

Siblings of Children with Cancer

Childhood cancer touches all members of the family, with especially long-lasting effects on siblings. The diagnosis creates an array of conflicting emotions in siblings; not only are the siblings concerned about their ill brother or sister, but they usually resent the turmoil that the family has been thrown into. They feel jealous of the gifts and attention showered on the sick child, yet feel guilty for having these emotions. The days, months, and years after diagnosis can be difficult indeed, for the sibling of a child with cancer.

Many parents have expressed regret and guilt over how they have handled the pain and worry of their “healthy” children. Perhaps reading about their experiences will help you find time to listen to and express your love for the frequently overlooked brothers and sisters.

Emotional responses of the siblings

Brothers and sisters are shaken to the very core by cancer in the family. Their parents, the leaders of the family clan, are immobile for a while. There is no time, and little energy, to focus on the siblings. During this major crisis for the siblings—this time when they are flooded with anger and concern, jealousy and love, when they are in conflict as never before—they often have no one to turn to for help. They may feel utterly alone, abandoned, desolate in their pain. If you recognize these strong emotions of siblings as normal, not pathological, you will be better able to help your child talk about and cope with his overpowering feelings.

Although the time after diagnosis is emotionally potent, stress levels associated with life-threatening illnesses tend to decrease over time. Siblings also tend to have good psychological outcomes. In many cases, siblings report the experience as life changing in many positive ways.

Concern for sick brother or sister

Children really worry about their sick brother or sister. It is hard for them to watch someone they love be hurt by needles, sickened by medicines, lose weight, and be bald. It is hard to feel so healthy and full of energy when the brother or sister has to stay indoors because of weakness or low blood counts. The siblings may also

be old enough to understand that death is a possibility. There are plenty of reasons for concern.

Fear

It is very common for young siblings of children with cancer to think that the disease is contagious, that they can “catch it.” Many also worry that one or both parents may get cancer. The diagnosis of cancer changes children’s views that the world is a safe place. They feel vulnerable, and they are afraid. Depending on their age, siblings worry that their brother or sister may get sicker or may die. Some siblings develop symptoms of illness in an attempt to regain attention from the parents.

Fears of things other than cancer may emerge: fear of being hit by a car, fear of dogs, fear of strangers. Many fears can be quieted by accurate and age-appropriate explanations from the parents or medical staff. This parent indicates that even with explanations, questions may continue to come up for years:

My three-year-old daughter vacillated between fear of catching cancer (“I don’t ever want those pokes”) to wishing she was ill so that she would get the gifts and attention (“I want to get sick and go to the hospital with Mommy”). She developed many fears and had frequent nightmares. We did lots of medical play, which seemed to help her. I let her direct the action, using puppets or dolls, and I discovered that she thought there was lots of violence during her sister’s treatments. She continues to ask questions, and we are still explaining things to her, four years later.

Jealousy

Despite feeling concern for the ill brother or sister, almost all siblings also feel jealous. Presents and cards flood in for the sick child, Mom and Dad stay at the hospital with the sick child, and most conversations revolve around the sick child. When the siblings go out to play, the neighbors ask about the sick child. At school, teachers are concerned about the sick child. Is it any wonder that they feel jealous?

The siblings’ lives are in turmoil, and, being human,

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they feel a need to blame someone. It's natural for them to think that if their brother didn't get sick, life would be back to normal.

As this parent indicates, it's possible for a sibling to envy the ill child to a dangerous extent:

Our nine-year-old son seemed to be dealing with things so well until one evening as I was tucking him in he confided that he had tried to break his leg at school by jumping out of the swing. He began to cry and told me he doesn't want his brother to be sick anymore; that he needs some attention, too. I was always so concerned with our sick child that I didn't realize how much our healthy child was suffering.

Guilt

Young children are egocentric; they feel that the world revolves around them. It is logical to them to feel that since their sister has cancer, they caused it. They may have said in anger, "I hope you get sick and die," and then their sister got sick.

This notion should be dispelled right after diagnosis. Children really need to be told, many times, that cancer just happens, and no one in the family caused it. They need to understand that just because you think something or say something, it doesn't make it happen.

Beyond feeling guilt for causing the cancer, most siblings feel shame for their normal emotional responses to cancer like anger and jealousy. They think, "How can I feel this way about my brother when he's so sick?" Assure them that the many conflicting feelings they are experiencing are normal and expected. As a parent, share some of your conflicting feelings (anger at the behavior of a child on prednisone, guilt about being angry).

Some children even feel guilt for being healthy. They think, "Why should I feel great when he's so frail and sick?"

Abandonment

When parental attention revolves around the sick child, siblings may feel isolated and resentful. Even when par-

ents make a conscious effort not to be so preoccupied with the ill child, siblings still perceive that they are not getting their fair share of attention and may feel rejected, as this parent discovered:

One day when my four-year-old son was in day care, we had to unexpectedly bring Erica in for emergency surgery on a septic hip. (It turned out to be a life-threatening surgery, and she ended up staying in for weeks.) I called the day care and said that I couldn't pick up Daniel by closing time, and the teacher said, "No problem, I live right across the street, and I'll take him home for dinner." We went to get Daniel that evening, and he was very withdrawn. Later, he exclaimed, "All the mommies came. Then teacher turned out the lights, and you didn't come to get me." Then he burst into tears. In hindsight, one of us should have gone to bring him to the hospital to just sit with us. It was tense there, but at least he would have been with us, included as part of the family.

Sadness

Siblings have many very good reasons to be sad. They miss their parents and the time they used to spend together. They miss the life they used to have, the one they were comfortable with. They worry that their brother or sister may die. Some children show their sadness by crying often; others withdraw and become depressed. Often children confide in relatives or friends that they think their parents don't love them anymore.

This sibling drew a painful conclusion from arrangements made to care for him during his brother's illness:

When Jeremy was very sick and hospitalized, we sent his older brother Jason to his grandparents for long periods of time. We thought that he understood the reasons, but a year after Jeremy finished treatment, Jason (nine years old) said, "Of course, I know that you love Jeremy more than me anyway. You were always sending me away so that you could spend time with him." It just broke my heart that every time he made that long drive over the mountains with his grand-

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parents, he was thinking that he was being sent away.

Anger

Children's lives are disrupted by a brother or sister's diagnosis of cancer, and it can make siblings very angry. Questions such as "Why did this happen to us?" or "Why can't things be the way they used to be?" are common. Children's anger may be directed at their sick brother, their parents, relatives, friends, or doctor. Children's anger may have a variety of causes, for instance, being left with babysitters so often, unequal application of family rules, or additional responsibilities at home. Because each member of the family may have frayed nerves, explosions of temper can occur, as this parent relates:

As we were driving home from school one day, Annie was talking, and I was only half listening. All of a sudden I realized that she was yelling at me. She screamed, "See, this is what I mean. You never listen, your mind is always on Preston." I pulled the car over, stopped, and said, "You're right. I was thinking about Preston." I told her that from now on I would try to give her my full attention. I realized that I would really have to make an effort to focus on what she was saying and not be so distracted. This conversation helped to clear the air for a while. I tried to take her out frequently for coffee or ice cream to just sit, listen, and concentrate on what she was saying.

Worrying about what happens at the hospital

Children have vivid imaginations, and when they are fueled by disrupted households and whispered conversations between teary parents, children can imagine truly horrible things. Seeing how their ill sister looks upon returning from a hospital stay can reinforce their fears that awful things happen at the clinic or hospital. Age-appropriate, verbal explanations can help children understand what happens at the hospital, but nothing is as powerful as a visit. Of course the effectiveness of a visit depends on your child's age and temperament, but many parents said bringing the siblings along helps

everyone. The sibling gains an accurate understanding of hospital procedures, the sick child is comforted by the presence of the sibling, and the parent gets to spend time with both (or more) children.

Another method that minimizes worry is reading age-appropriate books together. Many children's hospitals have coloring books for preschoolers that explain hospital procedures with pictures and clear language. Adolescents might be helped by seeing videos on the subject or joining a sibling support group.

Veteran parents suggest that another way to reduce siblings' worries is to allow even the youngest children to help the family in some way. As long as children have clear explanations of the situation and concrete jobs to do that will benefit the family, they tend to rise to the occasion. Make them feel they are a necessary and integral part of the family's effort to face cancer together.

Concern about parents

Exhausted parents often are not aware of the strong feelings of their healthy children. They sometimes assume that children understand that they are loved and would be getting the same attention if they were the one who had cancer. But siblings frequently do not share their powerful feelings of anger, jealousy, or worry because they love their parents and do not want to place additional burdens on them. It is all too common to hear siblings say, "I have to be the strong one. I don't want to cause my parents any more pain." But burdens are lighter if shared, and parents need to try to encourage all of their children to talk about how they are feeling.

Sibling experiences

Simply understanding the depth of the pain and fears of your "healthy" children eases their path. Being available to listen, to say, "I hear how painful this is for you," or "You sound scared. I am, too," makes siblings feel that they are still valued members of the family, that even though their brother or sister is absorbing the lion's share of parents' time and care, they are still cherished. Even if parents do not have large amounts of time to spend with them, siblings need to hear that what they

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feel matters. If parents understand that these overwhelming emotions are normal, expected, and healthy, they can provide solace.

Helping siblings cope

Here is advice from several families on ways to help the brothers and sisters cope:

- Make sure that you explain cancer and its treatment to the siblings in terms that they understand. Create a climate of openness, so that they can ask questions and know that they will get answers. If you don't know the answer to a question, write it on your list to ask the doctor at the next appointment, or ask your child if he would like to go to the appointment with you and ask the question himself.
- Make sure that all the children clearly understand that cancer is not contagious. They cannot catch it, nor can their ill brother give it to anyone else. Impress upon them that nothing the parents or brothers and sisters did caused the cancer.
- Bring home a picture of the brother or sister in the hospital, and carry a tape recorder back and forth to relay songs and messages.
- It is very hard for mothers and babies or toddlers to be separated. Some families leave out family photo albums for the caregiver to show the toddler whenever she gets sad.
- Try to spend time alone with each sibling.
- If people only comment on the sick child, try to bring the conversation back to include the sibling. For example, if someone exclaims, "Oh look how good Lisa looks," you could say, "Yes, and Martha has an attractive new haircut, too. Don't you like it?"
- Share your feelings about the illness and its impact on the family. Say, "I'm sad that I have to bring your sister to the hospital a lot. I miss you when I'm gone." This allows the sibling an opportunity to tell you how she is feeling. Try to make the illness a family project by expressing how the family will stick together to beat it.
- Include siblings in decision making on matters such as how chores will be done, or devise a schedule for parent time with the healthy children.
- Allow siblings to be involved in the medical aspects of their sister or brother's illness, if they wish it. Often the reality of clinic visits and overnight stays are easier than what siblings imagine. Many siblings are a true comfort when they hold their sister or brother's hand during spinal taps or bone marrows.
- Give lots of hugs and kisses.
- Be sure to alert teachers of siblings about the tremendous stress at home. Many children respond to the worries about cancer by developing behavior or academic problems at school. Teachers should be vigilant for the warning signals, and provide extra support or tutoring for the stressed child or teen. Continue to communicate frequently with the teachers of the siblings to make sure you are aware of any developing problems.
- Expect your other children to have some behavior problems as part of living with cancer in the family. This is a normal, not pathological, response.
- The child with cancer receives many toys and gifts resulting in hurt feelings or jealousy in the siblings. Provide gifts and tokens of appreciation to the siblings for helping out during hard times, and encourage your sick child to share.
- Encourage a close relationship between an adult relative or neighbor and your other children. Having a "someone special" when the parents are frequently absent can help prevent problems and help your child to feel cared for and loved.
- Take advantage of any workshops, support groups, or camps for siblings. These can be of tremendous value for siblings, providing fun and friendships with others who truly understand their feelings.

Positive outcomes for the siblings

After stating all of the above potential troubles that your children might experience, it is important to note that

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many siblings exhibit great warmth and active caretaking while their brother or sister is being treated for cancer. Their empathy and compassion seem to grow with the crisis. Some brothers and sisters of children with cancer feel that they have benefited from the stressful experience in many ways, such as increased knowledge about disease, increased empathy for the sick or disabled, increased sense of responsibility, enhanced self-esteem, greater maturity and coping ability, and increased family closeness. Many of these siblings mature into adults interested in the caring professions, such as medicine, social work, or teaching. Character can grow from confronting personal crisis, and many parents speak of the siblings with admiration and pride.

This fact sheet was adapted from *Childhood Cancer: A Parent's Guide to Solid Tumor Cancers*, by Honna Janes-Hodder and Nancy Keene, © by Patient-Centered Guides. For more information, call **(800) 998-9938** or see www.patientcenters.com.