



**Supporting the
Siblings of a
Seriously Ill
Child**

Safe Crossings Program for Grieving Children and Teens
at Providence Hospice of Seattle

Safe Crossings is a grief support program of
Providence Hospice of Seattle
serving grieving children, teens,
their families and schools.

Safe Crossings offers consultation, education
and emotional support to families who are
providing care to a seriously ill loved one or have
experienced the death of a loved one.

Please contact Safe Crossings at
206-320-4000 or **888-782-4445**
for more information.

Or visit our website at
www.providence.org/safecrossings

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SUPPORTING THE SIBLINGS OF YOUR SERIOUSLY ILL CHILD

When a child is diagnosed with a serious illness, it is natural for the entire family to experience a grief response. When you as a caregiver have a greater understanding of how children experience change and loss, it can assist you in helping your children through the normal and necessary process of adjusting and grieving.

While children are naturally strong and resilient, your intentional support is important in helping them establish a solid framework to make sense of difficult experiences now and throughout their lives.

We have created this booklet to explore the impact a child's serious illness can have on their siblings, including the unique grief responses that may occur. Many of the insights have been provided by families and children who have walked this journey. We encourage you to consider the tools and conversation examples as a way of increasing your confidence in sharing difficult information as you strive to best support your children.

GENERAL FACTORS

Children grieve as part of a family.

As roles and responsibilities adjust to accommodate new needs in your family, your children may grieve not only because their sibling is ill, but also the many small and large changes that follow, such as:

- Changes in daily routine
- Decreased emotional availability of adult caregivers
- Increased individual responsibilities within the family
- Changes in the ability of the ill sibling to interact as they have in the past

Children re-grieve.

Caregivers often express surprise when their children shift from "being fine" to having difficulties in school or relationships as a result of the illness. It may be helpful for you to know that children work through grief in cycles. As your children develop, they will use new skills to gain further understanding and an ability to express how their sibling's illness impacts their lives.

Children are repetitive in their grief.

Your children may ask the same questions repeatedly about the details of their sibling's illness; this is a normal way children attempt to better understand what is happening in their life. When you answer your child's questions with consistent information, it enables a greater sense of stability and trust, a necessary foundation for them to be able to process their grief in healthy ways.

Young children are concrete thinkers.

You may find yourself wanting to use "softer language" to describe the illness to your children, but we've learned from other families that this can actually lead to more confusion. The best way to communicate with your children about the illness is through concrete, truthful language that utilizes correct medical terms.

Children have "magical thinking."

It is common for all children to think they have the power to make things happen in their lives, which can lead them to feeling responsible for their sibling's illness. It is important to convey to your children that thoughts and feelings are not powerful enough to cause sickness, emphasizing that the illness is no one's fault.

Children worry about their own well being.

It is developmentally normal for a child to be most concerned with his or her own security and well-being. Because you may become increasingly focused on your ill child's needs, siblings may worry about how you will take care of them as well. Many parents describe siblings becoming more clingy or expressing jealousy, as well as the challenges involved in balancing time between the ill child and his or her siblings.

Children have regressive behaviors.

In the midst of this challenging time, your children may revert to behaviors they have previously outgrown (i.e., bedwetting, thumb sucking, etc). This is a common and normal expression of grief in children of all age groups. Your children may benefit from individual attention in a way they were comforted at an earlier age, for example, a favorite bedtime story, stuffed animal or blankie.

SUPPORTING YOUR CHILDREN AS THEY GROW AND CHANGE

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As your children grow and develop, the way they experience, understand and interact with the world around them changes as well. As you have probably experienced already, this journey also requires you to grow in an understanding of their needs.

Because of the challenges your family is already facing, this may feel somewhat daunting. You may find it difficult to distinguish whether your children's behavior is due to normal developmental changes or as a result of the impact of the illness in your family. Both are probably true!

Below is a simple outline of behaviors to anticipate at the different stages of your child's development, considering the challenges your children experience with a seriously ill sibling. We have also included suggestions intended to assist you as you support your children. Note that the many of the characteristics described are often interchangeable between age groups, depending on each child's unique development.

AGES 2 - 4

Characteristics:

- Because language is not yet mastered, feelings are often seen in behavior.
- Grief responses are intense but brief.
- Are highly aware of parent's reactions.
- Often regress in behavior and skills.

Ways to support:

- Provide comfort and reassurance that they will be cared for. If there will be changes in who will provide care, share specific names and any other details.
- Continue to meet basic needs, such as healthy meals and snacks, consistent bedtimes, and other activities related to maintaining a regular schedule.
- Provide honest information.

AGES 4 - 7

Characteristics:

- May act as though nothing has happened, grieving in spurts.
- Are often concerned about how and why their loved one became sick, and ask repetitive questions about this.
- Exhibit regression in behavior and skills.

Ways to support:

- Provide clear, honest information regarding the illness.
- Provide consistent answers to questions.

AGES 7 - 11

Characteristics:

- Have morbid curiosity.
- Wish to “fit in;” are more socially aware and concerned with how others are responding.
- May desire privacy, and not want information shared, i.e., with friends and teachers.

Ways to support:

- Encourage and validate healthy expression of feelings.
- Engage in physical activities as an outlet for grief expression.
- Be available, but also allow alone time.
- Consult with them about what information they want shared.

AGES 12 - 18

Characteristics:

- Have a more complex understanding of death and loss.
- Experience an emotional struggle between independence and dependence.
- More likely to talk with someone outside the family.
- May demonstrate grief through physical or behavioral expressions.

Ways to support:

- Encourage and validate healthy expression of feelings.
- Listen, listen, listen with openness.
- Recognize and affirm the need for time alone and with peers.

TALKING TO YOUR CHILDREN ABOUT THEIR SIBLING'S ILLNESS

You may find it challenging to share difficult information with your children if a sibling has been diagnosed with a serious illness.

It is normal to...

- want to protect your children.
- worry about how they will be affected by your emotions.
- be concerned about the effect of the illness on them.
- be unsure of their ability to understand what's happening.
- receive mixed advice from others.

However, without good information your children may...

- intuit that something has changed.
- interpret body language, stress & tone of voice.
- become concerned or anxious.
- overhear confusing conversations.
- imagine a situation to be different than it actually is.

HELPFUL SUGGESTIONS:

Anticipate the best time and setting to initiate the conversation with your children. Be aware of any initial fears that may need to be addressed, such as relocation and changes in routine.

Allow some choice and control about when and where your children would like to hear the information, such as at dinner, bedtime or in the car.

Example: "Would you like for us to talk about it now, or would you prefer a different time?"

Inform your children that there is new information about the medical condition that you would like to talk about. This honors your children's importance in the family.

Example: "We took your sibling to the doctor today, and the doctor told us some news about your sibling's illness. It feels important for us to share this with you."

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Tell the truth using correct medical language.

Example: “You know your sibling has been in the hospital all week. We’ve learned from the doctor that your sibling has an illness called glioblastoma multiforme, which is a type of brain cancer. Your sibling will have to start taking a medicine called chemotherapy, which may mean he or she will have to be in the hospital for a while.”

Expressing your own emotions can give your children the confidence to share their feelings.

Example: “I might cry as I try to tell you this, because this news makes me sad.”

Invite your children to ask questions. Provide honest, simple answers. If you don’t know the answer, it is okay to say,

“That’s a really good question, but I don’t know the answer either. Would you like for me to try to find out some more information about that for you?”

Reassure your children that their needs will continue to be met by the people in their lives who love them. Your children may need specific details, including names of those who will help care for them, and should definitely be told if there will be significant changes in their routine.

Example: “Grandma will be staying with us and helping while your sibling is receiving the treatment. She will drive you to school and soccer practice.”

Causation and contagion. Explain to your children that no one caused the illness, and if it is true, that they cannot catch the illness.

Examples: “It’s no one’s fault.” “There’s nothing anyone did or said that could have caused your sibling to get sick.” “It is important to know that your sibling’s illness is not the type that others can catch.”

If the sibling is discharged home from a hospital setting and needs increased care, provide information to your children about any equipment and treatment that will be provided in the home. Keeping your children’s routines as normal as possible is helpful. Acknowledge the impact and talk openly about any changes which will occur in their routine. If possible, involve your children in simple care giving tasks, such as sharing a comfort item or glass of water.

If your children are school age, it is important to consult with each child in your family about his/her wishes before sharing any private information with school staff or other families. It is not unusual for a child to desire that no one at school be told about the illness.

FOR FURTHER READING

You may borrow some of these resources by contacting Safe Crossings at (206) 320-4000, or look for them at your public library. Most are also for sale at online retailers such as www.amazon.com, unless otherwise noted.

Ages 3-6

The Goodbye Book

By Todd Parr

a moving and accessible story about saying goodbye through the lens of a pet fish who has lost his companion.

The Color Monster: A pop-up book of feelings

By Anna Llensa

By illustrating such common emotions as happiness, sadness, anger, fear, and calm, this book encourages young children to open up with parents, teachers, and daycare providers.

Remembering Crystal

By Sebastian Loth

A beautifully written and illustrated book that introduces a big subject to young children.

Ages 6-12

Grief Is A Mess

By Jackie Schuld

An illustrated book for grieving children and adults who need a healthy dose of understanding, comfort, and laughter.

My Many Colored Days

By Dr. Seuss Paintings by Steve Johnson and Lou Fancher

Using a spectrum of vibrant colors and a menagerie of animals, this unique book provides a way for parents to talk with children about their feelings.

AGES 6-12

Aarvy Aardvark Finds Hope

by Donna O'Toole

A read aloud story about loving and losing, friendship and hope.

Ocho Loved Flowers

by Anne Fontaine

The story of a young girl who learns how to say goodbye to her beloved cat while treasuring memories. A helpful, sensitive way to support a child when the death of

Ages 6-12 (Cont'd)

Ida Always

By Caron Levis and Charles Santoso

A beautiful, honest portrait of loss and deep friendship told through the story of two iconic polar bears.

Gentle Willow: A Story for Children About Dying

Bb Joyce C. Mills, Ph.D

A gentle book that addresses changes that often take place when a death occurs.

Wherever You Are My Love Will Find You

By Nancy Tillman

A picture book that expresses the depth of love and how it exists each and every day.

Anh's Anger

By Gail Silver

A beautifully illustrated book that gives children and caregivers some concrete tools for dealing with anger and other difficult emotions.

Everett Anderson's Goodbye

By Lucille Clifton

A touching portrait of a little boy who is trying to come to grips with his father's death.

The Invisible String

By Patrice Karst

A story explaining that bonds exist no matter the circumstances.

A Terrible Thing Happened

By Margaret Holmes

A simple story that normalizes feelings and provides coping strategies after a traumatic experience occurs.

Ages 13-18

Healing Your Grieving Heart for Teens: 100 Practical Ideas

By Alan D. Wolfelt, Ph.D.

This book provides practical ideas to help support teens through their unique grief experience.

Help for the Hard Times: Getting through Loss

By Earl Hipp

A guidebook that helps teens understand their experience with grief and loss. This book provides healthy coping strategies for teens to work through their grief.



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