

Helping Children Cope with a Sibling's Serious Illness



Learning Objectives

After reviewing this Guide you will be able to:

- Anticipate your other child(ren)'s reactions to their sibling's illness
- Understand how to respond to and support the siblings
- Prepare for potentially difficult conversations with siblings and others

Introduction

From the time that their sibling is diagnosed with a serious illness, any other children in the family will need support. New concerns and anxieties are present for both children and parent(s). Being aware of these and talking about them right from the start will help to create an environment that fosters good communication and strengthens relationships.

Common Sibling Feelings

There is no way to truly know what another person is feeling or experiencing. Anyone, including members of the same family, can have a very different reaction to the same circumstances.

Here are some commonly expressed worries and feelings from siblings of all ages. It is important to remember that how a child responds depends not only by age, but by their past experiences of illness, death, and grief; their relationship with the person who is ill; family, social, and cultural norms about communication, emotions, and grief; and their own personality and beliefs. While these may be worrisome to you, they are natural responses. Honoring the responses, no matter how you feel, is part of the process. What matters is helping the sibling feel seen and heard and safe with your love.

• Feeling abandoned or invisible

Siblings may understand the increased demands on a parent caring for the sick child. At the same time, they may feel that their accomplishments, activities, joys, and/or interests are no longer seen and valued. Even as their basic needs are met (with people available to

(continued)



**COURAGEOUS
PARENTS
NETWORK**

feed them, take them to and pick them up from school and activities, help them do their homework and more), the absence of their parents in these day-to-day activities may still leave them feeling sidelined. Fear of seeming selfish may make them hesitate to ask for attention. Or, they may act provocatively to get attention (for example, being defiant, having tantrums, taking unnecessary risks).

Some children can feel better supported by being invited into conversations about their sibling and the family. Although the conversations may be difficult, feeling included as a member of the care team allows the sibling to both contribute and be acknowledged. Depending on the child's age and maturity level, participation also can be a teaching moment as you model that hard topics can be tolerated and honest conversations had. A therapist or child-life specialist can help you determine if and when your child is capable of managing this privilege—and responsibility.

• **Jealousy**

Feelings of jealousy may be related to feelings of abandonment. A child may wish for the amount of attention their sick sibling receives. Again, they may act out as a way of expressing jealousy. They may express the wish that they also were sick in order to get attention. They may even pretend to be ill. Or, they may become more withdrawn. Depending on their age, a sibling may understand that their jealousy is not necessarily rational. But they may also have a strong sense of what is "fair." Responses like these can be alarming for a parent, but they are natural responses.

• **Guilt... or relief**

Siblings may question why this happened to their brother or sister, and not them. Or they may feel responsibility, worry, or guilt that their actions (or even thoughts) caused this problem for their sibling. Alongside these concerns, they may be experiencing relief that it was not they who was diagnosed with a disease.

• **Pressure to achieve or be perfect**

Many children feel that they must somehow compensate for their sibling's special needs. They may set unrealistically high expectations for themselves. They may try to cause little trouble and to behave well, knowing that the family is dealing with a lot. It can be easy for parents to take well-behaved children for granted or for their pain to be unappreciated, as they do not show overt signs of distress. However, attempting to handle issues on their own may put pressure on the child. A school or other counselor can help you and your child manage the additional stress.

• **Fear of the future**

Very young children have difficulty grasping the concept of the future. However, as they age, children are better able to grasp the implications of having a sibling with a serious

(continued)

illness. Concerns about the sibling's noticeable decline and the possibility of death may lead to separation anxiety—not wanting the parent or sibling to leave their side. Older children may also become preoccupied with the idea of death or the possibility that they are also sick. Some siblings may find that they have trouble focusing on their own future. Again, a counselor or therapist can help with this.

- **Feeling alone or isolated**

Some siblings may isolate themselves from peers who have not experienced trauma. It is helpful for them to know that there are other children in the same situation and that they are not alone. Ideally, they can join a sibling support group that provides an outlet for expressing their feelings and concerns among others who have them too. Such groups may be hard to find, but hopefully a social worker is able to direct you to local or online sibling support programs. Children may also benefit from gentle encouragement to return to play and other favorite activities shared with others. There are also many books written for children to help them understand illness, death and grief. www.notifbutwhen.org

Foundations for Good Conversations

Having difficult conversations with the sibling in a way that is appropriate for their age and/or developmental stage will increase trust. Disguising or dismissing your feelings, even if you want to be protective, may increase your child's anxiety. Openly seeking support for yourself, from friends or professionals or both, will signal that it's good to acknowledge feelings and find help if needed.

- **Acknowledge changes in the family**

Everyday changes in the family are often the things that the sibling focuses on and may be the true cause of their concerns, at least initially. Acknowledging changes that are occurring or may occur (such as hospitalization or parental absence or travel or relocation) may help to address feelings of vulnerability.

Parenting roles may also shift. The primary caregiver may need to spend more time outside the home, attending medical appointments or staying at the hospital with the sick child. One or both caregivers, if there are two, may need to leave a job, or take on additional hours or a second (or third) job. The more that parents can agree on how to manage the changes, and how to communicate when they cannot be together, the greater the chance that siblings will experience consistency and feel protected and cared for.

Be aware that children also want to protect and care for their parents. This instinct can leave siblings feeling responsible for their parents' emotions. Modeling your own expressions of feelings in both difficult and joyous times will help your other children feel more comfortable coming to you. Reinforce feelings of love and affection for all your children.

(continued)

Tell siblings that you will do the best you can to share your time. Describe how they will be cared for when the parents are not available. Wherever you can, talk about what will remain the same. These conversations will help siblings know that they are seen and will be safe.

- **Consider the age of the sibling and their level of understanding**

Children internalize information and relate to the world around them differently at different ages and developmental stages. You may choose to seek support from a psychologist, social worker, or child-life specialist who will help you understand how best to communicate with siblings based on their age and level of understanding.

- **Invite siblings to help**

You can help siblings feel included by inviting them to be helpful. Even young children can organize toys or entertain the sick sibling. They may have their own ideas about how to help.

When Siblings Ask

Some siblings may be very direct with their questions. Others may be more reserved or may even choose to keep their questions to themselves. Some will seek information outside the family and online. A general guideline is to offer short, accurate pieces of information and allow space for siblings to decide what, if any, additional information they are seeking. If siblings do not ask, offer information and provide opportunities to have conversations.

- **Prepare yourself**

Children can be very bold and far less inhibited than adults. Sometimes their questions can be disconcerting and may make you uncomfortable. For example, many parents dread conversations with their children about death and the possibility that a beloved family member might die. A professional can help you anticipate what some of the most challenging questions might be and how you might respond. Then you can be prepared in the moment.

- **Make certain you are responding to your child's actual concern**

It is important not to give children information they haven't really asked for. It helps to know what is prompting their comment or question. One helpful strategy is to ask questions like, "Did you hear something about that?" or "What are your ideas about that?" Or, you could open the conversation by saying, "Tell me what you mean by that." The answers provide clues that will help you address the child's interest or concern in a way that is appropriate to their age and ability to absorb the information.

- **Offer answers only to what is being asked**

Your child may have questions on a topic about which you have very specific thoughts or feelings (such as death). You may find yourself offering too much information,

(continued)

overwhelming your child, or information that isn't really what they are asking for. For example, a young child asking if their sibling is going to die may really be asking when their sibling is going to die (or vice versa). It can be clarifying to answer the question with a question. A response like "That's a good question. Are you thinking about what dying would look like, or something else?" will allow you to understand what the child already knows or has predicted. In fact, they may have an entire framework and their own answer. They may just be asking to see how you respond to the topic.

- **Be truthful and direct**

Children are very good at knowing when a parent is keeping something from them, so giving false or inaccurate information can be harmful to your relationship. Use language that leaves little room for confusion. For example, euphemisms for death and dying (like "passing on" or "going somewhere better") can easily be misinterpreted. By telling the truth and being direct, you are building the foundation for long-term, open communication between you and your child. This is how a child feels safe to share concerns and worries—no matter what they are.

- **Identify and address misunderstandings**

Children may have a lot more knowledge than you think they have, even if you haven't been the one to share the information. If the sibling has a question or expresses a concern on a specific topic, first ask questions to find out what they think and already know. Then you will be able to clear up any misperception or correct information that simply is not accurate.

For example, your child may repeat something they overheard in a telephone conversation. You can say, "I think you heard me talking about some test results. Your sibling has many tests, and the doctors put all the results together to understand what is happening. That was only one test. We will know a lot more later." Or a friend may repeat their parent's comment. You can say, "Of course they are very concerned. But they don't have the whole story. Is there something that you would like to ask about?"

- **Use your own experience to create meaningful connections**

It can be difficult to acknowledge changes in your sick child's condition. These changes impact your own emotional and physical health, and your other children are bound to notice. Excluding the siblings, even if your intention is to protect them, will only increase their anxiety. Acknowledging and explaining what is going on and how you are feeling about it will allow them to recognize that they, too, are experiencing reactions to the situation. For example, if you are experiencing a change in appetite or in your sleep habit (trouble sleeping or sleeping more) you can share that and validate what also may be happening for them.

(continued)

- **Help facilitate conversations with others**

Siblings will not be the only ones with questions. Their teachers, friends and friends' parents might ask your children some of the same difficult questions. By communicating openly with your other children, you are modeling the conversations they may have with others. It may be important for you to be present with your child to guide and support them as they explain things to their peers. You may also consider reaching out to other adults in their lives, such as teachers and coaches, to prepare them as well.



Conclusion

Parenting a child with a serious medical condition can feel especially difficult when there are other children to parent and care for as well. No one can be in two places at once, so you will not always be able to attend to your other children as you would like. This pull can provoke feelings of anxiety and guilt. At times you will need and want to be more available than is possible. Acknowledging this and finding quiet times for conversation will help your other children see that you are doing the best you can.

For guidance on helping siblings cope with death, see the Courageous Parents Network site www.CopingWithLoss.org.