You Can Do This:

A Parent's Guide to Helping Siblings Cope with Life-Threatening Illness

(adapted from the video interviews @ courageousparentsnetwork.org/video-library/caring-for-the-family/other-children-siblings/)



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Content Director for **COURAGOUS PARENTS NETWORK** with tips from fellow Parents

It's important to talk from the very beginning about the other children.

The minute one child gets diagnosed, all the focus and all the attention, ends up on that particular child and their special needs. Unfortunately, this sometimes means that the other children in the family get ignored. As a parent, you need to keep in mind that your other children still have to go to school, get dressed, bathe, eat, be picked up or taken somewhere. It becomes about how to take care of all of everyone in the family's schedules, practical needs, and emotional needs. This is hard but you can do it.

Children understand that their parents need to give special attention to their sick sibling, but they often report that they felt almost abandoned by their parents. They feel like they are handed off from one person to another and that these people are often not their parents. They report feeling pushed aside.

LET'S TALK

Sometimes, this leads to feelings of jealousy. The sick child is getting presents and special visits from people, and the healthy child feels that it is unfair.

Sometimes, the healthy siblings also experience feelings of guilt around why this happened to their sibling and not to them. They may also feel relieved that they are healthy, but they don't want to say that aloud to anyone. They worry about their parents and don't want to put any more pressure or burden on them, so they do not share how they are feeling.

Children in this situation can behave in all sorts of ways: they may behave perfectly and sit very quietly so they don't cause another problem. They know their parents are already upset and that the situation is already difficult, so they are going to be super good. And then there are other times when the child may act out or have trouble separating from the parents because they are scared and anxious: maybe they don't want the parent to leave the house, or they have trouble in school, or they have trouble going to sleep at night.

It is important for you as the parent to find time to be with your healthy children – even if it is not a lot of time, it is better than no time. For example, if your sick child is napping at home or in the hospital, you can leave to spend that time with your other children.

Parents need to own how stretched they feel and even share that with the other children. Tell them how much you love them and that you are going to do the best you can.

You can't be in two places at one time. Sometimes you will feel guilty about having to care for your sick child and not being able to be with your other children. It is really important to talk to your children about this, so that they understand that you want to be with them as well. Tell them that you are going to do the best you can to divide your time. Tell them that if they were sick, you would be doing this for them too.

Let them know that if there are special things or special events, at least one parent is going to try and be there.



You can model and teach communication skills to your other children.

Tell your healthy children that it is their job to let you know when they need something. Tell them that you want them to tell you how they are feeling and that is safe for them to do that, even if their feelings are sad or angry ones.

Then be sure to check in with them every day, even if it only by phone from the hospital. If you're staying at the hospital, make sure you call home to say goodnight or call and say How was school? What did you do today? You can use Skype or FaceTime.

Always give your children a sense of what is happening and invite them to help.

We always want to make sure children have information that is right for their age. You don't have to do this by yourself. You can get help from a psychologist, a social worker or somebody at the hospital to let the siblings know what is actually going on and how they can be part of it too.

Wherever possible, invite your other children to be helpful. Kids like to help. They don't want to feel left out, so use the people at the hospital or the clinic or wherever the treatment is occurring to bring the other children in.

Even just an hour with their sick sibling can be helpful because it lets them see what is going on. If your child is in the hospital, bring your other children in so they can see what the room looks like, what the playroom looks like, and that it is not a scary place. If you leave them out, their imagination and worry may lead to images or bad fantasies about something bad happening.

They're going to have questions. It's important not to lie to them.

Depending upon how old your other children are, they may ask lots of questions. They may ask a couple of questions and run away and then come back a few days later with more.

Do not to lie to them. Give them short pieces of information. Let them take it and think about it, and if they come back and say, "Remember when you said...?" now they have another question and you can answer it then.

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It is helpful to prepare yourself for the questions.

Kids can be very bold and far less inhibited than adults and they sometimes ask difficult questions directly. For example, if they hear that their sibling is very sick and in the hospital, they may ask, "Is she going to die?" Depending on the child's age when they ask this question, they probably aren't asking if the sister could die eventually, but is she going to die soon (today, this week).

This sort of question can be very upsetting to hear from your child and you probably won't know how to answer it right away. It can be helpful to get a professional – such as a psychologist or social worker – to help you anticipate what some of the hard questions might be. Then you can prepare for how you want to answer them, what you want your child to know. When you are prepared in this way, you can give answers in a caring and confident way. By thinking about it ahead of time, you can prepare information so that it is less scary for your other children to hear.

Be careful: It's important to know what the child is really asking. Don't give them information they haven't really asked for.

Sometimes, when a child asks, "Is she going to die?" what they're really asking is, "Is she going to die today?" If the answer to that question is "No", you can answer "No." You do not and probably should not tell them that their sibling may die later, unless they ask the question, "Could my sister die?" Then you should answer honestly that "Yes, it is possible."

It is also important to find out what your child thinks and already knows.

Children learn things from all different places and may have a lot more knowledge than you think they have. It is very important to understand what your child already knows, even if you weren't the one to give them that information.

Also, if your child has an interesting question about what happens when somebody dies, be careful how you answer the question so that you do not give them too much information for their age. You may have your own ideas about life after death, but your child may not be ready to hear them.

To keep it safe for your child, try responding like this: "That's a great question. What do *you* think?" Then you can learn what your child is really thinking or already knows. They may have an entire idea in their mind and answer for the question. They just needed to ask it to see what you would do and how you would react. You may also learn that they don't understand at all or that their imagination has created a scary situation in their mind, and you can help them with that in a way that they can handle.

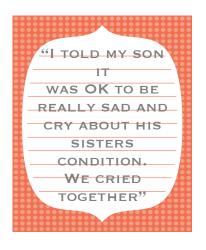
Selected Additional Tips from Parents

Our older children helped give their brother his medicine.

If we couldn't answer a question that our sons had about their brother, we asked the **child-life specialist** to answer it.

We tell our older daughter, age 13, everything about her sister's condition. **We don't keep anything from her.**

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.

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.

Print Your Own Conversation Cards

Print and gift these cards to your children, giving them an outlet and opportunity to express their thoughts and questions. Be sure to set a time specific time each week to discuss anything your child would like to share from the cards. Setting and sticking to a discussion time will help your child to feel heard and taken care of. These cards can also be used as a tool for a grief counselor or school support person.











