



HOSPICE OF THE WESTERN RESERVE

Pediatric Caregiver Training Guide

Caring for the Physical and Emotional Needs of You and Your Child

INTRODUCTION AND REFERENCE



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.

This pediatric caregiver's guide, in memory of
MICHAEL JAMES PENDER
1971-1991

is made possible by a generous gift from The Michael Pender Memorial Fund of The Cleveland Foundation. In 1980, Michael was injured in an accident that left him with serious medical problems. Until his death in 1991, Michael became an inspiration for others through his determination to live his life as fully as possible, his compassion for people, his deep affection for family, and his never-ending courage, spirit and faith. Michael aspired to help others, especially children, who might have disabilities, illnesses, or require special attention.



Welcome

Thank you for choosing the pediatric team, a specialized service of Hospice of the Western Reserve. Your care team members are committed to ensuring your choices are respected. They will care for your child while supporting your emotional and spiritual wellbeing.

When your child has been diagnosed with a serious illness, we know that decision making can feel overwhelming. While we cannot give your family its "normal" back, the specialized support of the pediatric team can help restore some balance to daily life while improving your child's quality of life.

Palliative/hospice care focuses on your whole child, and how their illness and treatments affect your entire family. The team tends to your child's comfort, eases their pain and provides emotional support. Care can be provided concurrently with chemo, radiation or other curative treatments your child may already be receiving.

The team will collaborate with your child's primary doctor to develop a customized plan of care and provide an extra layer of support to alleviate symptoms and side effects. They understand the stress childhood illness creates for the whole family. Their circle of care extends to parents or guardians, siblings and grandparents. Your pediatric team is available to help you navigate the healthcare system, make decisions and access benefits.

We value the trust you have placed in us to care for you and your loved one during this vulnerable time and are honored to play a role in supporting your family. The pediatric team is available 24/7 to answer your questions, alleviate your concerns and ease your burdens. Do not hesitate to call on them anytime, day or night.

Sincerely,

Jennifer Palmer RN, CHPPN

*Pediatric Team Leader,
Hospice of the Western Reserve*

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Introduction

HOSPICE OF THE WESTERN RESERVE'S PEDIATRIC CARE PROGRAM cares for any child with a life-threatening illness. Care is provided wherever the child lives, whether at home, in a nursing facility, at a hospital or at one of our inpatient care centers. Our focus is pain and symptom management for your child and emotional support for your family.

When a child has been diagnosed with a life-threatening illness, decision making may become difficult. The goal is to help families identify and express their preferences for their child's care. We strive to give families the support they need to maintain balance and normalcy in their lives. This caregiver training guide offers information to supplement the services we provide. It is not meant to be a substitute for our care or services. We have included educational video links to assist the family with daily caregiving tasks. You may find these especially helpful. Our website, hospicewr.org, also has numerous other resources to make caring for your child easier and more enriching.

Your care team is available 24/7 to answer your questions, alleviate your concerns and ease your burdens. Do not hesitate to call anytime, day or night.

Frequently Asked Questions

How do I obtain pediatric hospice/palliative care services for my child?

A referral can be made by anyone, including a family member, friend or healthcare professional. To start the admission process, call 216.916.5520. A member of the team will return the call the same day.

What is the role of the pediatric team?

The team focuses on managing pain and other symptoms to improve your child's quality of life and on supporting the family.

Do I need to stop chemotherapy, radiation or other curative treatments for my child to take advantage of pediatric hospice/palliative care services?

No. Curative treatments and care can be provided concurrently. Your pediatric team collaborates with the child's doctor or specialist to provide an extra layer of support.

Can we keep my child's doctor?

Yes. The team will collaborate with your child's pediatrician or specialist on a customized plan of care.

Are services covered by insurance?

Most services are covered by private insurance or Medicare/Medicaid. Hospice of the Western Reserve also relies on donations and grants to help us provide unreimbursed services.

Our team can meet with patients and families to discuss financial options such as payment plans if necessary.

Specialized Pediatric Team

Our pediatric team works closely with each child's physician to create an individualized care plan. The pediatric team consists of these specially trained professionals:

The **Pediatric Medical Director and Team Physicians** consult the pediatric team and primary physician on palliative care issues, including pain and symptom management, ethical dilemmas and decision making.

The **Nurse Practitioner** supervises the team, provides consultation and clinical care.

The **Pediatric Nurse** visits the child and family, provides nursing instruction and care, oversees pharmaceutical and medical equipment and coordinates communication between physician and team members to ensure continuity of care.

The **Pediatric Social Worker** promotes a child's normal development, counsels family members on issues that affect the family unit and identifies community resources to assist with legal and financial needs.

The **Nursing Assistant** helps a child with personal care, such as bathing.

The **Spiritual Care Coordinator** provides the child and family with support and guidance in discussing the meaning and value of life.

The **Expressive Therapist** uses art and music to assist the child and family in life review.

Trained **Volunteers** provide supportive visits and companionship to a child as well as respite for family members.

The **Pediatric Bereavement Coordinator** supports family members prior to and at least 13 months after a child's death.

Volunteer Services

Hospice of the Western Reserve trains volunteers who are passionate about our mission and caring for others. Each volunteer has unique interests, skills, life experiences and talents. Volunteers receive extensive training and are individually evaluated. Your care team will discuss how volunteers can help you.

Volunteers can provide:

- ◆ Respite so caregivers may leave for short breaks
- ◆ Transportation
- ◆ Limited hands-on care
- ◆ Assistance with medical forms
- ◆ Spiritual support
- ◆ Spending time with siblings to give parents a break
- ◆ Bereavement Support

Special needs for which volunteers can be requested:

- ◆ **Once a month:** light housekeeping, yard work, shopping, meal preparation for freezing
- ◆ Legal assistance for families who are financially unable to pay
- ◆ Limited beautician services
- ◆ Massage therapy

On-Call Service

Questions, concerns and problems can arise at all times, including at night and on weekends. We encourage you to use the on-call service when needed. A nurse is always available to answer your questions.

The on-call service number is on the communications card provided with this guide.

When you call, you'll be asked for your child's name and the reason for your call. The on-call nurse will be notified and will return your call as soon as possible. Please do not use your telephone while awaiting this return call. All calls are returned within 15 to 20 minutes. If your call is not returned in 15 to 20 minutes, please call again.

If there is a medical emergency or a change in your child's condition, call us first. Please do not call 911.

Notes

Respite Care

What is respite care?

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

How is respite obtained?

The patient is placed in a facility or inpatient unit. Respite can last up to five days and can occur every benefit period. The patient will receive all medications and treatments. Remember, when using respite care, the setting is different but the care does not change.

How should we prepare for respite?

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

How should the patient get to the facility?

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

Symptom Control

Why is symptom control needed?

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

Where will the patient go for symptom control?

Usually the patient will be admitted to Hospice Inpatient Care Units (Hospice Houses). However, if the patient's physician or family caregiver prefers, an admission can be arranged at a local hospital. Many local hospitals contract with Hospice of the Western Reserve to provide this service. The cost is included in the benefit program if admission is arranged by the pediatric team.

How will this admission be arranged?

Your hospice nurse will first speak with the patient's physician and your family. Then the nurse will arrange for the admission at either the agreed upon hospital or Hospice Inpatient Care Unit. The nurse will also arrange for patient transportation, if needed. If you believe the patient needs symptom control care, call the nurse.

Expectations and Responsibilities for Continuous Care

What continuous care is

- ♦ Extra care provided in intermittent shifts in your place of residence when there is a need for managing pain or symptoms
- ♦ Care is started when ordered by the physician
- ♦ RNs, LPNs, HNAs (Hospice Nursing Assistants) and Volunteers may come in during this time to provide teaching and assistance
- ♦ An RN will visit daily and as needed
- ♦ Your pediatric team will oversee care and support your family

What continuous care is not

- ♦ A service to take the place of friends and family
- ♦ Continued for an indefinite period of time
- ♦ Around the clock care
- ♦ Necessarily staffed by licensed nurses; sometimes Hospice Nursing Assistants or Volunteers provide care.

What you can expect from your team:

- ♦ We will teach and assist you in giving medications, personal care, treatments and other specific procedures that might be ordered by the patient's physician.
- ♦ We will reposition bed bound patients regularly as needed for comfort and to prevent skin breakdown.
- ♦ A patient who is incontinent will be bathed and changed frequently.
- ♦ The pediatric team will document in the home. There may be documentation left in your home until the continuous care is concluded.
- ♦ Staff will remain awake and alert at all times.
- ♦ Your team will be courteous and respectful.

- ♦ Team members will conduct themselves as guests in your home.
- ♦ Our team members will bring their own food and beverages.
- ♦ Team members may have a 30-minute meal break, but will remain accessible to the patient. They may also have two 10-minute breaks during an eight-hour shift.
- ♦ Team members will not smoke in your home.
- ♦ The patient's primary nurse or designee will make a visit each day to ensure continuity and ongoing plan of care implementation.
- ♦ You may encounter different staff members while you are receiving this service, including volunteers.
- ♦ Your team will determine how long continuous care will be provided in collaboration with your physician.
- ♦ The team's physician may visit to evaluate your plan of care and assist in the management of symptoms.

What we expect from you:

- ♦ Stay involved in the patient's care.
- ♦ Ask questions freely and as often as needed.
- ♦ Be available for the primary nurse visit each day if applicable.
- ♦ An opportunity to make decisions you think are in the best interests of the patient, such as not turning in bed, refusing medications, etc. Please discuss those decisions with your team.
- ♦ Assist in planning for the patient's care when the continuous care episode has concluded.
- ♦ Provide a space for the staff member to sit and document the care provided.
- ♦ If you are not satisfied with a particular care team member in your home, it is your right to refuse to have that person return. Please report this to your pediatric team.

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 steps and porch railings. Your house address should be clearly visible from the street during the day and night to guide your pediatric team and other visitors.

Pet Control

For the safety of your pediatric 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 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 pediatric 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 any 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. 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 seriously ill child 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 it is possible to do so safely, move and stay with the patient and other family members in 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 the 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 you or the patient 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.

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 you or the patient 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.

Personal Planning

Advance Care Planning

When living with a patient that has a serious illness, there are many things you are faced with that are out of your control. With the support of your pediatric team, you and your child can talk more about what they are comforted by, and how they want to be treated, supported and remembered.

Your team will have resources available that will help guide those conversations.

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.

Personal Information and Records

General recommendations:

1. Make a list of your assets.
2. Make copies of all important documents. Keep the originals in a safe, fire proof, locked place. Make sure there is more than one key and that your family knows where the key is kept.
3. Label any other keys that you have for the benefit of those handling your affairs later on.
4. If you have any questions regarding your estate, contact your attorney or speak with the pediatric team regarding the use of a volunteer hospice attorney.

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 pediatric 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.

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 terminally 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 Reserved 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 pediatric team must agree that the patient is terminally ill. If the patient is improving or if the illness has stabilized, the pediatric 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 pediatric 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 pediatric 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.

Financial Responsibilities

I (we) understand that costs which are not approved by Hospice of the Western Reserve and not in compliance with the agreed upon plan of care may include the following:

- ◆ Deductibles and co-payments
- ◆ Care and treatment provided when no insurance coverage is available
- ◆ Care and treatment not related to the serious illness
- ◆ Room and board fees not covered by the third party payer
- ◆ Residential (level of care) room and board charges at a hospice inpatient care unit
- ◆ Any cost incurred for treatment with a physician and/or facility not contracted with Hospice of the Western Reserve
- ◆ Medications not covered under Medicare Part D
- ◆ Ambulance transport prior to hospice admissions is not authorized by the pediatric team

Billing

- Q:** Will there be a co-pay or deductible for hospice services?
- A:** Possibly, for some services depending on the insurance coverage and the level of care your loved one receives. Medicare pays Hospice of the Western Reserve directly for each day hospice is responsible for care. During hospice care, the patient should not receive a bill for services covered by Medicare. The current arrangement the patient has under Medicare Part B will continue to cover the doctor's costs. If any questions come up regarding billing, ask your pediatric team for help.

The patient or immediate family will be billed for any amount applied toward their personal deductible and/or co-pay after the partial payment has been received from the insurance company. Payment plans and options can be arranged in situations where payment would create a financial hardship for the patient or immediate family members.

A patient or family may also request a financial assessment to determine eligibility for payment plans and other financial options. A pediatric team social worker can provide more information and connect you to our Financial Services Team.

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 pediatric 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 pediatric team of other agencies providing care and services to me.
- ♦ Be at home and available for the visits scheduled with pediatric 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 pediatric 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 pediatric team. The Team Leader may be contacted at the designated team office for further assistance with the resolution.
- ♦ Treat pediatric team 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 pediatric 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.

Family 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 pediatric 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

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:

- ♦ 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, etc.)
 - ♦ 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, 1-800-368-1019, 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。

تدعو غللا لمدادخ نإف، ءةغللا ركذا ثدحتت تنك اذا: تظوحلم - (مؤر
مؤرب لصنتا. ناجملاب لئل رفاوتت
مكئبل او مصلا فتاه- 216.383.6688.

قرعلا ساسا ىلع زىمى الو اهب لومعمل ءىلاردفلا ءىندملا قوقحل نىنواوب
وأين طولالصلال مزتلى Hospice of the Western Reserve وأنوللا وأ
سنجلأ وأ قاعال وأ نسلأ

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 cumple 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 nsọ èdè Yorùbú ofé ni iranlọwọ lori èdè wa fun yin o. E pe ẹrọ-ibanisọrọ yi 216.383.6688.

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



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.