

Communicating Effectively and Compassionately to Help Siblings Cope



INTRODUCTION

From the time that their sibling is diagnosed with a serious illness, the other children will need support. The family dynamic shifts. New worries and anxieties are present for both the sibling and the parent. Parents may ask themselves, “How can I best parent my other children when so much of my energy and emotions are focused on my sick child,” and siblings question, “What about me?” or “What will the future be like now?” Being aware of the worries, yours and theirs, talking about them right from the time of diagnosis will help to strengthen relationships and create an environment that fosters good communication.

It is important to *always give the siblings a clear sense of what is going on and invite them in.* Siblings want to be part of the conversation. We hope this guide will give you tools to start those conversations.

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Common Sibling Feelings

There is no way to see inside to what a sibling might be feeling and certainly not all siblings feel or experience things in the same way. Even those within the same family can have very different reactions to the new circumstances and family dynamic. However, at CPN, we hear a number of commonly expressed worries, concerns, and feelings from siblings of all ages.

It is important to keep a developmental frame and remember that how children respond depends largely on how old they are. *(See Developmental Chart, p.10)*

Feeling abandoned or invisible

The moment a child is diagnosed, much of the family's attention and learning will shift focus to that particular child and their situation. Though siblings often have a greater understanding of the increased demands on their parents' efforts to care for the sick child, they still report feeling pushed aside by parents or shuffled to other caregivers. While basic needs are still met with people to feed them, pick them up, take care of them, and help them do their homework, the absence of their parents in these day-to-day activities can still leave them feeling sidelined. Siblings talk about being overshadowed by the concerns and activities of the sick child, stating that they feel invisible as if their accomplishments (big or small), their activities, joys, or interests are no longer seen and valued. This can also lead to them feeling selfish when they ask for attention.

Jealousy can arise

Suddenly, the sick sibling is receiving gifts, visits, and garnering more attention than they might otherwise. Children may be jealous of how much of their parents' time their sibling is getting, even if it is for things like doctor appointments.

Siblings may begin acting out as a way of expressing their jealousy, or they may become more withdrawn. Siblings often sense that the jealousy is not rational but they cannot help but feel that things are no longer fair. Children may even say they wish they were sick too so they could get attention which can be alarming for a parent to hear, but is a natural response.

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Siblings may also experience guilt ... or relief

Parents often express that the diagnosis of a child seems random, senseless and out of left field. Siblings feel the same way and often this leads them to question why this happened to their brother or sister, and not them. Or they may feel responsibility, worry, or guilt that their actions caused this problem with their sibling. Alongside the guilt, they may also be experiencing relief that it was not them who was diagnosed with a disease.

Pressure to achieve or be perfect

Siblings are often very worried about burdening their parents. Some siblings seek to cause little trouble and to behave well because they don't want to rock the boat. They know the family is already dealing with a lot. Good behavior is still a good thing, but it can come hand in hand with less communication from the siblings about their emotions, and more stress as they attempt to handle things on their own. Many siblings feel they must somehow compensate for their sibling's special needs and set unrealistically high expectations for themselves.

Fear of the future

For very young children, the concept of the future is very hard to grasp. As children age, they are better able to grasp the implications of a sibling with a serious illness. They have many of the same concerns parents have regarding care of the sick child and end of life. The child may have separation anxiety and not want the parent or sibling to leave their side, or they may have trouble focusing on their own future plans.

They feel alone

Just like parents, siblings need peers who truly understand and can empathize with their unique situation. They need to know that they are not alone, but finding others who are experiencing a similar family dynamic is difficult for siblings. An awareness of their own unique family situation may also lead siblings to stop reaching out to peers who have not experienced trauma. They are often also hesitant to connect with other siblings for fear of seeing into the future.

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Foundations for Good Conversations

The age of the sibling and their level of understanding

The way you communicate and explore feelings with your other children will change as they age. While many of the feelings siblings have will be the same regardless of age, the ways they express their feelings will vary. The way you communicate with them about their experiences and feelings will depend on their ability to understand and their developmental stage. Children internalize information and relate to the world around them differently at different ages. To make certain that the information received is age-appropriate, you may choose to seek support from a psychologist, social worker, or child-life specialist, to help guide these conversations with your children.

Consider what is happening in the family

Along with the sibling's developmental stage, you will also want to consider what is going on with your seriously ill child. Are you early in diagnosis? In a crisis or medically intense period requiring many doctor visits or time in the hospital? Has your sick child reached a plateau and life feels like you are on an even keel? Each of these situations may bring up new feelings and questions for your other children. How you respond to them may also need to adjust. It is also important to remember that while much of what is happening in the family is focused on the sick child, everyday changes in the family (job shifts, moves, etc) are often the things that the sibling focuses on, and may be the true cause of their emotions.

Understand and acknowledge that your feelings affect your children

Children take their cues from the adults around them, especially their parents. They often sense sadness, tension or worry even when it is not spoken. Children—especially siblings of an ill child--want to protect and care for their parents. This instinct can leave siblings vulnerable to feeling responsible for their parents' emotions. Modeling healthy expression of emotion in both the difficult times and joyous ones will help your children not only better understand your emotional state, but also learn that it is ok for them to come to you with their feelings.

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The Siblings Will Have Questions

Siblings have questions. Some may be very upfront about their inquiries, while others may be more reserved or may even choose to keep their questions to themselves. Whether spoken or unspoken, you can be sure that those questions exist in their minds. It's important to answer as truthfully as possible while also checking in that they have all the information they need. Offer short pieces of information and allow space for them to process and decide if there is more they want to know. For the siblings who seem to never ask anything, remember to provide them with opportunities to ask questions and to keep them updated on the situation.

Prepare yourself

Kids can be very bold and far less inhibited than adults, which means they sometimes ask really tough questions right up front. These questions can be disconcerting and may make you uncomfortable. It can be helpful to find a professional (a psychologist, social worker, or child-life specialist) to help you anticipate what some of the hardest questions might be. Then you can prepare for how you want to answer them, what you want your child to know, or what they are developmentally ready to know. By preparing yourself, you can give answers in a compassionate and kind yet confident way, and not feel panicked in the moment that you're going to say the wrong thing. Being prepared will make the answers less scary for your child, even if it's difficult information to hear.

Be truthful

Being truthful in your answers will help build trust. As difficult as the truth may be, children want to know. By modeling truth-telling, you are building the foundation for long-term open communication between you and your child; one where your child feels safe to share concerns and worries no matter what they are.

Be certain you know what your child is **REALLY** asking before you respond

It is important not to give children information they haven't really asked for. For example, they may ask, "Is my sister going to die?" Depending on their age when they ask this question, they probably aren't asking if the sister could die; but rather, if she is going to die soon (today or this week). It can be very alarming to hear such questions and it is important to find out what your child is **really** asking. Think about their capacity to understand your answer, so that you can respond appropriately.

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Your answer is best when it answers *ONLY* what is being asked

Your child may also have questions on a topic that you have very specific thoughts or feelings about (such as death), which may lead you to provide too much information, and possibly information that is not appropriate for the age of your child. One helpful strategy to get a greater understanding of what is really being asked, and to pause before you give information, is to answer with a question. For example, try answering “That’s a great question. What do you think?” Then you can learn what your child already knows or has predicted. They may have an entire framework and an answer for the question. They may just need to ask a question to see how you respond to the topic.

Sometimes questions come from misinformation

Children learn things from all different places and may have a lot more knowledge than you think, even if you haven’t been the one to share the information. What they know, or think they know, may not be accurate. Misperceptions can be frightening for your child and cause their imaginations to run wild. As parents it is often the instinct to then provide LOTS of information as a method of clearing up the misunderstandings. Again, first find out what your child thinks and already knows. Try to clear up their confusion without giving them an explanation that is more than they are asking for or developmentally ready to handle.

For example, your child may repeat something they overheard in a telephone conversation, but they have taken it out of context. You can say, “I think you heard me talking about some test results. Your brother 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 about the situation. You can say, “Of course they are very concerned. But they don’t have the whole story. What concerns you?”

Help facilitate conversations with others

Your child’s diagnosis will be a defining feature of their siblings’ lives. The sibling’s ability to communicate the family’s unique situation will be important to how they build relationships 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 going forward. Depending on their age, it may be important for you to be present during these interactions with others to guide your child as they explain things to their peers. You may also consider reaching out to other adults in their lives, such as teachers, to help guide them as well.

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Sometimes the hardest questions create the best connections

Eventually you will be faced with shifts in your child's condition, and the siblings are bound to notice. As parents, it can be difficult to acknowledge these changes and the impacts they are having on your own emotional and physical health. But again, answering truthfully will help the siblings recognize that they may be feeling the same things or experiencing the same physical responses to the situation (e.g., sleep or appetite changes).

Excluding siblings, even if your intention is to protect them, only increases their anxiety that something bad is happening. When siblings ask these hard questions what they are often really asking is to be included in the process of making hard decisions in the family. They want to be seen as part of the team, not a by-stander. Including them in hard conversations will strengthen their trust in you and your bond with them.

Invite children to help

Wherever possible, invite your other children to be helpful. Kids like to help. For example, they could help with bath time. Siblings don't want to feel excluded, so use the resources that you have at the hospital or the clinic or wherever the care/treatment is occurring to bring them in. If your child is in the hospital, bring the siblings in so they can see what the room looks like, what the playroom looks like, that it's not a scary place. Even spending just an hour at the hospital can be very helpful.

Talking is Hard

Keep at it and remember you are doing the best you can

No one can be in two places at one time, and sometimes you will feel guilty about having to attend to your sick child and not being able to be with your other children. At times, you will see opportunities to have these conversations; other times you may not know what to say. And sometimes, the moment will seem "right" and the conversations will just come. You are doing the best you can and your children see that.

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From Other Parents

Here are some helpful insights to help you along the way.

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- “It is important to let your other children know that you want to be with them as well. Tell them how much you love them, and that you are going to do the best you can to spend time with them. Tell them that you are going to do the best you can to share your time. Then when time allows, be sure to spend time with them. Feel comfortable pointing out the opportunity to be with them, ‘I am so happy I got to come see you play soccer today and we had that time alone in the car today. I know sometimes it feels like I spend so much time with your brother/sister, but this time is important to me too.’ ”
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- “Tell your other children that you want them to tell you how they are feeling — that it is safe for them to do that. Let them know that if there are special things or special events, someone is going to try and be there. And that if there is something they need, that they absolutely should let you know. Tell them that nothing is too small or unimportant, if it is important to them.”
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- “Be sure to check in with them every day, even if it is only by phone, Facetime, Skype or Zoom. Simple check-ins are a great way to say ‘I see you’ and may open larger conversations.”
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- “If you’re staying at the hospital, make sure to say goodnight. Ask about their day, their friends, teachers, school. You can also tell them what you’ve been doing at the hospital with their sibling. This helps keep the other children in the loop, letting them know what’s going on, so they don’t wonder or worry more than necessary.”
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- “If we couldn’t answer a question that our sons had about their brother, we asked the child-life specialist to answer it.”
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- “We tell our older daughter, age 13, everything about her sister’s condition. We don’t keep anything from her.”
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- “I told my son that it was OK to be really sad and cry about his younger sister’s illness. We cried together. We got our older daughter grief counseling from the very beginning, so she would have someone to talk to, to share her sadness with in case she was trying to protect us.”
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- “We had to teach our older daughter’s teachers about the situation at home, so they would know what she was going through at home with her brother. Sometimes we let other family members stay with our daughter at the hospital, so we could be home with our other children.”
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From Siblings

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- “My parents listened to and valued me and my brother's opinions about what was going on with my brother. They even included us in some of his doctors and therapist appointments. We never felt like bystanders but really part of our brother’s life.”

 - “I had a lot of questions about my brother and what would happen in the future, They always answered honestly. I appreciated their willingness to talk about hard things with me.”

 - “They always told me that my sister wasn’t my responsibility, They kept me focused on my own success in school, in sports and always showed interest in what I was up to. I was able to go away to college and ‘do my own thing’ without guilt.”

 - “After putting my brother to bed, my mom would jump in bed with me and we would just talk — usually about nothing special but that time really helped me.”
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CONCLUSION

A Loving Connection

As parents, we want the best for ALL of our children. Being alert to the needs of the siblings, responding to them the best you can with open and honest conversations, will help you maintain a loving connection and keep your entire family strong. We encourage you to keep talking, and of course, seek advice and professional help for yourself and your children when you need help to keep the dialogue going.

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How Children Understand Death (by Stages of Development)

<p>Ages 0 – 2 years</p> <p>●</p> <p>Sensorimotor Stage</p>	<p>Infants gain understanding of the world by using their senses and body movement and learning is very fast during this period. A child learns object permanence or that things continue to exist even though they cannot be seen (think of a child playing peek-a-boo). They also come to understand that their actions can cause things to happen in the world around them (think of a child playing with a jack in the box). Infants have no understanding of death and experience it as separation. They are often aware of caregiver feelings and it is important to maintain routines and avoid separation from significant others.</p>
<p>Ages 2 – 7 years</p> <p>●</p> <p>Preoperational Stage</p>	<p>Learning at this stage happens through imitation of others, pretend play, and drawing. Language growth is rapid and children learn to use words and pictures to represent objects. Children are egocentric and still struggle with logic or understanding other points of view. They tend to think about things in very concrete terms. Preschool age children see death as temporary and reversible. Magical thinking is characteristic, and it is common for preschoolers to see death as a result of bad thoughts.</p>
<p>Ages 7 – 11 years</p> <p>●</p> <p>Concrete Operational Stage</p>	<p>While children in this stage are still very concrete or literal in their thinking, their thinking is becoming more logical and organized and they begin to use reasoning. The egocentrism of the earlier stages lessens and they begin to understand that their thoughts are unique to them and become better at thinking about how other people might view a situation. Children begin to understand that death is final but still have difficulty understanding that death is inevitable or could happen to them.</p>
<p>Ages 11 years – Adult</p> <p>●</p> <p>Formal Operational Stage</p>	<p>At this stage abstract thought emerges and children begin to reason out problems. They develop the ability to systematically plan for the future and think critically about hypothetical situations. They begin to think more about moral, philosophical, social or political issues and their role in them. Adolescents understand that life is fragile and have an adult-like understanding of death.</p>



To better understand the stages view this video:

<https://www.youtube.com/watch?v=IhcgYgx7aAA>