



HOSPICE OF THE WESTERN RESERVE

# Training Guide for Caregivers

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



## OUR MISSION

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

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

# Welcome

**THANK YOU FOR CHOOSING HOSPICE OF THE WESTERN RESERVE** Each member of our paid and volunteer staff is committed to providing compassionate, exceptional care. We are honored that you and your loved one have placed your trust in us and promise to focus on your priorities, values and goals of care. Your care team includes your loved one (the terminally ill person), you and other family caregivers and your hospice care team members. Our shared goals are directed by the patient and loved ones.

Hospice care is dedicated to personal choice. Your care team members are committed to ensuring your healthcare choices are respected. They will provide physical assistance and medical care while supporting your emotional and spiritual wellbeing.

This caregiver training guide offers information that you may need to supplement the services that we provide. It is not meant to be a substitute for our care or services. It delivers quick reference to practical information. We have included website links to training videos created specifically for the home caregiver. These may be particularly helpful. Our website, [hospicewr.org](http://hospicewr.org), also has numerous other resources that were created to help make home caregiving easier and more enriching.

We are available 24/7 to answer your questions, alleviate your concerns and ease your burdens. Do not hesitate to call anytime, day or night.

It is a privilege to be invited into your life and home and to play a role in your journey.

Sincerely,



**William E. Finn**

*President and CEO*

*Hospice of the Western Reserve*

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# Introduction

**HOSPICE CARE PROVIDES COMFORT** for the patient and support for you – the caregiver. We work to manage pain and other symptoms of illness. Staff and trained volunteers provide emotional support and can help your whole family explore spiritual questions that often arise when someone is terminally ill. You and your loved one are always in control of the care plan.

## How do you help someone who is dying?

Hospice workers are often asked that question. The answer can't be found in techniques or textbooks. Medications and treatments are important, but the real work of hospice is **being physically and emotionally present**. Sharing the final stage of life's journey with someone who is dying is the most important thing you can do for them. Simply be there.

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

## Confidence in Your Caregiving

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

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

Whatever your questions and concerns may be, please let us know. **We are here for you, too.**

## Hospice Care Team Members

Specially qualified and trained team members provide hospice services. The individual receiving care and their caregivers are vital members of the care team. Together, the team creates a plan that maintains individual dignity and ensures all physical, emotional and spiritual needs are taken care of.

A **Primary Care Physician** is responsible for continued medical management of your loved one's care. The **Hospice Physician** acts as a resource for hospice medical care and reviews the plan of care on a regular basis.

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

Your **Social Worker** helps you and your loved ones explore care options, finds other community resources and offers emotional support. Social workers are available for individual and family support. Our social workers are dedicated to helping the patient and their family with the many areas of life impacted by an illness.

**Hospice Nursing Assistants** often have the most frequent interactions with patients; they can be a great source of helpful information. Our nursing assistants are experienced in hospice and palliative care. Each holds the specialty certification, STNA, meaning they have additional training and have passed an exam administered by the State of Ohio. They offer important personal care and assistance with bathing and dressing. They are also present for emotional support.

**Spiritual Care Coordinators** explore ways to find joy, meaning and purpose in life, even at the end of life. For those who have a religious faith, this may include working closely with your spiritual advisor and faith community. Everyone can benefit from a listening ear, guidance and willingness to explore universal questions, forgiveness and hope.

Art and music experiences by **Therapists**, **Volunteers** and other members of your hospice care team can enhance visits, provide symptom relief and allow opportunities for life review and the creation of legacies.

The **Pharmacist** strives to relieve pain and manage other symptoms with minimal side effects and maximum benefit.

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

**Overnight and Weekend Team Members** assure access to care 24 hours a day, seven days a week. Your loved one's comfort and your comfort level as a caregiver are our priority.

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

**Volunteer Service Managers** help identify areas in your life where a volunteer may offer assistance. They discuss volunteers' roles with patients and their loved ones before asking a volunteer to join the team.

**Volunteers** are valuable members of your team and a great source of support. Volunteer staff receive extensive education and are dedicated to maintaining the patient's privacy and dignity.

### Volunteers can help in many ways:

- ◆ Providing a friendly visit or respite for a caregiver
- ◆ Offering spiritual care support
- ◆ End of Life Doula support through legacy work, life review, vigil planning and vigil presence
- ◆ Support for pet needs through Pet Peace of Mind<sup>®</sup>, to include walks, feeding and transportation to veterinarian visits
- ◆ Assisting with occasional housekeeping and meal preparation
- ◆ Providing simple legal assistance
- ◆ Making periodic phone calls through check-in programs to ensure patient needs are met
- ◆ Providing support to veterans through our Peaceful & Proud Program
- ◆ Delivering comfort massage or Reiki
- ◆ Helping fill a special request to bring fulfillment and comfort through the Moments to Remember program (If your loved one has a special request or wish, please tell a team member.)

# Frequently Asked Questions about Hospice Care

## Q: What is hospice care?

**A:** Hospice is compassionate, comfort-oriented care for the terminally ill with an emphasis on pain management, symptom control and spiritual and emotional support for the patient and family. A hospice physician certifies that a patient has a prognosis of six months or less if the disease runs its expected course.

## Q: Where can hospice care be provided?

**A:** Care is provided anywhere a patient calls “home” such as a private home, group home, nursing or assisted living facility, one of our inpatient hospice care units (“hospice houses” – see page 9) or a hospital.

## Q: How long can a patient receive hospice care?

**A:** At admission, a physician certifies the disease has advanced to the point that the patient has months rather than years to live if the illness runs its expected course. Each week, the patient’s hospice care team re-evaluates and monitors if the patient’s condition remains appropriate for hospice care. Re-certification occurs at the three-month and six-month points and every two months thereafter. Sometimes, patients experience improved health and do not need continuing hospice support. If their condition deteriorates later, they can be readmitted.

## Q: Who pays for hospice care?

**A:** There are no out-of-pocket costs for any services or medications related to the patient’s terminal illness. Hospice of the Western Reserve is a Medicare/Medicaid certified hospice program, offering a comprehensive Hospice Benefit. This benefit covers the cost of all hospice care team services, medications and treatments related to the terminal illness, medical supplies and durable medical equipment. Many medical insurance companies have similar plans that cover hospice services.

## Q: Does the patient keep their own doctor?

**A:** Yes, hospice patients may continue to be served by their own physicians. Hospice team members work with each physician, serving as a liaison between physician, patient and family. We also

have physicians who are certified in hospice and palliative medicine and nurse practitioners on staff. If you wish to change physicians or if the patient does not have a primary care physician and wishes for one of our hospice physicians or nurse practitioners to oversee care, please notify the hospice care team.

## Q: What if the patient moves during hospice care?

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

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

**A:** We will always honor the wishes of the patient or their designated representative for care. If services are no longer needed or desired, the patient must sign a discharge form. There are times when a patient’s condition stabilizes; the hospice care team will discuss discharge. The patient may then join our Western Reserve Navigator program (see page 8) and a team member will call and visit periodically to check on the patient’s condition. If you notice changes in the patient’s physical health, do not hesitate to call us. Hospice services will always be available when needed.

## Q: How does Hospice of the Western Reserve offer support to caregivers and other loved ones?

**A:** We provide support from clinical staff, personal care for the patient, counseling, art and music experiences, spiritual care, pharmacy services and more – all of which help caregivers return to the role of spouse, child, parent or friend. We offer caregiver respite if family members need a break from the stress of caregiving. Our social workers can help navigate the complexities of terminal illness. Our volunteer program is available to create Moments to Remember for patients and families by helping them create memories and achieve special wishes. Our bereavement staff is available to help loved ones manage their grief.

## On-Call Service

Questions, concerns and problems often occur at night, on weekends and during holidays. We encourage caregivers to use our on-call service when these needs arise. We want you to feel confident calling for support. A team member is always available to speak with you to address your concerns and provide help. The Hospice of the Western Reserve office number will always work, 24/7, day and night.

Please refer to the Communication Card on the back of this booklet for names and contact numbers. Keep it in an easily located area in the home.

If you call for support after 4:30 p.m., or on weekends and holidays, our answering service will promptly answer. The operator will request the patient's name and the reason for your call. They will then ask you to hang up and not to use your telephone while awaiting the call back. The on-call team member will be notified and will return your call 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, call Hospice of the Western Reserve first. If someone has called 911, please notify Hospice of the Western Reserve as soon as possible so we can assist with care coordination.**

**Provide the hospital registration clerk with the patient payment ID card you received from your hospice care team.**

## Hospice Care in Assisted Living Communities & Nursing Centers

Assisted living communities and nursing centers have become more common and popular. Many younger and healthier people are entering senior communities with the intention of aging in place, even as their medical needs change. The medical community refers to all these living environments as “alternative home” settings. They include: assisted living, nursing facilities, long-term care centers, group homes or other residential care settings.

People living in long-term care settings may receive hospice care. We have dedicated Hospice of the Western Reserve teams that partner with alternative home staff to provide hospice care for individuals who live in these settings. We provide the same support and care for a resident there as we would for a person living in a private home. Even though your loved one is living in a facility, you are still a caregiver. Please refer to Page 4 to see ways our support can help you feel more confident and comfortable in this role. All of our services are included: expertise in pain and symptom management, grief support, ongoing consultation and access to our on-call hospice staff. By working together, we enhance the residential facility's excellent services.

If the patient is eligible for the hospice benefit, 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, your hospice social worker will help locate a facility that works in collaboration with Hospice of the Western Reserve.

## ADDITIONAL SERVICES



## Peaceful & Proud: Personalized Care for Veterans

**TO MEET THE SPECIAL NEEDS OF VETERANS**, Hospice of the Western Reserve has developed the Peaceful & Proud program. Through Peaceful & Proud, Hospice of the Western Reserve's paid and unpaid staff receive training in trauma-informed care and other emotional issues for veterans, such as remorse or regret, anxiety and substance abuse.

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

Hospice can be provided in a patient's home, at our inpatient hospice care centers, hospital and assisted living communities or in VA contracted facilities for eligible veterans.

Hospice of the Western Reserve has earned a Level 5 designation in the We Honor Veterans program, the highest level a hospice can achieve.



## Western Reserve Navigator Palliative Care Services

**WESTERN RESERVE NAVIGATOR** is a non-hospice program offered through Hospice of the Western Reserve. It is a palliative care program which works to provide a specialized care model for patients and their families living with a serious illness. Western Reserve Navigator provides supportive and palliative care services to those who could benefit from symptom management, emotional support, and/or community resources to enhance their quality of life. We not only work to support our patients but also their families. We are your eyes and ears, working with your physician to keep you comfortable at home and out of the hospital.

### Results of Western Reserve Navigator include:

- Fewer trips to the ER and admissions to the hospital
- A decrease in caregiver stress
- Improved coordination of healthcare services
- Increased health information and referral to community resources

Patients in this program may receive palliative care and curative care at the same time. You may remain in the Navigator program for as long as needed and can be admitted to hospice later if necessary.

Through Western Reserve Navigator, an Advanced Practice Registered Nurse (APRN) and Social Worker will assess for medical needs or social support and follow up based on those needs. We also have trained volunteers to access in several roles. Registered Nurse support is available for medically based phone calls and needed follow up. You will have access to caring support 24 hours a day, 7 days a week.

## Services at Our Hospice Inpatient Care Units

Hospice of the Western Reserve offers three home-like inpatient hospice units (“hospice houses”). They all offer an array of services to meet patients’ and loved ones’ needs.

For additional information such as smoking policies, transportation, advanced directives and Do Not Resuscitate orders, medications, personal items to bring with you, insurance and billing, room and board charges and physician and nurse practitioner services, please refer to our Guide to Amenities and Services and Inpatient Unit Admission Guide.

### Levels of Care Provided at our Hospice Inpatient Units

Your hospice care team, in collaboration with your attending physician, will determine if a change in your loved one’s level of care is necessary.

#### *Pain and Symptom Management/ General Inpatient Level of Care (GIP)*

At times, admission to an inpatient hospice unit may be necessary and recommended to address a patient’s pain or other symptoms that cannot be optimally or feasibly managed at their current location. This level of care ends when your hospice care team determines that pain or other symptoms are optimally managed.

Discharge plans must be discussed beginning at the time of transfer/admission. Anticipated day of discharge will be communicated once the effectiveness of the plan of care has been determined. In some situations, symptoms become managed quicker than anticipated. In those cases, the patient must be changed to the Routine Level of Care or discharged.

Patients often return to the same residence once pain and symptoms are controlled or optimally managed. If this is not an option, the hospice team will assist in transitioning to an alternate care setting. **While a patient remains in the GIP level of care, there are no room and board charges.**

In some situations, a patient’s care needs or goals may lead to your hospice care team recommending

or requiring that they be admitted to a contracted hospital for the General Inpatient Level of Care.

### *Respite Care*

A patient may be admitted for five days of Respite Care if their caregiver needs a short interval of rest from caregiver duties. The caregiver must intend to resume caregiving after the respite admission.

An extension of up to five additional days of respite care may be approved in extenuating circumstances. In these situations, the patient must be transitioned to the Routine Level of Care. Room and board fees will apply for any days beginning on the sixth day. Extensions to this level may only be provided in contracted nursing facilities or a hospice inpatient unit.

**Room and board charges apply beginning on day six.**

### *Residential (Routine) Care*

Short-Term Residential Care assists patients who are unable to care for themselves, have limited capacity or no family caregiving resources. Hospice of the Western Reserve is committed to providing Short-Term Residential Care (prognosis of four to six weeks) at our hospice inpatient units on a limited basis based on bed availability. Eligibility criteria and room and board charges apply.

### *Home Away from Home in the Final Days Option*

When an illness brings a short life expectancy (typically one to 14 days), there may be a need to move a patient from their home or hospital to one of our hospice inpatient units. This option provides a comfortable, safe and peaceful home away from home in the patient’s final days. This gives loved ones access to a 24-hour hospice care team to assist with direct care needs. Family and friends have the opportunity to focus their time and attention on supporting and being present with the patient and each other. Eligibility criteria apply to this program. Please ask to speak with a hospice team member if you feel this may apply to your situation. **Room and board charges apply.**

## Extended Care/ Continuous Care

Continuous Care is a level of care that addresses pain, nausea, shortness of breath or other hard-to-manage symptoms that may require more intense skilled care than can be managed at the patient's home without additional skilled nursing intervention. This level of care is meant to be short term. Your hospice care team (based on symptoms) intermittently provides clinicians who enhance the care already being provided by the current caregivers. Ongoing reassessment will ensure that the appropriate level of care is maintained to achieve optimal symptom relief. Your hospice care team may, at any point, recommend a transfer to one of our hospice inpatient care units if the symptoms persist.

This is recommended only if it is no longer feasible to achieve optimal symptom management in the patient's residence.

Once symptoms are controlled, the patient will return to routine hospice care. Extended Care is not meant to be a substitute for the patient's hospice care team or caregivers at home. It is for managing active difficult symptoms.

### What can you expect of us while receiving Extended Care?

In addition to regular visits by your hospice care team, you may encounter different staff members while you are receiving this service, including trained volunteers.

While in your home, our staff will electronically document the care given during the visit and keep other staff members updated on the patient's response to the plan of care. We will reposition bed bound patients and bathe/change incontinent patients frequently for comfort and to keep skin healthy and comfortable.

Our staff will always remain awake and alert, will conduct themselves as guests in your home and will be courteous and respectful at all times.

They 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 eight to 12-hour shift.

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

Stay involved in your loved one's care. Please be available for visits from your hospice care team and assist in planning for their care when their current symptoms are managed. Ask questions freely and as often as needed.

You are always welcome to make decisions you feel are in the best interests of your loved one, such as not turning in bed, refusing medications, etc. Please discuss these decisions with your primary care team.

## Patient Travel Information

There may be occasions when a patient needs to travel outside our service area. Many hospices across the United States are willing to collaborate with Hospice of the Western Reserve. Please notify your hospice care team as soon as possible – at least five business days prior to traveling – so we can arrange for your access to hospice care.

Our policy supports travel outside our service area for up to 14 consecutive days. If staying longer, please inform your hospice care team. They will make alternate arrangements and provide appropriate forms for you to complete.

If the patient's status changes during travel and requires inpatient care, we will assist with transferring hospice care.

## A Weapons-Free Work Environment

Western Reserve Care Solutions, Inc. maintains a weapons-free workplace, facilities and campuses. All non-law enforcement personnel who enter the agency's grounds or premises are prohibited from carrying handguns, firearms, or any other weapons, even if they have a valid license. Please see the Home Safety section on p. 23 for information on the Weapons-Free Work Environment policy as it applies to providing care in private homes and other residential locations.



# Symptom Management

Any question, day or night, call us: 800.707.8922.

Be confident that we're here for you.

[hospicewr.org/caregiver-training](https://hospicewr.org/caregiver-training)

## Pain

Pain is whatever the person says it is. Sometimes pain can be worsened because of spiritual or emotional reasons. No matter the reason for the pain, your care team will work to identify what type of pain it is. Knowing why there is pain helps find the right way to treat it.

### Questions that will be asked:

- ◆ Where is the pain?
- ◆ How would you describe it? Stabbing? Sharp? Dull? Ache? Burning?
- ◆ How often does the pain happen?
- ◆ How long does it last?
- ◆ What makes it better? Worse?
- ◆ Does it make certain activities hard or impossible to do?
- ◆ Can you rate it 0-10 or use a picture scale?

All medications have side effects. Some, like constipation, are normal and are easily treated with medications. Others, like sleepiness, may be normal in the beginning, but may need changes. If there is a new symptom, notify your care team. They can develop a new plan to manage the pain and/or side effects.

For those that cannot report their own pain, look for signs like moaning, frowning, restlessness, tears or fast breathing. These can be signs of pain.

### Helpful hints on managing pain:

- ◆ Use the medications as instructed
- ◆ Do not increase or decrease medications without talking to your hospice care team
- ◆ Apply hot or cold compresses
- ◆ Use distraction: TV, music or a game might help until the medication works
- ◆ Consult with your hospice care team about developing a relaxation technique or guided imagery intervention
- ◆ Try guided imagery or meditation recordings
- ◆ Use light touch or massage

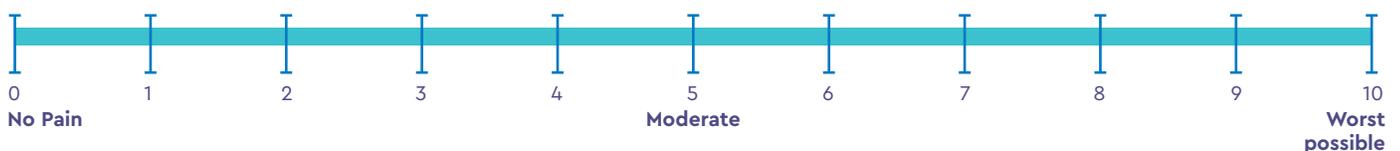
### Call your Hospice Care Team if:

- ◆ The pain is new or worse
- ◆ The medications no longer seem to work
- ◆ There are side effects

## WONG Baker FACES® Pain Scale



## 0-10 Numeric Pain Scale



## Shortness of Breath/ Breathing Difficulty

- ◆ Open window or use a fan
- ◆ Raise head of bed
- ◆ Encourage slow calm breathing
- ◆ Provide relaxing environment
- ◆ Cool cloth to face
- ◆ Take prescribed medications
- ◆ Use oxygen if prescribed

### ▶) Call if:

- ◆ It is a new symptom
- ◆ Interventions do not work
- ◆ Face/fingers become discolored or blue
- ◆ Fever is present
- ◆ Moist productive cough
- ◆ You have questions

## Anxiety

Feeling afraid, nervous, worrying, irritable, unable to sleep

- ◆ Provide calm, dimly lit quiet place to relax
- ◆ Use prayer/meditation
- ◆ Provide distraction or use relaxing music
- ◆ Use guided imagery/visualization
- ◆ Reiki, therapeutic touch, massage
- ◆ Aromatherapy
- ◆ Provide medications as directed
- ◆ Be reassuring/present

### May be caused by:

- ◆ Infection
- ◆ Inability to urinate
- ◆ Pain
- ◆ Unrelieved symptoms

### ▶) Call if:

- ◆ Anxiety is new
- ◆ Unrelieved with interventions

## Restlessness

Can't rest, focus, concentrate, constantly moving  
Almost half of people have this in the last 48 hours of life

- ◆ Use a soft voice
- ◆ Provide reassurance
- ◆ Do not argue if confused
- ◆ Keep the patient safe from harm
- ◆ Be present
- ◆ Use distraction
- ◆ Comfort Touch or massage
- ◆ Give medications as ordered

### ▶) Call if:

- ◆ Restlessness is new
- ◆ Interventions are not working

## Fatigue

Extreme exhaustion, increased sleeping, no desire to eat, not doing usual activities

- ◆ Plan rest periods
- ◆ Plan activities when energy is the highest
- ◆ Plan important and meaningful things first
- ◆ Don't plan multiple activities on the same day
- ◆ Use medical equipment
- ◆ Assist with bathing, dressing or household activities
- ◆ Ask for help. Say yes to friends and family

### ▶) Call if:

We can provide

- ◆ Nursing assistants
- ◆ Volunteers
- ◆ Respite stay outside of the home
- ◆ Equipment: hospital bed, wheelchair, bedside commode, walker
- ◆ Help finding hired care
- ◆ Transportation



## Helpful Relaxation Techniques

Everyone has their own way to relax. By following these simple steps for relaxation, your ability to manage stress and improve breathing will increase.

- ◆ Find a place free of distraction and interruptions
- ◆ Dim the lights and turn off the television
- ◆ Silence phones
- ◆ 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 begin to slow down as you begin to focus on exhaling. As breathing slows, instruct the patient to let the weight of their body sink into the chair or bed. Ask them to imagine a favorite place, moving around in this place and noticing all the colors, sounds and smells of the surroundings.

Encourage them to enjoy this place and the relaxing feeling it engenders. Movement is free, and breathing is easy. Allow the patient to continue to relax and enjoy the music. It is okay for the patient to fall asleep. When they are ready to return from this place, gently instruct them to slowly move fingers and toes and return to an upright position.

## Seizures

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

### DO

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

### DO NOT

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

### ▶) Call your Hospice Care Team if:

- ◆ The seizure is a new occurrence, is unusual, lasts longer than a few minutes or results in injury

## Mental Changes or Delirium

- ◆ Personality changes, unexplained change in mood, confusion, not sleeping
- ◆ Speak slowly and clearly
- ◆ Provide safe environment
- ◆ Attempt to tell them where they are or who people are
- ◆ Do not argue with patient if they don't understand
- ◆ Explain what and why you are doing something

### ▶) Call your Hospice Care Team if:

- ◆ Symptoms are new
- ◆ Interventions are not working



## The Role of Nutrition

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

### Difficulty Swallowing

#### Things to do:

- ◆ Position patient close to a sitting position
- ◆ Change the thickness of the fluid
- ◆ Give soft, easy to chew food
- ◆ Chop or puree difficult to chew food
- ◆ Soften food with a thin liquid, sauce or gravy

#### Things to avoid:

- ◆ Avoid dry or crumbly food: crackers, chips, pretzels
- ◆ Avoid seeds or foods with small pieces: rice, nuts, popcorn, beans
- ◆ Raw vegetables or hard fruit

### Thickened Liquids

- ◆ Blend fruit and juice to a thickness like syrup
- ◆ Use pudding, yogurt, baby cereal to add calories and thicken liquids
- ◆ Use commercial thickeners: your hospice care team will demonstrate how to use these

### Decreased appetite

- ◆ Start the meal with a clean mouth
- ◆ Rinse with mouthwash between meals
- ◆ Sip on mint-flavored water, tea or ginger ale
- ◆ Eat meals together
- ◆ Provide choices in food
- ◆ Keep snacks available
- ◆ Metallic taste can be improved with gum, mints, lemon drops
- ◆ Try sweetening foods
- ◆ Room temperature or cold foods have less smell and may be easier to eat
- ◆ Avoid use of metal; it can leave a metallic taste
- ◆ Try frozen fruits like bananas, grapes, strawberries

### Tips for providing mouth care:

- ◆ Clean the mouth with toothpaste and soft toothbrush or toothettes
- ◆ Use diluted mouthwash for mouth freshness
- ◆ Use hard candy, ice chips, popsicles, frequent sips of water to treat dry mouth
- ◆ Spray the mouth with a mister filled with cool water to treat dry mouth (a mixture of 1 tsp. of baking soda in 8 oz. of water)

## Medications

### Medications: DO:

- ✔ Tell your team if you have only 3-4 days of a medicine left
- ✔ Keep all medication away from children and pets
- ✔ Give medicine exactly how it was ordered
- ✔ Record when and how much of an “as needed” or “PRN” is given
- ✔ Inform your hospice care team of any vitamins, herbal medications or over-the-counter medications you take or begin taking
- ✔ Inform your hospice care team if a medication is added or changed by someone other than the hospice team

### Medications: DO NOT:

- ✘ Change a medication dose or stop taking a medication without telling your hospice care team
- ✘ Give medication to anyone other than the patient
- ✘ Crush a medicine unless told to by your hospice care team
- ✘ Give more than what has been ordered

**OPIOIDS AND SEDATIVE DRUGS** are commonly used to control symptoms in patients at the end of life. Many of the medications used to treat pain and symptoms have an effect on the central nervous system and may cause drowsiness or sleepiness. Examples are morphine for pain or shortness of breath, Haldol for nausea or vomiting and Ativan for anxiety.

Many times the drowsiness will stop after the person's systems gets used to the medicine. Many patients receiving new medications or with severe illness will nap or drop off to sleep normally during the course of a day because they have reduced energy due to their disease, and not necessarily due to any medications. Patients do rest and sleep more as the disease progresses. If you are concerned about the drowsiness or sedative side effects, please let your hospice team know of your concern. If the patient desires to be more alert, changes in the medication can be made.

### How to Make Medication Time Easier for Patient and Caregiver

To make swallowing pills easier, moisten mouth with water or add pills to applesauce or pudding. Some pills may be cut in half.

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

### Side Effects of Medications

- ◆ Sleepiness: Can last for 1-3 days. The body will usually adjust
- ◆ Constipation (no bowel movement or small hard stools): increase liquids if possible; medication may be started routinely or if needed to help
- ◆ Diarrhea/loose stools: do not take medication to stop it unless your hospice care team instructs
- ◆ Some side effects will decrease or go away
- ◆ Some symptoms may be a result of changes in the illness

### ▶) Call your Hospice Care Team if:

- ◆ Itching, rash or hives occur
- ◆ Patient has upset stomach or is vomiting
- ◆ Side effects last longer than expected
- ◆ Side effects are causing distress
- ◆ Patient is feeling too sleepy, less aware

# Medication Disposal

*Ohio Revised Code (B) (9)*

*Section 3712.062*

Under division (B) (9) of section 3712.062 of the Ohio Revised Code, if the family refuses to dispose of opioids/medications despite written notice, Hospice of the Western Reserve will report to local law enforcement the quantity and type of any remaining controlled substances containing opioids that were included in the patient’s transdisciplinary plan of care.

Hospice of the Western Reserve will take responsibility at the time of death to facilitate and supervise and/or dispose of controlled substances and other medications.

A medication must be made unusable by another person when it is past the expiration date, when medication is stopped and at the time of death.

This law requires the hospice to inform the police if there is a refusal to destroy medication.

## Home Care

The patient’s family/caregiver will be instructed on the disposal of medications on admission and ongoing. A nurse will witness disposal of medications, particularly at the time of death. Documentation of the education, performance of disposal or the refusal to destroy medications will be entered into the electronic medical record.

If a family refuses to dispose of medications or have Hospice of the Western Reserve nurse facilitate disposal, local authorities will be notified.

### Medication Disposal: How to

- ◆ Pills: Add sufficient amount of water until they have dissolved
- ◆ Suppositories: Cut them into pieces
- ◆ Cream/Ointment: Squeeze out what is left
- ◆ Transdermal: Cut up (use gloves if available or use care not to touch transferable medication area)
- ◆ Liquid: Pour out.
- ◆ Syringes/injectable: Remove what is inside
- ◆ Medications should not be flushed down a toilet or put down a drain
- ◆ Add used coffee grounds, kitty litter, or flour to bag/can/container so nobody will try to take medicine or attempt to divert it
- ◆ Place in a trash receptacle, preferably inside an opaque bag, if able, to further discourage identification

### Additional Disposal Methods at Home:

- ◆ Utilize any community or pharmaceutical program allowing for proper disposal of medications as available
- ◆ Utilize Ohio State Drug Repository Program if able and appropriate
- ◆ Consider eliminating any personal health information from the pharmaceutical labeling (peel label off, crossing off with a black permanent marker)

### Nursing Home or Facility

The disposal of medications will be handled according to the facility’s policies with review and collaboration with Hospice of the Western Reserve.

### Hospice Inpatient Units

Medication destruction will be completed by the nurses (non-controlled substances) and the pharmacist (controlled substances per Ohio Board of Pharmacy authorization and investigational medication as permitted per research protocols). Destruction will be accomplished as above.

If abuse or drug diversion is suspected or the family refuses to dispose of medications or have Hospice of the Western Reserve nurse facilitate disposal, local authorities will be notified. For additional information from the

FDA, please visit

[hospicewr.org/fda-safe-disposal](http://hospicewr.org/fda-safe-disposal).

## Oxygen

The use of oxygen is determined by the doctor and hospice nurse and must be used as instructed. The patient or responsible caregiver must sign an Oxygen Agreement Letter when using any oxygen. To notify others that oxygen is in use, you must post “No Smoking” signs that are visible to all visitors. There are two devices provided by your care team that deliver oxygen tanks and oxygen concentrators.

### Oxygen Safety

- ◆ Keep in place with good air flow
- ◆ Keep away from flames or any lit objects
- ◆ Post "No Smoking" signs at entryways
- ◆ Plug into a grounded outlet
- ◆ Store unused tanks on their side away from fire sources
- ◆ Have smoke detectors on each floor
- ◆ Have a fire extinguisher in the home

### DO NOT

- ☒ Smoke or use e-cigarettes or any vaping device in the building
- ☒ Use extension cords or surge protectors
- ☒ Use hair spray or other aerosol sprays when oxygen is in use
- ☒ Use petroleum-based products
- ☒ Store tanks in the trunk of a car

### Oxygen Use

- ◆ Replace tubing at least every 3 months or if it becomes kinked
- ◆ Place tubing prongs curved side down and wrap behind ears
- ◆ Use gauze wrapped around tubing for soreness
- ◆ Use only at prescribed level
- ◆ If nose becomes too dry use NON-petroleum-based gel like K-Y jelly around nasal passages

### Oxygen Problems

- ◆ Call immediately if equipment stops working
- ◆ If electricity goes out or equipment stops working, use the cylinders provided and contact your hospice care team immediately to determine a plan
- ◆ Call your hospice care team if you have questions or problems

*Smoking while using oxygen can cause facial burns, property damage and death. People who smoke pose a threat to themselves, loved ones, caregivers, neighbors and pets.*

*Many items that would not normally burn in normal air will ignite when increased oxygen levels are present. When oxygen is used, it creates an oxygen-enriched environment. This lowers the temperature at which everyday household items such as bedding, furniture, clothing and even human hair ignite and burn.*

## Preventing Infection

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

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

### *Wash your hands before and after:*

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

## Respiratory Hygiene

Respiratory hygiene/cough etiquette are measures designed to limit the transmission of respiratory infections by droplets in the air.

- ◆ Cover your mouth and nose with a tissue
- ◆ Put your used tissue in the waste basket
- ◆ Or, cough and sneeze into your upper sleeve, not your hands
- ◆ Wash your hands with soap and water or clean with an alcohol-based cleaner

## Coronavirus 2019 (COVID-19)

Hospice of the Western Reserve adheres to recommendations or mandates from the Ohio Department of Health and CDC to promote the safety of our patients, families, the hospice care team and our community during the COVID-19 pandemic. The hospice care team maintains strict infection control practices aimed at mitigating the risk of virus spread.

## 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 1–4 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.

### *How to Prevent the Flu*

It is important that caregivers and family members get a flu shot annually, between September and November. Some patients have weak immune systems and are unable to respond to the flu vaccine and so they are very susceptible to the flu. It takes 2–3 weeks for the body to build antibodies to the vaccine and protect you from the flu. The flu shot lasts approximately 12 months and must be repeated every year.

## Shingles

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

Symptoms of shingles include a tingling feeling on one side of the body which starts itching and then becomes a rash. Fluid-filled blisters then develop from the rash. These fluid-filled blisters are contagious to caregivers or family members who have not had chicken pox. When these blisters dry and crust over (in about 3–5 weeks) they are no longer contagious. Visitors and anyone caring for the patient who has not had chicken pox should wait until the patient is no longer contagious before visiting. Check with your doctor immediately if you have been exposed to Shingles and you have not had Chickenpox or the Varicella vaccine.

## Blood-borne Pathogens

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

### Helpful Hints

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

## Prevention of Bleeding

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

### Helpful Hints

- ◆ Avoid using sharp objects (knives/scissors/razors)
- ◆ Be careful not to bump into your loved one while you are caring for them
- ◆ Use an electric shaver not a manual razor
- ◆ Drink warm fluids and/or eat fruit to help reduce the likelihood of constipation, which can cause bleeding (See Side Effects of Medications, page 17)
- ◆ Use a soft toothbrush, sponge, or toothette to prevent gums from bleeding; avoid flossing
- ◆ Blow nose gently

### ▶) Call your Hospice Care Team for:

- ◆ 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 skin
- ◆ Bleeding – apply moderate pressure to the area if possible and call your hospice care team

## Preventing the Transport of Bed Bugs

Bed bugs have become a nuisance throughout the United States. Please tell your hospice care team if you know or suspect there are bed bugs present where the patient lives. This will help them to use safety procedures to prevent their transport outside of the home or facility.

When the care team visits a home or facility where bed bugs are suspected or known they are required to wear protective shoe covers and coveralls.

Your hospice care team will only bring supplies or equipment they need for the visit. These will need to be placed on hard surfaces such as a table, chairs without fabric upholstery or similar pieces of furniture. Any equipment or supplies that your hospice care team takes with them from the home or facility will be sealed in a plastic bag before they leave.

When a patient must be moved from a home or facility with known or suspected bed bugs to a hospice inpatient care unit, hospital, nursing home, assisted living or other location, the hospice care team will bathe the patient and place them in a clean gown provided by your hospice care team. The receiving facility will be notified of the reason for transfer.

In this situation, patients and family members are not permitted to bring any personal items such as purses, bags, clothing, luggage, hygiene kits, etc. Any of the patient's medications taken with them will be placed in a sealed plastic bag. Family members are asked to inspect their clothing prior to accompanying the patient. The hospice care team will notify the transportation company, funeral home and any other agency or service that will have personnel or equipment coming into the home that there is a possible or confirmed infestation.

## Home Safety

### Electrical

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

### Walkways

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

Outdoor entryways should be well lit and clear of debris, ice, leaves and snow. Provide secure outside step and porch railings. The house address should be clearly visible from the street during the day and night to guide your hospice care team and other visitors.

### Pet Control

For the safety of your hospice care team and your family pets, we ask that you contain any pets prior to team members entering the home. Care team members have the right to request that pets be contained and to refuse to enter the home if they are not. In the event that a team member is bitten by a family pet, Hospice of the Western Reserve is obligated to report the bite to the health commissioner of the district in which the bite occurred. Please see [codes.ohio.gov/oac/3701-3-28v1](https://codes.ohio.gov/oac/3701-3-28v1) for more information.

## Bathroom

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

## Telephone

Be certain that all cell and cordless phones are charged and place hospice care team and emergency phone numbers in easy-to-find places near phones. Keep a phone near the patient's bed or chair, within easy reach. If your loved one is alone for all or part of the day, ask a friend, neighbor or other family member to make periodic calls, or consider an emergency monitoring device.

## Fire Safety

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

Clear all pathways and keep all exits open and unblocked. If you have a deadbolt, keep the key near the door and let everyone in the household know where to find it. Do not leave fireplaces and space heaters unattended while in use. Fireplaces should have screens or doors which are kept closed. Heaters should have screens or an automatic shutoff device. Kerosene heaters require good room ventilation. Never smoke or have open flames in your home if oxygen is being used or stored. Keep fire extinguishers within reach at home and replace them before their expiration date.

## A Weapons-Free Work Environment

Western Reserve Care Solutions, Inc. maintains a weapons-free workplace. In private homes or other residential locations, patients/responsible family members will be requested to remove any firearms from the home while staff or volunteers are there providing care. If firearms cannot be removed from the home, it will be requested that they be unloaded and placed in a secure and locked location, separate from the ammunition, and/or that the weapon is secured. In the event that a patient or family declines the request to remove or secure firearms, a determination will be made as to whether the environment is safe and if services will be able to continue. Please read the "Services at Our Hospice Inpatient Care Units" section on pp. 9-10 for background on how the policy applies at Hospice of the Western Reserve's facilities and campuses.

## Emergency Response

The agency conducts and participates in periodic emergency preparedness drills in order to test the agency's and community's emergency response plans. Team members will communicate with you in the unlikely event that these could affect you.

In the event of an actual emergency, including natural and man-made disasters, life-threatening situations or utility failures, please contact 911. Please notify the agency as soon as feasible. Follow the directions of the community emergency response system from the radio or TV.

Team members will be assigned to contact patients and families in affected emergency areas to assist with emergency response. Please contact the agency to assist in the event that the patient and/or caregiver must be moved or evacuated from their location or are transported to a hospital or emergency shelter.

## Emergency Medication Distribution

The agency, in cooperation and mutual agreement with health departments throughout Northeast Ohio, is authorized to serve as a closed point of distribution of medications needed to counteract a health threat in the event of a man-made or natural disaster. Medications and health department educational materials would be distributed to patients and their household members by team members and volunteers. This would eliminate the need to access community points of medication distribution.

## Evacuation

Have an evacuation and backup plan ready. Determine where the patient may be moved to, such as the home of a neighbor or friend. Communicate the plan to everyone involved. Prepare to shelter in place if travel or evacuation is prohibited due to weather or other conditions. Notify the agency if the patient and/or caregiver need to change locations.

## Sheltering in Place

There are many online resources that can be used to help plan for emergencies that may affect communities for a few days or possibly longer. County and city health departments, emergency management departments, Homeland Security and Ready.gov all offer guidance on how to prepare for these situations. Having a terminally ill household member makes these preparations even more important. We encourage you to access these sites in order to develop and implement emergency plans that meet your particular household situation. Plans may include emergency kits, alerts, family reunification and communications.

### Some items to consider:

- ◆ Food and water supplies: 3–5–day supply of water (1 gallon per person per day) and unrefrigerated, ready-to-eat foods
- ◆ Medications, patient care supplies and personal care supplies
- ◆ Light sources (flashlight, extra batteries)
- ◆ Battery operated radio or TV
- ◆ First aid kit
- ◆ Warm clothing/blankets/sleeping bags
- ◆ Cash in small denominations
- ◆ Identification, bank account and insurance policies in a waterproof container
- ◆ Matches in a waterproof container
- ◆ Plastic plates, cups and utensils
- ◆ Household chlorine and a medicine dropper

## Tornado Safety

A Tornado Watch means that local weather conditions exist for a tornado to develop. A Tornado Warning means that a tornado has been sighted and you should take shelter. Remain calm. If possible, move the patient to a basement. If you do not have a basement, move to the lowest level of the building in an interior room without windows, a hallway away from windows or doors or any protected area away from windows or doors. If a patient cannot be moved from their room or to a lower level, they should be moved towards an inner wall and covered with blankets. Drapes and blinds should be closed to reduce the risk of flying glass.

## Utility Failures

In the event of a utility failure, report the problem to the utility company. If the utility failure will require the patient or caregiver to change locations, please notify the agency.

### Power Outage

If the patient uses a medical device or equipment that requires an electrical source, switch to the backup energy source, if this does not occur automatically. If the patient uses an oxygen concentrator switch to the back-up tanks (see oxygen on page 19). Unplug appliances and equipment until after the power has been restored. Contact the agency if the patient needs to change location or to notify the oxygen supplier for additional oxygen. If a crisis occurs, call 911.

### Gas Leak

If you know or suspect a natural gas leak leave the area immediately and go to a safe location. Natural gas has a “rotten egg” smell. Do not do anything that could cause a spark or ignite the gas such as using electrical devices (telephones, light switches, garage door openers, e-cigarettes, etc.); using open flames (matches, lighters, cooking, candles, fireplaces) or starting vehicles. Contact the gas company. Inform the local police and fire departments. Do not re-enter the building until the gas company has given the approval. Contact the agency if the patient or caregiver need to change locations.

### Water Outage/Shortage

If a water outage or shortage occurs, use emergency bottled water or purchase bottled water. Follow advisories, notices and directions for using or boiling water. Restrict the use of available water for drinking. Contact the agency if the patient or caregiver need to change locations.

## Providing Physical Assistance to Your Loved One

Hospice of the Western Reserve has created 10 short, educational Caregiver Training videos that demonstrate how to provide essential care during daily activities such as walking, bathing and toileting. These are not meant as a substitute for one-on-one education from your hospice care team but may help you become more confident in your role as caregiver. For the full series of videos please visit [hospicewr.org/caregiver-training](http://hospicewr.org/caregiver-training).

If you do not have access to the internet, or if you prefer in-person training, one of our hospice home health aides can be scheduled to provide an instructional training visit.



### Ambulating with Your Loved One

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

### Assistance Using a Bedpan

When assisting someone to use a bedpan, it is always recommended to use gloves.

1. Explain to the person what you are planning to do.
2. Lower the bed into a flat position.
3. Help the person roll to one side in bed.
4. Place the bedpan squarely under the buttocks.
5. Roll the person back over on top of the bedpan.
6. Double check to be sure the bedpan is in the right position.
7. If able, place the person into a sitting position. Place toilet paper or a warm wash cloth next to the person.
8. Give the person some privacy, but stay close (outside the door) to hear if help is needed.
9. When they are done, lay their head down and carefully roll the person to one side to remove the bedpan.
10. Help cleanse the area if assistance is needed and pat dry.
11. Dispose of waste in the toilet and clean out the bedpan.
12. Remove gloves and wash hands.



## Assistance out of a Bed to a Chair

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

## Assistance from Sitting to Standing

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



## Caring for a Bedbound Patient

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



## Assistance Using a Commode

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



## Giving a Bed Bath

1. Gather the following supplies if giving a bed bath: wash basin, soap, lotion, washcloths and towels, gloves and clean clothes.
2. Place warm water in the basin and add soap to the wet washcloth.
3. Wash, rinse then dry one area at a time using very little soap (to avoid drying of the skin). Cover each cleaned area with a towel or blanket before moving to the next area. A common strategy is to start with the extremities and wash the trunk last.
4. Consider changing the water halfway through washing the patient so that it remains warm.
5. Check for dry skin and be sure to use moisturizing soap and lotion if you notice this.
6. Call the nurse if you notice any red areas that do not go away after several hours.
7. Keep sheets dry and wrinkle free to prevent pressure sores.
8. Be sure to turn your loved one and reposition them every two hours to prevent pressure sores.

## Skin Care

Keeping the skin moisturized and clean with frequent position changes (every two hours) is important during illness. If the skin is very dry, use moisturizing soaps and lotions.

## Positioning Your Loved One

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



## Providing Mouth Care

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



## Pulling Up a Loved One in Bed

**\*This is a two-person task**

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

## Changing Bed Sheets

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



### What is a draw sheet?

Learn more at  
[hospicewr.org/Caregiver-Training](https://hospicewr.org/Caregiver-Training)

## Assistive Equipment Use

*Using assistive equipment: walkers, canes, wheelchairs, bath benches and shower seats, etc.*

- ◆ Assistive equipment should not be used alone until the patient has been shown how to use it properly.
- ◆ If the patient is unsteady, a walker or cane should not be used without some assistance during walking.
- ◆ Equipment can be cleaned using soap and water and towel dried before subsequent use.
- ◆ A pad or pillowcase on the wheelchair seat will also help keep it clean.
- ◆ Make sure the chair or bench is secure and dry in the tub/shower before using the equipment.
- ◆ Remove all throw rugs to reduce the risk of falling.

### ▶) *Call your Hospice Care Team if:*

- ◆ The patient has fallen
- ◆ The equipment is cracked or broken
- ◆ There are any questions about the proper use of the equipment

## Caring for a Catheter

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

### Helpful Hints

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

### ▶) Call your Hospice Care Team if:

- ◆ The catheter is not draining
- ◆ The urine has an odor or change in color
- ◆ The patient spikes a fever

### Hands-On Caregiver Training

Hospice Nursing Assistants (HNAs) are available to provide instruction/training to prepare families and caregivers to provide safe personal care. Examples of the training they can provide:

- ◆ Transfer techniques
- ◆ Incontinence care
- ◆ Skin care/bathing
- ◆ Mouth care
- ◆ Safety

Contact your hospice care team if you are interested in having a training visit. Instructional videos are available at [hospicewr.org/caregiver-training](https://hospicewr.org/caregiver-training) to assist caregivers.

## Notes

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## Cardiopulmonary Care

### Chronic Obstructive Pulmonary Disease (COPD)

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

### Heart Failure (HF)

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

#### Fatigue

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

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

#### Breathing Techniques

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

In the second technique, sit in a comfortable position with hands resting on the abdomen.

Inhale slowly through the nose, feeling the stomach muscles relax. The chest does not rise. Then, tighten the stomach muscles and exhale slowly through pursed lips.

#### Managing Shortness of Breath with Medication

Your hospice care team might suggest medicine to help relieve shortness of breath. Research shows opioids (e.g., morphine) can help reduce exhaustion and relieve the feeling of breathlessness. Your hospice care team will help explain the use of any medications. A fan may also help lessen the feelings of shortness of breath.

#### ▶) *Call your Hospice Care Team if:*

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

#### Relaxation

Relaxation may be useful to cope with the physical and mental stress of COPD and HF.

Your hospice care team can provide assistance in relaxation techniques. Some general examples can be found on page 14.





## Dementia Care

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

### Caring for Yourself

Studies have shown that many caregivers who are taking care of someone with dementia experience feelings of depression as the disease nears the end (see Caregiver Needs on page 40).

### Disease Progression

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

### Cognitive

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

### Functional

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

### Nutritional

- ◆ Progressive loss of appetite
- ◆ Loss of ability to feed oneself
- ◆ Weakened capacity to swallow, increasing the risk of choking or aspiration (taking fluid and food into the lungs) and resulting in pneumonia

### Complications

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

## Dementia Symptoms

### Behavior Challenges

Each person with dementia experiences unique changes in behavior. It is important to note that while the changes can be upsetting, the person is not acting this way on purpose. There are underlying reasons such as pain or illness, noisy environment with over-stimulation or unfamiliar/unrecognizable surroundings. Your loved one may be frustrated because communication is difficult or because they can't complete an activity that used to be simple. Any changes in behavior should be discussed with your hospice care team so that a comprehensive assessment can be done.

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

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

### Creating a Calm Environment

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

## Communication

Of all the complications of dementia, the struggle to communicate may be the most troublesome. Memory loss and confusion can create barriers in a once close relationship.

In addition, it is harder to understand the patient's wants and needs. Avoid quizzing your loved one, such as, “Don't you remember?” Instead, offer reminders. Speak in a loving, patient tone. A firm or loud tone and rapid pace of your words may unintentionally express negative attitudes. A relaxed, lower tone of voice conveys patience. Getting a clear response from the patient is not the goal. Communicating to the patient is what is important – not what you get back.

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

### What Can Be Done

- ◆ Look directly at your loved one, approaching them from the front.
- ◆ Use a gentle touch to get attention and provide a physical connection.
- ◆ Avoid sudden movement as the patient may startle easily.
- ◆ Greet your loved one using their first name.
- ◆ Use short, simple words and sentences, or try gestures to help explain.
- ◆ Speak slowly, clearly and deliberately, but do not talk to them like a child.

## Dementia Care

- ◆ Give one-step directions.
- ◆ Ask questions one at a time. Patiently wait for a response, give extra time to respond.
- ◆ Accept silence. They may not talk as much as before.
- ◆ Eliminate background noise and distractions.
- ◆ Maintain eye contact at eye level, for example when they are sitting, sit also.
- ◆ Smiling helps to gain and keep attention.

## Pain and Discomfort

Pain can go unrecognized and untreated if the person is not able to express degrees of pain or other symptoms. Part of the comprehensive pain assessment is the PAINAD tool. A member of your hospice care team will use it during each visit to determine their level of pain. Simple measures such as repositioning or applying a warm compress can help alleviate discomfort.

Medications may be required to improve the level of comfort.

## Sleeping

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

### Suggestions:

- ◆ Limit intake of alcohol and caffeine.
- ◆ Plan days with interesting activities and increased exposure to daylight.
- ◆ Establish consistently scheduled times for getting up and going to bed.
- ◆ Limit daytime napping.
- ◆ Establish a bedtime routine.
- ◆ Avoid activities that might be upsetting or cause agitation near bedtime.
- ◆ Stay calm if your loved one wakes in the middle of the night.

## Eating

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

### Suggestions:

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

## Overeating

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

### Suggestions:

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

## Swallowing

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

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

### Suggestions:

- ◆ Keep eating and speaking separate to avoid choking.
- ◆ Avoid lengthy mealtimes which contribute to fatigue.
- ◆ Do not leave your loved one alone while eating.

For more tips and suggestions, see Nutrition on page 16.

## Interventions in Dementia Care

### Feeding Tube

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

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

### Medications

After review of all current medications, new medicines may be ordered, depending on the stage of the dementia. In general, medications meant to slow the advancement of Alzheimer’s dementia are no longer appropriate during the end stages of the illness when the focus of care is on comfort. All medications will be discussed with the caregiver(s) by the hospice care team.

See Medication on page 17 for more information or ask your hospice care team.

### Creative Caregiving

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



## Spirituality and People with Dementia

Spirituality is a connection to a higher sense of self and purpose in life. It is expressed in our beliefs, actions, faith and relationships with God or a higher power, self, others and creation. For people with end-stage dementia, the emotional aspects of spirituality are more meaningful, as they connect with the heart rather than the intellect. Re-affirm that life is precious, love is available and joy in the present moment is possible.

### Suggestions:

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

## Unique Grief and Loss for Dementia Caregivers

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

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

Talking about the grief you are experiencing sometimes requires help from a professional. Your hospice care team is available to provide support.

Hospice of the Western Reserve offers bereavement services that provide support, encouragement, education and resources for 13 months following the death of your loved one.

## Caregiver Needs – We Are Here for You

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

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

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

Being a caregiver can be a valuable time to create lasting and positive memories together. You may feel a sense of inner peace or a stronger sense of self-worth. You and your loved one may find moments of joy and laughter in your time together; your relationship may become more emotionally intimate. You may find time to close some unfinished business with your loved one, saying things that you need to say.

### *Caregiving responsibilities can feel overwhelming. Please be aware of:*

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

### *To effectively care for another person, you need to care for yourself. Here are some valuable suggestions:*

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

### *Maintaining good health is a priority.*

Get enough rest, eat properly and exercise.

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

### *What would you like to have help with?*

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

### *What questions do you have about providing care?*

- ◆ How do I administer medication?
- ◆ If my loved one is not eating, is starvation a possibility?
- ◆ Can we take outings?

### *What worries you?*

- ◆ Being alone and missing my loved one
- ◆ My loved one suffering and being in pain
- ◆ What are my financial obligations?

We are committed to answering your questions, supporting your needs and helping you feel more at peace and confident in caring for your loved one.

## Final Days

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

From 1–3 months before death, it is common for a person's world to focus inward. There is a shift away from the outer more social world. This is not a withdrawal of love from you, but a need to focus energy inward. Your presence is very important.

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

## Signs and Symptoms of Approaching Death

As the patient prepares for the final stage of life, you may notice physical changes taking place. Not all of these signs will appear at the same time and some may never appear at all. Please let us know what you see and experience. Your hospice care team will help you identify these changes and support you through this difficult time. You have undertaken the most precious service by caring for a loved one. It is our desire to be present with you and the patient during the last days and hours. Your hospice care team will coordinate this supportive presence for you.

### ►) *Call Your Hospice Care Team for:*

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



## Important Things to Attend to When Someone Dies

Often when death occurs, even expected death, the sadness can be overwhelming and interfere with the ability to take care of important matters that must be attended to in a timely manner. You may think, “Where do I begin?” and feel at a loss to start the process. Having a checklist may help you be more efficient and thorough. Although this list is not exhaustive, it highlights important tasks that need to be taken care of and when.

### Immediately

Notify necessary parties. Your hospice care team is available to help make these phone calls.

Hospice of the Western Reserve – if a hospice care team member is not present at death, you should call immediately:

- ◆ Family
- ◆ Funeral Home
- ◆ Physician
- ◆ Attorney

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

### After the Funeral

Obtain the following documents:

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

### Contact the following:

- ◆ Government agencies or benefits program, including alliances or unions that may be making payments to the deceased
- ◆ Creditors owed money by the deceased (credit cards, mortgage company, automobile loan agency)
- ◆ Social Security Administration to determine if you are eligible for benefits
- ◆ The deceased’s bank to handle financial matters (roll over joint accounts; determine if deceased had a safe deposit box or a bank security box and follow appropriate procedures)
- ◆ Human Resources at the deceased’s place of employment (if they were working) to discover whether there are monies you are entitled to such as vacation pay, death benefits, final wages, retirement plans, or other types of compensation
- ◆ Your attorney to discuss estate matters; do not pay any of the deceased’s debts until after meeting with a lawyer

### Request change of beneficiary or name forms from the following:

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

Cancel or forward mail and newspaper delivery if necessary. Cancel automatic payments like annual memberships or subscriptions and online bill payments.

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

## Grief and Loss

Grief is a normal, necessary, natural reaction to any loss. It is a roller coaster of emotions that involves physical, social, behavior, intellectual and spiritual responses. There is no right or wrong way to grieve. Each person grieves differently, in their own way and on their own timetable. During the course of caring for someone who is terminally ill, you may encounter feelings of grief known as “anticipatory grief”. Even with anticipatory grief, however, there is no way to be fully prepared for the deep sadness you may feel after the death of a loved one.

The hospice bereavement team will continue to offer guidance and support as you adjust to changes in your life. A bereavement coordinator will contact you in the weeks following the death to offer support and to describe group and individual services that are available throughout the year. If you would like to talk with someone sooner, please call 216.486.6838 and ask to be connected to your bereavement coordinator. Additional resources can be found at [hospicewr.org/grief](https://hospicewr.org/grief).

### Suggestions to Promote Healing

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

## Children Grieve Too

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

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

There is wide variability in the understanding of death at a young age. By age seven, most children understand the key elements of death – that it is permanent and irreversible. Accepted developmental and grief responses of 3-5-year-old children include a lack of time/space concepts, belief of death as temporary and reversible, magical thinking, fear of abandonment, and a need for physical comfort, reassurance, and a stable routine. As children mature, so does their understanding of death. The child moves from wanting to understand death in a concrete way to a morbid curiosity about the specifics of death and dying to reacting similarly to adults, but with fewer coping mechanisms.

As adults, answer all questions simply and honestly, reassure about the future, provide opportunities for feeling expression that include art and music, and allow them to be included in any funeral plans or rituals.

## Common Grief Reactions

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

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

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

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

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

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

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

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

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

## Notes

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## Personal Planning

### Advance Care Planning

There is no easy way to plan for future healthcare decisions but the best time to do it is when you are still in good health. During a health crisis, it may be too late, too difficult or just impossible to understand what your loved one wants. You and your loved one can prepare to make the choices that are right for you by developing advance directives in the form of living wills and durable powers of attorney for healthcare. These documents only become active when the person they cover is not able to make or communicate their own healthcare choices. They can be changed at any time.

Please access a free guide to assist with these forms. This all-inclusive booklet, titled *Courage in Conversation: Communicating your goals of care and healthcare choices in Ohio*, includes decision making resources, information and Ohio's living will, healthcare power of attorney and tissue donation forms. Ask a hospice care team member for a copy or visit [hospicewr.org/decisions](https://hospicewr.org/decisions).

### The Living Will

Written instructions tell physicians and family members what life-sustaining treatment is acceptable if an individual becomes unable to make decisions.

A standard Living Will form can be obtained from your hospice care team or online at [hospicewr.org/decisions](https://hospicewr.org/decisions).

### Healthcare Power of Attorney

A document that allows a person to name an advocate to make healthcare decisions on their behalf when unable to communicate, either temporarily or permanently.

The person named to make healthcare decisions needs to follow the values and instructions that have been discussed.

## 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 (DNR-CC) order, a person receives any care that eases pain and suffering, but no resuscitative measure to save or sustain life.

With a DNR-CC 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.

When a DNR-CC order is NOT in place, review and approval must be obtained by the Hospice Care Unit Clinical Team Leader prior to admission. Consultation with others, including the Administrator On-call, may be necessary.

If your hospice care team's assessment indicates that the patient's condition is worsening, and we would not be able to support them because of their desire to be resuscitated, we will call 911 and have them transferred to a hospital that can meet your goals of care. Ongoing discussion of a patient's goals of care while in the inpatient hospice care unit is very important to ensure that your wishes are met. The Hospice Care Units do not maintain resuscitative equipment or medications; therefore, we are limited in our ability to support an individual who has a cardiac arrest. If a patient does not have a DNR-CC and arrest, we will call 911 and start CPR.

## The Gift of Life: Organ and Tissue Donation

Organ and tissue donations are the gift of life. Through such donations, the lives of others can be prolonged, saved or improved. We realize that this is a difficult decision to make, especially at a time when you are experiencing intense grief, but many families have later said that their pain and loss was somewhat eased by having given a gift of life to another. If your loved one is an organ or tissue donor, please inform your hospice care team so these arrangements can be made for you.

If you would like more information about organ and tissue donation, please ask a 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, and music are commonly used in planning a memorial service. Reflect on the person's life; think about their values, special events, life's work, hobbies, travels and contributions. It will help you cope with your grief.

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

Hospice of the Western Reserve's Spiritual Care Coordinators can assist you in planning a memorial service for your loved one and are also available to conduct a memorial service.

### Things to Remember:

- ◆ **Music** Music affects our feelings and the atmosphere in which we remember our loved one. Select hymns, songs or other music that are your loved one's favorites, bring comfort or celebrate their life.
- ◆ **Readings** Reflective passages of sacred text, poems, and short stories are all helpful in remembering the person you are celebrating. Some faith traditions may require scripture be read, but many faiths are flexible and will include other types of readings as well.
- ◆ **Symbols of life** Consider using pictures, items from a person's hobbies, avocations, important moments in life, symbols of accomplishments or milestones achieved.
- ◆ **Homily, eulogy, meditation** Special thoughts and reflections help us integrate the music, readings, and symbols with the loved one's life and indicates ways the departed inspired us.

## Personal Information and Records Checklist

LOCATION

**Living Will** \_\_\_\_\_

**Durable Power of Attorney for Healthcare** \_\_\_\_\_

**General Durable Power of Attorney** \_\_\_\_\_

Name \_\_\_\_\_

Address \_\_\_\_\_

Phone \_\_\_\_\_

**Will**

Attorney \_\_\_\_\_

Executor of will \_\_\_\_\_

*If you do not have a will, we encourage you to prepare one. If you do have a will, it is a good idea to review it at this time and share it with family members and others named in the document. Volunteer attorneys are available through Hospice of the Western Reserve to help you prepare or review legal documents.*

**Insurance Policies and Policy Numbers**

Life insurance (group and/or individual) \_\_\_\_\_

Health insurance \_\_\_\_\_

Home insurance \_\_\_\_\_

Auto insurance \_\_\_\_\_

Disability insurance \_\_\_\_\_

Renter's insurance \_\_\_\_\_

**Insurance Agent/Broker** Name \_\_\_\_\_

Address \_\_\_\_\_

Phone \_\_\_\_\_

**Real Estate Deeds** Location of property \_\_\_\_\_

Titles in name of \_\_\_\_\_

# Personal Information and Records Checklist

## LOCATION

**Mortgages, records, or mortgage payments information** \_\_\_\_\_

**Stocks, bonds, certificates of deposit** \_\_\_\_\_

**Brokerage firm/broker**  
Name \_\_\_\_\_  
Address \_\_\_\_\_  
Phone \_\_\_\_\_

**Savings account**  
Name \_\_\_\_\_  
Account # \_\_\_\_\_

**Checking account**  
Name \_\_\_\_\_  
Account # \_\_\_\_\_

**Safe deposit box**  
Location of box and key \_\_\_\_\_  
Name box is under \_\_\_\_\_  
City, state, federal tax \_\_\_\_\_

**Returns for the past several years** \_\_\_\_\_

**Birth certificate** \_\_\_\_\_

**Social security card** \_\_\_\_\_

**Marriage/divorce certificates** \_\_\_\_\_

**Automobile titles** \_\_\_\_\_

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

**Military discharge papers** \_\_\_\_\_

**Contracts** (e.g., Installment purchase agreements) \_\_\_\_\_

**Business records** \_\_\_\_\_

**Receipts for furs, jewelry, etc.** \_\_\_\_\_

**Credit cards** \_\_\_\_\_

## Memorial Worksheet

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

One of the ways we are able to do this is to offer assistance in planning for the time ahead.

Having accurate memorial information available for newspapers and the funeral director is an important task; most of this can be done in advance. We 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.

We are honored to care for you and your family during this important time. Some families and friends choose to make tribute gifts or to direct gifts in lieu of flowers. Every donation is appreciated and meaningful to our families.

### *Patient Information*

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip Code \_\_\_\_\_

Birthplace \_\_\_\_\_

Came to the area from \_\_\_\_\_ When \_\_\_\_\_

Occupation \_\_\_\_\_

Names of spouse and other loved ones \_\_\_\_\_

\_\_\_\_\_

Major/area employer no. of yrs. \_\_\_\_\_

Church/religious affiliation \_\_\_\_\_

Organizations/offices \_\_\_\_\_

Major achievements/honors \_\_\_\_\_

Military service/recognition \_\_\_\_\_

Charity of choice \_\_\_\_\_

## Memorial Planning

For many patients and families, pre-planning the funeral offers an amount of control and comfort. It provides an opportunity for all involved parties to share their ideas and choices 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 preplanned and prepaid funeral. Along with peace of mind, preplanned funerals and may also secure a lower 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 your 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 name and plot number \_\_\_\_\_

Specific instructions \_\_\_\_\_

Organ donor organization \_\_\_\_\_

Contact number \_\_\_\_\_

Body donation organization \_\_\_\_\_

Contact number \_\_\_\_\_

## Probate

The following explanation is information, not legal advice. Hospice of the Western Reserve urges you to consult an attorney for legal needs. There are two functions of Probate Court:

1. Once a person dies, Probate Court becomes involved to ensure the proper distribution of 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 of the Western Reserve volunteer attorneys cannot provide this service.)

## Financial Power of Attorney

A legal document in which someone gives another person the authority to make specific financial decisions or assumes certain financial responsibilities.

It is advisable to consult an attorney or legal aide to obtain this document. Volunteer attorneys are available for free; contact your hospice care team if you need a volunteer attorney.

## Notes

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## VA Benefits

There are specific burial benefits that the 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, 10th Floor, Cleveland, Ohio 44114  
Benefits information and assistance: 800.827.1000  
Veterans of Foreign Wars: 216.522.3510

### Veterans Service Commission

1849 Prospect Avenue, E #150  
Cleveland, Ohio 44115  
216.698.2600  
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.

## Giving Back

Families and friends often ask, “How can we thank you for your services?” By giving back, you help ensure that compassionate care will be available to other families in need. Your contribution will directly support patient care and no gift is too small. Below are a few ways you can help, but for the most current information, please visit our website at [hospicewr.org/Ways-to-Give](http://hospicewr.org/Ways-to-Give).

### In Lieu of Flowers, Request Donations

Include Hospice of the Western Reserve and [hospicewr.org](http://hospicewr.org) in your loved one’s obituary. You will honor their memory with a lasting gesture that helps others, while thanking the caregivers who helped you through a difficult time.

### Create an Estate Plan

What do you wish your philanthropic legacy to be? Perhaps you wish to help other families as you have been helped. Consider the future and make Hospice of the Western Reserve a beneficiary of your will or life insurance policy or transfer a gift directly from your IRA. Please let us know of your intentions so we can support your wishes.

### Inscribe a Memorial Brick or Granite Tribute

Honor your loved one by placing an inscribed stone or brick in any of our three memorial gardens – Ames Family Hospice House, David Simpson Hospice House, and the Medina Inpatient Care Center. Other tribute garden options include dedicating a granite bench personalized with a name or sentiment and planting a tribute tree. Visit [hospicewr.org/tributes](http://hospicewr.org/tributes) for options.

For more information on any of these programs, or to make a gift over the phone, please call the Development Office at 216.298.0245.

To make a gift online, please visit [hospicewr.org/Tribute](http://hospicewr.org/Tribute).

We look forward to talking with you soon.

### Volunteer

Many of our volunteers have been touched by a hospice experience. You have talents that our patients and families need, and we offer a variety of volunteer opportunities for individuals and groups. Pick up groceries. Read a story. Feed a pet. You decide how often and in what way you want to help. Details are available at [hospice.org/volunteer](http://hospice.org/volunteer).

### Walk with Us

Each June, the annual Walk to Remember attracts more than 2,000 friends of Hospice of the Western Reserve who gather to celebrate life and to remember their loved ones. Details are available at [hospicewr.org/wtr](http://hospicewr.org/wtr).

### Third Party Fundraisers

Do good while having fun with your friends, service group, civic club, religious organization, or company. Organize a putt-putt golf outing. Hold a bowling event. We’ll provide the help you need to get started and encouragement along the way.

## Reference

### The Hospice Medicare Benefit and other insurance coverage

Medicare provides a special program for those needing hospice care. The hospice benefit covers services, medications, supplies and equipment needed for the comfort of seriously ill patients. All services, medications, supplies and equipment related to the terminally 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.

Medicare Part D coverage will be assessed upon admission. Payment for medications not authorized under Part D are the patient's responsibility.

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

### Hospice Eligibility Explained

- ◆ Patient has Medicare Part A
- ◆ Patient's doctor and the hospice medical director have confirmed the terminal illness
- ◆ Patient signs a statement choosing hospice care benefits
- ◆ Patient receives care from a Medicare-approved hospice (Hospice of the Western Reserve is Medicare-approved)
- ◆ Patient has months rather than years to live.

### The Hospice Benefit Periods Explained

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

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

If a patient has symptoms such as increased pain, acute nausea, vomiting, or shortness of breath that are proving difficult to manage at home, a few days in one of our three hospice inpatient care units may be necessary. The need for this must be assessed by a hospice nurse. If such a trip out of home is needed, the hospice care team members will help arrange transportation.

The Medicare Hospice Benefit requires the preauthorization of any hospital stay related to the terminal illness, including the emergency room. Call your hospice care team day or night before making a trip to the hospital.

### Medicaid

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

### The Champus Program (TRICARE Insurance)

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

### Private Insurance

Most private insurance carriers have hospice coverage within their program. We will contact the insurance company regarding the coverage. Please contact your primary nurse or social worker with any changes to your healthcare coverage or if you have any questions.



## 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 care team, which includes the physician, and continuously discuss goals for my care, activities of daily living and quality of life.
- ◆ Participate in the management of care that may involve personal care, treatments and medication administration.
- ◆ Inform the hospice care team of other agencies providing care and services to me.
- ◆ Be at home and available for the visits scheduled with hospice care 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 hospice care 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 care team. The Team Leader may be contacted at the designated team office for further assistance with the resolution.
- ◆ Treat hospice caregivers with respect and courtesy, understanding that if they are not afforded such respect and courtesy, they will leave the home immediately. Subsequent visits will be scheduled with the assistance of the Team Leader.
- ◆ Call the hospice care team (if after hours, the On-call Team) with any questions, change of condition or symptoms.
- ◆ Call Hospice of the Western Reserve, rather than 911, for immediate assistance.

## Patient and Family Bill of Rights

Learn more at [hospicewr.org/rights](http://hospicewr.org/rights).

### Grievance Procedures

Your satisfaction is our priority. Hospice of the Western Reserve is committed to ideal patient care. We encourage you to speak to us regarding any problem affecting your care. If you are not satisfied with the care provided, we urge you to take the following steps:

- ◆ Talk over your concerns with your hospice care team. Most concerns will be resolved this way. If your concern is not resolved, call the Team Leader.
- ◆ If this concern occurs during the weekend or in the evening, request the Supervisor On-call when calling the on-call nurse.
- ◆ You may also contact the Administrator On-call by calling 216.255.9071.
- ◆ Call or write the Chief Quality Officer at 216.486.6007 who will respond to your concern within 48 hours.
- ◆ If your concern/complaint still has not been addressed to your satisfaction, call the Chief Clinical Officer at 216.383.3730.
- ◆ At any time, you have the right to refer the problem to:

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

Or, call the toll-free Ohio Department of Health hotline: 800.342.0553

## Corporate Compliance Plan

### Standards of conduct

In concert with our mission, Hospice of the Western Reserve operates in an ethical and conscientious manner, adhering to laws and regulations in providing hospice care and services to the communities we serve. The agency will tolerate no fraud, waste or abuse in conducting our business or in delivering services to our patients and families. As an employee or volunteer of the agency, everyone has the responsibility to act in a manner which upholds the law, to actively participate in and promote compliance, and to report any activity they become aware of that violates any law or regulation.

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

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

## Patient Privacy and Confidentiality

The agency 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 and its affiliates have the following privacy rights:

- ◆ To have electronic access to the agency's Notice of Privacy Practices via the website [hospicewr.org/privacy](http://hospicewr.org/privacy)
- ◆ To receive a paper copy of the organization's Notice of Privacy Practices upon request
- ◆ 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 healthcare information
- ◆ To request an accounting of disclosures of health information.
- ◆ The privacy policies detail the requirements for each of these rights and provide procedures for implementation. Staff and volunteers at the agency are provided with periodic training regarding patient rights with respect to health information.

## Compliance and Privacy

Mary Kay Tyler, MSN, CNP, CHPCA

*Chief Quality Officer*

*Privacy and Compliance Officer*

Hospice of the Western Reserve, Inc.

17876 St. Clair Avenue

Cleveland, Ohio 44110

Phone: 216.383.3745 or 216.486.6007

Email: [mktyler@hospicewr.org](mailto:mktyler@hospicewr.org)

HIPAA hotline voicemail: 216.383.6688



## Non-Discrimination Statements

### English

Hospice of the Western Reserve complies with applicable Federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability, or sex.

Hospice of the Western Reserve does not exclude people or treat them differently because of race, color, national origin, age, disability, or sex.

Hospice of the Western Reserve:

- ◆ Provides free aids and services to people with disabilities to communicate effectively with us, such as:
  - Qualified sign language interpreters
  - Written information in other formats (large print, audio, accessible electronic formats, other formats)
  - Free language services to people whose primary language is not English, such as:
    - Qualified interpreters
    - Information written in other languages

If you need these services, contact 216.383.6688.

If you believe that Hospice of the Western Reserve has failed to provide these services or discriminated in another way on the basis of race, color, national origin, age, disability, or sex, you can file a grievance with:

Mary Kay Tyler, MSN, CNP, CHPCA  
*Chief Quality Officer*  
*Privacy and Compliance Officer*  
 Hospice of the Western Reserve, Inc.  
 17876 St. Clair Avenue  
 Cleveland, Ohio 44110  
 Phone: 216.383.3745 or 216.486.6007  
 Email: [mktyler@hospicewr.org](mailto:mktyler@hospicewr.org)

You can file a grievance in person or by mail, fax, or email. If you need help filing a grievance, Mary Kay Tyler 216.383.6688 is available to help you. You can also file a civil rights complaint with the U.S. Department of Health and Human Services, Office for Civil Rights electronically through the Office for Civil Rights Complaint Portal, available at <https://ocrportal.hhs.gov/ocr/portal/lobby.jsf>, or by mail or phone at: U.S. Department of Health and Human Services, 200 Independence Avenue SW., Room 509F, HHH Building, Washington, DC; 20201, 800.368.1019, 800.537.7697 (TDD). Complaint forms are available at <http://www.hhs.gov/ocr/office/file/index.html>.

## Español (Spanish)

Hospice of the Western Reserve cumple con las leyes federales de derechos civiles aplicables y no discrimina por motivos de raza, color, nacionalidad, edad, discapacidad o sexo. Hospice of the Western Reserve no excluye a las personas ni las trata de forma diferente debido a su origen étnico, color, nacionalidad, edad, discapacidad o sexo.

Hospice of the Western Reserve:

- ◆ Proporciona asistencia y servicios gratuitos a las personas con discapacidades para que se comuniquen de manera eficaz con nosotros, como los siguientes: Intérpretes de lenguaje de señas capacitados.
- ◆ Información escrita en otros formatos (letra grande, audio, formatos electrónicos accesibles, otros formatos).
- ◆ Proporciona servicios lingüísticos gratuitos a personas cuya lengua materna no es el inglés, como los siguientes: Intérpretes capacitados.
- ◆ Información escrita en otros idiomas.

Si necesita recibir estos servicios, comuníquese con 216.383.6688

Si considera que Hospice of the Western Reserve no le proporcionó estos servicios o lo discriminó de otra manera por motivos de origen étnico, color, nacionalidad, edad, discapacidad o sexo, puede presentar un reclamo a la siguiente persona:

Mary Kay Tyler, MSN, CNP, CHPCA  
*Chief Quality Officer*  
*Privacy and Compliance Officer*  
 Hospice of the Western Reserve, Inc.  
 17876 St. Clair Avenue  
 Cleveland, Ohio 44110  
 Phone: 216.383.3745 or 216.486.6007  
 Email: [mktyler@hospicewr.org](mailto:mktyler@hospicewr.org)

Puede presentar el reclamo en persona o por correo postal, fax o correo electrónico. Si necesita ayuda para hacerlo, Mary Kay Tyler 216.383.6688 está a su disposición para brindársela. También puede presentar un reclamo de derechos civiles ante la Office for Civil Rights (Oficina de Derechos Civiles) del Department of Health and Human Services (Departamento de Salud y Servicios Humanos) de EE. UU. de manera electrónica a través de Office for Civil Rights Complaint Portal, disponible en <https://ocrportal.hhs.gov/ocr/portal/lobby.jsf>, o bien, por correo postal a la siguiente dirección o por teléfono a los números que figuran a continuación: U.S. Department of Health and Human Services 200 Independence Avenue, SW Room 509F, HHH Building Washington, D.C. 20201 800.368.1019, 800.537.7697 (TDD) Puede obtener los formularios de reclamo en el sitio web <http://www.hhs.gov/ocr/office/file/index.html>.





HOSPICE  
OF THE  
WESTERN  
RESERVE

# HOSPICE CARE

CARE TEAM: \_\_\_\_\_

# CALL \_\_\_\_\_

ANYTIME, DAY OR NIGHT, WEEKENDS OR EVENINGS

Member of your Care Team include:

- ◆ Nurse: \_\_\_\_\_
- ◆ Nursing Assistant: \_\_\_\_\_
- ◆ Social Worker: \_\_\_\_\_
- ◆ Spiritual Care: \_\_\_\_\_

If not able to reach assistance at number listed above, call 440.942.6699.

800.707.8922 | [hospicewr.org](http://hospicewr.org)

Certified Medicare/Medicaid Hospice, Licensed in Ohio  
Joint Commission on Accreditation of Healthcare Organizations



If you do not speak English, language assistance services, free of charge, are available to you. Call 216.383.6688.

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