



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 Reserve is Medicare-approved)
- ♦ Patient has months rather than years to live.

The Hospice Benefit Periods Explained

The Medicare Hospice Benefit consists of two 90-day benefit periods followed by an indefinite number of 60-day periods. At the end of each period, the 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 لكل رفاوتت
مكئبل او مصلا فتاه- 216.383.6688.

قرعلا ساسا ىلع زىمى الو اهب لومعمل ءىلار دفلا ءىندمل قوقحل نىنواوب
وأين طولال لصالا 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 ijọba 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.



HOSPICE OF THE WESTERN RESERVE

Pediatric Caregiver Training Guide

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

**SECTION 2:
PAIN MANAGEMENT**



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Pain Management

As a patient of Hospice of the Western Reserve, your child's comfort is our focus. Being pain free can often eliminate other issues. Your child may eat, sleep and participate in regular activities better. Feeling comfortable is the best way to help your child celebrate their day-to-day life.

Your hospice team will respond quickly to reports of pain and will make every effort to keep your child comfortable. Your doctor and hospice nurse will develop the most effective pain management plan by gathering information from you on how your child feels. You will be included in all pain relief measures.

To best serve your child's pain management needs, tell your hospice nurse everything about their pain. It may help to keep a journal. Write down the times when pain seems to be worse than others.

Be sure to tell your nurse about any other prescription medicines your child may be taking. Check with your nurse before using any over-the-counter or herbal medicines because they can interact with your child's prescribed pain medicine. Do not give your child medicine that has been ordered for another child or an adult.

Children, even infants who cannot verbalize their discomfort, are able to communicate pain in a variety of ways. Facial expressions, crying and body movements can all be signs of discomfort. Sometimes, a child may deny feeling pain to prevent taking bad-tasting medicine. In these cases, we rely on your instincts and close relationship with your child to alert us to their pain.

►) *Call Your Hospice Care Team If:*

- ♦ You think your child's pain is not adequately relieved or their pain has increased
- ♦ They complain of, or you sense, a new pain or sign of discomfort
- ♦ They experience side effects of medications such as constipation, sleepiness or an upset stomach
- ♦ They are not taking their medications
- ♦ You have any questions regarding your child's pain management plan

Emotional Pain Management

Many factors cause pain, and pain is not always physical. Emotional and spiritual pain are just as real as physical symptoms. For example, a child may feel sad about not being able to play like other children. That sadness can contribute to their physical pain. Anger, loss of control, loneliness and fear can all contribute to the experience of physical pain. Children will not always communicate these feelings through words and direct conversation. Instead, they will express their emotions through play, art, activities and music. Your hospice team will use these expressive experiences to better understand your child. Talk to your child about their feelings and encourage them to express their emotions through activities such as puppet play or drawing.

In some cases, a child may think their pain is punishment for something they did wrong. Positive reinforcement and assuring them that this experience is not their fault is very important.

Common Myths About Children's Pain

Myth: Infants do not feel pain.

Fact: Infants demonstrate indicators of pain through facial changes.

Myth: Children tolerate pain better than adults.

Fact: People tolerate pain better as they get older.

Myth: Pain is harder to treat in young children because they can't tell you where it hurts.

Fact: By the age of four, children can accurately point to the spot that is hurting them and/or mark the spot that hurts on a picture. Painful areas in younger children can be determined through close observation and assessment.

Myth: Children will tell you when they are in pain.

Fact: Children may not want to tell you about pain they're having because they may be afraid of getting shots or they may not like the taste of the pain medicine. They also may assume that adults know they're in pain and that they don't need to tell you. Adolescents may not want to take pain medicine for fear of it preventing them from being as active as they want, i.e., socializing with friends or driving.

Myth: Children get used to pain and/or having painful procedures done.

Fact: Children often remain quiet during repeated painful procedures because they see that crying upsets their parents. Other times, they become increasingly upset just anticipating receiving medicine. Honest, simple explanations of what your child will experience builds trust. Remind children that it is okay to cry. Your calm, reassuring presence is helpful.

Myth: You can tell how much pain a child is having by their behavior.

Fact: Some children in a lot of pain are very quiet. Others are very active. Some school-age children and adolescents become aggressive. Every child has a different temperament and coping strategy.

Myth: Narcotics are much more dangerous for children than for adults.

Fact: Narcotics are no more dangerous for children than for adults. Addiction to pain medication is rare in children.

Myth: Giving children narcotics will cause them to stop breathing.

Fact: Reports of decreasing respirations in children receiving narcotics are rare.

How Children Act to Pain

Every child shows signs of pain differently. Sometimes a child will display behavior related to pain as they anticipate feeling it. The following behaviors are typical indicators of pain.

Birth to 6 months

- ♦ Rigid arms and legs
- ♦ Loud, sometimes shrill crying
- ♦ Tightly closed eyes
- ♦ Creased eyebrows

6 months to 18 months

- ♦ Pulling at the part of the body that hurts
- ♦ Loud crying
- ♦ Facial grimacing often with eyes open

Toddlers and young children

- ♦ Loud crying or screaming
- ♦ Use of words such as "owie," "boo-boo," "feel funny," "hurt," or "ouch"
- ♦ Thrashing of arms and legs
- ♦ Uncooperative or aggressive behavior
- ♦ Uncharacteristic clinging
- ♦ Putting arms out for hugs
- ♦ Restlessness and/or irritability

School-age children

- ♦ Tend to try to "put off" or "stall" a painful procedure by finding other things to do
- ♦ Stiffing muscles
- ♦ Grinding or gritting teeth
- ♦ Tightly close eyes

Adolescents

- ♦ Tend to vocalize pain when asked
- ♦ May be quick to temper
- ♦ May withdraw and be quiet

Medications

The best way to control pain is to stop it before it starts. If delayed until pain is severe, medications do not have sufficient time to work well. Our goal is to keep your child as comfortable as possible. Give them their pain medication on a regular basis to help prevent the reoccurrence of pain.

Medications come in different forms including liquids, pills, suppositories, skin patches, ointments and creams. Call your hospice nurse if you have questions regarding your child's medication or dosage.

Suggestions for Giving Children Pain Medicine:

- ♦ Have them suck on a Popsicle to numb their tongue and decrease the taste of a bitter medicine.
- ♦ The taste and smell of some medicines can be altered with:
 - ♦ Chocolate syrup or chocolate milk
 - ♦ Grape juice
- ♦ If they have difficulty swallowing medications in pill form, you can:
 - ♦ Change the form of the medicine depending on the need
 - ♦ Crush pills and give them with a small amount of pudding, ice cream or applesauce
 - ♦ Always check with your nurse before modifying medications.
- ♦ For infants and small children taking medicine by mouth:
 - ♦ Give slowly using a dropper or small syringe
 - ♦ Do not squirt a large amount of medicine in an infant's mouth all at once
 - ♦ Aim at the inside of the cheek rather than the back of the throat to prevent gagging
 - ♦ Blowing a small puff of air in an infant or child with neurological deficits face often produces a swallow reflex.
- ♦ If your child is nauseated:
 - ♦ Give them a small amount of a carbonated beverage before or after the medication

- ◆ If the medication has a bad smell, have them hold their nose and drink the medicine through a straw.
- ◆ When giving medicine rectally, insert the square-shaped end first.
- ◆ To halve suppositories, cut them in half lengthwise to get the most accurate dosage.

Before giving your child any medicine:

- ◆ Read the label to be sure you are giving them the correct medicine.
- ◆ Give the medicine exactly as ordered unless your doctor or hospice nurse tells you differently.
- ◆ Give scheduled medicine on a regular schedule, even if your child is not complaining of pain.
- ◆ Notify your hospice nurse if they develop any apparent side effects from the medicine or if the medicine does not seem to be working.
- ◆ Let your hospice nurse know if you are running low on medications (less than a two day supply).
- ◆ Keep all medicine out of reach of children and pets.

DO NOT:

- ✗ Give your child's medicine to anyone else, including other children
- ✗ Crush pills or modify medicines without checking with your hospice nurse
- ✗ Give more than the amount of medicine ordered
- ✗ Tell your child that medicine is "candy"

Giving medicine via feeding tube

- ◆ Flush oily medications with a carbonated beverage to avoid the medicine sticking to the side of the tube.
- ◆ Dilute thick medicines with a small amount of water to ease delivery.
- ◆ Mix "sprinkle" medications (medicines in capsules that can be opened and

"sprinkled" – always check with your nurse first) with a small amount of puréed fruit and water to keep it from sticking to the tube.

Addiction to Medication

Taking medicines to stop pain is a treatment, not a bad habit. Many studies show that pain medications used this way rarely cause addiction. It is very important that every child be supported with the right kind and amount of pain medicine.

Non-Medicine Treatments for Pain Relief

Medicine is important, but you can help control pain with non-medicine interventions as well. Gentle comfort measures, like the suggestions below, can help your child express their pain.

- ◆ Have your child "adopt" a doll, giving the doll medicine when you give it to them.
- ◆ Provide bubbles for them to "blow away the pain".
- ◆ Use distractions such as music, singing and playing.
- ◆ Rock them gently or sway back and forth (rather than bouncing).
- ◆ Use massage, relaxation or guided imagery with deep breathing exercises.
- ◆ Have them soak in a tub of warm water, or apply ice packs if they have swelling.

Home Remedies

Hospice of the Western Reserve recognizes and respects our patients' cultural differences. There are many traditional ethnic and cultural remedies for pain and comfort. Many are inappropriate for children and can have negative side effects or can interact with medicine children are taking. Inform your hospice nurse of any home treatments you are using. We will make every effort to accommodate your traditions and cultural practices.

WONG Baker FACES® Pain Scale



Neonatal Infant Pain Scale (NIPS)

VARIABLE	FINDING	POINTS
Facial Expression	Relaxed (Restful face, neutral expression)	0
	Grimace (Tight facial muscles, furrowed brow, chin, jaw)	1
Cry	No cry (Quiet, not crying)	0
	Whimper (Mild moaning, intermittent)	1
	Vigorous crying (loud scream, shrill, continuous). If infant is intubated, score silent cry based on facial movement	2
Breathing pattern	Relaxed (Usual pattern for this infant)	0
	Change in breathing (Irregular, faster than usual, gagging, breath holding)	1
Arms	Relaxed (No muscular rigidity, occasional random movements of arms)	0
	Flexed/Extended (Tense, straight arms, rigid and/or rapid extension, flexion)	1
Legs	Relaxed (No muscular rigidity, occasional random leg movements)	0
	Flexed/Extended (Tense, straight legs, rigid and/or rapid extension, flexion)	1
State of Arousal	Sleeping/awake (Quiet, peaceful, sleeping or alert and settled)	0
	Fussy (Alert, restless and thrashing)	1
Heart Rate	Within 10% of baseline	0
	11-20% of baseline	1
	>20% of baseline	2
O₂ Saturation	No additional O ₂ needed to maintain O ₂ saturation	0
	Additional O ₂ required to maintain O ₂ saturation	1

Face, Legs, Activity, Cry, Consolability scale (FLACC)

SCORING			
Categories	0	1	2
Face	No particular expression or smile.	Occasional grimace or frown, withdrawn, disinterested	Frequent to constant frown, quivering chin, clenched jaw
Legs	Normal position or relaxed	Uneasy, restless, tense	Kicking or legs drawn up
Activity	Lying quietly, normal position, moves easily	Squirming, shifting back and forth, tense	Arched, rigid or jerking
Cry	No cry (awake or asleep)	Moans or whimpers; occasional complaint	Crying steadily, screams or sobs, frequent complaints
Consolability	Content, relaxed	Reassured by occasional touching, hugging, or being talked to; distractable	Difficult to console or comfort

Pain Medication Side Effects

All medicines have potential side effects which are not considered allergic reactions, however not everyone will experience them. Fatigue, nausea and constipation are common side effects of pain medication. Side effects may worsen when first starting new pain medication and may take two to three days to improve. Please contact your hospice nurse with questions regarding side effects.

Nausea and Vomiting

Nausea and vomiting are common problems that may result from medicine or medical treatments, motion, constipation, infection, pain, anxiety or fear. If your child is nauseous or vomiting, notify your hospice nurse. An anti-nausea medication may be prescribed.

What can be done:

- ◆ Rest and limit position changes. Slowly sip Pedialyte or ginger ale; avoid caffeinated beverages.
- ◆ Continue clear fluids for 24 hours, adding Popsicles, broth, or Jell-O in small amounts every 15–20 minutes.
- ◆ Slowly introduce dry toast, crackers or dry cereal.
- ◆ Rinse their mouth thoroughly after vomiting and practice good oral hygiene.
- ◆ Take anti-nausea medicine as directed.

DO NOT let your child:

- ☒ Eat or drink 1–2 hours after vomiting
- ☒ Eat heavy, fatty meals
- ☒ Be around strong smells
- ☒ Lie down after eating

▶) Call Your Hospice Care Team If:

- ◆ Vomiting recurs after resuming clear liquids
- ◆ Vomit is bright red or dark brown (looks like coffee grounds)
- ◆ Your child is unable to swallow

Constipation

Constipation often occurs from pain medication combined with lowered eating, drinking and activity. Keep track of your child's bowel routine and report any changes to your hospice nurse. If your child has not had a bowel movement after two days, your hospice nurse may advise trying a new medicine.

What can be done:

- ◆ Use stool softeners and laxatives as prescribed.
- ◆ If your child is not on a restricted diet, increase fluid, fruit and fiber. Fluids may be more effective if warmed to room temperature.
- ◆ Increase physical activity if possible.

Diarrhea

Diarrhea, or loose watery stools, can cause stomach cramps, weakness and, if persistent, dehydration. If your child experiences diarrhea, they should drink as much water as is comfortable. They may also drink other clear, non-caffeinated liquids, such as ginger ale or Pedialyte, and eat Jell-O or broth until the diarrhea stops. If diarrhea stops for at least eight hours, they may try eating dry toast, crackers, bananas, rice and continue clear liquids. Slowly add other foods in small portions, avoiding dairy products, fresh fruit and vegetables, and greasy or spicy foods until your child's bowels return to normal.

Helpful Hints:

- ◆ Keep rectal area clean and dry using mild soap and water.
- ◆ Do not take anti-diarrhea medication unless instructed by your hospice nurse

▶) Call Your Hospice Care Team If:

- ◆ Persistent diarrhea
- ◆ Light-headedness
- ◆ Fever
- ◆ Your child is unable to urinate



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**SECTION 4:
COMMUNICABLE DISEASES**



Communicable Diseases in the Home

A COMMUNICABLE DISEASE IS ANY DISEASE THAT CAN BE SPREAD FROM ONE PERSON TO ANOTHER. Common communicable diseases are influenza (the flu), chicken pox, pink eye and lice. They can be spread person to person, or by contact with a contaminated object. An ill child may be more likely to contract a communicable disease due to a compromised immune system. Other factors such as age, nutritional status and current state of health can make a person more susceptible. These diseases, while not serious for a healthy child, can be serious for an ill child. Frequent hand washing is the best way to prevent the spread of communicable diseases. Immunizations are available for many of the diseases.

Common Communicable Diseases

DISEASE	SYMPTOMS	INCUBATION PERIOD	HOW IT'S SPREAD	HOW YOU CAN CONTROL IT	ADDITIONAL INFORMATION
Chicken Pox	Blister-like rash; progresses to scabs; low fever; weak and tired	11–20 days	Direct contact with an infected person; spread by droplets or airborne from an infected person's nose or throat; discharge from the person's blisters (the scabs are not contagious)	Isolate infected person until all the blisters are scabbed over VACCINE AVAILABLE (Varicella)	Live vaccine—see Immunization section
Measles (Rubeola)	Fever, runny nose and eyes, cough and eyes sensitive to light; dark red raised blotchy rash that starts on the face on day 3–7	12–17 days	Direct contact with an infected person's nose or throat secretions; germs can live in the air up to two or more hours	IMMUNIZATION REQUIRED (MMR) Keep away from others for 7–9 days after the rash first appears	Seldom seen anymore because of vaccines; outbreaks would be well-publicized; frequently confused with roseola and other rashes
Common Cold	Sore throat, watery eyes and nose; sneezing, general aches and chills	12–72 hours	Direct contact with an infected person's respiratory droplets or articles with nose/throat discharges	ANTIBIOTICS ARE INEFFECTIVE	WASH HANDS after ALL contact with nasal discharge and sneezing
Mumps	Fever followed by painful, swollen glands under the jaw or in front of the ear on one or both sides; may also have stomach pain and headache	12–25 days	Contact with an infected person's saliva and by droplets from their saliva	IMMUNIZATION REQUIRED (MMR) Keep away from others for at least nine days after swelling begins	Seldom seen anymore because of vaccines; Strep throat or mono can cause very swollen glands
German Measles	Rash, low fever, headache, sore throat, cough, swollen glands	12–23 days	Direct contact with droplets from the nose and throat of an infected person	IMMUNIZATION REQUIRED Keep away from others for at least 4 days after rash appears	Dangerous to unborn child if contracted by pregnant woman; routine screening during pregnancy

Common Communicable Diseases

DISEASE	SYMPTOMS	INCUBATION PERIOD	HOW IT'S SPREAD	HOW YOU CAN CONTROL IT	ADDITIONAL INFORMATION
Pink-Eye (Conjunctivitis)	Redness of eye(s) and swelling of eyelid, tearing, burning, itching, thick colored discharge, may be sensitive to light	24-72 hours	Direct contact with an infected person's discharge or direct contact with articles or fingers contaminated with discharge	Keep away from others until treatment has started and redness decreased	Spreads very rapidly through families; throw away all eye makeup and clean contact lenses if used
Flu	Sudden onset of fever, chills, headache and sore muscles; runny nose, sore throat and cough	1-3 days	Contact with respiratory droplets from an infected person or with articles soiled with nose and throat discharges	Keep away from others until fever and other symptoms improved	IMMUNIZATION AVAILABLE You CANNOT get the flu from the shot; vaccines do not contain live virus
Impetigo	Blistered, pus-filled bumps that progress to yellowish crusted, painless sores; itching	2-10 days	Contact with draining sores or articles soiled by discharge from an infected person	Keep away from others until 24 hours after treatment completed and sores are healed	Spreads very rapidly; common sites are around the nose and mouth
Head Lice	Itching and irritation of the scalp with small light gray insects and/or white eggs (nits) that are attached to the base of hairs and are not easily removed; check behind the ears and the neck	7-10 days	Contact with an infected person and their personal belongings such as hats, combs and brushes	Keep away from others until scalp has been treated with medicated shampoo and the person is nit-free	All personal items such as combs, brushes, bedding, stuffed animals etc., should be cleaned at the same time as the head; family and friends should be examined and treated as needed
Scabies	Small raised areas of skin containing fluid or tiny burrows under the skin resembling a line; often between fingers, underside of wrists, arms, belt lines; itching is intense, especially at night	2-6 weeks	Direct skin-to-skin contact with an infected person	Keep away from others until infected person and the house has been treated; this problem frequently returns after the first treatment is completed and needs to be repeated	

Common Communicable Diseases

DISEASE	SYMPTOMS	INCUBATION PERIOD	HOW IT'S SPREAD	HOW YOU CAN CONTROL IT	ADDITIONAL INFORMATION
Fungal Infections	Ringworm of the Scalp Round, crusty scaly patches; Hair may break off	10-14 days	Contact with an infected person, animal, or personal articles that have been in contact with infected lesions	Personal cleanliness	Household contacts and animals should be examined and treated as needed
	Ringworm of the Skin Flat, inflamed ring-like crusty scores that may itch or burn	4-10 days	Contact with an infected person, animal, or personal articles that have been in contact with infected lesions	Medical treatment with anti-fungal medication	
	Ringworm of the Feet Itching and cracking of the skin, especially between the toes	Unknown	Contact with an infected person, animal, or personal articles that have been in contact with infected lesions	Wear shower shoes in public places	Athlete's foot can be contracted at public pools, gym showers, etc.
Strep Throat	Sudden onset of fever, sore and red throat, white spots on the back of the throat, tender and swollen glands on neck	1-3 days	Contact with respiratory droplets or contact with an infected person	Keep away from others until 24 hours after antibiotic treatment has started; change the child's toothbrush 24 hours after treatment started	Always give correct amount of medication as often and for the entire length of time it is prescribed
Scarlet Fever	Same symptoms as Strep throat; also a tongue coated with little white dots and a rash that is sand-paper like, especially on the abdomen; high fever; possible nausea and vomiting	1-3 days	Contact with respiratory droplets or contact with an infected person. Scarlet fever is accompanied by Strep	Keep away from others until 24 hours after antibiotics are started; change the child's toothbrush 24 hours after treatment started	Always give correct amount of medication as often and for the entire length of time it is prescribed



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**SECTION 5:
CARING FOR YOUR CHILD AT HOME**



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Caring for Your Child at Home

When a person is confined to bed, all of the body's systems must be treated with care. A child confined to bed needs help repositioning for comfort, eating and drinking, routine personal care, and maintaining good skin care and hygiene. In addition, a child confined to bed needs opportunities for play and diversion. Particular attention should be given to the psychological impact immobilization may have on them and your family. To help, place their bed near family and at the center of the room to maintain interaction with family. Keep them in a chair as much as possible.

Helpful Hints:

Have these items on hand:

- ◆ Moist, disposable wipes
- ◆ Appropriately sized diapers (if applicable)
- ◆ Disposable gloves
- ◆ A small table or serving tray
- ◆ Several small pillows
- ◆ Skin lotion
- ◆ Extra bed linens
- ◆ Bedpan or urinal
- ◆ Absorbent pads to protect the bed

Hospital Beds

Hospital beds can be helpful for older children, particularly those who can use the bed controls to change their positions, etc.

Hospital beds can prevent back strain if your child's own bed is low to the ground. Clean the bed as needed with a mild soap. Be sure the wheel brakes are locked at all times, especially with very active children. Your child's bed and its location are an important part of their world. Talk with them about their preferences.

Different types of mattresses can be used for additional comfort. Your hospice nurse can discuss the options with you. If using an air mattress, check the pressure every day. Be sure the air pump for an air mattress is in a safe place under the bed. Never use pins, needles or other sharps around an air mattress.

Helping Your Child Reposition in Bed



Depending on your child's size, you may be able to gently lift them for repositioning. If not, and your child is able to assist you, allow them to help as much as they can. Raise the rail on the side you want to turn them toward and slide them close to you as you stand at the side of the bed. Gently turn them toward the side rail and pull their hips back toward you.



If your child is unable to help with repositioning, use a lift sheet. Raise the rail on the side you want to turn them toward and gently roll them to their side. Fan-fold a sheet tucked half-lengthwise under their back. Roll them to the other side (side rail up on that side now). Move to the opposite side (rail down so you can reach) and gently pull the sheet out. To turn side to side, pull the sheet toward you, place pillows for support. To lift to their head off the bed, use a second person, each grabbing a side of the sheet.

Changing Bed Linens

Working from one side of the bed (side rails up on the other), gently pull up dirty linen and tuck under your child's back. Place fresh linen on the mattress and fit around the corners of the mattress. Tuck the clean linen under the dirty ones. Put the side rail up, roll your child over the "lumps" and move to the other side. Remove the dirty linen, then spread and tuck in the fresh linen.

Helpful Hints:

- ◆ Explain to your child what you are going to do before you begin.
- ◆ Use pillows/wedges/rolled towels for back support and between the knees.
- ◆ Place bed in flattest position tolerable.

Using a Bedpan

When assisting your child with a bedpan:

- ◆ Wearing gloves is recommended
- ◆ Roll them to one side of the bed
- ◆ Have them lift their buttocks by putting pressure on heels
- ◆ Slide the bedpan under them and have them roll back over bedpan
- ◆ Check the position of the pan
- ◆ Allow privacy but stay close
- ◆ When finished, have them roll off the bedpan
- ◆ Remove bedpan and roll them back
- ◆ Help cleanse the area if assistance is needed and pat dry
- ◆ Dispose of waste in toilet and clean bedpan
- ◆ Remove gloves and wash hands

Using a Urinal

If your child is using a urinal:

- ◆ Wearing gloves is recommended.
- ◆ Help position your child on the side of the bed.
- ◆ Help place the penis in the urinal if needed.
- ◆ Provide privacy but stay close.
- ◆ When finished, offer tissue or dab dry.
- ◆ Dispose of waste in toilet and clean urinal.
- ◆ Remove gloves and wash hands.

Helpful Hints:

- ◆ Explain to your child what you are going to do before you begin.
- ◆ Powder the bedpan to reduce friction.

Helping your Child to a Chair, to Stand or to Walk

When lifting your child to carry or reposition them:

- ♦ Raise the head of the bed.
- ♦ Stand at the side of the bed and have them turn to face you.
- ♦ Swing their legs to the floor as you gently assist them to a sitting position.
- ♦ Take a moment to let them adjust to sitting up.
- ♦ Wait an additional short time if you are getting ready to walk.
- ♦ Place the chair in which they will sit at the head of the bed, facing the foot of the bed.
- ♦ Face your child and put your right foot between their knees.
- ♦ Keeping your back straight, reach under their arms and gently hug them while raising them off the bed.
- ♦ Swing toward the chair.
- ♦ To return to bed, follow the same steps in reverse.

Helpful Hints:

- ♦ Explain to your child what you are going to do before you begin.
- ♦ Protect your back by bending your knees and lifting with your legs. Keep your back straight while reaching as little as possible.
- ♦ Be sure that the chair is stable, or wheelchair brakes are locked.

Walkers, Shower Chairs and Benches

The use of assistive devices such as walkers or canes should be discussed with your hospice nurse who will be sure that you and your child are instructed in their correct use. Most equipment can be cleaned with soap and water. Be sure to dry all equipment after cleaning to prevent slips. You can protect the pads of wheelchairs to prevent soiling and stains. Keep wheelchair brakes locked when your child is not moving.



Stand at the side of the bed and have them turn to face you.



Swing their legs to the floor as you gently assist them to a sitting position.



Keeping your back straight, reach under their arms and gently hug them while raising them off the bed.

LEARN MORE ONLINE

For the full series of videos, please visit hospicewr.org/caregiver-training.

The Physical Environment

Children who are confined to bed should be given input regarding where/how they sleep and how they interact with the day-to-day activity of the home. Allowing your child to have input in decision-making will ease boredom and feelings of isolation and helplessness. Below is a list of problems you may encounter and some positive suggestions. Your hospice nurse can offer other suggestions based on your child's needs.

Problem:

Your child wants to sleep in their own bed, but their physical condition makes it impossible

Helpful Hints:

- ◆ Dress up the hospital bed with bright sheets and pillows they choose.
- ◆ Make a tent over the side rails.
- ◆ Allow them to show other family members how to use their bed's controls.
- ◆ Get their input on where the bed is placed.

Problem:

Inability to go outside or into a different room

Helpful Hints:

- ◆ Hang mobiles, flags, kites or bright objects around the room, provide a fan for air movement.
- ◆ Change the position of their bed in the room frequently.
- ◆ Place their bed near a window if possible.
- ◆ If unable to change the position of their bed, have your child reposition in the bed (i.e., sleep with their head at the foot of the bed). Make unusual events like this into "special events".
- ◆ If possible, roll your child's bed outside when the weather is nice.

Problem:

Feelings of isolation, boredom and/or abandonment by friends

Helpful Hints:

- ◆ Encourage friends and family to visit and interact.
- ◆ Include your child in family-centered activities such as dinnertime, watching TV, birthday parties, etc. Have a backup setting such as a couch or reclining chair so that your child's position in the home can vary with family activities.
- ◆ Allow some privacy when friends visit. Adolescents and teenagers need private space to interact with one another.
- ◆ Encourage your child to do activities that can be done even bed bound, such as board and card games, video games and computer games.

Problem:

Feelings of helplessness

Helpful Hints:

- ◆ Allow your child to make as many decisions as possible (e.g., what and when to eat, what clothes to wear).
- ◆ Encourage your child to perform as much of their own personal care as possible.
- ◆ Put any items your child may need within reach so they don't need to ask for help repeatedly.



Problem:

Struggle between independence and dependence

Helpful Hints:

- ◆ Explain all treatments and the reasons for them.
- ◆ Provide physical assistance when necessary, but encourage your child to participate with repositioning, etc.
- ◆ Provide adequate protection for the bed linens so that any accidents or food spills are less upsetting.

Problem:

Reaction to body image

Helpful Hints:

- ◆ Buy clothes that fit should your child lose or gain weight due to their condition.
- ◆ Encourage your child to wear regular clothes during the day and pajamas at night.
- ◆ Provide privacy for your child when performing personal care.

Problem:

Attention seeking behaviors

Helpful Hint:

- ◆ Children rely on consistent rules and find comfort and security in not being treated differently. Continue to set behavior parameters whenever possible.

Notes



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**SECTION 6:
DEVELOPMENT STAGES**



General Development Stages

The following age-specific highlights of motor control and psychosocial development are meant to guide you to recognize the average. Not all children develop according to the average. Illness also may delay a child's development in these areas. Please discuss any concerns with your hospice team.

INFANT: BIRTH TO 3 MONTHS

Motor Control

- ♦ Can grasp
- ♦ Turns head when cheek is touched
- ♦ Shows strong suck or gag reflex
- ♦ May lift head, but unsteady
- ♦ Stares at faces, objects
- ♦ Hand often goes to mouth
- ♦ Responds to sounds by turning head or looking startled
- ♦ Can lift head when on stomach
- ♦ Rolls from stomach to back

Psychosocial Development

- ♦ Develops trust in first year, may develop mistrust if basic needs unmet or lacking
- ♦ Enjoys being held, cuddled, touched, talked to
- ♦ Responds with smile to familiar faces
- ♦ May gurgle in response to human voice
- ♦ Begins to develop relationship with primary caregiver
- ♦ Communicates through crying and gestures
- ♦ Sucks finger to sooth self
- ♦ Explores through taste and touch

INFANT: 3 TO 6 MONTHS

Motor Control

- ♦ Reaches for objects
- ♦ Turns objects with fingers
- ♦ Passes objects from hand-to-hand
- ♦ Holds head steady
- ♦ Rolls over completely
- ♦ Bears weight on legs
- ♦ Sits with support

Psychosocial Development

- ♦ May smile in response to stimulation or human face
- ♦ Coos and gurgles when talked to
- ♦ Laughs aloud
- ♦ Responds to and enjoys interaction with others
- ♦ Enjoys free motor play and large soft toys

INFANT: 6 TO 9 MONTHS

Motor Control

- ♦ Sits alone steadily
- ♦ May suck thumb
- ♦ Holds own bottle
- ♦ Bangs or throws objects
- ♦ May crawl or creep

Psychosocial Development

- ♦ May begin to show fear and separation anxiety
- ♦ Can make sounds and imitate some gestures
- ♦ Likes hearing sounds they make repeated back to them
- ♦ Turns head when sound is heard
- ♦ Can show excitement

INFANT: 9 TO 12 MONTHS

Motor Control

- ◆ Grasps with thumb and forefinger
- ◆ Pulls self upright to stand
- ◆ Has some sense of balance and may stand alone momentarily
- ◆ Cruises (walks while holding onto furniture or hands of adult)
- ◆ Crawls, creeps
- ◆ Begins to climb
- ◆ Opens cupboards, drawers
- ◆ Learns to feed self

TODDLER: 1 TO 2 YEARS

Motor Control

- ◆ Walks without holding on
- ◆ Runs within a few weeks of walking (awkwardly, same initial walking)
- ◆ Goes from sitting to standing without using hands (15 months); kneels without support
- ◆ Climbs in adult chair and turns around to sit
- ◆ Backs into child's chair to sit
- ◆ Pulls and pushes toys while walking
- ◆ Bends without losing balance
- ◆ Climbs stairs on knees, goes down by scooting on buttocks
- ◆ Throws and drops toys for another to retrieve
- ◆ Removes shoes and socks
- ◆ Feeds self
- ◆ Puts objects in ears, nose

PRESCHOOLER: 3 TO 5 YEARS

Motor Control

- ◆ Increased muscle coordination
- ◆ Potty training complete
- ◆ Dresses self
- ◆ Walks on tiptoes
- ◆ Stands on one foot
- ◆ Throws objects overhead
- ◆ Pours liquid from pitcher
- ◆ Puts on shoes

Psychosocial Development

- ◆ Responds to own name
- ◆ Initiates communication by reaching out arms to be picked up
- ◆ Follows simple directions
- ◆ Shows fear of strange objects and strange voices
- ◆ Imitates definite speech sounds and facial expressions
- ◆ Begins to communicate by pointing to desired object
- ◆ Recognizes the meaning of "no-no"

Psychosocial Development

- ◆ Tolerates separation from the primary caregiver
- ◆ Beginning to potty train
- ◆ Uses words to communicate with others
- ◆ Becomes less dependent on the primary caregiver
- ◆ Remains unaware of dangers to self and others
- ◆ Knows 3–20 words
- ◆ Recognizes objects
- ◆ Has increased periods of play activity
- ◆ Responds to simple commands
- ◆ Shows emotions such as jealousy, frustration, anger, affection
- ◆ May throw temper tantrums
- ◆ May have favorite security/comfort object

Psychosocial Development

- ◆ Shows vigorous, intensive behavior and strong imagination
- ◆ Learns to depend on own initiative for action
- ◆ May undertake goals or activities that conflict with those of parents or others
- ◆ Language development (adds 1000 words to vocabulary)
- ◆ Imitates adult behaviors
- ◆ Very curious, asks "why?"
- ◆ Can tolerate periods of separation from parents
- ◆ Can communicate and understand others

PRESCHOOLER: 3 TO 5 YEARS

Psychosocial Development *CONTINUED*

- ◆ Performs self-care activities (e.g., washes hands, brushes teeth)
- ◆ Learning right from wrong
- ◆ Develops sexual awareness and modesty
- ◆ Plays with peers; may develop "imaginary friends"
- ◆ Knows first and last name
- ◆ Speaks in 4–6-word sentences, speech 50–75% intelligible
- ◆ Begins to tell stories about pictures
- ◆ Needs predictability, relies on rituals and routines
- ◆ Has vague concept of time

YOUNGER SCHOOL AGE: 5 TO 9 YEARS

Motor Control

- ◆ Neuromuscular skills refined
- ◆ Climbs, hops and gallops well; has improved balance
- ◆ Can throw and catch
- ◆ May learn to tie shoes

Psychosocial Development

- ◆ Wants to do tasks and activities through to completion for feeling of achievement
- ◆ Starts to develop the social and physical skills needed for playing games
- ◆ Learns to get along with others of the same age
- ◆ Starts to develop a conscience and morals
- ◆ Starts to develop good feelings and attitude about oneself
- ◆ School is a large part of their life
- ◆ Can reason and understand cause and effect

OLDER SCHOOL AGE: 9 TO 12 YEARS

Motor Control

- ◆ Physical skills and capabilities continue to develop
- ◆ May experience coordination problem due to rapid growth spurts

Psychosocial Development

- ◆ Assumes responsibility for jobs around the house
- ◆ Engages in competitive sports and outdoor activities
- ◆ Seeks independence from adults and learns to depend on oneself
- ◆ Develops and keeps friendships with peers
- ◆ Develops moral and ethical behavior

ADOLESCENT: 12 TO 18 YEARS

Motor Control

- ◆ Physical skills and capabilities continue to develop
- ◆ May experience coordination problem due to growth spurts

Psychosocial Development

- ◆ Development of identity is shaped by rapid and marked physical changes
- ◆ May struggle to fit into roles or to integrate their values and concepts with those of society

- ◆ Accepts the changes in the body and appearance, has intense concern over physical appearance
- ◆ Develops appropriate relationships with males and females of the same age
- ◆ Interested in peers of both sexes
- ◆ Accepts the male or female role appropriate for own age
- ◆ Becomes independent from parents and adults
- ◆ Develops morals, attitudes and values needed for functioning in society
- ◆ Trust is very important
- ◆ May shift between mature and child-like behaviors and show mood swings



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**SECTION 7:
EMOTIONAL AND SPIRITUAL SUPPORT**



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Emotional and Spiritual Support

Children are naturally spiritual beings, experiencing life through all of their senses. The language children use to express spirituality relies on art, music, activity and rituals. Children ask their questions and express their feelings, hopes and fears through this language. Children's spiritual needs include unconditional love, forgiveness, hope and safety. The way children express their spirituality will vary depending on their age, experiences, culture, religion and family belief systems. Your hospice team will help your child express their spirituality through play, music and art, and help loved ones communicate with them about these issues.

Role of the Spiritual Care Coordinator

A **Spiritual Care Coordinator** is available to help meet your child's spiritual needs, as well as those of their family and caregivers. Your hospice team will help connect your child and family with religious/spiritual figures such as a priest, rabbi, minister, guru, or other holy person, honoring and supporting the belief system that is already in place.

A Spiritual Care Coordinator can:

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

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

- ♦ Sleeplessness, nightmares or oversleeping
- ♦ Substance abuse
- ♦ Anger or acting out
- ♦ Anxiety or fear of dying
- ♦ Depression or mood changes
- ♦ Withdrawal or isolation
- ♦ Feelings of guilt for causing sadness
- ♦ Feelings of hurting their family by leaving them

Many seriously ill children share their questions and concerns with those to whom they are closest. Be honest with your child and validate their questions. If they ask a question to which you don't know the answer, reflect the question back to them to see what they think. It's okay to say, "I don't know." You should speak your child's language, using age-specific means to communicate, and allow them to express their feelings.

Other Ways of Expression

Children under 12 usually express themselves best through concrete means, such as coloring, painting, journaling or play-acting. Older children tend to use more expressive means such as journaling or music.

- ♦ Give your child crayons, paints, pastels, clay, etc. to allow them to express feelings and thoughts related to spiritual questions. (This also can be a family project.)
- ♦ A book with spiritual/faith-based themes may help your child share feelings verbally. Read the book ahead of time to make sure it holds similar beliefs to your family's. Your hospice nurse can make recommendations.
- ♦ Use toys or other objects familiar to your child to act out abstract concepts such as afterlife/heaven, God/higher power or angels/spiritual beings.
- ♦ Allow your child to reflect on their feelings, beliefs and thoughts through storytelling, poetry and writing. Your child may or may not want to share these.
- ♦ The music your child listens to can be a glimpse into their spiritual beliefs, questions and struggles. With your child's permission, using music can be a springboard into spiritual conversations.

Caring for Yourself and Your Extended Family

Your Emotional and Spiritual Needs

It is helpful to have the significance of your loss recognized and understood. When appropriate, seek to connect or reconnect to a faith community, and have your faith rituals honored. Talking about your inability to protect your child from harm and recognizing you may have unrealistic guilt feelings may ease stress. Seek to sort through feelings of anger, fear and relief when your child's pain is over. Examine your child's and your own spiritual views on living and dying. Talk to and about your child, creating warm loving memories.

Suggestions that may help:

- ♦ Encourage family members and caregivers to discuss feelings openly.
- ♦ Be assured that your feelings are valid and that there is no "right" way to feel. People grieve differently.
- ♦ Nurture your spirit: Take a walk, go to a movie, get together with friends.
- ♦ Consider talking with a friend who has been through a similar experience.
- ♦ Accept help from others but, when needed, set limits on visits and phone calls. Make a list of your support team's phone numbers.
- ♦ Take time for pleasant moments with your child: Read stories, sing songs, give back rubs, share and laugh about fun memories.

The following questions may be useful to guide discussions with your child:

- ♦ What do you think "God" (or use the name of Allah or Buddha, as appropriate) is like? (What toy, object, or animal does your child have that reminds them of what "God" is like?)
- ♦ What scares you as you think about the future?
- ♦ What do you think happens to people after they die? (Heaven? Afterlife?)
- ♦ If your child has experienced the loss of a loved one or pet, ask what that was like.
- ♦ Have you had any dreams about dying? What were they? What was it like? Have you shared your dreams with anyone? Who?
- ♦ Do you pray by yourself? For what? How often?
- ♦ Who do you believe loves you no matter what and always will? Describe how this feels.
- ♦ What do you do that makes you feel "safe?"

Siblings

A child's illness affects the entire family. Give special attention to the siblings' emotions. Encourage siblings to find someone they trust to whom they can express their feelings. Siblings can be encouraged to express their feelings through coloring, painting, journaling, play-acting, etc.

Classmates and Teachers

Families often wonder how to interact with schools when their child has a life-threatening illness. Schools may not have encountered this situation before and may be uncertain how to help students and their families. The Hospice of the Western Reserve pediatric team, along with the school liaison, can help families and school professionals work together to maintain a high quality of life for the ailing student. We can review the student's medical condition and hospice goals and provide some guidelines and additional programming that might be helpful.

Families have a right to expect that the school adapt to and offer educational services. In some cases, the school will offer home tutoring for students to continue their studies. However, many students want to continue to go to school even though their illness may require that their school day and activities be modified.

When students who are ill are able to and want to continue to go to school, school professionals can work with parents to make decisions about how many hours of school a child can attend, how medications or illness affect the student's day, what activities are possible and what staff support is required to assist with this plan.

School staff can meet with your family to work these details out. The pediatric team and school liaison are available for assistance at this and all key decision-making points.

Typically, teachers, nurses, principals and sometimes social workers or guidance counselors are involved.

One of the school's concerns will be the social fabric of the school and how your child will interact with peers in the classroom. This is a situation we often encounter, and our team is available to help teachers and students understand your child's illness and what they may be experiencing. We will also address any worries or fears that other students may have and promote healthy communication. Other students' ability to have some education and discuss their concerns helps make everyone comfortable and promotes healthy peer-to-peer interactions. Classmates may want to offer assistance. Provide concrete ideas to classmates' families about what is helpful to you, such as preparing meals, doing yard work, or taking siblings out for an activity. Designate one parent from the class to act as a point person to coordinate these services.

The following questions may help guide your discussions with your other children:

- ◆ What do you understand about your brother's/sister's illness?
- ◆ How has the illness of your brother/sister changed the life of your family?
- ◆ What is most difficult for you about your brother's/sister's illness?
- ◆ Do you ever think that he/she may die? What is that like?
- ◆ Why do you think your brother/sister got sick?
- ◆ Do you pray for your brother/sister? For what? When?
- ◆ Where do you think he/she will go if he/she dies? What is that like for you?



HOSPICE OF THE WESTERN RESERVE

Pediatric Caregiver Training Guide

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

**SECTION 8:
THE FINAL DAYS**



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The Final Days

This information may be something that you as a parent feel the need to know right away, or it may be something you'll want to refer to as you see changes in your child. Many parents say that not knowing what to expect is far worse than knowing. Your hospice nurse can review the changes that usually occur with you. You are encouraged to call your hospice nurse if you see any one of the changes described below beginning to happen.

Physical Signs and Symptoms of Approaching Death

As your child prepares for the final stage of life, you may notice physical changes taking place. Not all these signs will appear at the same time, and some may never appear at all. Your hospice team will help with these changes and support you through this difficult time.

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

Your child will gradually spend more time sleeping during the day and, at times, will be difficult to arouse. This symptom is a result of a change in the body's metabolism. Try to spend more time with your child during those times of greatest awareness.

Restlessness can be part of the dying process. Some children become restless and pull at their bed linen. Your child may become increasingly confused about time, place and close and familiar people's identity. Offer reassurance. Remind them what day it is, what time it is and who is in the room will be comforting. Soft music and dim lights may be calming. If they are in a hospital bed, keep the side rails up for safety. Again, your presence, just being near, is very important.

Incontinence (loss of control) of urine and bowel movements may occur. Your hospice nurse or nursing assist can get you pads or diapers for your child's comfort. You may notice a decrease in the amount of urine, and it will be darker in color. This is to be expected as the kidneys and intestinal system begin to slow down.

Your child may have moist-sounding breathing. Relaxed vocal cords and a small amount of oral secretion collecting in the back of the throat cause this. Your child does not feel any discomfort from this and may not even be aware of it. Elevating the head of their bed or turning your child on their side will usually quiet these breathing sounds.

You may notice a change in your child's breathing patterns. There may be 10–30 second periods of no breathing, referred to as apnea. This symptom is very common and may occur in the final stage of life.

Clarity of hearing and vision may change. Keep some soft light on in their room. Assume that your child can hear, since hearing is thought to be the last of the senses to diminish. Explain what you are doing. Even if your child is unable to respond to touch or voice, continue to speak to them. The sound of your voice and your words may be a source of comfort. Speak in a soothing voice.

Pain and discomfort may diminish as death approaches, and your child may not appear to be in pain. They may make moaning sounds, which may not necessarily signify pain. To insure effective pain management, continue to give medications as directed by your hospice nurse.

Your child's arms and legs may become cool to the touch and bluish in color. There also may be mottling (reddish blue blotches) on the underside of their hands and feet. You may notice that the underside of their body is somewhat darker in color. These physical signs are a result of blood circulation slowing down and do not necessarily indicate that the person is too cold. Fevers may occur as well.

When the Time is Here

At the time of death, when your child's life journey has ended, please call your hospice team. Hospice staff will assist you at this time. There is sacredness in this event and often rituals are very important for families. Giving your child a bath and dressing them in their favorite clothes is a final ritual of letting go and saying goodbye. Your hospice nurse can assist you during these moments. These moments can also be a time for your family to be together, to pray, to love, to just be there. Families can take all the time they need to say goodbye.

Providing care, presence and love is the greatest gift we can give to each other. Saying goodbye is one of the hardest things to do. Now is the time to heal your heart and spirit. Hospice of the Western Reserve will be with you on your journey of grief and healing.

Funeral Planning

Funeral planning is a time to plan the celebration of your child's life and decide how you want to memorialize them. When you feel ready, the hospice staff is available to assist you to create a plan that reflects your traditions, culture, value and child's life.

Things to Consider:

- ♦ You or a hospice staff member can contact the funeral home of your choice to arrange a meeting.
- ♦ Decide whether you want the funeral at the funeral home or in a place of worship.
- ♦ You or a hospice staff member can contact a clergy member or another person of your choosing to officiate at the service.
- ♦ Decide whether you want cremation or burial. If you choose burial, you will need to choose a burial site.
- ♦ Decide what you will need to gather together to remember your child's life. Use pictures, video, stuffed animals, toys, videos, etc.
- ♦ Think about whether you want friends or loved ones to do a reading, give a tribute, carry a candle, etc.
- ♦ Be creative in your planning. There is no "right" way or any ridged rules in planning a funeral, nor does it have to be elaborate.
- ♦ Select hymns or songs that are your child's favorites, that bring comfort, or that celebrate your child's life.
- ♦ Reflective passages of sacred text, poems, and short stories are helpful in remembering and celebrating your child.

Communicating the Concept of Death with Children

All children, especially a sibling, will be affected in some way by a death in the family. The death of a brother or sister is a major event in a child's life. Their response to this loss will vary, based on factors such as:

- ♦ The nature of the child's illness and circumstances of their death
- ♦ The developmental and chronological ages of the child who died and the surviving children
- ♦ The relationship between the deceased child and surviving children (unresolved feelings of guilt and resentment they may have over the attention the child received still may exist)

It is not uncommon for surviving siblings to feel they must fill the void in the family created by their brother or sister's death. Parents should help them understand the uniqueness of each individual.

Children who are too young for explanations need love from the significant people in their lives to maintain their own security.

Young children may not verbalize their feelings about a death in the family. They hold back their feelings because they are so overwhelming. As a result, they may appear to be unaffected. It is more common for them to express their feelings through behavior and play. Regardless of their ability or inability to express themselves, children do grieve, often very deeply. Do not try to protect children by leaving them out of the discussions and rituals associated with the death. It may leave them feeling anxious, bewildered, and alone. They may seek answers to their questions at a time when they most need the help and reassurance of those around them. It is okay for children to see you cry – it is a sad time.

Determining if a Child Should Attend a Funeral

Depending on the age of the child, give them some information about the funeral, wake or service, and allow them to make the choice about whether or not to attend. Choice is important, however be prepared to follow through with the child's decision. Sometimes other people such as friends or relatives may voice disagreement about a child attending. Be firm in your decision.

If the child chooses not to attend, other ways of saying goodbye may be considered, either at this time or later. It is never too late to say goodbye. A personal memorial service, a letter writing activity, or another ritual can be done if the child desires.

Preparing a Child for a Funeral

Discuss the events of the day step by step, including the service, procession and cemetery. To the best of your ability, discuss the environment (i.e., what the funeral home will look like, smell like, etc.). If the deceased is in a closed casket, explain the reason and reinforce that the body is inside even though it cannot be seen. If there will be an open casket, discuss what the body will look like and how it will feel (i.e., cool and hard, like a wall). You may say the deceased will appear to be sleeping and review the difference between sleep and death (i.e., when you are dead you do not breathe, and your heart does not beat). You may tell them it is okay to touch the body, if they choose.

If the body is to be cremated, help the child understand this is another way to take care of a body after it has died. You may say that a very hot heat quickly turns the body into ashes and that all the remains or ashes are placed in a special container called an urn. Stress with the child that since the body has stopped working, the child who died doesn't feel, see or hear anything during this process.

Review what will be expected of the child. Discuss possible feelings that adults and children may experience and how these feelings may look (i.e., sadness and crying). Let them know that some people, including themselves, may be giggling or laughing. Explain that this does not mean that people are not sad, but people experience a lot of different feelings for different reasons.

Helpful Approaches:

- ♦ Encourage the child's participation (i.e., letters, pictures, or placing small objects in the casket).
- ♦ Designate a trusting adult to be available for children. Parents are not always able to deal with their own grief as well as care for their children, especially during a demanding time such as a funeral.
- ♦ Remember that children grieve sporadically. They may need to take a break. Bring some favorite toys or books for them and allow them to leave to play in a designated area.



General Concepts of Death for Children

AGES	COMMON DEVELOPMENTAL CHARACTERISTICS	GRIEF REACTIONS	HELPFUL APPROACHES
2–5 years	<ul style="list-style-type: none"> ♦ Magical, fantastical thinking ♦ Active fantasy life ♦ Highly egocentric ♦ Blames self for bad things ♦ Not able to verbalize needs and fears ♦ Need to repeat things 	<ul style="list-style-type: none"> ♦ Confusion ♦ Agitation at night, afraid to go to sleep ♦ Able to appreciate a profound event has occurred, but may not understand permanence of death ♦ Seem unaffected ♦ Repeated questions 	<ul style="list-style-type: none"> ♦ Simple honest words ♦ Reassurance about the future ♦ Secure and loving environment ♦ Drawing, reading, active play ♦ Support play as form of expression ♦ Include in the funeral rituals
5–8 years	<ul style="list-style-type: none"> ♦ Able to think concretely and logically ♦ Language increases ♦ Increased memory capacity, both long and short term ♦ Increased awareness of feelings and expectations of others ♦ Peers important 	<ul style="list-style-type: none"> ♦ Wants to understand death in a concrete way ♦ Denial, anger, sorrow ♦ Distress ♦ Acts as though nothing has happened ♦ Wants to be like peers ♦ Repeated questions ♦ Needs regular physical activity 	<ul style="list-style-type: none"> ♦ Look for confused thinking ♦ Answer questions simply and honestly ♦ Offer physical outlets ♦ Reassurance about the future ♦ Drawing, reading, playing together ♦ Include in funeral rituals
8–12 years	<ul style="list-style-type: none"> ♦ Enjoy games and competing ♦ Begin to have increased understanding of self and relationship to world ♦ Increased propensity for language ♦ Able to reason through situations using problem solving skills 	<ul style="list-style-type: none"> ♦ Shock, denial, anxiety, distress ♦ Try to cope ♦ Understands finality of death ♦ Curiosity about specifics of death and dying ♦ Needs regular physical activity ♦ Wants to be like peers 	<ul style="list-style-type: none"> ♦ Answer questions directly and honestly ♦ Reassurance about the future ♦ Create times to talk about feelings and questions ♦ Offer physical outlets ♦ Reading ♦ Include in funeral plans and rituals
12–18 years	<ul style="list-style-type: none"> ♦ Needs independence ♦ Thinks abstractly ♦ Puberty has begun by now ♦ False sense of immortality ♦ Peer group important ♦ Begin to have intimate relationships 	<ul style="list-style-type: none"> ♦ Shock, anger, distress ♦ Depressed or withdrawn ♦ React similar to adult, but have less coping mechanisms ♦ Feel isolated, especially from peers 	<ul style="list-style-type: none"> ♦ Allow and encourage expression of feelings ♦ Encourage peer support ♦ Groups may be helpful ♦ Utilize other adults ♦ Maintain consistent environment ♦ Include in funeral plans and rituals

It is important to remember that all the reactions outlined above are normal expressions of grief in children. In the grief process, time is an important factor. Experts say that children should resume a normal routine about six months after a significant death in their life. If the child's reaction seems to be prolonged, seek the professional advice of those who are familiar with them, such as teachers, clergy members or their pediatrician.

Helping A Child Develop Personal Rituals of Healing

Rituals are an important part of human existence. Children have many rituals in their lives, and it is appropriate and helpful to give them specific rituals designed to help them through their grief. These do not need to be elaborate. Several examples follow:

A father had a small bell engraved with the name and dates of birth and death of his newborn. The bell was to be rung by any member of the family who was feeling sad. He told the family that every time the bell rang, the baby laughs in heaven.

Children broke a small clay pot and wrote a problem associated with death and grieving on each piece. These problems were things such as fighting with siblings, poor grades in school, not wanting to do chores, etc. As each problem was resolved, that piece of the pot is glued back into place. Eventually, the pot was displayed prominently in the home as a visual reminder of how the family worked together to resolve the problems and their grief.

A child can write a letter to the deceased. Even the very young can draw a picture to express how they feel about the person who died. The letter(s) can then be placed in the casket or kept at home in a special memorial book.

A memorial book can be created for children to use. They can put pictures, drawings, letters and even small physical items such as a favorite sock or scarf in the book. Then you can tell stories about each item to bring back the happy memories of that person.

A four-year-old child who was grieving the loss of his older sister took her picture out of an album and told his mother to put it on the top of their Christmas tree. He said that his sister could be the Christmas angel. The family agreed to this and created a new tradition in their home.

Possible Reactions in School:

- ♦ Retells events of the death and funeral
- ♦ Dwells on things they used to do with the deceased
- ♦ Is disruptive in class, has trouble concentrating
- ♦ Instigates fights
- ♦ Rejects old friends and teams up with classmates who have lost a parent or sibling
- ♦ Becomes the "class clown"
- ♦ Is preoccupied with medical cause of loved one's death
- ♦ Spends free time walking or sitting alone
- ♦ At times appears unmoved by the death
- ♦ May become overly sensitive and tearful
- ♦ Drops out of after-school activities
- ♦ Assumes role of loved one who has died
- ♦ Mentions talking to the deceased
- ♦ Relates dreams about the deceased
- ♦ Attempts to phone home often during school hours
- ♦ Is preoccupied with their own death

Signs A Child Needs Outside Intervention:

- ♦ If they pretend absolutely nothing has happened
- ♦ If their school work takes a dramatic decline or the child develops a fear of school
- ♦ If news of a death or other significant loss was kept from them for a long time or if they were told lies about the death
- ♦ If they threaten suicide
- ♦ If they panic frequently
- ♦ If they frequently physically assault others or are cruel to animals
- ♦ If they had a difficult relationship with the deceased or behave poorly with family members
- ♦ If they become involved with drugs or alcohol
- ♦ If they begin committing serious socially delinquent acts
- ♦ If they are unwilling or unable to socialize with other children

Adult Grief

Grief in Grandparents and Other Special People

Grandparents enjoy very special relationships with children and experience profound grief at their loss. They not only mourn the loss of their grandchild but also their dream of the family's future. They may feel helpless to protect their own child from the pain of grief. Grandparents and other special people in a child's life, such as aunts, uncles and close friends, often are not acknowledged as grievers and do not receive the support they need. Include grandparents and other special people in the rituals of grief, perhaps with a special honor at the funeral or memorial service. Share your grief with them instead of trying to protect them from your pain. Encourage them to seek out their own support or support groups.

Parents and Caregivers

While parents are caring for a critically ill child, they often neglect to take time to care for themselves. Recognizing your emotional and spiritual needs and acting on them often enhances your ability to cope and to enjoy time with your child. Below are some normal reactions to grief that you may experience:

Physical

- ♦ Appetite – increase or decrease
- ♦ Difficulty breathing
- ♦ Chest tightness
- ♦ Dizziness or fainting
- ♦ Fatigue
- ♦ Flare-up of chronic conditions such as allergies, asthma or migraines
- ♦ Insomnia
- ♦ Muscle tightness
- ♦ Numb or tingling extremities
- ♦ Slowed speech, stuttering
- ♦ Sweating
- ♦ Upset stomach, gastrointestinal problems

Behaviors

- ♦ Absent-minded
- ♦ Accident prone
- ♦ Fingernail biting
- ♦ Hair twisting
- ♦ Nightmares
- ♦ Searching and calling out
- ♦ Teeth grinding
- ♦ Treasuring objects of the deceased
- ♦ Visiting places of the deceased

Emotional

- ♦ Agitation, anger
- ♦ Depression
- ♦ Dread, fear
- ♦ Helplessness
- ♦ Impulsive behavior
- ♦ Indecisiveness
- ♦ Jealousy
- ♦ Lack of feelings, loss of interest in living
- ♦ Loneliness
- ♦ Moodiness
- ♦ Relief

Intellectual/Cognitive

- ♦ Difficulties concentrating
- ♦ Errors in speech or numbers
- ♦ Loss of creativity, productivity
- ♦ Over-attention to details
- ♦ Sense of presence: feelings that your loved one is physically close

Despite the grief and fatigue, spending time with friends and family is a step in the healing process. Speak with your loved ones about your need to know you and your family will be cared for emotionally and spiritually through the dying and bereavement process. Ensure the support of family and friends as your child dies, letting them know your needs and wishes.

Reflect on your child's significance. Think about their values, courage, beauty and strength. Talk about special events and occasions. Remembering your child in this way will help you understand and cope with your grief.

Try finding someone who can listen to your concerns and hear your story without judgment. Parents need the significance of their loss recognized and understood. When appropriate, seek to connect or reconnect to a faith community and have your faith rituals honored. Be open about your need to sort through feelings of anger, fear and relief when your child's pain is over. Try examining your child's and your own spiritual views on living and dying. Talk to and about your child, creating warm loving memories.

Helpful Approaches:

Be gentle with yourself. Grief is a normal, natural and necessary process when there has been loss. We have physical and emotional responses. Be familiar with the normal experiences of grieving. You may often feel overwhelmed. Remind yourself that what you are going through is normal.

Be willing to engage in your own grief work. Grief work is hard. It takes a lot of energy. Allow yourself to really experience your feelings. As much as you may resist, lean into your pain. To heal, you can't get around grief – you must go through it.

Remember that grieving takes time. There is no timetable for grief. People grieve in their own way. Experiences and emotions can recur. Don't measure your experiences against others. Be patient with yourself and allow yourself to heal at your own pace. Trust yourself to do what is right for you.

Beware of expectations. Unrealistic expectations can hinder healing. In wishing to "handle it better" you may expect more from yourself than is possible at this time. Family and friends may place expectations on

you: "It's been three weeks, months, a year – you must be better now – you must be back to normal." Expressed or implied, these are unrealistic expectations and pressure.

Tell and retell what happened. Talking about your child and the experience of their death is helpful. Good memories also are very important. Encourage others who knew your child to share their stories.

You may or may not cry often. When you cry, realize that it is therapeutic. Don't fight the tears. They may come at the most unexpected times.

Take care of yourself. The physical and emotional experiences of grief are real. Sleeplessness, change in eating habits, inability to concentrate, periods of anxiety, mood swings, over activity and anger or guilt are a few of the experiences you may have.

While it may seem impossible, balancing rest, recreation, spiritual practices and work become even more important at this time. Physical exercise promotes relaxation. Consider a quiet walk. Draw upon your spiritual beliefs.

Relationship to Your Community

You and your family will continue to interact with outside institutions such as your religious community or your child's school. You have the right to choose what information to share with others. You may want to base this on what is most comfortable for you and what will be helpful to your grieving children. In general, it is helpful for the day care, school and religious community to know what has happened in order to be sensitive to your needs. Sometimes a modified or shorter school schedule can be created to ease children's workload and stress during the early stages of grief.

Older children's guidance counselors can explore whether plans for post-graduation should be altered following a loss with your family. Hospice of the Western Reserve's school liaison staff can contact the school and assist in developing a plan to help your child and other children at the school. Our staff can provide information about the grieving process and normal reactions in children. You are not responsible for other people's responses.

Grief Support Services

We know that this is a profound experience for you and your family. Hospice of the Western Reserve is here to support you as you adjust. We are available for several months as you move along grief's journey. Remember, there is no formula for grief. In the first few weeks after your child's death, our bereavement team will contact you to provide support, encouragement, education and resources.

- ♦ **SUPPORT GROUPS** for adults, adolescents, and children
- ♦ **INDIVIDUAL SUPPORT** for all age groups as needed, conducted by the professional bereavement staff or trained volunteers
- ♦ **ABOUT GRIEF** newsletter mailed directly to you with six editions of helpful readings on common grief issues. Each issue contains the schedule of support groups.
- ♦ **WORKSHOPS** held periodically throughout the year that focus on preparing for the holidays and dealing with practical grief concerns.
- ♦ **NON-DENOMINATIONAL MEMORIAL SERVICES** are offered for hospice families, friends, staff and volunteers to remember those who have died in the past year
- ♦ **SUPPORT TO SCHOOLS** is offered through the Western Reserve Grief Services. Fellow students of the patient and/or their siblings often have troubling questions about a child's illness and death. Our bereavement team is available to offer education and support in cooperation with schools.
- ♦ **OUR BEREAVEMENT CAMP**, Together We Can, is a summer camp for children ages 6 to 12 who have experienced loss. Campers work together to reduce feelings of isolation, validate their grief and provide positive memory-making experiences in a fun atmosphere. This healthy program helps siblings heal and move forward.

Hospice of the Western Reserve grief support programs are open to the community and are facilitated by our professional bereavement staff and other counselors with the assistance of trained volunteers. If the bereavement staff can be of any service to you at this time, discuss your needs with your hospice team.