

**LTFU**

Long-Term Follow-Up Study

Winter 2022

# Update

## LTFU Study siblings

While cancer research usually focuses on the patient, a cancer diagnosis affects the entire family. This is especially true for siblings.

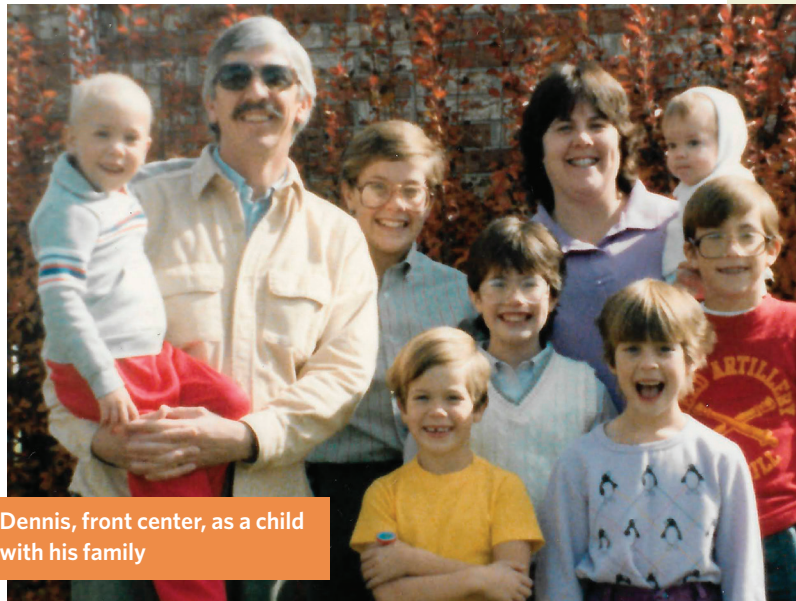
Having a sibling treated for cancer during childhood is stressful. Family and school routines can change when parents must focus time and attention on the child with cancer. Parents' ability to work may also be affected, resulting in further hardships for some families. This upheaval may cause a range of emotions in siblings, such as worry, sadness, guilt, and even anger.

But how are siblings doing many years after this experience? Do these feelings persist? And how do they affect siblings' health? We asked LTFU Study siblings to share their experiences.

### The siblings

**Jack.** Jack was in the fourth grade when his sister was diagnosed with cancer in 1975. His parents traveled from northeastern Massachusetts to Boston for his sister's treatment. "I remember getting bounced around a lot when my parents were at the hospital, going to neighbors or relatives," he says. "It was difficult at times. Childhood cancer is a completely different ballgame now—my sister is one of the first ones who lived."

**Dennis.** Dennis' brother was diagnosed with cancer in 1985 at four years old; Dennis was five and the fifth of seven siblings.



Dennis, front center, as a child with his family

They lived in Wyoming, which lacked a pediatric cancer treatment center, so his mom took his brother to Denver for treatment. "She would spend months there; sometimes we went, other times our grandmother came out to support us," Dennis says. "Then when my brother was five, he had a stroke that left him with severe permanent disabilities. He and I were really close, so in a way, I lost my best friend."

**Kelly.** Kelly's sister had cancer in 1977 when Kelly was three and her sister five, and she had a relapse in 1984. Kelly remembers her friend's mother telling her that her sister was in the hospital. "Those moments you never forget—coming off the bus happy, laughing with my best friend, happy to see my friend's mom, and then the crushing feeling. I remember the exact spot in the yard where I was told."

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### A NOTE FROM US

Your health information is influencing childhood cancer survivorship care around the world! The LTFU Study's annual Investigator Meeting was held virtually in June 2021 because of COVID-19. While I missed seeing colleagues in person, it provided the opportunity for 600 researchers from 167 hospitals in 35 countries to attend and learn about the latest advances in survivorship care after childhood cancer.

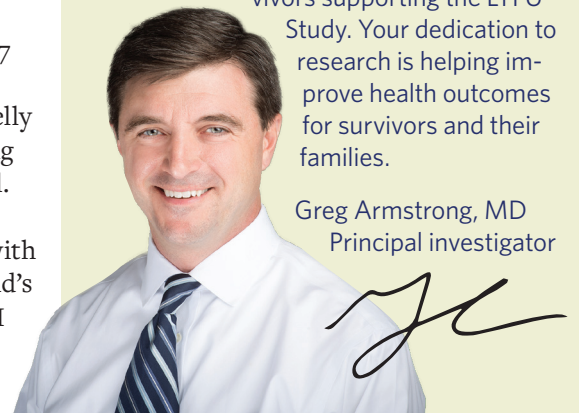
These advances are based on data you have provided. Thank you for completing the most recent survey during the last two years.

**Beginning in 2022, you will receive the next LTFU Study survey.** It will be a little shorter than the previous survey and, for the first time, will ask about your experiences accessing health care, the quality of the care you receive, and the impact of the cost of your care. Look for your survey soon!

**This issue of the LTFU Update** focuses on siblings of childhood cancer survivors. Siblings in the study share their experiences, reminding us that childhood cancer can have lasting effects on the whole family. You'll also learn about LTFU research on sibling health and find resources that support families that are affected by childhood cancer.

Thank you to all of the siblings and survivors supporting the LTFU Study. Your dedication to research is helping improve health outcomes for survivors and their families.

Greg Armstrong, MD  
Principal investigator



# LTFU Study siblings

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The relapse brought Kelly a lifetime of worry: “I was always protective of her, always scared what was coming next. The relapse being 7 years later—you don’t see it coming. We constantly lived in fear of the follow-up checks, the imaging tests, the bloodwork, if my sister had any symptom—‘Uh-oh, is this it?’”

## Family effects

Cancer affected the siblings’ families in varied ways. While Kelly was the middle child, she took on the older caretaker role. “My sister had to wear a wig to school and got made fun of. I remember taking it upon myself at 10 to physically punish a boy teasing her on the playground,” says Kelly. “Did my worry for her ever stop? No. It’s become ingrained



Kelly, right, with her siblings

in my personality—I went into healthcare.” In spite of her worries, though, Kelly remembers her childhood as amazing: “I look back, and I was so fortunate. We are an incredibly close family. My parents were great parents, but I believe going through what we did also makes a difference.”

While cancer can pull a family together, it can also create divisions. As Dennis shares, “My parents got divorced in 1986—with the cancer, the long-distance treatment, seven kids, my brother’s new disability, the pressures that come with an upended existence... it didn’t work out. Cancer didn’t cause my parents’ divorce, but the stresses associated with cancer likely exposed and hardened the unmendable cracks. Our family dynamic was drastically altered by cancer and its reverberations.”

## Health effects

In addition to effects on family dynamics, a sibling’s cancer diagnosis can also impact their sibling’s health. A recent study by Dr. David Buchbinder from the Children’s

Hospital of Orange County looked at how the concerns of siblings in the LTFU Study changed over time. About two-thirds of siblings reported having concerns about their future health and cancer risk on their first survey, but these concerns decreased as they grew older.

The number of siblings reporting concerns also differed by the year their sibling was diagnosed. Among siblings of survivors diagnosed in the 1970s, almost three of four siblings had concerns about their future health and risk for cancer. The number reporting concerns decreased to about one in two for siblings of survivors diagnosed in the 1990s—likely related to improvements in cancer treatments.

Understandably, siblings with a brother or sister who received intensive therapy or experienced serious health problems related more health concerns. “Health problems in the cancer survivor may lead the sibling to worry about the survivor’s well-being and create ongoing sibling concerns,” says Dr. Buchbinder. “It is important to ensure that siblings have support to cope and manage stress relating to their own personal health.”

## Increasing support

The importance of early sibling and family support has spurred the creation of programs that provide services after a cancer diagnosis.

Many pediatric cancer centers offer programs for cancer patients and siblings. Alex’s Lemonade Stand Foundation, a Pennsylvania-based nonprofit, has a SuperSibs program that is dedicated to comforting, encouraging, and empowering siblings during their family’s battle against childhood cancer.

Our LTFU Study participants’ reflections also emphasize the need for parent and caregiver support programs. A variety of organizations offer online resources to support families, for example:

- National Cancer Institute ([www.cancer.gov/about-cancer/coping/caregiver-support/parents](http://www.cancer.gov/about-cancer/coping/caregiver-support/parents))
- American Childhood Cancer Organization ([www.acco.org/24-hour-online-support/](http://www.acco.org/24-hour-online-support/))
- St. Jude Children’s Research Hospital ([together.stjude.org/en-us/for-families/parents/support-networks.html](http://together.stjude.org/en-us/for-families/parents/support-networks.html))

Today, more than ever, there is greater appreciation for the need to support families affected by cancer. Thank you to our sibling participants in the LTFU Study who have shared memories of their cancer experience and continue as partners in research to increase understanding about the long-term effects on childhood cancer patients and their families.



Citation: “Health-related and cancer risk concerns among siblings of childhood cancer survivors: a report from the Childhood Cancer Survivor Study (CCSS).” *Journal of Cancer Survivorship*, May 2021.



# Perspectives from psychology research:

## Cancer and families

“The dynamics in the family change quite a bit when a child is diagnosed with cancer,” says Rachel Tillery, PhD, pediatric psychologist.



“Primary caregivers spend a lot more time with the sick child, and that’s really difficult for the sibling. If they don’t know what’s happening, it can create uncertainty.” She says that even with a good prognosis, with limited information, siblings may imagine

the worst-case scenario. This may explain why some siblings have higher anxiety compared to peers without a sibling with cancer.

But sibling research also shows resilience. “It’s a struggle in the beginning when uncertainty is high, but once everyone starts to understand what the diagnosis means and what the treatment trajectory will be, most families return to their baseline,” says Dr. Tillery. “We see minimal impact on siblings’ social functioning and sometimes even see ‘post-traumatic growth’—growing from this difficult experience. We also see that siblings can be more mature than their peers. So it’s a mixture of difficulties and distress, but also positive growth from the cancer experience, and resilience.”

### Long-term effects

Research on long-term effects of cancer on families is limited. Dr. Tillery reports, “Even though siblings and families exhibit resilience, there are still unmet needs, and we need to explore those needs. From our research on the challenges of transitioning off treatment, 60-65% of caregivers talked about siblings’ distress and not having had adequate psychological care for them during this time.”

For Dr. David Buchbinder, volunteering at the SIBS (Special and Important Brothers and Sisters) session at Camp Okizu during medical school led to a long-standing interest in understanding the psychosocial impact of cancer on families.

Dr. Buchbinder, a pediatric hematologist-oncologist at the Children’s Hospital of Orange County, acknowledges that despite the best intentions of pediatric cancer care teams, time and resources are often limited to address the needs of siblings of cancer patients.

### LTFU Study siblings

Siblings participating in the LTFU study have been important partners in Dr. Buchbinder’s research that has helped us understand how the family cancer experience affects sibling health behaviors and health concerns. “The LTFU sibling cohort represents an amazing voice in survivorship research,” says Dr. Buchbinder. “Our studies have shown that siblings are generally doing well, which reflects their incredible strength and courage. But we need to be mindful that we may underestimate the struggles that some siblings face, even many years after a sibling had cancer.”

### Addressing sibling needs

Addressing sibling needs is a passion Dr. Buchbinder shares with members of Sibling Partnership for Advocacy, Research, and Care in Childhood Cancer (SPARCCC), a collaboration involving the pediatric cancer community. SPARCCC has highlighted the importance of anticipating and meeting siblings’ needs. Despite having a published standard of psychosocial care for children with cancer and their families, this standard is often not met in day-to-day care of siblings. As a result, SPARCCC recently teamed up with Mattie Miracle Cancer Foundation to focus on overcoming barriers to meeting the supportive care needs of siblings.



## Helping with the impact of cancer on families

According to Dr. Tillery, research suggests ways to help families experiencing cancer:

- Give siblings opportunities to process this experience with someone
- Provide appropriate medical information to siblings throughout the cancer experience that’s understandable and age appropriate to help with their coping and adjustment
- Consider family therapy, especially as you’re trying to go back to a new normal and establish new routines
- Help siblings rebuild their relationships with their parents and sibling with cancer, remembering that sometimes we need outside support to help that happen
- Help children learn to identify their emotions