



Caring For Siblings

A cancer diagnosis does not affect just the child but the whole family. How we care for our other children is important too. Here are suggestions from other parents.

Be honest. Use words they can understand that are age appropriate. Encourage them to ask questions.

"We were totally honest with all of our children. They need to feel that they can trust us to know when to worry and when they didn't have to worry. Also we learned that people in the community will tell your children everything even if you don't, so they need to hear it from you."

"We talked about it freely so they felt they could too. Now, three years after diagnosis, our daughter is writing about how scared and sad she was when her brother was diagnosed with Leukemia."

Reassure them. Tell them they didn't do or say anything that caused their sibling's cancer. Assure them that childhood cancer isn't contagious and it is very rare.

"Siblings need reassurance that they are not going to get sick too. My 5 year old was in hysterics when she woke up with a sore throat one morning about a month after her sister's diagnosis. She had a terror-stricken look on her face, I immediately reassured her that this was a typical cold, nothing to worry about and I said the words "this is not a sign of cancer – you can't catch cancer or give cancer". This seemed to reassure her immensely."

"One of the most difficult things I did following the diagnosis of my child with cancer was to leave his side to go home and be with his sisters. We were fortunate in that our daughters were with their grandmother in our home but despite that they needed to see their parents. They needed to be with us to be comforted and told about what was happening. On the first night my husband went home and I stayed with our son and on the second night I went home and spent some time with them. They really needed it."

"If you have young siblings in the house, make sure they understand that they did not do anything at all to cause their sibling's illness—little ones tend to internalize and believe that they can cause things to happen from their thoughts; e.g., if they are mad at their sibling one day and the sibling is diagnosed the

next, a very young child might worry that their anger was to blame. "

Make time for family visits at the hospital. Let them visit the hospital. Don't worry that the hospital will be too traumatic. Imagining what happens there is usually scarier than seeing a sick brother or sister.

"Sibling pizza night at the hospital was a huge hit for our girls. When our daughter was in the hospital, her big sister would come every Saturday afternoon with a video from the video store (they go through the hospital videos pretty quick) and we would have a family picnic of pizza and ice cream on my daughter's hospital bed. Then we would put the girls in their jammies and they would snugg up in bed (IV tubes and all) and watch their video together. It actually became an event that they looked forward to when they knew there was going to be another hospital stay."

"My parents were incredibly helpful in maintaining stability and a loving environment for our two older daughters, who at the time were 3 1/2 and 5 1/2. During all the in-patient stays the girls were cared for by my parents and they all came up to visit us at the hospital for each of his hospitalizations. These visits were therapeutic for everyone. The children got to know the hospital and staff and knew James was getting better but understood that I had to stay by his side. The girls were encouraged that their visits helped James feel better and since they knew we were relying on them for their help, I think they felt more invested and involved in his treatment. They never uttered any resentment about James' illness and we tried our best to spread attention around evenly. If James napped, we might go out for a walk in New Haven, which offers an array of excellent restaurants and a pretty town green."

Make them feel special too Find things that they like to do that make them feel special.

"Above all, remember that although they aren't sick, siblings still need their parents. Remind them that you love them, and shower them with affection. Hugs and kisses can't cure cancer, but they can help all your children remember they are part of a family and surrounded by love."

"We made sure we had special things planned for our older daughter during her sister's hospitalizations. We had a new baby in the house at diagnosis, so our daughter's Grandmother had her hands full taking care of a newborn. We made sure we had other family members come in specifically to help/play with our five year old. Every hospitalization, one of her aunts would come and do "lunch and a movie" with her."

"My other children got very tired of everyone asking how their brother is doing. My daughter told me it makes her feel invisible. Be sure they are not invisible at home."

"I also made sure that every day we were away from our older child because of treatments; we had a special treat for her just from us. It wasn't expensive, usu-

ally a craft project or book but with a note telling her how much we loved her and how special she was to us and we wanted her to share with us the story/or craft when one of us got home. This gave her something to look forward to each day.”

“All of Carlos’s scheduled in-patient hospitalizations were done over the weekend so that my husband and I could switch off taking care of Carlos and our other two girls at home. To make all the driving back and forth easier and more fun for the girls we always did two things – they became our traditions and the girls even looked forward to these weekends when we would be split between the hospital and home. Jeff would take the girls on the way to change places with me on Saturday afternoon to a Climbing Wall in Wallingford just 15 min from the hospital and then I would always take them to our favorite restaurant when we got home and we would have a Saturday night slumber party. The girls felt special getting to sleep in Mommy and Daddy’s big bed and the climbing wall was always lots of fun and something we didn’t have close to home.”

“Our five year old needed to feel like there was something she could do to help her brother. We explained to her about germs and told her she could help get rid of the germs and help her brother by washing her hands well. She took this very seriously and felt much empowered.”

“Let the siblings “help” with dressing changes if appropriate. Our oldest son wanted to see what we were doing each night and helped “flush” Luke’s catheter. You have to be careful to keep things sterile so another option is to let the child dress a “wound” on a stuffed animal or parent while the other parent is changing the dressing.”

Encourage them to express their feelings. Give them a journal to work through their emotions. Allow them to be angry, sad or scared and reassure them that all these feelings are normal. If necessary, consider counseling to help your kids deal with their concerns or frustrations.

“If your kids get mad, act out, wet the bed, acknowledge that you are mad/sad/scared too - they need to hear that what they are feeling is “normal” and that you are stressed as well. My oldest wet the bed every night when Luke was in the hospital - all 6 months.”

“To help the girls (ages 6 and 8) at the time of Carlos’s diagnosis we started a new game after dinner where the girl’s dolls and stuffed animals put on a show for us to tell us how they were feeling about Carlos being sick. Especially about how much time and attention he needed. The girls in turn would comfort their dolls by telling them what we had told them – Carlos will get better, he isn’t going to die, cancer is not contagious. This really enabled the girls to open up about their own feelings without being afraid of hurting us. At first they were tentative and timid but as more and more Dolls came forward to share their feelings they really got into it and we all learned something from each other. It made us all feel better and safer. Sometimes the stuffed animals would just break into song – so we had some good laughs as well.”

Talk about your family situation with teachers. They can be a tremendous support to children during the day.

"If there is a sibling, be sure to tell their teacher/daycare provider what is happening. In our case, we had to pull Luke out of daycare but his provider ended up sitting for us a few times so we could attend a support group. Our oldest son's preschool ended up having a fundraiser to help us with medical expenses. We didn't tell them anything but the truth: Luke had a rare form of liver cancer and would be getting chemo for 6 months."

Ask your hospital child life specialist for help. Find out if the hospital offers special activities for siblings. There are lots of great camps offered to siblings of childhood cancer survivors. Look for them in our guide, The Purple Pages.