

HOSPICE OF THE WESTERN RESERVE



Caregiver Guide

Introduction

Patient Care

Reference

Bereavement

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Mission

Hospice of the Western Reserve provides palliative 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

In recent years there has been a substantial growth in the number of patient/family units receiving hospice care in our communities. With this kind of care, there are many great benefits.

The staff at Hospice of the Western Reserve created the Caregiver Guide to assist the caregiver in understanding hospice care, and learning what the benefits are in electing hospice care. Our goal is to provide you with an immediate source of information that will answer many of the questions you might have, as the patient goes through the life-limiting process.

The focus of hospice care is comfort. The hospice staff works to: manage pain and symptoms, provide emotional support, and assist in supporting spiritual care needs. The patient and caregiver determine the focus of hospice care with help from the hospice team. Hospice staff meets the patient and caregiver where they are and moves with them through the journey.

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 something more is needed. The real work of hospice is being physically and emotionally present with the patient through the trials and joys.

Hospice care is provided to seriously ill persons throughout the world. There are over 3,000 programs in the United States. Hospice of the Western Reserve has served seriously ill persons in Northern Ohio for over 25 years. It is Ohio's largest hospice and operates as an independent, non-profit, community-based hospice.

We realize that patients and families have choices when arranging for care. Hospice of the Western Reserve thanks you for choosing us as your provider of hospice services. We are honored to be entrusted by you. Your feedback is important and assists us in improving our services. Hospice of the Western Reserve asks for your comments and questions, whatever they may be. Please bring to our attention any concern you may have so that improvements or corrections can be made as quickly as possible.

Getting Started with Hospice

Referrals for hospice care may come from any of the following:

- Doctor
- Nurse
- Social Worker
- Family or friend
- Patient
- Clergy

To start the process of admission into hospice care, call: **216.383.3700** or **800.707.8921**.

Where can hospice care be provided?

- In a private home
- Group home
- Nursing facility
- Hospice House
- Hospital
- Assisted living
- Anywhere the person lives

Does a patient have to accept hospice care?

No. Hospice care is a choice with consent given voluntarily by the patient or their designated representative.

Do I keep my own doctor?

Yes. Hospice of the Western Reserve works directly with the patient's doctor.

What happens if I move away from Cleveland?

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

If I no longer want or need hospice services, what happens?

We will always honor the patient/family wishes 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 with the patient the need to be discharged. 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 for the patient when needed.

Hospice Services in a Long-Term Care Facility

People living in long-term care homes may receive hospice care. Long-term care facilities include nursing homes, assisted living facilities or group homes. 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 homes in the Northeast Ohio area.

Hospice care enhances the care provided by a nursing facility staff. If the patient is eligible for a hospice benefit through their 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 you locate a facility that works in collaboration with Hospice of the Western Reserve.

The Hospice Team Members

Hospice services are brought to you by a group of people...the team. You, your physician and your caregivers are also vital members of the team. This team decides on the plan of care which is reviewed regularly. Each team member has a role:

Primary physician:

Your primary physician works closely with the team. Your doctor reviews the plan of care and is responsible for the continued medical management.

Hospice physician:

The hospice physician works with the staff and the patient's regular physician. The hospice physician is a resource for information regarding hospice medical care and reviews each case at regular intervals.

Hospice nurse:

The patient and caregiver can expect the nurse to teach the caregiver how to care for the patient. This includes instruction on medications, moving a patient, skin care, etc. The nurse also keeps the doctor updated on the patient's condition. You can expect to see the nurse at least once a week or more often as needed.

Social worker:

A serious illness involves much more than medical problems. Dealing with an illness includes understanding what is happening within the patient/family unit. The social worker is someone who is available for counseling and with whom you can share your feelings about these issues. He or she is also there to help you with exploring care options, legal and financial issues and can identify community resources for further assistance.

Nursing assistant:

The nursing assistant is available to provide bathing, shampoos and other types of personal care to the patient. The frequency of visits is based on the needs of the patient and family.

Spiritual care coordinator:

Spiritual care is non-judgmental support for patients and families dealing with the meaning and value of life and relationships. For those who confront spiritual and religious issues, our task is to provide support and guidance on this final journey. To do so, we must establish a trusting relationship full of love, kindness, hope, and strength. Spiritual care staff work in conjunction with the patient's clergy and faith system.

Expressive therapists:

The expressive therapist uses the tools and methods of art and music to help the patient and caregiver understand and express their feelings, as well as provide pain management. They also assist the patient and caregiver in life review and with the creation of legacies.

Masso therapist:

The masso therapist works with the hospice team to integrate massage therapy into the

patient's plan of care. Massotherapy promotes comfort and relaxation.

Bereavement coordinator:

The bereavement coordinator provides grief support and counseling that extends to family members 13 months after the patient's death. Individual and group support is offered as well as a newsletter, memorial services, and specialized programs.

Coordinator of volunteers:

The coordinator of volunteers helps identify areas in the lives of patients and families where our volunteer staff can offer assistance. Thoughtful consideration is given to assigning just the right volunteer in response to each individual request. A coordinator of volunteers is always available to explore with patients and families how they can benefit by having their own specially-trained hospice volunteer.

Pharmacist:

The pharmacist works collaboratively with the hospice nurses, physicians and other team members to assure an individualized medication regimen for each patient. The goal is to assist with selection of medication to relieve pain and symptoms with minimal side effects and maximum relief.

Dietician:

The dietician is responsible for all aspects of nutritional services to patients at Hospice House. In addition, the dietician serves as a clinical resource to the clinical teams to provide suggestions on the nutritional plan of care. The dietician attends team meetings and assists in educational endeavors that improve staff knowledge level as related to nutritional care at end of life.

Volunteer Services

Hospice of the Western Reserve trains men, women and teens interested in caring for others. Each volunteer is unique in their interests, skills, life experience and talents. Volunteers receive extensive training and are individually evaluated. The team will discuss the use of a volunteer with you before asking a volunteer to join the team.

Volunteers can:

- Provide breaks (respite) so that the caregiver may leave for short intervals
- Provide companionship
- Conduct limited hands-on care
- Provide spiritual care support
- Provide bereavement support
- Provide vigil support
- Assist with office duties and phone support

Special needs for which volunteers can be requested:

- Once a month: light housekeeping, yardwork, shopping, meal preparation for freezer
- Legal assistance for patients who are financially unable to pay
- Beautician services (limited basis)
- Provide massage therapy and reiki

Keep in mind that volunteers may only remind the patient to take his or her medication.

Our volunteers help in other ways too.**You will see them:**

- Providing care at Hospice House
- Working at the reception desk
- Visiting hospice patients in nursing facilities
- Performing office work
- Gardening and maintaining the Hospice House grounds

If you think you might use the services of a volunteer, discuss this need with your team nurse or social worker.

Spiritual Care

Spirituality is central to what makes us human. In recognizing that we are much more than physical beings, Hospice of the Western Reserve provides spiritual care in a non-judgmental manner through the use of professional spiritual care coordinator and trained spiritual care volunteers.

A spiritual care coordinator can:

- Assist with the exploration of the relationship with oneself, others, God, a higher power, and nature
- Help the patient and family work through anxiety, fear, pain, frustration and confusion
- Act as a companion to patient and family on the journey towards death
- Explore the meaning and sense of being connected with life and death
- Assist the patient and family with the preparation of funeral or memorial services

Spiritual care is useful as a means of increasing the patient's physical comfort. The following signs and symptoms may indicate a need for spiritual support:

- Sleeplessness
- Substance abuse
- Acting out
- Displacement
- Anger
- Anxiety
- Projection
- Depression
- Over sleeping
- Mood changes
- Fear of dying

Palliative Care

This program offers comprehensive symptom management for individuals in the community who have a life-limiting illness who may not meet the criteria of hospice care or who do not elect to have hospice care. The team is composed of advance practice nurses, registered nurses, physicians and spiritual care. Other members of the transdisciplinary team are resourced as necessary to meet the physical, emotional and spiritual needs of the patient and family. Referrals to Palliative Care are made through the referral office.

Patient Travel Information

Hospice of the Western Reserve understands that there are occasions where you 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 to provide care at your destination of travel. **Please notify your hospice team as soon as possible, at least 5 business days prior to your travel.** We will need time to contact a hospice and make arrangements for your access to hospice care.

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

If your health status changes during the time you are away and you require in-patient care, we will recommend that you transfer your hospice care to the hospice provider in your area of travel.

If you have any questions regarding traveling, please consult your hospice team.

On-call Service


Oftentimes, questions, concerns, and problems occur during the night or on weekends. We encourage you to use the on-call service when these needs arise. A nurse is always available through the on-call service.

The on-call service number for Hospice of the Western Reserve is on the card you have placed near your telephone, similar to the example below.

Our answering service will answer your call. Give them the patient's name and the reason for your call. The on-call nurse will be notified and return your call. Please **do not** use your telephone while awaiting this return call! All calls are returned within 15 to 20 minutes. If your call is not returned in 15 to 20 minutes, please call again.

If there is a change in the patient's condition or a medical emergency **call Hospice first.**

We request that you **do not** call 911.

 HOSPICE OF THE WESTERN RESERVE	COMMUNICATION CARD
Primary Site: _____ Monday thru Friday 8:00 a.m. - 4:30 p.m. Office #: _____ Toll Free #: _____	PRIMARY TEAM MEMBERS NURSE: _____ SOCIAL WORKER: _____ NURSING ASSISTANT: _____ SPIRITUAL CARE: _____ PHYSICIAN: _____ PHARMACY: _____ OTHERS: _____ _____
After 4:30 p.m., weekends and holidays: 440.942.6699 800.665.2619	
Headquarters & Hospice House: Monday thru Friday 8:00 a.m. - 4:30 p.m. 216.383.2222 800.707.8922	
Emergency Number if unable to reach your team: 216.383.1750	
<small>196-250 (11/10)</small>	hospicewr.org

Suffering

Matters of the heart and mind can cause pain and discomfort. At Hospice of the Western Reserve, we will take into account your personal, cultural and/or ethnic beliefs. Psychosocial and spiritual care is provided to you and your family to help you cope with loss, changes in relationships, exploring meaning and values.

In helping to care for your loved one, the hospice team focuses on matters of the heart as well as changes in the physical body.

Suffering can be present when changes are experienced in any of the following areas:

Physical

- Pain and symptom management

Spiritual

- Fear about the unknown
- Internal distress
- Faith concerns
- Meaning and purpose

Personal

- Change in roles and responsibilities
- Unresolved relationship issues
- Loss of enjoyment
- Unfinished business
- Other losses

Family

- Relationship stress
- Concern for loved ones
- Financial worries

What can be done:

- Listen to your loved one's concerns
- Make time to be present. Just sitting with your loved one can provide comfort
- Share your concerns with the team
- Seek out other support systems such as friends, faith based community, professionals
- Use the entire Hospice of the Western Reserve team to help relieve suffering (Spiritual Care, Art or Music Therapy)
- Refer to "Pain Management" (page 8)

Patient and Caregiver Pain Education

In keeping with Hospice of the Western Reserve's mission, we will make every effort to relieve your suffering, improve your comfort, promote your quality of life and choice in end-of-life care. Managing your pain is most important to us. Pain is whatever you say it is, existing whenever you say it does.

- Your reports of pain will be believed
- Education about pain and pain relief measures
- A concerned team committed to pain prevention and management
- A concerned team that responds quickly to reports of pain
- Effective pain management
- You and your family will be included in the plan of care

DO:

- Ask the team about what to expect regarding pain and pain management
- Discuss pain relief options with your team
- Work with your team to develop a pain management plan
- Report pain when it first begins
- Report any problems you think the pain medications may be causing, as there are probably ways to make these better
- Tell your team if you are having any difficulty getting your medications or concerns about taking them
- Report feeling of anxiety

When to call Hospice:

- Experience an increase in your pain
- Experience a new pain or discomfort
- Experience no relief in pain
- Experience side effects, which may include constipation, drowsiness and/or nausea
- Have any questions regarding pain management
- See a rapid decline or change in patient

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. The hospice team will continually evaluate pain symptoms for each patient.

What can be done:

- Try to describe the pain. Use words like:
 - Sharp
 - Shooting
 - Dull
 - Burning
 - Constant
 - Squeezing
 - Aching
- Try to rate the pain
 - “0” (zero) is no pain
 - “10” is the worst pain
- Relaxation techniques (see page 20)
- Distraction can be very helpful
 - Watch a movie
 - Visit with family or friends
 - Play a game
- Soak in a tub, if able
- Hot or Cold Packs
- Music
- Guided imagery
- Touch, light massage
- Look for signs of discomfort for patients who cannot speak
 - Moaning
 - Restlessness
 - Tears
 - Frowning
 - Tenseness

When to call Hospice:

- New pain
- More pain
- Unbearable pain
- Need for more pain medicine in a day than usual
- If unable to take pain medicine for any reason
- When there are signs of discomfort for patients who cannot speak
- Any questions or concerns
- No bowel movement for 2 days

Medications

Medications come in different forms, including: pills, liquids, inhalants, patches suppositories

and ointments. Medications may be changed into different forms depending on the need, such as difficulty swallowing.

DO:

- Read the label before taking the medicine
- Take medicine exactly as it is written on the prescription or as ordered by the physician
- Take routine medication on a regular schedule
- Use “break-through” or “in-between” medicine as ordered and instructed by the hospice nurse and physician
- Call the hospice nurse if the medicine does not seem to be working
- Keep a written schedule and record when and how often medication is being taken
- Avoid alcoholic beverages while taking your medicine. Consult the hospice nurse with any questions
- Call the hospice nurse if there are questions regarding the dosage and or medication changes
- 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 hospice nurse
- Take more than the amount of medicine that is ordered

Helpful Hints:

- To ease swallowing pills, moisten the 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.

Comfort Kit

If a comfort kit is placed in the home, keep it closed and in a safe place. The hospice nurse will provide directions and instructions on its use when the time is appropriate.

- ★ **Keep the comfort kit sealed and in a safe place until notified by the hospice nurse**

Medication record and schedule

Place medication record and schedule into the plastic bag provided by the Hospice of the Western Reserve nurse. Place the bag by the refrigerator with the Hospice of the Western Reserve magnet. Keep the DNR card in this bag.

Medication Disposal:

- Remove any personal information from the medicine label (peel label off, crossing off with a permanent black marker)
- If suppository form – cut up
- Ointments or creams – eject remainder into a bag, can or container
- Patches – put on gloves and cut up and place in opaque bag
- Injectables – withdraw remainder and inject into a bag, can or container
- Syringes – eject remainder into a bag, can or container
- Liquid – pour into a bag, can or container
- Oral tablets – add liquid to dissolve (see below)
- 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 to be wasted
- Add water to dissolve pill or tablet dosage forms. Allow some time for the dissolving process to begin
- Add used coffee grounds, kitty litter, or flour to the bag/can/container to render the mixture undesirable and unusable

- Place in a trash receptacle, preferably inside an opaque 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.

12/2/08: revised version of Hospice of the Western Reserve Medications: Disposal of Medications Practice

Management of Controlled Substances

Controlled substances are specific medications deemed by legal authorities to have a greater need for careful and precise accountability due to their inherit properties as well as increased societal diversion and abuse issues. Examples of controlled substances include many pain medications like morphine, some anxiety medications like Ativan® (lorazepam), central nervous system stimulants like Ritalin® (methylphenidate), and some medications to promote sleep like Restoril® (temazepam). 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. The following is information to promote the careful management/use of controlled substances as well as the proper disposal of controlled substances:

- Use only as directed and educated by your hospice team. Using less than ordered may provide poor management of your symptoms while using more than ordered may lead to serious adverse effects
- Contact your hospice team if you experience any side effects, continue to have symptoms, or if you have any further questions
- Do not share medications with any other people
- Do not cut, open, crush, or otherwise alter the medication unless instructed to by the nurse

- Make sure your hospice nurse knows all the medications you are taking, including over-the-counter, herbal, experimental, or alternative medications
- Any suspected diversion/misuse will be investigated and discussed with your hospice team. A specific plan of care will be put into place to address any issues – examples include ordering a smaller amount of medications, pill counts with each visit, or changing to another medication
- Store your medications in a safe place where accountability is thoroughly maintained and is out of the reach of any children or pets

Disposal of Controlled Substances

- See Medication Disposal (page 9)

When to call Hospice:

Call the hospice nurse or physician with any questions regarding your medication

- Any side effects
- If medications are running low (less than a 2-day supply)

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 you work through any side effects you may have.

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, the patient should 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. If the patient gets uncomfortable or hasn't had a bowel movement in three days, call your hospice nurse.

Nausea

When the patient starts a new pain medicine, there may be a day or two of nausea. Call the hospice nurse who will arrange for some medicine to help the patient during these early days. **Do Not** stop taking the pain medicine without speaking to the hospice nurse first.

Constipation

Constipation occurs when bowel movements become less frequent, resulting in hard, dry stools. As a result it becomes difficult to have a bowel movement. Frequently this is accompanied with abdominal discomfort. Causes of constipation can be from the use of pain medications, not eating or drinking as much, a change in diet, weakening physical condition, and less physical activity.

What can be done:

- Drink as much fluid as is comfortable
- Warm liquids can benefit, such as warm prune juice
- Eat more fruits and fruit juices
- Increase physical activity if possible
- When possible, establish routine times for toileting
- Sit upright on the toilet or commode
- If using a bedpan, stay in a sitting position
- Take laxative or stool softeners if prescribed and instructed by the hospice team and doctor
- Ask the hospice nurse before starting a bowel stimulant or stool softener medication

When to call Hospice:

- No bowel movement in two days
- Abdominal pain or cramping
- Nausea and or vomiting
- Blood in stools

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.

What can be done:

- Switch diet to clear liquids (liquids that you can see through when in a glass)
Examples: water, broth, ginger ale
- Keep rectal area clean and dry using mild soap and water
- **Do not** take anti-diarrhea medication unless instructed by a hospice nurse
- If diarrhea has stopped for 8 to 12 hours: try dry toast, dry crackers, bananas, rice and clear liquids. Avoid:
 - large meals
 - very hot or cold foods
 - milk or dairy products like cheese or ice cream
 - spicy or fatty foods
 - caffeine, alcohol and tobacco
 - fresh fruit, raw vegetables or popcorn

When to call Hospice:

- Diarrhea continues
- Light-headedness
- Fever
- Unable to urinate
- Diarrhea or oozing of stools

Caring for a Catheter

A catheter is a tube that is inserted into the bladder. 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:

- Observe 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
- 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 penis is uncircumcised, gently pull back the foreskin before cleaning and replace it afterward
- If the patient is pulling on the catheter, put on an adult diaper
- When turning from side to side, move the drainage bag from side to side
- Irrigate the catheter if the nurse has instructed

How to irrigate the catheter:

- Gather the irrigation kit, sterile water, gloves, a clean towel, or underpad and an alcohol wipe before starting.
- Wash your hands, put on gloves, and pour the water into the provided container (comes with the syringe).
- Place the underpad under the section of tubing that will be disconnected. This protects the bed and the patient from getting wet.
- Disconnect the tubing, keeping both sections clean (the nurse will show you how). Wipe the tubing end with the alcohol wipe. Try not to touch these end pieces.
- Using a syringe filled with sterile water, secure the syringe tip inside the tubing that is connected to the patient. Depress the bulb or plunger which will release the water into the catheter. **Do Not** force the water in if you meet resistance.
- Remove the syringe and place the open end of the catheter in the basin and let the water drain out. Keep the catheter from touching the basin. The nurse will tell you if you need to repeat this flushing.
- When done, reconnect the tubing. Check to make sure it is secure.

- Check that the patient is clean, dry and comfortable.
- Dispose of the drainage in the toilet, discard any sterile water you poured out but did not use. Clean the syringe and the water container with hot soapy water, rinse and allow to air dry.

*** You should use a new irrigation kit (syringe, water container, basin) every week. Always throw away the gloves and wash your hands.**

When to call Hospice:

- Catheter is not draining
- Urine has an odor
- Fever

Nutrition

It is normal for the seriously-ill patient to eat and drink very little. The kindest thing we can do is not shame the patient for not eating. There are more important things to share in this final stage of life. How much we care can be shown by respecting the choice the patient has made. 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.

It has been shown that most seriously ill patients do not benefit from artificial fluids or foods. These measures may cause nausea, vomiting, increased congestion, pain and many other problems. Let the patient to take the lead, the body knows best.

DO:

- Eat what you feel like eating or what appeals to you
- Eat when hungry, but do not force yourself to eat
- Eat when pain is decreased
- Try eating more often during the day; 3 to 6 light meals are usually better tolerated
- Eat when less fatigued; rest before eating whenever possible
- Avoid eating when nauseated

- Try small portions
- Take fluids between meals instead of with meals; fluids with meals can make you feel full
- If you do not feel like drinking, try ice chips, Popsicles
- Rinse your mouth, and keep lips moist

Snacks:

- Have preferred snacks readily available

Enhancing meal enjoyment:

- Share meal times
- Set a nice table, add candles or flowers, play music, garnish food to make it more pleasing to the eye
- Use a warm (or 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
- Use herbs, spices, and other seasonings
- Add wine to sauces or meats/fish/poultry near the end of the cooking time to add an interesting and subtle flavor

Changes in Taste & Smell

As a result of some medications, treatments or the progress of illness, foods may taste and smell differently. Foods may not taste and smell as they should or they have little or no taste at all. Either can reduce appetite.

What can be done:

Mouth care:

- Begin each meal or snack with a clean mouth. Brush your teeth and use a mouth rinse. Try brushing your tongue lightly with a soft toothbrush
- Frequently rinse your mouth between meals with cool water, mint-flavored water, tea, or ginger ale
- Chew lemon drops, mints or gum (sugarless unless you have diarrhea) to help eliminate a metallic or bitter taste as well as relieve mouth dryness

If foods taste bitter, metallic, or just not right:

- 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: red meats, tomatoes, coffee, tea, and chocolate
- Eat milder tasting foods
- Marinate meats, chicken, and fish; use orange juice, wine, Italian dressing, sweet & sour sauce, teriyaki sauce
- Add sugar
- Season foods with tart flavors: lemon, lime, other citrus, vinegar, sweet & sour sauce
- Avoid serving foods in metallic containers or with metal utensils; use plastic or glass
- Try freezing and eating fruits: grapes, oranges, cantaloupe, watermelon, berries, and bananas
- Eat fresh vegetables as they may be more appealing than canned or frozen

If foods taste too salty:

- Try adding sugar to help mask a salty flavor. For example, add sugar to soups, tomato sauces, casseroles, salad dressings, gravy

If foods taste too sweet:

- Add a pinch of salt
- Serving foods at cold temperatures decreases their sweet taste

If foods taste too bland:

- Use herbs and seasonings in food preparation
- Experiment with strong flavored foods
- Alternate bites of different tasting foods within a meal. For example, pineapple and cottage cheese, grilled cheese with tomato soup

Guidelines for Boosting Calorie and Nutrient Intake

To boost calories and ensure you are getting the most value out of foods, focus on foods that are “calorie dense” or high in calories. The emphasis should be on foods that are rich

in nutrients, such as protein, vitamins, and minerals as well as calories.

Suggestions for boosting protein

- Add meat, poultry, fish, eggs, cheese or milk to soups, casseroles and potato dishes
- Mix dry powder milk into milk, soup, casseroles, cereal and milk dishes such as custard and pudding
- Add an instant breakfast mix to milk

Suggestions for boosting calories

Butter or margarine

- Add to hot cereals, casseroles, vegetables potatoes, rice, noodles
- Spread on bread, sandwiches, toast, crackers, rolls
- Mix with herbs and spread on meats, poultry, & fish
- Consider a nutrition supplement drink: Ensure, Boost, or Breeze are commercially prepared drinks; another good choice is an instant breakfast type drink. Blend in ice cream, flavored syrups, or fruit for variety

Mayonnaise or salad dressings

- Spread on sandwiches
- Use in egg, chicken, tuna or vegetable salads
- Add to dips and sauces

Sour cream

- Add to any style of cooked potatoes, rice, pasta or vegetables
- Use as a dip for raw vegetables or fruits
- Mix into soups, muffin batter, casseroles, sauces

Half-and-half, cream, or evaporated milk

- Add to milkshakes, hot chocolate, coffee, tea
- Use in place of milk or water in soups, sauces, batters, custards, puddings, mashed potatoes
- Use on cold cereal

Cream cheese

- Spread on fruit slices, vegetables,

- specialty breads, crackers
- Add to gelatin molds
- Use flavored cream cheeses to add variety

Cheeses, cubed & shredded, cottage cheese, ricotta cheese

- Melt or serve cold on bread, toast, taco chips, crackers
- Add to casseroles, mashed potatoes, scrambled eggs, vegetables
- Melt on burgers, hot dogs, meatloaf
- Use for snacks with crackers or fruit

Yogurt

- Select whole milk yogurts
- Custard-style, fruit-on-the-bottom, and cream-style are usually higher in calories
- Mix in gelatin

Brown sugar, maple syrup, honey, jam, jelly

- Use in cooked cereal, on pancakes or waffles, to top biscuits, breads, crackers
- Use as topping for fruit, ice cream
- Use as a glaze on meats and vegetables

Difficulty in Swallowing

When a person has difficulty swallowing, there is increased risk for aspiration (taking food or fluids into the lungs) and choking. By changing the texture of foods and/or thickness of fluids along with focusing upon specific eating techniques, this risk can be decreased.

In general, foods that are easy to chew, moist enough so that they slide down your throat, and are soft and 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.

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. These types of foods should be avoided. Also avoid dry, hard, sticky, limp and fibrous foods, plus 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.

Tips for safer swallowing:

- Eat in a pleasant and relaxing environment; minimize distractions such as TV
- **Do Not** eat alone
- Allow sufficient time for eating, but avoid long mealtimes which may cause fatigue
- Sit up straight (hips at a 90 degree angle)
- Position your head slightly forward with your chin down to prevent food from going down the airway
- Eat slowly; Take only one bite at a time and chew food thoroughly
- If one side of the mouth is stronger, chew on that side
- Keep lips closed during chewing and swallowing
- Concentrate on swallowing. **Do Not** breathe until you have completely swallowed
- Swallow all the food in your mouth before talking
- 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
- Clean the mouth after eating

Tips for preparing food in a blender & enhancing flavor:

- To blend foods, use liquids with flavor such as soup, fruit juice and milk. Other options are gravy, cream sauces, and salad dressing
- Casseroles and mixed dishes can also be blended. If a preparation is too thin, add a commercial thickening agent, mashed potato flakes or baby cereal flakes
- Add one to two tablespoons of fat

such as olive oil, sour cream, mayonnaise, butter or margarine to foods for calories and flavor

- For fiber, vitamins, & minerals, eat fruits (applesauce, bananas, pears, and peaches) and vegetables (green beans, carrots, peas, beets, sweet potatoes) pureed to the safest consistency
- Season food with herbs and spices
- Purchase pureed baby foods for convenience and season to enhance flavor
- Use garnishes to make the pureed food look more attractive. Top entrees with contrasting color sauce

Pureed diet:

- **Breads & Cereals**

Cream of wheat, cream of rice, smooth cereals; gelatin, pureed pasta and rice

- **Eggs**

Pureed scrambled eggs (blend with bread & milk)

- **Milk products**

Milk; smooth yogurt; smooth custard; pudding

- **Fruits**

Pureed fruits (no seeds or skins); juices; applesauce

- **Vegetables**

Pureed vegetables (no seeds or skins); juices

- **Fats**

Gravy; margarine; butter; sauces or broths; cream mixed with pureed fruit

- **Meats & Meat Substitutes**

Pureed, meats or casseroles with gravy or broth to moisten

- **Soups**

Pureed soups

- **Desserts**

Smooth custard and pudding

- **Beverages**

Thicken as needed with commercial thickening agents

- **Sugars & Sweets**

Honey; sugar; syrup; fruit jellies

Tips for preparing thick liquids (to decrease chance of choking)

- Add a commercial thickening agent (powder) to all liquids (juices, soups, coffee, milk, milkshakes, etc.) to bring them to the correct consistency; usually nectar or honey thick.
- Prepare milkshakes in a blender with milk, ice cream, and instant breakfast mix
- Mix soups in a blender with potatoes and vegetables until smooth
- Thicken soups with mashed potato flakes or baby cereal flakes
- Combine pureed fruit and fruit juice to the consistency of nectar
- Thicken liquids with pureed fruits, yogurt, dried infant cereal, yogurt, or pudding
- Blenderize a ripe banana into a milkshake, nutritional supplement, or juice
- Add pudding or custard to milk or yogurt and blenderize

Cookbooks

- *Meals for Easy Swallowing* by Vicki Appel, Sandy Calvin, Gena Smith, Donna Woehr. For copies, contact the Muscular Dystrophy Association, 1.800.572.1717
- *Recipes for Easy Chewing and Safe Swallowing* by Maxine Dereiko. Contact Dereiko-Teutsch and Associates, P.O. Box 8366, Portland, Oregon 97207

Foods to avoid

- Foods that crumble and form pieces: crackers, chips, pretzels, taco shells
- Foods that consist of small pieces: rice, corn peas, popcorn, granola, raisins, beans, nuts
- Foods that can stick to the mouth: peanut butter, cream cheese
- Foods with fibrous parts or seeds: celery, fruits with peels, some whole meats
- Foods that are hard to chew: tough meats, whole raw vegetables, hard fresh fruit, hard breads such as 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

Tips for Lowering Salt Intake

Use less added salt

- **Foods higher in salt:**
Table salt, seasoning salts, soy sauce, BBQ sauce, Worcestershire sauce, bullion
- **Better options:**
Herbs & Spices; for example basil, pepper, thyme or an herb/spice blend like Mrs. Dash

Eat less salty foods

- **Foods higher in salt:**
Salted crackers, chips, popcorn, and pretzels
- **Better options:**
Unsalted crackers, pretzels, popcorn, chips

Eat less cured foods

- **Foods higher in salt:**
Ham, bacon, sausage, smoked or pickled fish, hot dogs, cold cuts, corned beef, koshered meats, anything packed in a brine (pickles, olives, etc.)
- **Better options:**
Fresh meats (beef, pork, veal), poultry & fish including shellfish

Eat less processed foods

- **Foods higher in salt:**
Frozen dinners, instant rice or noodle mixes
- **Better options:**
Regular rice & noodles, lower salt varieties of frozen dinners

Eat less canned foods

- **Foods higher in salt:**
Canned soups, vegetables, fish, vegetable juices
- **Better options:**
Fresh or frozen vegetables. Reduced salt canned soups

High Potassium Foods

If you need to limit your potassium, decrease your intake of the following foods:

Fruits:

- Avocado
- Bananas
- Cantaloupe
- Dried Fruits
- Grapefruit Juice
- Honeydew Melon
- Oranges
- Orange Juice
- Peaches, fresh

Beans:

- Baked Beans
- Black Beans
- Blackeyed Peas
- Butter Beans
- Chick Peas
- Crowder Peas
- Great Northern Beans
- Kidney Beans
- Lentils
- Lima Beans
- Navy Beans
- Pinto Beans
- Split Peas

Vegetables:

- Broccoli
- Collard Greens
- Spinach
- Tomatoes
- Tomato or V-8 Juice
- Tomato Soup

Potatoes:

- Baked White Potato
- Baked Sweet Potato
- French Fries
- Instant Potato Mixes
- Potato Chips
- Restaurant
- Home Fries
- Yams

Other Foods:

- Chocolate
- Molasses
- Nuts

Salt Substitutes:

- Lite Salt
- No Salt
- Salt Sense

Managing Seizures

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

DO:

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

DO NOT:

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

When to call Hospice:

- Seizure is unusual
- Seizure is a new occurrence
- Seizure lasts beyond a few minutes
- Seizure 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.

What can be done:

- Avoid using sharp objects (knives, scissors, razors)
- Make sure sufficient light is available when moving around
- Use an electric shaver
- Drink warm fluids and/or eat fruit to help reduce the likelihood of constipation
- Use soft toothbrush, sponge, or “toothette” to clean teeth
- **Do Not** floss teeth
- Blow nose gently

Avoid:

- Using sharp objects (knives, scissors, razors)
- Flossing teeth
- Bumping against objects—turn lights on
- Becoming constipated

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 pressure if possible and call Hospice**

Edema Fluid Restriction

Fluid Retention

Edema (swelling) may occur if fluid builds up and is retained in various parts of the body, such as legs, ankles, feet and or hands. Sometimes edema will increase if less protein in a diet, lessened physical activity or an increase in salt or sodium intake

DO:

- Raise the affected area, above the heart if possible
- Limit salt intake
- Take diuretic (water pills) as ordered by doctor
- Increase mobility if possible

DO NOT:

- Wear any tight clothing, belts, socks, rings, watches or shoes
- Cross legs or ankles when sitting

*** See nutrition section for tips and specifics of low salt diet suggestions**

Fluid Restriction**General recommendations for counting fluids:**

- Fluids that may need to be calculated into your diet are:

– Alcoholic beverages	– Milk
– Carbonated beverages	– Popsicles
– Coffee	– Sherbet
– Fruit Juice	– Soup
– Gravy	– Tea
– Ice Cream	– Water
– Jello	
- Fluids taken with medication
- Fluids from solid foods: Although some

water is found in all foods, especially fruits and vegetables, this fluid is not usually counted toward your fluid allowance

- You will need a set of standard measuring cups

Nausea and Vomiting

Nausea and vomiting are common abdominal and stomach symptoms that often occur together, but may occur separately. As part of the body's protective measures, they usually happen as a response to chemical, bacterial or viral attacks to the body.

Nausea and vomiting are often associated with movement, treatments (chemo/radiation therapies), medicines, constipation, disease changes, infection, pain and anxiety.

For nausea

DO:

- Reduce anxiety
- Take laxatives as ordered
- Try to remain still, getting lots of rest
- Take anti-nausea medication as directed
- Slowly sip ginger-ale or peppermint tea

DO NOT:

- Eat heavy meals
- Eat fatty foods
- Be around strong odors
- Do any excessive activity
- Lay down after eating

For vomiting

DO:

- Rest
- Rinse mouth thoroughly after vomiting
- Begin to eat slowly after episode
- Take ice chips, popsicle or flavored ice for hydration
- Continue taking clear liquids for 24 hours (Ginger ale, Jello, Gatorade)
- Sip liquids slowly in small amounts
- 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 resuming clear liquids
- Vomit is bright red or dark brown
- Continued constipation
- Unable to swallow

Use of Oxygen

Oxygen is a medication and must be ordered by the doctor. The doctor and the hospice nurse determine when a patient may benefit from the use of oxygen. It is important to know how to use oxygen safely.

Important Safety Reminders

- **Do Not** smoke while using oxygen
- Stay at least 10 feet from any source of sparks (radios, TVs, or other electrical equipment)
- **Do Not** use hair spray or other aerosol sprays while using oxygen
- **Do Not** use or store oxygen near sources of heat
 - Keep room well ventilated
 - Keep candles or other lit objects out of room
 - Have a fire extinguisher available
- **Do Not** use lotions, face creams or any petroleum products (Vaseline) while handling or using oxygen

How is oxygen supplied?

There are 3 ways in which oxygen can be supplied. They are oxygen tank, concentrator or liquid oxygen. The doctor and hospice nurse will determine which method is best for each individual need. The company that provides the oxygen and the hospice nurse will teach you how to use the oxygen equipment.

Oxygen tanks:

- Most common way oxygen is supplied in the home
- Provides approximately 5–6 hours of oxygen
- Used occasionally, or “as needed”



When using an oxygen tank:**DO:**

- Keep tank secured in carrying cart in upright position
- Tanks not currently being used should be stored on their side and away from heat sources
- Keep valve protection cap in place when tank is not being used

**DO NOT:**

- Grab the tank by its valve
- Drop the tank or allow tanks to hit each other

Oxygen concentrators:

- Electrical device that purifies oxygen from room air
- Provides nearly pure oxygen through nose tube (cannula) or mask
- May use a humidifier bottle attached to concentrator to filter the room air
- Has alarm that 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 3 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

Liquid oxygen:

- Contained in large tanks under low pressure
- Usually used for people needing a higher liter flow of oxygen on a 24 hour basis
- Administered through oxygen tubing either with nasal cannula or facial mask

How will I know how much oxygen to use?

- Known as liter flow
- Doctor prescribes liter flow to meet physical needs
- A flow meter is on all 3 types of oxygen equipment with numbers on it, usually ranging from 1 to 5
- A flow meter knob, or valve, is used to set prescribed liter flow

*** Do Not change liter flow without checking with hospice nurse first**

Oxygen tubing**Helpful hints:**

- Clear tubing attached to oxygen tanks/ concentrator which provides way for oxygen to travel from equipment to the patient, either through a cannula, or facial mask
- Tubing is routinely changed every 3 months, along with humidifier bottle, cannula and/or mask and as needed
- Replace tubing if it becomes blocked or kinked

Using Nasal Cannula/Face Mask**Helpful hints:**

- Face mask is easily put over nose and mouth area. It is held in place with elastic band around the back of the head with an adjustable band over bridge of nose
- Nasal cannula has 2 prongs that go gently into the nose. Make sure prongs are curved downwards; bring tubing around each ear to help hold the prongs securely

- Replace nasal cannula/mask if it becomes discolored or cracked
- Irritation may occur when using nasal cannula, and can usually be relieved by putting water-based lubricants, such as K-Y Jelly around nasal passages
- **Do Not** use Vaseline to moisten nasal passages!
- If tubing causes ear soreness, pad tubing with cotton or gauze around ear area

When should I call the oxygen provider?

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

What should I do If electricity goes out?

- Since oxygen concentrators use electricity, the oxygen company provides at least 2 tanks for security and in case of power outage
- If electrical power should stop, **Do Not** panic. Use oxygen tanks provided for continual oxygen usage
- 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

Shortness of breath is an uncomfortable feeling. This feeling experienced in varying degrees by many patients is frightening and causes a lot of concern and anxiety. Shortness of breath may have several causes including the disease process, feelings of distress, or fatigue. There are a number of things the hospice team can do to relieve this distress.

What can be done:

- Try to stay calm
- Soft music or keep room quiet
- Prop head up in bed/chair
- Cool cloth to face
- Massage
- Try to relax

- Breathe slowly in through nose, out through mouth
- Conserve physical energy – pace activity and sit whenever possible
- Take medication as instructed
- Open a window or use fan to create movement of air
- If oxygen has been ordered be sure that it is on

When to call Hospice:

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

Relaxation

Everyone deserves some time every day to take care of his or her physical and mental health. Everyone has his or her own way to relax. Here is a simple guide for self-relaxation. By following these simple steps, the ability to manage stress and improve breathing will increase.

- Find a place free of distraction
- Tell family members not to disturb or interrupt you
- 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 if sleep occurs. In fact, this technique may be used to assist in falling 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 person may not be able to do everyday tasks and is only comfortable when in bed. They will need help with personal care, moving and transferring in the bed, eating/drinking and will need added skin protection due to decrease mobility.

What can be done:

- **Hospital bed:**
 - May be helpful for both the patient and caregiver. A hospital bed can be useful in providing comfort as the head and the feet of the bed are adjustable. Its height is also adjustable making care easier for the caregiver
- **Using a hospital bed:**
 - Make sure the brakes are locked at all times, except if wanting to move the bed
 - Raise the bed to waist height when providing care, this will help prevent back injuries
 - Always put the bed in the lowest position when assisting and/or getting out of bed.
 - **Do Not** allow children to play on or with the bed.

Why is protecting the skin more important at this time?

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). At times a special mattress is applied to the bed and can help in skin protection. The hospice nurse will determine if this is a good option in each individual situation.

Types of special mattresses:

- **Egg Crate Mattress Pad** is a foam pad that goes over a mattress, which can be easily cleaned with soap and water
 - When using an egg crate mattress pad make sure the pointed ends are

up and use a twin fitted or flat sheet over the pad for stability on top of the mattress

- **Air Mattress** is an overlay that electrically pumps air into and inflates the mattress
 - When using an air mattress use a twin fitted or flat sheet over the pad for stability
 - Never use pins on the sheets
 - Place the air pump in a safe location under the bed or at the foot of the bed
 - Check the air mattress daily to make sure pressure is maintained

Positioning in bed:

- 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 on the closest shoulder
- 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
- Adjust head pillow for comfort
- Provide blankets for warmth if needed
- It may be necessary to give a dose of pain medication before moving the patient
- It is not unusual for a bed bound patient to moan during the turning, THIS SHOULD NOT CONTINUE

ONCE A COMFORTABLE POSITION IS ACHIEVED

What can be done if a patient can no longer help in turning?

- **Lift Sheet** is a flat sheet or extra large towel that can be placed under the patient and is used in moving without pulling on the patient's body. Your hospice nurse and/or hospice nursing assistant will instruct on the placing and use of a lift sheet, if needed



Changing bed sheets with the patient in the bed:

- 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
- Remove dirty sheet and roll 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 dirty sheet
- Pull out the dirty 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

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

Using a bedpan

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

Assistance out of bed to chair

Remember to take care of your back when assisting patient out of bed.

- Bend your knees
- Keep your back straight
- Move slowly
- Have chair placed in position at the head of bed, facing the foot of the bed before beginning (close, so movement from bed to chair is done in one step)



- If transferring to a wheelchair be sure brakes are locked before moving patient
- Bring 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 their arms and have them place their arms on your shoulders
- Hug patient gently while raising off the bed and gently pivot from bed toward chair
- Lower patient to the chair, bend your knees and keep back straight when doing this

Assisting from sitting to standing position

- Assist patient to move to edge of bed or chair
- Stand directly in front of them with feet shoulder width apart



- Reach under their arms and have them place their arms on your shoulders, bend your knees
- Hug patient gently while raising the patient to standing position, allow them to pull on your shoulders for stability.
- **Do Not** let go until you are sure patient is stable in standing

Walking assistance

Before walking:

- Allow patient to stand for a few seconds to get good balance and reduce dizziness
- Support by placing one arm around the

- waist or holding their clothes at the waist
- Walk with them by their side
- If oxygen is in use, tubing should be held to the side away from feet
- Move at the pace the patient does
- Look for signs for needed rest, (shortness of breath, moving unsteadily)

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

Helpful hints for use of walkers, canes and wheelchairs

- **Do Not** use walker or cane alone until shown how to use properly
- If walking is unsteady a walker or cane should not be used without some assistance during walking
- Clean with soap and water when dirty, make sure it is towel dried before using again
- Using a pad or pillowcase on the seat of the wheelchair can help in keeping seat of chair clean

Using a shower chair or bath bench

Shower chair or bath benches are used for safety in the bathtub during bathing, because weakness may prevent standing when showering or difficulty getting into a tub.

Helpful hints when using a shower chair or bath bench:

- Never use shower chair or bath bench when alone
- Remove all throw rugs from the bathroom for added safety
- Make sure chair or bench are secured in the tub and dry before getting onto equipment to reduce slipping



When to call Hospice:

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

Skin Care

Skin care is important during illness. Keeping the skin clean, moisturized, with frequent position changes are the basic ideas to keep in mind.

Ways to protect the skin:

- After bathing make sure all soap is rinsed off completely and the skin is dried thoroughly
- Every 4 hours turn and reposition to prevent skin breakdown
- Lotions applied to the skin can keep skin soft and decrease possibility of cracking

What can be done:

- Keep the skin clean and dry
- Bathe patient 2–3 times per week, or once a week if skin is very dry
- Use moisturizing soaps, like Dove and Tone
- Apply lotion
- Inspect the skin regularly for any areas that might be at risk

Helpful hints for giving a bed bath:

- A warm room, free of drafts, is most comfortable
- Gather all supplies before beginning:
 - basin(s) – if 2 are available, use one to wash and one to rinse
 - soap
 - washcloths, towels
 - gloves
 - lotion
 - clean gown or pajamas
- Fill basin(s) with warm water
- Apply very little soap
- Wash, rinse, and dry one area at a time. (face, ears, neck, shoulder, chest, arms, back, buttocks)

- Change the water and continue. (legs, feet, abdomen, and private parts)
- Apply lotion after bath

When to call Hospice:

- If any reddened areas appear that don't go away after several hours
- Any areas that are open or bleeding

Mouth Care

Regular mouth care helps maintain comfort. It 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.

What can be done:

- Cleanse the mouth and teeth two or more times per day
- It is recommended to sit during mouth care, but if unable lay to one side
- Brush teeth with tooth-paste and soft tooth brush (use toothette moistened with mouthwash for those with only a few teeth)
- Check mouth closely for redness or white patches
- Keep lips moist with water based lubricant such as KY Jelly, **Do Not** use 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 them

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

Infection Control and Communicable Diseases in the Home

Infection control promotes a safe, clean and comfortable environment which prevents the start or spread of infection. This is done by using a few basic steps.

Handwashing

Handwashing is the single most important step in the prevention of any infection. Wash your hands with liquid soap and warm water for 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.

DO:

- Wash your hands before and after:
 - Giving care to the patient
 - Using gloves
 - Using the bathroom
 - Eating or smoking
 - Contact with any body fluids

Alcohol-Based Hand Sanitizer

- These may be used when hands are not visibly soiled. They may be kept at the bedside for use when a sink isn't close to the patient care area. Apply the product to palm of hand (a small amount). Rub hands together covering all surfaces of hands and fingers until dry
- Only use before using gloves, after touching patient's intact skin or patient items, and on patient's hands prior to the patient eating or drinking

Helpful hints:

- Alcohol-based hand sanitizer can be purchased at drug stores and department stores

Precautions

- Disposable gloves are used by

caregivers when in contact with patient's body fluids (blood, urine, stool, wound drainage). Remove gloves and dispose of in trash immediately after use. Wash hands

- Place trash soiled with blood or body fluids in a leak-proof plastic bag and place in garbage/trash container for pick up
- Clean any body fluid spills as soon as possible (urine, blood, vomit, stool)
- 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
- Air out room when possible
- If needles, syringes, razors and other sharp objects are used by the patient, place them in the red container. Keep these sharp items and container out of the reach of children
- 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 their duties until they are well again. If this isn't possible, use good handwashing, gloves, and a disposable surgical mask to protect the patient until they are well again
- Request advice from your home care nurse about further precautions to take

Tuberculosis (TB)

Tuberculosis is a disease that is spread from person to person through the air by coughing, sneezing, singing and talking. Signs and symptoms of TB include fever, chills, night sweats, persistent cough (greater than 2 weeks), coughing up blood, weight loss and loss of appetite.

Precautions for the patient and caregiver include:

- The patient must:
 - have his/her own room and remain in the room until the doctor states he/she is no longer infectious

- cough or sneeze into a tissue with his/her head turned away from others
- take all medicine as directed for as long as directed
- wear a mask when others are in the room. If the patient leaves the room for any reason the mask must be worn
- The door to the room must remain closed
- Dispose of tissues in a plastic lined personal trash container. The plastic bag is placed inside another plastic bag before disposing in the trash
- Improve air flow in the room by keeping the window open with a fan circulating to the outside. Make sure the door has a one inch clearance with the floor
- Limit the time visitors are in the patients room to avoid exposure. They should remain at least three feet away from the patient
- Report any signs and symptoms to your doctor if you develop them
- Have a TB test done every three months while caring for a patient with TB
- If your TB test is positive take preventative medicine prescribed by your doctor

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 1 to 4 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.

Flu: Precautions:

- Get a flu shot in October or November. It is more important for the caregiver and family members of the patient to get a flu shot than the patient. 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 you the flu. It takes 2–3 weeks for your 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.

- Handwashing is very important in preventing the flu and other respiratory viruses.
- Flu is a serious disease. Flu shots work and do not cause the flu.

Hepatitis B

Hepatitis B is a disease caused by a virus which infects the liver. It is spread through blood or other body fluids by needle sticks, splashes of fluids in the eyes or mouth, or through sexual contact. Symptoms include yellow skin and eyes, dark urine, clay-colored stool, nausea, vomiting, and flu-like illness.

Precautions for the caregiver include:

- Use care with any sharp items during patient care (examples: razors, needles, lancets for finger sticks)
- Hepatitis B vaccine is available and recommended for anyone at risk
- Dispose of sharp items in the red container
- Use disposable gloves when in contact with patient’s body fluids
- Do not share personal items of the patients

Shingles

Shingles is caused by the same virus that causes chicken pox. After recovering from chicken pox, the virus lives on in the body. It 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 3 to 5 weeks they are no longer contagious.

Precautions for the caregiver include:

- If you have not had chicken pox you should not provide the care to the patient until you have received the chicken pox vaccine. Check with your doctor immediately.
- If they have not had chicken pox, ask them to wait until the patient is not contagious before the visit.

AIDS

AIDS is a disease caused by the HIV (Human Immunodeficiency Virus) virus. HIV is spread through blood, semen, vaginal secretions and other body fluids from infected persons by needle sticks, splashes of body fluid to eyes or mouth, use of contaminated needles and through sexual contact.

HIV is not spread through everyday contact such as toilets, clothing, phones, cups, plates, silverware or food prepared by an infected person. People don't get infected from sweat, saliva, tears or kisses. Bug bites don't give people HIV.

Symptoms at the start of the disease are flu-like. Infected persons then may live for several months to years without any symptoms. The virus lives in the body and is contagious during this time also.

Precautions for the patient and caregiver include:

- Use care with any sharp items during patient care (examples: razors, needles, lancets for finger sticks)
- **Do Not** share personal items of the patients
- Dispose of sharp items in the red container
- Use latex condoms to prevent the spread of the HIV virus through sexual contact
- Use disposable gloves when in contact with patient's body fluids

*** If you have any questions about infection control or contagious diseases please contact your home care nurse.**

Caregiver Needs

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 these feelings may affect your life and well-being.

Rewards of caregiving:

- Participation in care
- Inner sense of peace
- Times of laughter and humor
- Times of joy
- Intimacy
- Completing unfinished business
- Making memories
- Feeling appreciated
- Self-worth

Common concerns:

- Fatigue
- Fear of unknown
- Being overwhelmed
- Loss of control
- Loss of activities
- Financial worries
- Social isolation
- Emotional challenges
- Feelings of obligation
- Difficulty making plans

Helpful hints:

- Be aware of your feelings
- Remember that you are not alone
- Take care of yourself (rest, sleep, eat)
- Ask for help
- Know your limits
- Give yourself permission to say no
- Let the hospice team help you
- Seek support of others
- Utilize "Respite Care"

Final Days

The staff of Hospice of the Western Reserve supports you in caring for your loved one during the final stages of life's journey. Everyone's life is unique and so is everyone's journey toward death. We realize that this is a difficult time because people may not know what to expect. We hope this information will help you to be more informed and prepared. Even though you may be well informed, it is natural to be 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. There is much interior work to be done. This is not a withdrawal of love, but a need to focus energy inward. Your presence is very important.

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. Your hospice team will help you identify these changes and support you through this difficult time. We hope that this information will help you to be more informed and prepared. You have undertaken the most precious service by caring for a loved one.

When to call Hospice:

- **Decreased need for food and drink & difficulty in swallowing**

The patient will have decreased need for food and drink because the body functions are slowing down gradually. There may be difficulty in swallowing. The mouth may become dry and will need to be kept moist. The person will not experience hunger. The body has its own wisdom and knows what it needs.

- **Sleeping/difficult to arouse**

The patient will gradually spend more time sleeping during the day and at times will be difficult to arouse. This symptom 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/confusion**

It is common for a person to become restless and pull at the bed linen. 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 the side rails up for safety.

- **Visions**

The patient may have visions of people and things you cannot see. Visions are not necessarily frightening and are often comforting.

- **Seizure-like movements**

The patient may make some movements with arms, chest or face in the last few minutes of death, which are a part of the body's shutdown process. These are not to be considered seizures or seizure activity.

- **Unusual eye movement**

The patient's eyes may move unusually.

- **Foaming or orally expelling fluid**

The patient may foam at the mouth or orally expel fluid.

- **Incontinence/decrease in the amount of urine/darker urine color**

Incontinence (loss of control) of urine and bowel movements may become a problem. Your 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**

The patient may have moist-sounding breathing. This 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.

- **Change of hearing and vision**

Clarity of hearing and vision may change. Keep some soft light on in the room. Assume that the person can hear, since hearing is thought to be the last of the senses to diminish. Explain what you are doing.

- **Cooler body temperature/fevers**

The patient's arms and legs may 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**

You may notice a change in breathing patterns. There may be 10-30 second periods of no breathing. This is referred to as periods of apnea. This symptom is very common and may occur in the final stages of life.

- **Unable to respond to touch or voice**

Most of the time the patient will be unable to respond to touch or voice. Assume that the sense of hearing remains. Speak in a comforting voice.

- **Pain and discomfort may diminish**

Pain and discomfort may diminish as death approaches but continue to give medications as directed by the nurse.

- ★ **At the time of death, call hospice.**

Patient & 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 his/her 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 440.942.6699 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 their 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 their 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 he/she is not satisfied with his/her care or feel he/she has been discriminated against. They may 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.

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. Additionally, 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.
- Notify the 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. (Refer to the card on page 6).
- 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.**

What are my 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 Chief Strategic Officer at 216.383.3745. She 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 Operating 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:
1.800.342.0553

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 to the Chief Compliance Officer in person, by writing, via voicemail, e-mail or by calling the Compliance Hotline voicemail box.

How to contact the Chief Compliance Officer?

John E. Harvan, Jr.
Chief Compliance Officer
Hospice of the Western Reserve, Inc.
300 E. 185th Street
Cleveland, Ohio 44119-1330

phone: 216.383.3755

e-mail: jharvan@hospicewr.org

Compliance hotline voicemail box: (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 Chief 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 Chief Compliance Officer will have access to the Compliance Hotline voicemail box.

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.
 300 E. 185th Street
 Cleveland, Ohio 44119-1330

phone: 216.383.3745
e-mail: ssabur@hospicewr.org

HIPAA hotline voicemail:
216.383.6675

The Ethics Committee

Providing guidance and support on ethical matters relating to patient care.

Our ethics committee was formed to discuss ethical issues that sometimes arise when caring for patients. Discussions are held in a format that stimulates conversation and dialogue among staff members, patients, families, healthcare providers and members of the community.

Ethics \Eth'ics\, n. The discipline dealing with what is good and bad and with moral duty and obligation. Webster's 7th New Collegiate Dictionary (1969)

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.

Committee members

Ethics committee members include staff from various disciplines. It is also open to members of our Board of Trustees, volunteers and members of the community including physicians, clergy, attorneys and ethicists.

Team members are appreciative of your thoughtfulness. Although gifts are not acceptable, please consider a donation to Hospice of the Western Reserve to the Development Team.

How to contact the Ethics Committee?

Any staff member, patient, family member or healthcare professional involved with Hospice of the Western Reserve may request a consultation with the committee.

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.

The Hospice Medicare Program and other Insurance Coverage

The Medicare Hospice Benefit

Medicare provides a special program for persons needing hospice care. This program covers services, medications, supplies, and equipment needed for the comfort of patients. The services and items provided must be needed to treat the serious illness. Hospice is a program of care delivered in the patient's place of residence by a Medicare-certified hospice.

Pre-authorization:

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. Remember, that these restrictions apply only to the seriously ill diagnosis. Unrelated medical problems may be treated in your usual manner with your insurance coverage.

Who is eligible for this benefit?

- The patient who has Medicare Part A
- The patient whose doctor has confirmed the serious illness
- The patient who signs a statement choosing hospice care benefits
- The patient who receives care from a Medicare-approved hospice
- The patient who has months rather than years to live

What is a benefit period?

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 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.

What if I stop hospice care before a period is over?

Medicare allows the patient to discontinue the Medicare Hospice Benefit. The days left in that period are lost. The next time the patient enters the Medicare Hospice Benefit, they will enter the next period.

How does the Medicare Hospice Benefit cover hospitalization?

If a patient has symptoms that are proving difficult to manage at home, a few days in a hospital or Hospice House 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 House 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 you arrange transportation. The Medicare Hospice Benefit requires the pre-authorization of any hospital stay related to the serious illness, including the emergency room. Remember, *call Hospice day or night!*

How can the caregiver get a break?

Short breaks of an hour or two can be arranged

with the help of a volunteer. If a longer break is necessary, a period of up to five days will be arranged by the nurse or social worker at a contracted facility or Hospice House. This “break” is referred to as respite. Consider respite care if there is a family emergency, a need for the caregiver to go away, or as a needed break from caregiving.

How does the patient pay for hospice care?

Medicare pays hospice directly for each day hospice is responsible for care. During hospice care, you should not receive a bill for services covered by Medicare. If any questions come up regarding billing, ask your nurse or social worker for help.

How is my doctor paid?

The current arrangement you have under Medicare Part B will continue to cover the doctor’s costs.

Medicaid

Does Medicaid cover hospice services?

Yes, the Medicaid Hospice Benefit provides the same coverage as Medicare. Your Medicaid card will be used to confirm your 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)

Will a person on the Champus Program have a hospice benefit?

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

Private Insurance

What hospice benefits are available through my private insurance?

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

Will I have to pay 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.

If a person has no form of insurance, will hospice and palliative care be available?

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, and 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.

Patient/family guidelines for the Hospice Benefit

The Hospice Benefit provides coverage for palliative, comfort-oriented care and services. A hospice benefit is provided by Medicare, Medicaid, and some private insurances. The hospice nurse can determine if you are eligible for one of the benefits.

The following services are covered by a hospice benefit when pre-authorized by the Hospice Team:

- **Home care visits/physician services:**
All home care visits/services provided by the Hospice of the Western Reserve team as well as pre-authorized services provided by your attending physician are fully covered under the benefit. Physical, occupational and speech therapies are provided as based on the patient’s plan of care.
- **Medications:**
Pre-authorized medications that are related to the diagnosis for which hospice care is being rendered to you are fully covered. A list will be provided to you. Medications covered under this Benefit must be obtained from a pharmacy designated by hospice. Prescriptions will be filled with generic equivalents.

• **Supplies:**

Supplies that are pre-authorized by the Hospice nurse are fully covered. Supplies must be ordered by the hospice nurse and obtained from a hospice contracted supplier.

• **Hospitalization:**

Although most pain and symptom management problems can be managed at home, occasionally a short hospitalization may be necessary to control symptoms. Hospitalization must be facilitated by the hospice nurse with your physician’s approval and provided in a hospice in-patient unit at a contracted hospital or at Hospice House. The hospice nurse will provide you with specific information and directions if hospitalization is needed.

• **Respite:**

Respite care can be provided for the caregiver by admitting the patient into a nursing home or inpatient facility where Hospice of the Western Reserve has a contract. Respite care is usually provided for up to five days.

Benefit periods:

There are two (2) ninety day benefit periods followed by an indefinite number of sixty day periods. Recertification by the primary care physician is required at the beginning of each new benefit period.

Pre-authorization:

All health care services must be pre-authorized by the Hospice of the Western Reserve to be covered under the Hospice Benefit. If you elect to receive medical or hospital services which are not directly provided or authorized by the Hospice of the Western Reserve, you may either self pay for that service or revoke the Hospice Benefit. Re-election of the Hospice Benefit is available.

- ★ **The most important thing to remember to insure coverage under the Hospice Benefit is to contact your hospice nurse to assist you with questions and/or concerns.**

Respite Care

What is respite care?

There are times when caregivers need a break. Respite (or rest) care gives the caregiver the opportunity for time off or to attend a family event. Respite care supports the caregiver and is part of the benefit provided by Medicare, Medicaid, and most insurances.

How is respite obtained?

The patient is placed in a facility with which Hospice of the Western Reserve has a contract. Respite can last up to 5 days and is offered as needed. The patient will receive all medications and treatments. The physician may stop by, but this is not necessary since team members will provide the facility with all necessary care instructions. Remember, when using respite care, the setting is different but the care does not change.

How should the patient/caregiver prepare for respite?

Bring all medications (except narcotics) in labeled medicine bottles. Bring supplies, such as diapers, ostomy supplies and dressing supplies. Pack the patient's personal items (brush, comb, toothbrush, etc.) as well as any clothing the patient wants.

How should the patient get to the facility?

If at all possible, the family should take the patient and pick them up. If this isn't possible, discuss transportation needs with the team.

Symptom Control

Why is symptom control needed?

When the patient has increased pain, nausea, shortness of breath or some other problem, the hospice team may suggest a symptom control admission. The goal of this admission is to relieve or decrease the severity of the symptom. This type of admission is meant to be short, with the hope of returning the patient to their home as soon as possible.

Where will the patient go for symptom control?

Usually the patient will be admitted to Hospice

House. However, if the patient's physician or patient prefers, an admission can be arranged at a local hospital. Many local hospitals contract with Hospice of the Western Reserve to provide this service. The cost is included in the benefit program if admission is arranged by the hospice team with a contracted hospital.

How will this admission be arranged?

The hospice nurse will first speak with the patient, caregiver and physician. Then the nurse will arrange for the admission at either the agreed upon hospital or at Hospice House. The nurse will also arrange for patient transportation, if needed. If you believe the patient needs symptom control care, call the nurse.

Expectations & Responsibilities for Continuous Care

What is continuous care?

When the patient has a symptom such as increased pain, shortness of breath, or some other problem but desires to remain in their place of residence, the hospice team may suggest changing the level of care to "continuous care." This level of care requires a physician's order and is meant to be only short term. During the time that a patient is receiving this type of extended care, the patient's condition will be re-evaluated frequently to determine what level of hospice staffing is required to meet the patient's needs. The goal of providing extended care to the patient is to relieve or decrease the severity of the symptoms with the hope of returning the patient to routine hospice care.

How is care provided?

Hospice care will be provided in extended blocks of time of 2 to 4 hours or more. Occasionally, care may need to be provided around-the-clock for very severe symptoms; however, this is not the usual case. Various members of the hospice transdisciplinary team, including RNs, LPNs, Hospice Nursing Assistants, and volunteers, may come and go to provide the care needed. Your primary team will continue to oversee your care. This level

of care is not meant to take the place of family and friends or hired caregivers. It is not meant to provide solely for general daily care of the patient or safety needs; however, we'll be glad to assist and teach you in these areas while we are there to manage active symptoms of the patient.

What may you expect of us?

- We will teach and assist family caregivers in giving medications, doing personal care and treatments or other specific procedures ordered by your physician.
- 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 may you do to maximize the benefits of this service?

- 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.

Home Safety

Electrical safety

- Extension cords should be placed away from walkways
- Keep extension cords in good repair and check them often
- Extension cords should not be overloaded
- Keep unused electrical equipment unplugged
- Place safety covers in unused electrical outlets
- Store and use electrical appliances away from water
- Power bars (surge protectors) or outlet adapters are a safer choice
- Be certain that electrical cords from equipment (bed, oxygen concentrator, etc.) are placed out of walkways to prevent tripping or falling

Rugs, runners, and mats

- Remove as many rugs, runners and mats as possible from areas used by the patient
- Secure all loose rugs, runners and mats with double sided tape or rubber matting to prevent tripping and/or falling
- Replace or repair torn or frayed rugs
- Keep carpets tacked down

Telephone

- Keep a phone near the patient's bed so they may use it without standing or walking
- Be certain that all cell and cordless phones are charged
- Assist the patient in finding a phone if they are without
- Place hospice and emergency phone numbers in easy to find places near phones.
- If the patient is alone for all or part of the day, consider an emergency monitoring device. Ask your social worker for information about these

- If the patient lives alone or will be left unattended for periods of time, ask a friend, neighbor or other family member to call and check on the patient throughout the day

Fire safety

- There should be 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. Develop secondary escape plans in case primary plan cannot be carried out
- Include other family members, neighbors and/or friends to assist in evacuation if necessary
- Be certain to communicate evacuation plan to all involved
- Clear all pathways, never block an exit
- 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. Keep all such heaters away from water and clear of pathways. 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

Bathroom

- Tubs and showers need non-skid mats or strips to avoid falls
- Install grab bars in showers, tubs and toilet areas to help with transferring the patient
- Always check the water temperature before entering a tub or shower
- Consider a night light in the bathroom

Stairs and halls

- Keep stairs and halls clear and well lit
- Stairs need well-secured rails on both sides
- Avoid using the stairs wearing only socks, loose slippers, or smooth-sole shoes

Outdoors

- Entrance ways should be well lit and clear of debris, ice, leaves and snow
- Provide secure outside step and porch railings
- The house address needs to be clearly visible from the street during the day and night

Tornado safety

- Listen to your radio or TV for the latest weather updates. Tornado Watch means that local weather conditions exist for a tornado to develop. For Tornado warnings **seek shelter immediately**
- Remain calm
- In the event of a tornado move to the lowest level or basement of the home. If there is no basement then move patient/family to an interior room or hallway that does not have windows
- If the patient is unable to leave their room or go to another level of the home they should be moved towards an inner wall and covered 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

Electrical outage

- Call and report problem to the electric company
- If using an oxygen concentrator, switch to the back-up oxygen tanks. (see page 19)
- Call hospice so that we can alert the oxygen company to provide additional oxygen as needed
- If an alternative power supply is available, use it
- Keep a flashlight with working batteries ready for use
- Move the patient to other housing. Hospice can help you set up emergency respite care
- If a crisis occurs, call 911

Gas

- Call and report the problem to the gas company

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

Water outage

- Call the water company
- Use bottled-water for drinking or boil water for 20 minutes before use
- Restrict use of available water
- Call hospice. Consider moving the patient
- If a crisis occurs, call 911

Floods, explosions, and other disasters

- Follow recommendations of local authorities
- Listen to radio or TV for up-to-date news
- Notify local police or fire departments
- Be prepared to leave quickly
- If a crisis occurs, call 911
- Call hospice who will assist you with emergency respite for the patient

Evacuation

- Plan ahead in case of a situation or disaster that requires the patient to leave their home
- Develop a plan of where the patient may be moved to, including a neighbors, friends or other family members house. Have a backup plan in place just in case
- Decide ahead of time who will do what. Be sure to communicate plan to everyone involved
- Call hospice for assistance with transferring patient or admitting to a temporary hospice bed

Emergencies that prevent travel outside of home

For situations where travel may be prohibited due to weather or other conditions, prepare ahead of time by having in the home 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 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.**

Personal Planning

Preparing for the challenge of declining health

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 their choices. This conversation prepares them for a time when they may not be able to speak on their own behalf. During a health crisis, it may be too late, too difficult or impossible to say 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.

Advance Care Planning

Advance directives are documents in which instructions are given about the type of care someone would want or not want if they cannot speak for themselves. These are the Living Will and Health Care Power of Attorney.

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 their own decisions
- A person or their caregiver can request a standard Living Will form from the Hospice of the Western Reserve staff

Health Care Power of Attorney

- A document that allows a person to name someone to make health care decisions on their behalf when a person becomes unable to make them on their own, 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 the Hospice staff

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 to assume 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

Considerations

- Make copies of all important documents and give them to the physician, any family members, or concerned friends
- Talking about how we want to live as we approach death and communicating one's wishes for end-of-life care will ease the strain for loved ones when the time comes
- Imagine the conflicts that would come if someone were representing you without the benefit of knowing your specific wishes

If we can talk about how we want to live as we approach death and communicate our wishes

for end-of-life care, it will ease the strain for loved ones when the time comes. To share our wishes ahead of the time when they are needed will give the person who is named to represent us, the guidance they need to avoid conflict.

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.

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. It is the most special gift that any of us can ever make.

We realize that this is a difficult decision to make, especially when it must be decided at a time when families are experiencing the intense pain of grief. But, many families have later made the statement, "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.

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, music are commonly used in planning a memorial service. Reflect on your loved one's life. Think about his or her values, special events, life's work, hobbies, travels, and contributions. Honoring your loved one will help you understand and 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 you and your loved one.

Things to remember:

- **Music:** More than anything else, music affects our feelings and the atmosphere in which we remember our loved one. Select hymns, songs, or other music that is your loved one’s favorites, brings comfort or celebrates their life
- **Readings:** Reflective passages of sacred text, poems, 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, symbols with the loved one’s life and indicates ways the departed inspired us

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

What is Probate?

The following explanation is information, not legal advice. Hospice 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 their 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 volunteer attorneys are not able to provide this service.)

VA and Medicaid Benefits

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 & assistance:
 1.800.827.1000

Veterans of Foreign Wars:
 216.522.3510

or

Veteran’s 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.

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 Hospice families in many stages of dealing with a serious illness is a vital part of our mission. One of the many 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: _____

Birthplace: _____

Came to area from: _____ When: _____

Occupation: _____

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

Church Religious Affiliation: _____

Organizations/Offices: _____

Major Achievements/Honors: _____

Military Service/Recognition: _____

Bereavement Support

One of the special services of hospice is the Bereavement Program. Because patients and their families are important to us, our relationship with the family continues after the patient's death. The family and/or caregivers will be contacted by a member of our Bereavement Team shortly after the patient's death. Should anyone feel the need for support prior to our first contact, call hospice.

It is common and normal for anyone who has experienced the death of a loved one to have many emotions and feelings that are intense, confusing, and sometimes overwhelming.

Some of these feelings may include denial, anger, depression, abandonment, and guilt. During the bereavement period, there will be difficult times as well as times when growth and healing are felt. Each person moves through the grief process in a unique way. There will be variation within each family. Reaching out for each other, restoring old relationships, or creating new ones can help in the healing process. Those of us involved in hospice work find that hope, however it may be defined, is an important emotion during this time.

There is no way for the patient (whose death may be near) or the surrounding loved ones to be fully prepared for the loss. The knowledge that physical death does not diminish shared memories or ideas may give some comfort during this difficult time. Perhaps this quote from a person whose death was quite near will help define this hope.

“It seems good to know that things will go on. I don't know how things will go on for me, or even if they will. Yet, part of what I am will exist because I will be remembered just as I remember my family and friends who have already died. However, I don't remember them as dead, yet as alive in my memories. Someone will remember me in that way too.”

Grief Support Services

Hospice of the Western Reserve realizes that this can be a difficult time and we are ready to offer grief support services during the thirteen months after the death. These services are available to all family members and/or significant others.

- **Support Groups** for adults, adolescents, and children
- **Individual Support** for all age groups, as needed. Conducted by the professional bereavement staff or trained volunteers
- **About Grief** newsletter mailed directly to you with four editions of helpful readings on common grief issues. Each issue contains the schedule of support groups
- **Community Programs** that focus on coping with grief and loss include holiday and family programs, children's camps, Mother's Day/Father's Day workshops and educational series held periodically throughout the year
- **Wellness Programs** include expressive therapies, reiki, yoga and massage therapy that promote well-being and effective grieving
- **Non-Denominational Memorial Services** are offered for hospice families, friends, staff, and volunteers to remember those who have died in the past year

All Hospice of the Western Reserve grief support programs are open to the community and facilitated by our professional bereavement staff and other counselors with the assistance of trained volunteers.

Additional information will be sent to you at a later date. If the bereavement staff can be of any service to you at this time, discuss your need with the hospice staff (nurse, social worker, spiritual care coordinator.). The team wants you to have the support you need and will contact the bereavement staff regarding your request.

Children and Grief

In order to talk to children about grief in a language they can understand, it's important to be aware of the different developmental stages and reactions to death. Children need information, but giving them more than they can understand is not helpful and may further confuse them. It is important to ask children questions in order to get a better understanding of how they are feeling. It is also important to encourage them to talk openly and ask questions. Please contact a member of your hospice team if you need more information or assistance.

Children's Development Stages and Reactions to Death

Ages	Common Developmental Characteristics	Grief Reactions	Helpful Approaches
2–5 years	<ul style="list-style-type: none"> Magical, fantastical thinking Active fantasy life Highly egocentric May blame self for bad things May not be able to verbalize needs and fears Reversibility of concepts. Need to repeat things 	<ul style="list-style-type: none"> Confusion. Agitation at night; may be afraid to go to sleep Child may be able to appreciate a profound event has occurred, but may not understand permanence of death May seem unaffected Repeated questions 	<ul style="list-style-type: none"> Simple honest words, and phrases Reassurance Secure and loving environment Drawing, reading, books, playing together, active play Support play as form of expression Include in the funeral rituals
5–8 years	<ul style="list-style-type: none"> Child can think concretely and logically Ability to use language increases Increased memory capacity, both long and short term Increased awareness of feelings and expectations of others Peers important 	<ul style="list-style-type: none"> Want to understand death in a concrete way Denial, anger, sorrow Distress May act as though nothing has happened Desire to be like peers May repeat questions May need physical activity regularly 	<ul style="list-style-type: none"> Answer questions simply and honestly Look for confused thinking Offer physical outlets Reassurance about the future Drawing, reading, playing together Include in funeral rituals
8–12 years	<ul style="list-style-type: none"> Enjoy games, and competing Begin to have increased understanding of self and relationship to world Increased propensity for language Able to reason through situations using problem solving skills 	<ul style="list-style-type: none"> Shock, denial, anxiety, distress Try to cope Understand finality of death May have morbid curiosity, or want to know specifics about death and dying May need regular physical activity Want to be like peers 	<ul style="list-style-type: none"> Answer questions directly and honestly Reassurance about the future Create times to talk about feelings and questions Offer physical outlets Reading Include in funeral plans and rituals
12–18 years	<ul style="list-style-type: none"> Need independence Can think abstractly Puberty usually has begun by now May have false sense of immortality Peer group important May begin to have intimate relationships 	<ul style="list-style-type: none"> Shock, anger, distress May become depressed or withdraw May react similar to adult, but have less coping mechanisms May feel isolated, especially from peers 	<ul style="list-style-type: none"> Allow and encourage expression of feelings Encourage peer support Groups may be helpful Utilize other adults Maintain consistent environment Include in funeral plans and rituals

* Adapted from Dougy Center Handbook

Personal Information and Records Checklist

Location

Living Will

Durable Power of Attorney
for Health Care

General Durable Power
of Attorney

Attorney

Name:

Address:

Phone:

Will

Location of will

Executor of will

If you do not have a will, your first priority is to prepare one. If you do have a will, it is a good idea to review it at this time.

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

Location

Mortgages, records, or mortgage payments information

Stocks, bonds, certificates of deposit

Brokerage firm / broker

Name: _____

Address: _____

Phone: _____

Savings account

Name: _____

Acct #: _____

Checking account

Name: _____

Acct #: _____

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 you are 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

HOSPICE OF THE WESTERN RESERVE QUICK REFERENCE

Reaching your hospice team members when you have a need or a question is important. 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: _____

Volunteer: _____

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.