a lawyer.

Request change of beneficiary or name forms:

- IRA
- Life insurance policies
- Pension plans
- 401K plans
- Utilities
- Stocks/bonds

Cancel or forward mail and newspaper delivery if necessary.

Cancel automatic payments like annual memberships or subscriptions and on-line bill payments.

Make arrangements for final income tax return if appropriate and estate tax return as necessary.

There are various websites that provide helpful information. If you have questions, please feel free to call our Elisabeth Severance Prentiss Bereavement Center at 216.486.6838.

When you are sorrowful look again in your heart, and you shall see that in truth you are weeping for that which has been your delight.

–Kahlil Gibran

Grief and Loss

Grief is a normal, necessary, natural reaction to any loss. It is a roller coaster of emotions that involves physical, social, behavior,

intellectual and spiritual responses. There is no right or wrong way to grieve. Each person grieves differently, in their own way and on their own timetable.

During the course of caring for someone who is seriously ill, you may encounter feelings of grief known as “anticipatory grief.” Even with anticipatory grief, however, there is no way to be fully prepared for the deep sadness you may feel after the death of a loved one.

The Hospice Bereavement Team will continue to offer guidance and support as you adjust to changes in your life. A bereavement coordinator will be assigned to your family and will contact you after the death. A variety of services which include groups and individual support will be explained to you at that time. Additional resources can be found at hospicewr.org/grief or at hospicewr.org/bereavement-center-blog

Suggestions to Promote Healing

- Be kind to yourself.
- Schedule a check-up with your family physician if necessary.
- Get some exercise.
- Check frequently that you have balance in your life: rest, play, meditation and work.
- Reach out to others.
- Tell and re-tell the story.
- Don't fight the tears.
- Find a creative outlet: music, art, journaling.
- Confront guilt and regret.
- Be familiar with normal grief responses.
- Be patient with yourself. Grief takes time.
- Have realistic expectations of yourself.

Remember that you don't have to grieve alone. The bereavement team is here with comfort, hope and healing.

Tears are the silent language of grief. –Voltaire

Children Grieve Too

Like adults, children will grieve in their own unique ways. However, they are often unable to identify, let alone manage these big feelings. Also, the grief may not manifest itself until months or years later. The grief of children can be intermittent and expressed in a variety of ways.

Speak to children in a language they can understand. Be aware of the child's developmental stage and use simple and honest words or phrases. You may need to ask children questions to get a better understanding of how they are feeling. Ask your hospice team for our *children's packet* or to access our children's bereavement coordinators, who can help with this process.

There is wide variability in the understanding of death at a young age. By age seven, most children understand the key elements of death – that it is permanent and irreversible. Accepted developmental and grief responses of 3-5 year old children include a lack of time/space concepts, belief of death as temporary and reversible, magical thinking, fear of abandonment, and a need for physical comfort, reassurance, and a stable routine.

As children mature, so does their understanding of death. The child moves from wanting to understand death in a concrete way to a morbid curiosity about the specifics of death and dying to reacting similarly to adults, but with less coping mechanisms. As adults, answer all questions simply and honestly, reassure about the future, provide opportunities for feeling expression that include art and music, and include them in any funeral plans or rituals.

Common Grief Reactions

Shock – Shock and numbness is a typical grief reaction. You may feel as if you are on autopilot or just going through the motions. It takes the mind time to grasp that death has occurred.

Longing – You may feel a deep longing for your beloved. It takes time to accept the reality of the loss and you may find yourself searching for your loved. You might think you hear their voice or sense their presence.

Sadness – Not only will there be times you feel sad, you may experience waves of sadness. These waves are often unexpected and overwhelming and can bring tears.

Anger – Anger is one of the intense emotions that is a part of the normal grief reaction. Not everyone feels anger, but many do. You may be angry at the person who died, persons responsible, yourself, the situation or God.

Guilt and regrets – When someone dies we often second-guess ourselves. You may be wondering what would have happened if you had done or said things differently. You may blame yourself for things you had no control over. Remind yourself you did the best you could at the time.

Relief – Some bereaved feel a sense of relief after the death. You may be relieved of your constant worries, your responsibilities of caregiving, or your loved one suffering. This is a normal part of the grief process.

Sleeplessness – Sleeplessness is common shortly after the death. You may have difficulty falling asleep, staying asleep or waking very early. Thoughts and deep feelings often surface at night.

Changes in appetite – You may have an increased or decreased appetite.

Forgetfulness and inability to concentrate – Many people experience confusion, memory loss and difficulty focusing on tasks at the beginning of their grief journey. It is helpful to write lists, make notes and keep to the familiar.

Reference

The Hospice Medicare Benefit and Other Insurance Coverage

Medicare provides a special program for persons needing hospice care, which covers services, medications, supplies, and equipment needed for the comfort of patients. All services, medications, supplies, or equipment related to the seriously ill diagnosis must be pre-authorized by Hospice of the Western Reserve. Medicare pays Hospice of the Western Reserve directly at specified daily rates for care provided. Therefore, Hospice of the Western Reserve delivers care based on the plan of care and is not responsible for care obtained for the patient outside of this plan of care.

These restrictions apply only to the serious illness. Unrelated medical problems may be treated in the usual manner with your insurance coverage.

Eligibility

- Patient has Medicare Part A
- Patient's doctor has confirmed the serious illness
- Patient signs a statement choosing hospice care benefits
- Patient receives care from a Medicare-approved hospice
- Patient has months rather than years to live

Benefit Periods

The Medicare Hospice Benefit consists of two 90-day benefit periods followed by an indefinite number of 60-day periods. At the end of each period, the Hospice Team must agree that the patient is seriously ill. If the patient is improving or the illness has stabilized, the hospice team will discuss alternatives to hospice care with the patient and family.

Medicare allows the patient to discontinue the Medicare Hospice Benefit before a benefit period is over, however, the days left

in that period are lost. The next time the patient enters the Medicare Hospice Benefit, they will enter the next period.

If a patient has symptoms that are proving difficult to manage at home, a few days in a hospital or one of our Hospice Care Settings may be necessary. The need for this must be assessed by a hospice nurse. The types of problems that may warrant a trip to the hospital or Hospice Care Setting are increased pain, acute nausea, vomiting, or shortness of breath. If such a trip out of the home is needed, the hospice team members will help arrange transportation. The Medicare Hospice Benefit requires the pre-authorization of any hospital stay related to the serious illness, including the emergency room. ***Call Hospice of the Western Reserve day or night before making a trip to the hospital.***

Medicaid

The Medicaid Hospice Benefit provides the same coverage as Medicare. The patient's Medicaid card will be used to confirm eligibility for this benefit. Because this card is reissued every month, Medicaid asks that we verify eligibility every month as well.

The Champus Program (Tri Care Insurance)

Because we are a Medicare-certified agency, we can be the provider of hospice services for those persons with Champus coverage, which has the same benefits as the Medicare program.

Private Insurance

Many, if not most, private insurance carriers have hospice coverage within their program. We will contact the insurance company regarding the coverage. Please contact your primary nurse with any changes to your healthcare coverage or if you have any questions.

Patient and Family Bill of Rights

- ◆ Patient and family have the right to considerate and respectful care.
- ◆ Patient and family have the right to obtain complete and current information concerning services provided, diagnosis, treatment, advance directives, and prognosis in terms they can be reasonably expected to understand.
- ◆ Patient has the right to receive from his/her physician information necessary to give informed consent prior to the start of any procedure and/or treatment. When the patient requests information concerning medical alternatives, the patient has the right to such information, and to know the name of the person responsible for the procedures and/or treatment.
- ◆ Patient has the right to choose his/her attending physician.
- ◆ The patient has the right to refuse treatment to the extent permitted by law, and to be informed of the medical consequences of his/her action.
- ◆ The patient has the right to every consideration of his/her privacy, confidentiality, and security concerning his/her own Hospice care program.
- ◆ The patient has the right to have his/her property respected.
- ◆ The patient has the right to expect that all communications and records pertaining to his/her care should be treated as confidential.
- ◆ The patient has the right to expect reasonable continuity of care.
- ◆ The patient/family have the right to examine and receive an explanation of financial responsibilities regardless of source of payment.
- ◆ The patient has the right to be informed of the findings of assessment of physical, social, psychological, spiritual, economic and safety needs.
- ◆ The patient has a right to have an individual plan of care including assessment, planning, implementation, and evaluation by the appropriate team member.
- ◆ The patient has the right to participate, with family and team, in developing an individualized plan of care and when there is divergent thinking, an arena for further discussion can be provided. The Ethics Committee is a transdisciplinary group which can offer a confidential, nonjudgmental forum for reviewing and discussing ethical concerns. To report an ethical issue to the Ethics Committee, ask any hospice staff for a *Request to Review* form, or after office hours call 216.255.9051 to request assistance.
- ◆ The patient has the right to have care and teaching directed towards optimal quality of life in an environment that preserves dignity and contributes to a positive self-image.
- ◆ The patient has the right to the proper identification of team members and to receive adequate information about the persons responsible for the delivery of care, treatment, and services.
- ◆ The patient has the right to expect that team members have current knowledge in their respective fields.
- ◆ The patient has the right to appropriate assessment and to receive effective pain management and symptom management related to conditions of the serious illness.
- ◆ The patient has the right to have consent obtained for recording or filming, made for purposes other than identification, diagnosis, or treatment.
- ◆ The patient has the right to unlimited contacts with visitors and others.
- ◆ The patient has the right to be protected as a research subject and have his/her rights respected during research, investigation and clinical trials involving human subjects.
- ◆ The patient/family has the right to file a grievance if not satisfied with care or feels he/she has been discriminated against. Call or write the Director of Planning

and Evaluation or the Chief Executive Officer of Hospice of the Western Reserve at 216.383.2222. If his/her concerns are not resolved, he/she has the right to notify the Joint Commission for the Accreditation of Health Care Organization at 1.800.994.6610 and/or the Ohio Department of Health at 1.800.342.0553.

- ◆ If a patient has been adjudged incompetent under state law by proper jurisdiction, the rights of the patient are exercised by the person appointed pursuant to state law to act on the patient's behalf.
- ◆ If a state court has not adjudged a patient incompetent, any legal representative designated by the patient or in accordance with state law may exercise the patient's rights to the extent allowed by state law.
- ◆ The patient has the right to be free from mistreatment, neglect or verbal, mental, sexual and physical abuse, including injuries of unknown source, free from restraint or seclusion and misappropriation of patient property.

- Notify the Hospice Team if I need to cancel or change the time of the scheduled visit.
- Submit requests for volunteer support no less than 72 hours in advance with the understanding that the team will make every attempt to fulfill my requests.
- Resolve care issues through the hospice primary nurse. The team leader may be contacted at the designated team office for further assistance with the resolution.
- Treat hospice caregivers with respect and courtesy, understanding that if they are not afforded such respect and courtesy, they will leave the home immediately. The subsequent visit will be scheduled with the assistance of the team leader.
- Call the hospice team (if after hours, the on-call team) with any questions, change of condition or symptoms.

Call Hospice of the Western Reserve, rather than 911, for immediate assistance.

Patient Responsibilities

I (we) have consented for hospice services from Hospice of the Western Reserve and agree to:

- Participate in the development of my Plan of Care in conjunction with the Hospice Team, which includes the physician, and continuously discuss goals for my care, activities of daily living and quality of life.
- Participate in the management of care that may involve personal care, treatments and medication administration.
- Inform the Hospice Team of other agencies providing care and services to me.
- Be at home and available for the visits scheduled with Hospice Team members. I understand that I may have to allow one half hour before and after the scheduled time to accommodate traffic, weather conditions and unforeseen events.

Financial Responsibilities

- Costs which are not approved by Hospice of the Western Reserve and not in compliance with the agreed upon plan of care
- Deductibles and co-payments
- Care and treatment provided when no insurance coverage is available
- Care and treatment not related to the serious illness
- Room and board fees not covered by the third party payer
- Any cost incurred for treatment with a physician and/or facility not contracted with Hospice of the Western Reserve

Grievance Procedures

Hospice of the Western Reserve is committed to respond to all complaints. We encourage you to speak to us regarding any problem affecting your care.

If you have a complaint about the care provided, we urge you to take the following steps:

- Talk over the problem with your primary nurse or social worker. Most problems will be resolved this way. If your problem is not resolved, call the team leader. See the Quick Reference page on the back of this book for the name and office number.
- If this problem occurs during the weekend or in the evening, request the supervisor on-call when calling the on-call nurse.
- Call or write the Compliance Officer at 216.383.3745 who will respond to your concern within 48 hours.
- If your complaint still has not been addressed to your satisfaction, call the Chief Executive Officer at 216.383.3773 or the Chief Clinical Officer at 216.383.3730.
- If you are not satisfied with the results of the steps taken above, you have the right to refer the problem to the:

Ohio Department of Health
246 N. High Street
2nd Floor
Columbus, Ohio 43215-2429

or call the toll-free hotline:
800.342.0553

Corporate Compliance Plan

Standards of conduct

In concert with our mission, Hospice of the Western Reserve operates in an ethical and conscientious manner; adhering to laws and regulations in providing hospice care and services to the communities we serve. Hospice of the Western Reserve will tolerate no fraud, waste or abuse in conducting our

business or in delivering services to our patients and families. Everyone has the responsibility to act in a manner which upholds the laws, to actively participate in and promote compliance, as an employee or volunteer of Hospice of the Western Reserve, and to report any activity they become aware of that violates any law or regulation.

Anyone can report concerns regarding a lack of compliance in person, by writing, via voicemail, e-mail or by calling the Compliance Hotline voicemail box at **216.383.6688**.

Hospice of the Western Reserve's Compliance Hotline voicemail box is in place for use by staff, independent contractors, patients and families seven (7) days a week, 24 hours a day. Individuals can leave a confidential message for the Compliance Officer if they become aware of an alleged wrong doing or if they have any concerns regarding unethical or illegal conduct at, by or involving Hospice of the Western Reserve. Individuals will be asked to leave their name so they can be contacted for follow-up if necessary. However, anonymous messages will also be accepted. Only the Compliance Officer will have access to the Compliance Hotline voicemail box.

Compliance Office

Shareefah Sabur

Chief Strategy Officer
Hospice of the Western Reserve, Inc.
17876 St. Clair Avenue
Cleveland, Ohio 44110

Phone: 216.383.3745

E-mail: ssabur@hospicewr.org

Patient Privacy and Confidentiality

Hospice of the Western Reserve implements policies and procedures to accommodate patient privacy rights as required by and specified in the Privacy Rule of the Administrative Simplification provisions of the Health Insurance Portability and Accountability Act of 1996.

Patients cared for by Hospice of the Western

Reserve have the following privacy rights:

- ◆ To receive a paper copy of the organization's Notice of Privacy Practices
- ◆ To request restrictions on the uses and disclosures of health information
- ◆ To request to receive confidential communication
- ◆ To access their protected health information for inspection and/or copying
- ◆ To amend their health care information
- ◆ To request an accounting of disclosures of health information

The privacy policies of Hospice of the Western Reserve detail the requirements for each of these rights and provide procedures for implementation. Staff and volunteers at Hospice of the Western Reserve are provided with periodic training regarding patient rights with respect to health information

How to contact the Privacy Officer?

Shareefah Sabur
Privacy Officer
Hospice of the Western Reserve, Inc.
17876 St. Clair Avenue
Cleveland, Ohio 44110

Phone: 216.383.3745

Email: ssabur@hospicewr.org

HIPAA hotline voicemail:

216.383.6675

Ethics Committee

Our Ethics Committee was formed to provide guidance and support on ethical matters relating to patient care. Discussions are held in a format that stimulates conversation and dialogue among staff members, patients, families, healthcare providers and members of the community.

Some examples of ethical issues include:

- The decision to withhold or supply a patient's nutrition or hydration

- A patient's right to refuse treatment
- Determining a patient's capacity to make decisions and identifying a family spokesperson

The committee is not a decision-making body, but one that provides guidance and support in a non-judgmental manner. It does not replace those decisions made by physicians, other medical providers or the patient and family. All matters are handled with strict confidentiality.

A committee member may be reached by calling 1.800.707.8922 weekdays 8 a.m. to 4:30 p.m. or 1.800.665.2619 after hours.

Payment

Medicare pays Hospice of the Western Reserve directly for each day hospice is responsible for care. During hospice care, you should not receive a bill for services covered by Medicare. The current arrangement you have under Medicare Part B will continue to cover the doctor's costs. If any questions come up regarding billing, ask your Hospice Team for help.

Billing

Will I have a co-pay or deductible?

Hospice of the Western Reserve will bill you for any amount applied toward your personal deductible and/or co-pay after the partial payment has been received from your insurance company. It is *Our Care Promise* to provide comfort care to seriously ill people regardless of their ability to pay. Memorial gifts and private donations from the community, as well as grants and United Way funding, assist with covering the cost of care provided to patients and families without insurance. A Financial Resource Advocate can help patients and families discuss financial options. To set up an appointment with a Financial Resource Advocate, please call 216.383.2222, ext. 2290, or click the "Contact Us" option on our website at hospicewr.org.

Personal Planning

ADVANCE CARE PLANNING

There is no easy way to plan for future health care choices. It is a process of discovering the beliefs and preferences of the person you are caring for by discussing choices. During a health crisis, it may be too late, too difficult or impossible to know what someone wants. Patients and caregivers can prepare for this time by developing advance directives in the form of living wills and durable powers of attorney for health care.

Hospice of the Western Reserve has a free guide to assist with these forms. This all inclusive booklet, titled *Courage in Conversation: A Personal Guide*, includes decision making resources, information and Ohio's living will, health care power of attorney and tissue donation forms. Ask a hospice team member for a copy, or visit www.hospicewr.org/planning.

The Living Will

- Written instructions that tell physicians and family members what life-sustaining treatment one does or does not want at some future time if a person becomes unable to make decisions.
- A standard Living Will form can be obtained from Hospice of the Western Reserve.

Health Care Power of Attorney

- A document that allows a person to name someone to make health care decisions on his/her behalf when unable to communicate, either temporarily or permanently.
- The person named to make health care decisions needs to follow the values and instructions that have been discussed.
- You can request one of these forms from Hospice of the Western Reserve.

Do Not Resuscitate (DNR) Comfort Care Protocol

- A Do Not Resuscitate order is a physician's order; it is prepared by a physician or an advanced practice nurse.
- This means that CPR (cardiopulmonary resuscitation) would not be started if the heart or lungs stopped working; there are two types of DNR orders in Ohio.
- With a DNR Comfort Care order, a person receives any care that eases pain and suffering, but no resuscitative measure to save or sustain life.
- With a DNR Comfort Care Arrest order, a person receives standard medical care until the time that there is a cardiac arrest (heart stops) or a pulmonary arrest (breathing stops) but comfort care will continue.

Power of Attorney

- A legal document in which someone gives another person the authority to make specific financial decisions or assumes certain financial responsibilities.
- It is advisable to consult an attorney or legal aide to obtain this document.
- Volunteer attorneys are available through Hospice of the Western Reserve.

THE GIFT OF LIFE: ORGAN AND TISSUE DONATION

Organ and tissue donations are a gift of life. Through such donations, the lives of others can be prolonged, saved or improved. We realize that this is a difficult decision to make, especially at a time when you are experiencing intense grief, but many families have later said that the pain and loss was somewhat eased by having given a gift of life to another person.

If you would like more information about such donations please ask a hospice team member and arrangements will be made for further discussion.

Personal Information and Records Checklist

Location

Living Will _____

Durable Power of Attorney for Health Care _____

General Durable Power of Attorney _____

Name _____

Address _____

Phone _____

Will

Attorney _____

Executor of will _____

If you do not have a will, we encourage you to prepare one. If you do have a will, it is a good idea to review it at this time and share it with family members and others named in the document.

Insurance Policies and Policy Numbers

Life insurance (group and/or individual)

Health insurance

Home insurance

Auto insurance

Disability insurance

Renter's insurance

Insurance Agent / Broker

Name _____

Address _____

Phone _____

Real Estate Deeds

Location of property _____

Titles in name of _____

Personal Information and Records Checklist

Location

Mortgages, records, or mortgage payments information

Stocks, bonds, certificates of deposit

Brokerage firm / broker

Name

Address

Phone

Savings account

Name

Account #

Checking account

Name

Account #

Safe Deposit Box

Location of box and key

Name box is under

City, state, federal tax

Returns for the past several years

Birth Certificate

Social Security Card

Marriage / Divorce certificates

Automobile titles

When the person receiving care is no longer able to drive, a transfer of title and change in primary insured is recommended.

Military discharge papers

Contracts (e.g. installment purchase agreements)

Business records

Receipts for furs, jewelry, etc.

Credit cards

Funeral Planning

Pre-planning funerals provides an opportunity for all involved parties to state their needs and ideas at a less stressful time. Most funeral home directors welcome the opportunity to answer questions. Contact the funeral home of your choice to arrange a meeting. The funeral home director can also assist with an “Irrevocable Burial Contract”. This is a pre-planned and prepaid funeral. This will bring peace of mind and may also secure the price. Also, the purchase of an “Irrevocable Burial Contract” is considered a legitimate way to spend down liquid assets if qualifying for Medicaid. Speak with the hospice social worker or spiritual care coordinator if you need assistance with funeral planning.

If you have made funeral arrangements or wish to use the services of a specific funeral director, record that information here:

Funeral Home _____

Funeral Director _____

Address _____

Telephone _____

Cemetery _____ **Plot** _____

Specific instructions _____

If a family member is flying into town during your illness and/or plans to attend the funeral service: When making reservations have them notify the airline of the reason for the flight. Most airlines will issue the ticket at a reduced rate.

Memorial Form

Supporting our families in many stages of dealing with a serious illness is a vital part of our mission.

One of the ways we are able to do this is to offer assistance in planning for the time ahead. Having accurate memorial information available for newspapers and the funeral director is an important task, most of this can be done in advance. Hospice staff members are willing to help you in any way possible. This is best done prior to the death of your loved one, when there is time to think and talk, and gather complete information. The completed form can then be forwarded to the funeral director who is responsible for placing obituary notices and making other arrangements.

Patient Information

Name _____

Address _____

City _____ **State** _____ **Zip** _____

Birthplace _____

Came to area from _____ **When** _____

Occupation _____

Major/Area Employer _____ **No. of Yrs.** _____

Church Religious Affiliation _____

Organizations/Offices _____

Major Achievements/Honors _____

Military Service/Recognition _____

Memorial Planning

THE MEMORIAL SERVICE: A CELEBRATION OF LIFE

A memorial service provides a sense of completion for both the deceased and the survivors. Despite the grief and fatigue, spending time with friends and family is a step in the healing process. Sacred texts, poetry, and music are commonly used in planning a memorial service. Reflect on the person's life; think about his or her values, special events, life's work, hobbies, travels, and contributions. It will help you cope with your grief.

In most cases planning a memorial service falls to the immediate survivors. It is also common for the patient to participate in this planning. If the patient has reached an understanding and acceptance about their final moments on earth, planning a memorial service jointly can be very supportive to both of you.

Things to Remember:

Music-Music affects our feelings and the atmosphere in which we remember our loved one. Select hymns, songs, or other music that are your loved one's favorites, brings comfort or celebrates their life.

Readings-Reflective passages of sacred text, poems, and short stories are all helpful in remembering the person you are celebrating. Some faith traditions may require scripture be read, but many faiths are flexible and will include other types of readings as well.

Symbols of life-Use pictures, items from a person's hobbies, avocations, important moments in life, symbols of accomplishments, or milestones achieved.

Homily, eulogy, meditation-Helps us integrate the music, readings, and symbols with the loved one's life and indicates ways the departed inspired us.

Hospice of the Western Reserve's spiritual care coordinators can assist you in planning a Memorial Service for your loved one and are also available to conduct a memorial service.

PROBATE

The following explanation is information, not legal advice. Hospice of the Western Reserve urges you to consult an attorney for legal needs.

There are two functions of Probate Court:

1. Once a person dies, Probate Court becomes involved to ensure the proper distribution of his/her assets. We advise you to consult with an attorney regarding this process. An attorney can answer any questions related to probating an estate.
2. While a person is alive, Probate Court may become involved if the patient is determined by a physician to be incompetent (medically unable to make decisions on their own due to confusion, etc.). This determination is then ruled on by the court in a lengthy proceeding. A lawyer needs to instruct the family on this process. (Hospice of the Western Reserve volunteer attorneys are not able to provide this service.)

VA BENEFITS

There are specific burial benefits that the patient and family may be entitled to if the patient is an honorably-discharged veteran. It is recommended that all questions regarding entitlements be directed to the Department of Veteran Affairs. **The patient's discharge papers will be needed.**

United States Government
Department of Veterans Affairs
Cleveland Regional Office
1240 East 9th Street
Cleveland, Ohio 44114

Benefits information and assistance: 1.800.827.1000

Veterans of Foreign Wars: 216.522.3510 or
Veterans Service Commission
1849 Prospect Avenue, 2nd Floor
Cleveland, Ohio 44115
216.698.2600
1.800.750.0750 Ohio Relay Service (TTY)

MEDICAID RECIPIENTS

There **may be** financial assistance for burial expenses available through the state. Contact your **Medicaid case worker** for more information.

Helping you feel more confident managing your own symptoms

Your Hospice Team wants you to feel more confident, less anxious during this time. One way is by keeping symptoms managed. Team members will fill out this form and review it with you. Please let the team know any and all questions you have. Refer to this page to guide you through symptom control.

Do you have: _____

If YES, then: _____









Other: _____

If you continue to have _____ after completing the steps above OR you need assistance with anything, please call: _____

Hospice of the Western Reserve Quick Reference

Reaching your hospice team members when you have a need or a question is important. Add the names of your team members are listed below. The team members are available Monday through Friday, 8 a.m. to 4:30 p.m.

The office number is _____

Office location _____

Nurse _____

Social Worker _____

Nursing Assistant _____

Spiritual Care Coordinator _____

Coordinator of Volunteers _____

Team Leader _____

If you have a question or problem after office hours, on a weekend or holiday **call the hospice nurse on-call at:**

You will be given a card with this same information.
Please place it near your telephone so that it is always available.



HOSPICE OF THE WESTERN RESERVE

OUR MISSION

Hospice of the Western Reserve provides palliative and end-of-life care, caregiver support, and bereavement services throughout Northern Ohio.

In celebration of the individual worth of each life, we strive to relieve suffering, enhance comfort, promote quality of life, foster choice in end-of-life care, and support effective grieving.

17876 St. Clair Avenue
Cleveland, OH 44110-2602

Serving Ashtabula, Cuyahoga, Geauga, Lake, Lorain and Summit Counties with offices throughout, and outreach into Medina, Portage and Stark Counties.

Hospice Resale Shop in Lyndhurst

800.707.8922 | hospicewr.org

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