



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

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.**