



WESTERN RESERVE NAVIGATOR

Patient and Family Palliative Care Guide

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.

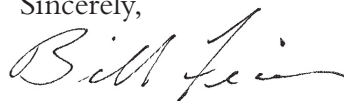
Welcome

WESTERN RESERVE NAVIGATOR PALLIATIVE CARE is a nationally recognized award-winning service offered by Hospice of the Western Reserve. If you are living with a serious, long-lasting disease, the support of our palliative care team can make your life – and the lives of those who care for you – much easier.

Quality of life matters. Through symptom management in your home or home-like setting, your team will help you stay more independent and reduce or prevent repeated hospitalizations. You can receive palliative care as an extra layer of support to help manage your symptoms along with the care you are already receiving from your primary doctors.

We are honored that you and your loved one have placed your trust in us. Thank you for choosing Western Reserve Navigator.

Sincerely,

A handwritten signature in black ink, appearing to read "Bill Finn", with a stylized, flowing script.

William E. Finn

President and CEO

Hospice of the Western Reserve

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Introduction

PALLIATIVE CARE IS SPECIALIZED CARE FOR

PEOPLE LIVING WITH A SERIOUS ILLNESS. This type of care is focused on providing relief from the symptoms and the stress of the illness. The goal is to improve quality of life for both the patient and the family.

Palliative care is based on a patient's needs, not on their prognosis. It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment.

Palliative care may be appropriate for individuals who have been diagnosed with a serious or advanced illness. Unlike hospice care, patients may choose to receive palliative care while continuing to pursue aggressive treatment, further diagnostic testing or skilled services.

Our palliative care team is comprised of nurse practitioners, social workers and trained volunteers. The palliative care team helps minimize stressful and costly emergency room visits and unnecessary hospitalizations. We work collaboratively with your doctor to better manage your symptoms.

Your Palliative Care Team

Advanced Practice Nurses address medical needs. Their focus is on:

- ◆ Managing pain, shortness of breath, constipation, anxiety, depression and other symptoms
- ◆ Collaborating with your primary physician on your goals of care.

Social workers assist with:

- ◆ Access to community resources
- ◆ Patient, family and caregiver support
- ◆ Advance care planning
- ◆ Goals of care

Trained volunteers provide:

- ◆ Spiritual support
- ◆ Social visits/companionship
- ◆ Respite for caregivers
- ◆ Legacy work



Emotional support is so important during health challenges. Our trained team members can help with difficult conversations about the completion of Living Will and Durable Health Care Power of Attorney forms. Completing these advance directives will allow you to specify your personal wishes, goals and preferences. Your care team can also help you complete paperwork for programs such as Medicare, Medicaid and Passport.

On-call Service

Questions, concerns and problems often occur at night, on weekends and during holidays. We encourage you or your caregivers to use our on-call service when these needs arise. To reach the on-call service, call 216.486.6512. 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 support. (This may include a visit.) The Western Reserve Navigator office number will always work, 24/7, day and night.

Please refer to the Communication Card for names and contact numbers. Keep it in an easily located area of your 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 waiting for the return call. 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.



Peaceful & Proud: Personalized Care for Veterans

Military service colors the way veterans face advanced illness. Providing palliative care for those who have served in our armed forces requires special sensitivity, understanding and respect. Peaceful & Proud has been developed to meet their needs. Through Western Reserve Navigator, palliative care can be provided in the veteran's own home, in assisted living communities or in VA-contracted facilities.

The emotional and spiritual components of palliative care can be especially meaningful to veterans. Through the Peaceful & Proud program, the Agency's staff and volunteers receive training in post-traumatic stress disorder and other service-related issues impacting veterans, such as remorse, regret, anxiety and substance abuse.

Veteran-to-veteran volunteering matches patients with volunteers who can relate to them as fellow service members. Counseling, storytelling, art and music therapy and legacy work are some of the other ways we work with veterans. Connecting veterans and their families with community resources is also a vital part of our work. Our social workers help navigate the complex maze of government agencies and services so they can get access to all the services and benefits available to them.

Veterans Recognition Ceremonies are another meaningful aspect of Peaceful & Proud. Veterans are honored for their service and presented with a commemorative lapel pin issued by the Ohio Hospice Veteran Partnership.

Billing: How do I pay for this service?

Most commercial insurance plans, as well as Medicare and Medicaid, cover palliative care. Your commercial insurance may require a copay. Contact a palliative care team member if cost or benefit coverage is a concern.

Palliative Care in Assisted Living Communities and 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 palliative care. We provide the same support and care for a resident there as we would for a person living in a private home.



Symptom Management

Pain

Pain is whatever the patient says it is. Determining whether pain is physical, spiritual or emotional helps develop a plan for pain management. Often, physical and emotional pain go hand in hand. Relief of pain helps the patient sleep, eat, move and perform normal activities. It can help patients feel less fearful or depressed. At the same time, physical pain may not be managed until the emotional or spiritual issues are addressed. Our team is trained in palliative care and will continually evaluate the nature and severity of pain.

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. 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 without talking to your palliative care team
- ◆ Apply hot or cold compresses
- ◆ Use distraction: TV, music or a game might help until the medication works
- ◆ Consult with your team about using relaxation techniques, guided imagery or meditation recordings
- ◆ Use light touch or massage

►) Call the palliative care team if:

- ◆ The pain is new or worse
- ◆ The medications no longer seem to work
- ◆ There are side effects
- ◆ You are unable to take the medication

Shortness of Breath/ Breathing Difficulty

Shortness of breath is an uncomfortable and sometimes frightening feeling that may be caused by disease process, fatigue or feelings of distress/anxiety. Patients and caregivers should try to stay calm if shortness of breath is present.

- ◆ Open window or use a fan
- ◆ Raise head of bed
- ◆ Encourage slow calm breathing, in through the nose and out through the mouth
- ◆ Provide relaxing environment
- ◆ Apply cool cloth to face
- ◆ Take prescribed medications
- ◆ Use oxygen if prescribed
- ◆ Conserve energy by restricting activity

Breathing Techniques

There are two breathing techniques that help patients take in more oxygen-rich air.

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.

SECOND TECHNIQUE: Sit in a comfortable position with hands resting on the stomach. 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.

►) Call if:

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



HELPFUL RELAXATION TECHNIQUES

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

- Find a place free of distraction and interruptions
- Dim the lights and turn off the television
- Silence phones
- Turn on soothing music (optional)
- Lie in bed or sit in a comfortable chair
- Lie down or sit quietly to focus on breathing

Naturally, breathing will begin to slow down as you begin to focus on exhaling. As breathing slows, let the weight of your body sink into the chair or bed. Imagine a favorite place. Imagine moving around in this place. Notice all the colors, sounds and smells of the surroundings.

Enjoy this place and the relaxing feeling it engenders. Movement is free, and breathing is easy. When you are ready to return from this place, slowly move fingers and toes and return to an upright position.

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
- ◆ Take medications as directed
- ◆ Be reassuring/present

May be caused by:

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

► Call if:

- ◆ Anxiety is new
- ◆ Interventions do not relieve the anxiety

Restlessness

Can't rest, focus, concentrate, constantly moving

- ◆ 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
- ◆ Take medications as ordered

► Call if:

- ◆ Restlessness is new
- ◆ Interventions are not working

Fatigue

A common symptom we treat is fatigue. It can be difficult for patients to perform everyday tasks such as dressing or putting away groceries. Making a plan to work around fatigue increases quality of life.

ISSUE	INTERVENTION	RATIONALE
Interrupted rest/sleep	<ul style="list-style-type: none"> • Establish routine, uninterrupted sleep patterns • Take short rests or naps during the day • Limit alcohol and tobacco use • Avoid caffeine and other stimulants • Get exposure to light daily 	Minimize time in bed
Nutrition	<ul style="list-style-type: none"> • Eat 6 small meals instead of 3 large meals • Increase protein snacks • Maintain frequent oral hygiene practices • Eat light bedtime snacks 	Food may help energy levels; less energy is needed for digestion with small frequent meals.
Distraction	<ul style="list-style-type: none"> • Encourage activities to restore energy, (e.g., time outdoors) • Listen to music, meditate and engage in hobbies • Plan and schedule activities 	Pleasant activities may reduce or relieve mental fatigue.
Mobility	Consider assistive devices such as walker, cane, bedside commode and/or wheelchair	Assistive devices help conserve energy.

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

Mental Changes or Delirium

Symptoms may include personality changes, unexplained mood changes, confusion, sleeplessness.

DO:

- ✓ Speak slowly and clearly
- ✓ Provide safe environment
- ✓ Attempt to tell them where they are or who people are
- ✓ Explain what and why you are doing something

DO NOT

- ✗ Argue with patient if they don't understand

►) Call the palliative care team if:

- ◆ Symptoms are new
- ◆ Interventions are not working

Nausea and Vomiting

Nausea and vomiting may be experienced for a number of reasons: starting a new pain medicine, an infection, anxiety or a change in the illness. Call your palliative care nurse if nausea or vomiting begins. Do not stop taking the pain medicine without speaking to the nurse first.

Helpful hints to combat nausea and vomiting:

- ◆ Avoid heavy meals, dairy products, fatty foods and strong smells.
- ◆ Avoid excessive activity and lying down after eating
- ◆ Do not force yourself to eat
- ◆ Maintain a quiet area with good air flow
- ◆ Take clear liquids: sips of water, ginger ale, peppermint tea, ice chips, popsicles
- ◆ Provide mouth care: brush teeth, clean dentures
- ◆ Wait two hours after vomiting to drink more fluids
- ◆ Follow a bland diet if no vomiting for 24 hours: toast, crackers
- ◆ Take medications as instructed by the palliative care team

►) Call if:

- ◆ Nausea or vomiting is new
- ◆ Nausea continues after interventions or medicine
- ◆ Nausea is associated with pain
- ◆ Vomit has blood or is black

The Role of Nutrition

When living with an advanced illness, it is normal to experience appetite changes and alterations in eating and drinking. Frequent oral care, small sips of fluid, ointment to the lips and light massage with lotion are all ways to promote comfort and provide support. Eating smaller portions more frequently may be helpful. Three to six light meals or smaller portions per day are usually better tolerated than traditional meal sizes. Try drinking fluids between meals instead of with meals to prevent feelings of fullness. Arrange meal times when you (or your loved one) are most rested and active. Do not force eating.

Difficulty Swallowing

DO:

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

Things to avoid:

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

Utilize 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 palliative 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
- ◆ Reduce metallic taste with gum, mints, lemon drops
- ◆ Try sweetening foods
- ◆ Serve food at room temperature or cold – foods will 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

DO:

- ☑ Keep a written record of when/how often medication is to be taken
- ☑ Keep all medication away from children and pets
- ☑ Take medicine exactly how it was ordered
- ☑ Record when and how much of an "as needed" or "PRN" medication is taken
- ☑ Inform your palliative care team of any vitamins, herbal medications or over-the-counter medications being taken
- ☑ Inform your palliative care team if a medication is added or changed

DO NOT:

- ☒ Change a medication dose or stop taking a medication without medical instructions
- ☒ Give medication to anyone other than the patient
- ☒ Crush a medicine unless instructed to do so
- ☒ Take more medicine than what has been ordered

Side Effects of Medications

- ◆ Sleepiness: Can last for 1-3 days. The body will usually adjust. Can occur with new medications or with changes in dosing
- ◆ Constipation (no, small or hard bowel movements): increase liquids if possible; medication may be started routinely or as needed to help.
- ◆ Diarrhea/loose stools: do not take medication to stop it unless your palliative care team instructs
- ◆ Nausea may occur for 1-2 days. Medication may be put in place to assist with this. Natural remedies may include: ginger ale, peppermint candy/gum
- ◆ Some side effects will decrease or go away
- ◆ Some symptoms may be a result of changes in the illness

►) Call your palliative care team if:

- ◆ Itching, rash, hives
- ◆ Upset stomach/vomiting
- ◆ Side effects last longer than expected
- ◆ Causing distress
- ◆ Feeling too sleepy, less aware

OPIOIDS AND SEDATIVE DRUGS are commonly used to control symptoms. 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. Often, the drowsiness will stop after the person's system gets accustomed 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. This may occur due to the disease, not necessarily due to any medications. Patients rest and sleep more as the disease progresses. If you are concerned about the drowsiness or sedative side effects, please let your palliative care team know of your concern. If you want to be more alert, changes can be made in the medication.

Home Care

The patient's family/caregiver will be instructed on the disposal of medications as needed.

If abuse or drug diversion is suspected or the family refuses to dispose of medications, local authorities will be notified. For additional information please refer to the Food and Drug Administration's (FDA) website.

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, to further discourage identification

Additional Disposal Methods at Home:

- ◆ Utilize any community or pharmaceutical program allowing for proper disposal of medications
- ◆ Utilize Ohio State Drug Repository Program if 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.



Oxygen

The use of oxygen is determined by the doctor and/or nurse practitioner and must be used as instructed. To notify others that oxygen is in use, you must post “No Smoking” signs that are visible to all visitors. There may be two devices provided the company that delivers oxygen: 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 the oxygen provider if equipment stops working
- ◆ If electricity goes out or equipment stops working, use the cylinders provided and contact your oxygen provider immediately to determine a plan

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:

- ◆ Providing patient care
- ◆ Using gloves
- ◆ Using the bathroom
- ◆ Eating or smoking
- ◆ 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

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.

Respiratory Hygiene

Respiratory hygiene/cough etiquette limits 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
- ◆ Cough and sneeze into your upper sleeve, not your hands
- ◆ Wash your hands with soap and water or clean with an alcohol-based cleaner

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 in October or 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.

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 trash 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 needs to be made daily; use household disinfectants appropriate to 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. Request "no visiting" if visitor has a cold or does not feel well
- ◆ If the primary caregiver or other family member is ill, the best choice would be to relieve the caregiver of duties until well again. If this isn't possible, use good hand washing, gloves and a disposable surgical mask to protect the patient
- ◆ Request advice from your palliative 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 your palliative care nurse if any unusual bleeding occurs. If bleeding occurs, apply moderate pressure to the area if possible.

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 9)
- ♦ Use a soft toothbrush, sponge, or “toothette” to prevent gums from bleeding; avoid flossing
- ♦ Blow nose gently

►) *Call your palliative care team if:*

- ♦ Blood is visible in urine, stool, sputum or vomit
- ♦ A bloody nose is experienced (several episodes or a nosebleed that is not easy to control)
- ♦ You notice multiple bruises
- ♦ Many small, reddish-purple spots appear under skin

Preventing the Transport of Bed Bugs

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

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

Your 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 team takes with them from the home or facility will be sealed in a plastic bag before they leave.

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 palliative care team and other visitors.

Pet Control

For the safety of your palliative care team and your family pets, we ask that you contain any pets prior to team members entering the home. 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, the organization 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 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 before a bath or shower.

Telephone

Be certain that all cell and cordless phones are charged and place palliative care team and emergency phone numbers in easy-to-find places near phones. Keep a phone near your bed or chair, within easy reach. If you are 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.

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.

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 if patient changes location.

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 changes location.

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 seriously 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 of your new location.

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 11). Unplug appliances and equipment until after the power has been restored. Contact the agency if the patient changes location. Patient/family should 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. Notify the agency if the patient has a change of address due to safety needs.

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. Notify the agency if the patient has a change of address due to safety needs.

Physical Assistance

Assistive Equipment Use

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

- ◆ Your care team can help identify needs and resources and obtain equipment.
- ◆ Assistive equipment should not be used alone until you have 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

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.

When home care is in place, they are your first call for catheter issues.

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, per instructions from your physician and/or homecare team

- ◆ Empty the drainage bag 1-2 times per day; empty leg bag 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

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 to perform everyday tasks such as walking short distances (i.e., down your driveway or around the house) or sitting at the dinner table. Your palliative 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. Those 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.

Breathing Techniques

There are two breathing techniques that help patients in end-stage cardiopulmonary disease take in more oxygen-rich air.

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.

Second technique – Sit in a comfortable position with hands resting on the abdomen.

Inhale slowly through the nose, feeling stomach muscles relax. The chest will not rise. Tighten stomach muscles and exhale slowly through pursed lips.

Managing Shortness of Breath with Medication

Your palliative 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 palliative care team will help explain the use of any medications. A fan may also help lessen the feelings of shortness of breath.

► *Call your palliative care team if:*

- ◆ You experience increased shortness of breath
- ◆ You need an increased use of an inhaler or nebulizer
- ◆ You feel excessively fatigued
- ◆ There are increased mucus secretions
- ◆ There are changes in color of secretions
- ◆ You have a fever
- ◆ You experience a weight gain of two or more pounds in one day, or five pounds in one week
- ◆ You are waking during the night, unable to breathe
- ◆ You experience pain in chest, arms, neck, jaw, or back that is not relieved by current medications

Relaxation

Relaxation may be useful to cope with the physical and mental stress of COPD and HF. See page 6 for additional “Helpful Relaxation Techniques”

Spirituality and Patients with COPD/HF

Exploring spirituality can be helpful emotionally and further enhance relaxation. Spiritual care volunteers may be helpful in discussing fears, regrets and hopes.

Consider the following:

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

Suggestions:

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

Phone Support: A Call to Connect

Your cardiopulmonary phone support team is comprised of volunteers who make monthly phone calls to patients with a cardio or pulmonary diagnosis who reside in a private residence. Caregivers of patients living in nursing facilities who are interested in receiving monthly phone calls from a volunteer should let their palliative care team know. We encourage patients and caregivers to use these calls to discuss any difficulties they may be experiencing.

A Call to Connect is a simple yet effective service that keeps you connected with your palliative care team. It provides support and monitoring of symptoms and reminds the family that their Navigator team is available to assist when needed.

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. Your palliative care team 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 22).

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. Changes in behavior should be discussed with your palliative 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.

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 them 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. The PAINAD tool looks at signs, like grimacing, moaning, and body rigidity, which can indicate 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. You may be able replace meals with high-calorie snacks.

Suggestions:

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

Overeating

In some instances, the person cannot sense fullness or differentiate nutritious foods from foods that are less healthy. 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.

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 occur in voice quality/tone, frequent throat clearing, poor oral hygiene and weight loss or dehydration.

During mealtimes, the person may experience uncoordinated chewing or swallowing, multiple swallows for each mouthful, pocketing of food in the cheeks, or coughing or sneezing during/ following eating. If the patient experiences pain or discomfort in the throat or chest when swallowing or has a sensation of food/liquid “sticking” in the throat, 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.

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 8.

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 palliative care team will respect your wishes.

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.

Connecting with Music

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

Suggestions:

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

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

The Importance of Touch

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

Suggestions:

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

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 palliative care team is available to provide support.

Care Transitions

Everyone's life is unique, and so is everyone's journey through a serious illness. Your palliative care team will do everything they can to help you feel more confident and less anxious when things begin to change. Your team can provide education on changes that may occur as a patient nears end of life. These changes will allow for identification of patient's wishes and goals and may involve conversations about the hospice level of care when appropriate.

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 seriously ill person. A caregiver is most often a family member or close friend.

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

Here are some valuable self-care tips:

- ◆ 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.

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.

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. Your social worker can connect you with community resources to help with your needs.

Planning Ahead

What questions do you have regarding future needs?

- ◆ Funeral arrangements
- ◆ Personal planning
- ◆ Advance care planning
- ◆ Living Will
- ◆ Durable Power of Attorney for Healthcare

Caregiver Needs

- ◆ Grief and loss
 - ◆ Specific to patient (e.g., loss of independence)
 - ◆ Specific to family/caregiver (e.g., anticipatory grief)
 - ◆ The gift of life – organ and tissue donation

Contact your palliative care team member to assist with planning for your future needs.

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.

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. Donations of any size are always welcome. Gifts directly support patient care and family services. And there are many additional, meaningful ways to give back. What a wonderful, lasting way to carry on the memory of those we love.

In Lieu of Flowers, Request Donations

Include Hospice of the Western Reserve and 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 Hospice 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.

Volunteer

Many of our volunteers have been touched by the care their loved one and family received. 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.

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/events.

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

Patient Responsibilities

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

- ◆ Participate in the development of my plan of care in conjunction with the palliative care team, which includes my physician.
- ◆ Inform the palliative care team of other agencies providing care and services to me.
- ◆ Be at home and available for the visits scheduled with palliative 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 palliative 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 palliative care team. The team leader may be contacted at the designated team office for further assistance with the resolution.
- ◆ Treat palliative care team members 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 palliative care team (if after hours, the On-call Team) with any questions, change of condition or symptoms.
- ◆ Provide information to the team that is important to care, treatment and services.

Patient and Family Bill of Rights

Learn more at hospicewr.org/rights.

Grievance Procedures

Your satisfaction is our priority. Our organization 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 palliative 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
- ♦ 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

HIPAA hotline voicemail: 216.383.6688

Ethics Committee

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

Some examples of ethical issues include:

- ◆ The decision to withhold or supply a patient's nutrition or hydration
- ◆ A patient's right to refuse treatment
- ◆ Determining a patient's capacity to make decisions and identifying a family spokesperson

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

Contact your palliative care team for more information: 216.486.6512

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

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

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>.

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

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.

ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 216.383.6688.

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.

注意：如果您使用繁體中文，您可以免費獲得語言援助服務。請致電 216.383.6688。

Hospice of the Western Reserve 遵守適用的聯邦民權法律規定，不因種族、膚色、民族血統、年齡、殘障或性別而歧視任何人。

تىوغلل اءءءاسملا تامءء ن اف ءءغلل ركءا ءءءءء ءءنك اءا :ءءوءءم - (مقر
مقرب لصلءا . نءءملا ب كل رفاوءء
مءببلا و مصلال ءءاء - 216.383.6688.

قءرءل ساساى لى لى ءى مى الو اءل لومءملا ءى لاردفلا ءى نءملا قوءقءل نى ناءوقب
و نسل و نى نءملا لصلال مءءلى Hospice of the Western Reserve و نولل و
سنءل و ءقاعلا .

AANDACHT: Als u Nederlands spreekt, kunt u gratis gebruikmaken van de taalkundige diensten. Bel 216.383.6688.

Hospice of the Western Reserve voldoet aan de geldende wettelijke bepalingen over burgerrechten en discrimineert niet op basis van ras, huidskleur, afkomst, leeftijd, handicap of geslacht.

ATTENTION : Si vous parlez français, des services d'aide linguistique vous sont proposés gratuitement. Appelez le 216.383.6688.

Hospice of the Western Reserve respecte les lois fédérales en vigueur relatives aux droits civiques et ne pratique aucune discrimination basée sur la race, la couleur de peau, l'origine nationale, l'âge, le sexe ou un handicap.

ACHTUNG: Wenn Sie Deutsch sprechen, stehen Ihnen kostenlos sprachliche Hilfsdienstleistungen zur Verfügung. Rufnummer: 216.383.6688.

Hospice of the Western Reserve erfüllt geltenden bundesstaatliche Menschenrechtsgesetze und lehnt jegliche Diskriminierung aufgrund von Rasse, Hautfarbe, Herkunft, Alter, Behinderung oder Geschlecht ab.

ATTENZIONE: In caso la lingua parlata sia l'italiano, sono disponibili servizi di assistenza linguistica gratuiti. Chiamare il numero 216.383.6688.

Hospice of the Western Reserve è conforme a tutte le leggi federali vigenti in materia di diritti civili e non pone in essere discriminazioni sulla base di razza, colore, origine nazionale, età, disabilità o sesso.

注意事項：日本語を話される場合、無料の言語支援をご利用いただけます。216.383.6688まで、お電話にてご連絡ください。

Hospice of the Western Reserve は適用される連邦公民権法を遵守し、人種、肌の色、出身国、年齢、障害または性別に基づく差別をいたしません。

주의: 한국어를 사용하시는 경우, 언어 지원 서비스를 무료로 이용하실 수 있습니다. 216.383.6688 번으로 전화해 주십시오.

Hospice of the Western Reserve 은(는) 관련 연방 공민권법을 준수하며 인종, 피부색, 출신 국가, 연령, 장애 또는 성별을 이유로 차별하지 않습니다. HHS은(는) 인종, 피부색, 출신 국가, 연령, 장애 또는 성별을 이유로 누군가를 배제하거나 다른 방식으로 대우하지 않습니다.

UWAGA: Jeżeli mówisz po polsku, możesz skorzystać z bezpłatnej pomocy językowej. Zadzwoń pod numer 216.383.6688.

Hospice of the Western Reserve postępuje zgodnie z obowiązującymi federalnymi prawami obywatelskimi i nie dopuszcza się dyskryminacji ze względu na rasę, kolor skóry, pochodzenie, wiek, niepełnosprawność bądź płeć.

ATENÇÃO: Se fala português, encontram-se disponíveis serviços linguísticos, grátis. Ligue para 216.383.6688.

Hospice of the Western Reserve cumpre as leis de direitos civis federais aplicáveis e não exerce discriminação com base na raça, cor, nacionalidade, idade, deficiência ou sexo.

ATENȚIE: Dacă vorbiți limba română, vă stau la dispoziție servicii de asistență lingvistică, gratuit. Sunați la 216.383.6688.

Hospice of the Western Reserve se conformează legilor Federale privind drepturile civile și nu discriminează pe baza rasei, culorii, originii naționale, vârstei, dizabilităților sau sexului.

ВНИМАНИЕ: Если вы говорите на русском языке, то вам доступны бесплатные услуги перевода. Звоните 216.383.6688.

Hospice of the Western Reserve соблюдает применимое федеральное законодательство в области гражданских прав и не допускает дискриминации по признакам расы, цвета кожи, национальной принадлежности, возраста, инвалидности или пола.

OBAVJEŠTENJE: Ako govorite srpsko-hrvatski, usluge jezičke pomoći dostupne su vam besplatno. Nazovite 216.383.6688.

Hospice of the Western Reserve pridržava se važećih saveznih zakona o građanskim pravima i ne pravi diskriminaciju po osnovu rase, boje kože, nacionalnog porijekla, godina starosti, invaliditeta ili pola.

DİKKAT: Eğer Türkçe konuşuyor iseniz, dil yardımı hizmetlerinden ücretsiz olarak yararlanabilirsiniz. 216.383.6688 irtibat numaralarını arayın.

Hospice of the Western Reserve yürürlükteki Federal medeni haklar yasalarına uygun hareket eder ve ırk, renk, ulusal köken, yaş, engellilik durumu ve cinsiyet ayrımcılığı yapmaz.

CHÚ Ý: Nếu bạn nói Tiếng Việt, có các dịch vụ hỗ trợ ngôn ngữ miễn phí dành cho bạn. Gọi số 216.383.6688.

Hospice of the Western Reserve tuân thủ luật dân quyền hiện hành của Liên bang và không phân biệt đối xử dựa trên chủng tộc, màu da, nguồn gốc quốc gia, độ tuổi, khuyết tật, hoặc giới tính.

AKIYESI: Bi o ba nsq èdè Yorùbú qfé ni iranlọwọ lori èdè wa fun yin o. Ẹ pe ẹrọ-ibanisọrọ yi 216.383.6688.

Hospice of the Western Reserve ẹle ilana ofin ijoba apapọ lori etọ arailu ati pe wọn ko gbọdọ sojuṣaaju lori ọrọ ẹya, àwọ, ilu-abinibi, ọjọ-ori, abarapa tabi jije ọkunrin tabi obinrin.

Notes

[illegible]



WESTERN
RESERVE
NAVIGATOR

PALLIATIVE CARE 216.486.6512

Advance Practice Nurse: _____

Social Worker: _____

Volunteer: _____

Call us for urgent needs that may arise due to your _____:

- ◆ Pain or swelling
- ◆ Nausea and/or vomiting
- ◆ Shortness of breath
- ◆ No urine output for 24 hours
- ◆ No bowel movement in 3+ days
- ◆ New or worsening wounds
- ◆ Increased anxiety or restlessness
- ◆ New or worsening confusion or agitation
- ◆ A recent fall or unsteadiness

Additionally, call us if you or your caregiver have concerns or questions, including:

- ◆ Volunteer needs
- ◆ Financial issues
- ◆ Recent hospitalizations
- ◆ Emergency Room visits

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

800.707.8922 | 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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