



**The National Children's Cancer Society
Lends Advice for Healthy Siblings
of Children with Cancer**

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OVERVIEW

In the United States, four out of five people have siblings. Most are acutely aware of the significance of the sibling relationship. Brothers and sisters are the first to teach the importance of lasting, intimate bonds. They show individuals how to overcome differences, work together as a team on a shared goal, demonstrate loyalty, heighten security and simply have a fun time at play. The connection between siblings is unparalleled.

When a child is diagnosed with cancer, a family's norms are shaken to the core. The patterns and rhythms of everyday life are significantly affected and can negatively impact a child's wellbeing. As parenting experts have noted, children with stability have better time management skills, do well with important regular tasks, display elevated organization skills, and understand boundaries and guidelines better.

The uncertainty of the future and a new daily routine can (understandably) have a negative impact on the psychological, emotional and physical state of the sick child's siblings. And while studies show that children with cancer develop more connections for emotional and practical support than their peers, their siblings are dealing with high levels of psychological distress and with fewer resources that address the turmoil they are experiencing.

Fifty-seven percent of young people (12-24 years old) who have a sibling with cancer are dealing with significant psychological obstacles inhibiting their ability to excel in life, compared to 9% of young people in the general population. These challenges include anger, guilt, resentment, isolation, fear, worry, sadness and anxiety.

WHAT STUDIES SAY ABOUT SIBLINGS OF CHILDREN WITH CANCER

Studies examining **post-traumatic stress (PTS)** reactions in siblings conclude that

29–38% exhibit moderate to severe cancer-related PTS

even years after their sibling's cancer treatment has ended.

Siblings of children with cancer have **higher rates of anxiety and depression** than the general population

Greater family support has consistently been associated with **less psychological distress and behavioral maladjustment.**

Social support from friends or classmates has been found to **stabilize emotional adjustments and resilience and reduce anxiety, social stress, depression and behavioral maladjustment**

Siblings of children with cancer have revealed they often **try to hide their negative emotions**



In order to offset the potential for long-term problems, it is important to understand the research on how siblings are affected and who is most at-risk.

Siblings included in a study published in the *Journal of Pediatric Psychology* showed the older a sibling is, the more they are affected. It also revealed that if the sibling is female, there was an increase in anxiety, loneliness and insecurities, with a decreased quality of life. It is essential to be supportive of all children, but especially those who are old enough to have a large emotional bond with their brother or sister. Older siblings are mature enough to realize what the illness means and the potential outcome.

The study also observed that when youth possess a positive personal outlook on life, they're likely to remain optimistic about their sibling's prognosis, and cope better than those who put their confidence largely in the medical professionals caring for their brother or sister. This does not diminish the need to communicate the work of the exceptional medical care team a child with cancer is working with, but it cannot stand alone.

A critical finding from this study was also that siblings experience the most trauma immediately following the cancer diagnosis of their brother or sister. When seeking help to strengthen your family, the earlier, the better.

Interestingly, the study showed that healthy siblings saw a decrease in stress during inpatient hospital stays. This is attributed to the trust in physicians and nurses, but also the comfort of knowing that something is actively being done to treat their sibling's cancer.

In the Systematic Review: Family Resilience After Pediatric Cancer Diagnosis, it was proven that families commonly grow closer through the trials of childhood cancer. While improving a family's resolve to triumph through difficult times is positive, it also requires a balance between supporting each other and not becoming overly enmeshed while doing so. ([Enmeshment](#) is a psychological term that describes the blurring of boundaries between people, typically family members. Enmeshment often contributes to dysfunction in families and may lead to a lack of autonomy and independence which can become problematic.)

Some tips to achieve the right balance are as follows:

- Try not to alter the family's power structure, role relations and relationship rules in reaction to distress
- If it is unavoidable, try and make the shift in the early months of figuring out the "new normal" during treatment
- Attempt to return to a state resembling the former family structure in the long run

THE BEST WAYS TO TALK WITH CHILDREN

Like so much of raising young people, shaping their perspective for a brighter outlook can start at home. However, as parents who are going through childhood cancer already have a scarcity of time to give, practical ways to begin adequate support are a necessity.

First, be open about a child's cancer with the rest of the family. It is difficult to digest the heart-wrenching diagnosis while keeping communication open. Children have similar feelings of despair and also need to share their sadness, anger and fears. As a parent, the focus at the forefront is to protect the children within a family. Siblings should be provided realistic information about

cancer without undermining the possibility of an eventual positive outcome. When information is completely hidden from the sibling, he or she can be convinced that the illness is too threatening to talk about.

While talking with healthy siblings about cancer, watch body language closely to be clued into feelings and then conversation can stem from there.

A parent's primary duty when a child has cancer is to give them the best possible chance at survival. Through comforting conversations with their healthy siblings though, children can be reminded they are every bit as important as their sister or brother going through cancer treatment.

Tell children that their brother or sister's cancer is no one's fault, and not to feel guilty that they continue to be healthy. Remind them if anything ever happened to them, they can be rest assured that everyone would be just as committed to solving any heartache or issue they go through. Remind them as they lash out or bottle up, or however the grief manifests itself, that they are loved. Tell them there is no right way to get through cancer and they are doing a good job.

Above all, remember that although they aren't sick, siblings still need their parents very much. Constant reminders of how much they're loved and showering affections will help children remember they are a valued part of the family and surrounded by care. Through all the uncertainty there are truths, and the facts to be relayed are that as a family together, everyone is going to get by. And doctors and nurses are going to do everything possible to get their brother or sister better, no matter where the best treatment can be found.

Read through age-appropriate resources in communicating about cancer whether [talking with a child](#) or [talking with a teen](#).

SUPPORT FOR SIBLINGS

During this time together, encourage children to keep up the activities they're involved in during or after school, and work with friends' parents to ensure they can still spend time with their peers. When there is a moment for family time, take the pressure off of making it a big event or outing. Everyone is feeling tired, but also have the desire to connect. When it can be arranged, it is important for one parent to spend time with healthy siblings every day. This time can be spent preparing a meal together, talking about the activities that are important to them or watching their favorite show with the snacks they love.

The takeaway from discussions with children should ultimately be, "It's still okay for you to have fun." Try to let them have a say in making plans and let them make the choices of what friend they want to visit or what they want to do. Studies examining support from a variety of different sources including parents, friends and school faculty have determined that children find support from their friends as particularly helpful.

In order to make sure children still have opportunities to enjoy time with friends, it is important to stay in touch with friends and family. As father of 3-year-old Hazel, who recently went through

"Even at a young age, (Sam's brother was almost 3 years old at diagnosis) I think it is important that the sibling is involved in the medical tasks. We used dolls and medical supplies to let him play and be a part of what was going on with Sam each day. We have also given him his moments to be "brave and strong" just like his brother."

– Linda, mother of Sam (neuroblastoma)

treatment for acute lymphoblastic leukemia, says about leaning on others, “We have never been made to feel needy when we asked for help, nor weak when we stumbled. The people in our lives have always willingly and lovingly come to our rescue when it was needed.”

Hazel’s parents, Nat and Elizabeth, say when they first found out about her diagnosis at 2-years-old, they could not get through the experience with grace and dignity. They simply had to get by however they could. In total, there are four children in the family, Paul (10), Gideon (8), Aurora (6) and little Hazel (3).

“My family of six was often split up, some of us attending chemo visits in the hospital two hours away, some of us trying to maintain a normal life in our hometown. Events were missed, vacations foregone and birthdays moved. This experience changed our lives in almost every way possible, but it never broke us, never destroyed our bond.” Nat said.

Having a source of encouragement continued throughout the school day is very important. Talk about what the family is going through with siblings’ teachers so they are aware and can be understanding and helpful to varying emotions and performance within the classroom.

“Siblings often fall by the wayside so parents need to be aware of feelings of neglect. Be open and honest about treatment and let them know that it is a family effort to support their sick brother/sister.”

– Casey (Survivor of Ewing’s sarcoma)

Hazel’s family depended on the support of wonderful friends from both church and school to help. “Our older kids’ activities have pretty much stayed the same through the process thanks to assistance from friends and family members running them to and fro when we couldn’t,” said Nat. “My children never really sought support from their peers, but just wanted to be doing normal things with them. Things weren’t

normal and haven’t been normal in our house for some time, but when they are with their friends at a school activity or party, their world is the same as it always was. They never forget Hazel has cancer, but for short spans of time at least they can escape it.”

To further confidence and feelings of usefulness, engage siblings in ways they can be there for their brother or sister in their sickest times. Encouraging frequent text messages and emails will make sure that anxiety is eased while memories are still being made.

Early on in Hazel’s treatment, she was gifted an iPad she uses frequently to communicate with her two brothers and sister when she is stuck in the hospital. “We use all of the latest technology to keep our kids connected. We FaceTime every day, sometimes for hours a day if Hazel is in the hospital,” shared Nat.

Encourage children to spend a lot of time with their sibling going through cancer. Don’t worry that the hospital visit will be too traumatic. Imagining what happens there is usually scarier than seeing a sick brother or sister. Let siblings choose which toys they think their brother or sister would like in the hospital, or something new and interesting to them, like a book they’ve read recently or game they’ve learned and are eager to share. Stress that any effort they’ve made with household chores is an extreme value to your family.

For Hazel’s siblings, their greatest emotion felt was fear. Paul, her oldest sibling, became consumed with concern for her health. He would watch Nat and Elizabeth to observe what they were most worried about and these things would fuel his anxiety. However, a small task like making sure visitors were very clean and sanitized gave him a sense he was doing something to help the situation.

TIPS BY AGE

Clearly, siblings in different age groupings vary greatly on their awareness, coping skills and attitudes. Here are some strategies the NCCS would suggest according to age:

Birth to 3 years old:

- If possible, keep infants physically near.
- If away, use FaceTime to visually connect with audio.
- Record stories and lullabies for bedtime.
- Do not attempt toilet training or other major developmental tasks until there is a somewhat consistent routine in place.

3-5 years old:

- Continue implementing standards and discipline as before.
- That being said, be aware toddlers may revert to behaviors they had grown out of because of stress, like having accidents or throwing tantrums.
- Give concise explanations of what their sibling with cancer is going through.
- Talk about feelings in an honest, but brief way. “I am crying because I am sad.”

6-12 years old:

- Enroll healthy siblings in a support group, often the pediatric oncology team can likely point to one or possibly manages a group themselves.
- Sign children up for one of the camps mentioned on page 7.
- If possible, let them decide who will be helping care for them traveling or absent overnight.
- Explain that all feelings experienced are okay, to reassure them all of their tough feelings are alright too.

13-18 years old:

- Arrange for a tour of the cancer clinic their brother/sister is at and encourage them to ask questions of the medical team.
- Keep their teachers apprised of updates and what the family is going through.
- Give teens abundant permission to talk about themselves, they’re probably receiving a lot of questions about their ill sibling.
- Ask them for help at home with chores and express gratitude freely.

“I have a younger sister and throughout treatment, she has always known everything about my cancer treatment. Telling the well child about their siblings’ health information brings them much closer to the child that is diagnosed.”

– James (Survivor of medulloblastoma)

CAMPS FOR SIBLINGS OF KIDS WITH CANCER

As referenced earlier, often times children who are going through cancer and the late effects throughout survivorship have an abundance of social connections and supportive peers. This can be accomplished for their healthy siblings as well. As author Hancock found in his study of camp experience for siblings of pediatric cancer patients, “Camp encourages discussion with peers and healthcare providers and facilitates participation in activities that improve knowledge, social confidence and esteem.”

There are several options for camps that support the emotional and psychological health of children without traveling too far. Find the closest camp available on one of these websites:

<https://www.alexslimonade.org/campaign/supersibs-sibling-support-childhood-cancer-families/camps-childhood-cancer-families>

<https://www.cancer.net/navigating-cancer-care/children/camps-and-retreats-families-and-children-affected-cancer>

<https://nancyslist.org/2017/11/16/camps-for-kids/>

https://www.cocai.org/index.php?option=com_geofactory&view=map&id=4

Attending one of these camps not only provides advantages for children, but for parents as well.

The Psychosocial Benefits of Camp

Camp has proven benefits for children with life-threatening illnesses and their siblings.

Benefits for patients and siblings include:

- A new or greatly improved sense of well-being
- Improved self-confidence
- Acceptance and understanding
- A welcome break from hospital routine
- Meeting other kids in the same circumstances and realizing they are not alone
- Meeting adults who are long-term survivors
- Feeling like a kid again

Benefits for parents include:

- Having a week to address their own needs
- A welcome break from hospital routine
- An opportunity to focus on other children
- An opportunity to feel “normal”
- Learning to “let go” and to allow their child to gain independence and grow in self-esteem

Camps for siblings dealing with their brother or sister’s cancer have been proven to reduce their level of grief according to studies. Siblings felt at camp they could express emotions and openly show their sadness, anger and happiness in ways that they could not do elsewhere.

HELPFUL ACTIVITIES

The NCCS' list of activities to engage in with your children to help their self-esteem, guilt, anxiety and worry.

INFANT- 2 YEARS OLD

PLAY WITH PLAYDOUGH

A wonderful opportunity to talk while playing, work out tension and worry, and have fun with the baby. Add special scents for an additional relaxation factor.

SHARE IN MESSY MOMENTS

Dig in the dirt, play with a water table, finger paint or any other craft found that makes a mess. Young children benefit from making messes as they learn to self-regulate and ease stress.

8 YEARS OLD- 13 YEARS OLD

WRITE THANK YOU CARDS

Make a list of people who have shown them kindness and point out the things they did that were helpful to the family. Ask children to write down how they feel about the person on their cards.

TRADE SOMETHING SPECIAL

When away or busy, trade something personal or special with each other. This will make both parents and children feel loved, comforted and supported through hard times.

CREATE A SCRAPBOOK

Give children time to plan for this activity. With notice, they can find materials they want to put in their scrapbook around the house and look through their memorabilia for favorite pictures, quotes and stories. This project will become an unforgettable experience they will treasure.

2 YEARS OLD- 8 YEARS OLD

FLY FEELING BALLOONS

Before setting balloons free, use a marker to draw different faces such as sad, happy, curious, worried, proud and surprised. Children will not only have an exercise to better relate to each emotion and understand that all the emotions are okay, but also communicate exactly how they are feeling.

READ BOOKS

Books are a great source of knowledge to increase understanding of their sibling's process with cancer. Interactive books like the [NCCS coloring book](#) also give great information a child can ingest while doing an activity they enjoy. Books about cancer, illness, hospitals and treatment are listed here:

- [A Friend in Hope](#) by Marisa Zammit
- [Sammie's New Mask](#) from the NCCS
- [Angels and Monsters](#) by Lisa Murray
- [Once Upon a Hopeful Night](#) by Risa Sacks Yaffe
- [Kidscope Kemo Shark](#) by H. Elizabeth King
- [The Paper Chain](#) by Claire Blake, Eliza Blanchard and Kathy Parkinson



POP CANCER BUBBLES

For the kids on the younger end of this spectrum, have them blow bubbles and be a chemo shark or radiation monster and pop the bubbles to kill cancer cells. This will give them relief while developing a small understanding of treatments.

PLAY DOCTOR

This type of play can help children cope with fear and get acquainted with new settings. Giving them doctor toys will help them be comfortable with hospitals and medical professionals.

MAKE COLORFUL PAPER CHAINS

Help children write feeling words on strips of construction paper and visit about what they mean. Examples could be love, life, hope, together, courage and fight. Let kids decide what order they want their strips in and where they want to hang their finished product. Children will learn new words to help them express themselves and understand their feelings.



HOSPITAL AND FOUNDATION SUPPORT

Many hospitals have programs in place where healthy children have the opportunity to interact with experts in research, social work and psychology of children and also speak with new friends who feel similarly in support groups.

When Hazel was receiving treatment at a hospital two hours away from the family's home, they were connected with resources from the oncology team like a family psychiatrist and child life specialist. Their psychiatrist met with Hazel's siblings nearly every day they were at the hospital. Their child life specialist monitored the healthy kids' progress and sat down with books about cancer to explain their tough situation.

"Gideon and Paul even took the books back to their school and asked to explain it to their class so their friends knew what was going on with their little sister. They each gave a presentation to their entire class to explain Hazel's cancer, how it was treated and what things to avoid if they were around her," Nat explained.

If support groups cannot be found nearby, there are online toolkits and free mailings kids can subscribe to. [SuperSibs](#), sends six sibling "comfort and care" mailings a year containing activities and resources to validate the difficult feelings of healthy siblings.

CONCLUSION

As one of our NCCS families has said, "Going through cancer, our family bond was strengthened and we're able to discuss really intense subjects as a family."

Families facing childhood cancer are going through hardships many will never know. But, with maintaining strong connections and communication, healthy siblings can be as adjusted and primed for a successful life, if not more so with the elevated coping mechanisms they've achieved. We have discussed many ways for a family to find comfort and care, and the NCCS has many [additional resources](#) so that no family will go through childhood cancer alone.

The National Children's Cancer Society (NCCS), headquartered in St. Louis, Missouri, is a not-for-profit organization providing support to families making their way through the daunting world of childhood cancer and survivorship. With over 30 years of experience serving nearly 42,000 children, the NCCS is able to take a "no matter what" approach to help families stay strong, stay positive and stay together. The NCCS has been recognized as a Better Business Bureau Accredited Charity and earned a GuideStar Platinum Seal of Transparency. For more information call 314-241-1600, visit [theNCCS.org](https://thenccs.org), or on Facebook and Twitter. To read all articles and white papers published by the NCCS, visit <https://thenccs.org/articles#>.