

50 years of survivorship: “Living the best life I can, each and every day”

Nancy Getsi, LTFU Study participant, shares her story.

It's been 50 years since I was diagnosed with Ewing sarcoma. I was 10 years old and living in Tennessee. At first, my pediatrician said my pain was hypochondria.

After X-rays and a biopsy, my doctor had difficulty sharing the bad news with us. Fortunately, a pathologist put us in touch with the Mayo Clinic in Rochester, MN. I went there for surgery and radiation, then we returned home.

My chemotherapy drugs were shipped to my local pediatrician, who infused them straight into my veins (ports hadn't been developed yet). It made me very ill, and I continued to get chemo through all three years of junior high, but I was a typical teen in most regards.

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I'm a big believer in the LTFU Study," says Nancy Getsi. "I need to know I'm doing my part."

A NOTE FROM US

The coronavirus has changed many things in our lives, but the Long-Term Follow-Up Study continues to move forward, thanks to dedicated participants like you. This issue shares one participant's story, and I think her resilience can inspire all of us. On page 2, you'll find our thoughts

and advice on survivorship in the pandemic, including links to helpful resources.

SURVEY UPDATE

Paper surveys Participants who did not complete the current follow-up survey via their personal myLTFU portal have all been sent a paper version. COVID-19 paused our survey mailout in April, but we have returned to the St. Jude campus on a limited basis to print and mail them. **We need to hear from everyone**, so please call **1-800-775-2167** or email ltfu@stjude.org if you'd like us to send you another copy.

myLTFU portal The survey is also open in the study portal. One of the great things about completing it here (in addition to saving trees and research dollars) is that you can compare some of your responses to more than 7,000 other participants and get early access to lots of interesting data.

Our important work continues. We thank all of you for being our research partners, and we wish you good health.

Greg Armstrong, MD
Principal investigator

Survivorship in a pandemic

Survivors are experiencing a range of physical and emotional challenges related to COVID-19. Members of the LTFU Study Education Committee share their experiences, encouragement, and expert advice.



Linda Rivard, RN, LTFU Study Education Committee member, and her son Billy, a cancer survivor.

For many cancer survivors, the ways in which the COVID-19 pandemic changed their lives feels strangely familiar. "I'm hearing people say, 'It feels like when I was first diagnosed,'" says Melissa Hudson, MD, Director of the Cancer Survivorship Division at St. Jude Children's Research Hospital.

"It relates back to their original experience—losing control, not being able to be around their support

system. Their lives have been turned upside down again," she explains.

New options emerge amid disrupted care

Many survivors have health issues related to their cancer or its treatment that have been linked to higher COVID-19 risk. Follow-up care is as important as ever, but many people are postponing clinical visits as they try to evaluate the risks of in-person appointments.

"One good thing to come out of this is telehealth," says Linda Rivard, RN, a survivorship nurse at Advocate Aurora Children's Hospital in Oak Lawn, IL.

Use of telemedicine efforts increased dramatically during the early days of COVID-19. Because of its

success, it may be here to stay—not to replace in-person care, but to offer an effective, efficient, and safe alternative to in-person care when a physical exam is not needed.

"Things are different

now," Linda says. "If you have an immediate concern or are scheduled for a follow-up appointment, communicate with your team. Even if you don't see

them in person, you can stay on top of things with a phone call or a remote visit."

Meanwhile, outpatient health care settings are reopening with new safety precautions in place, and are working hard to educate and reassure the public. If you have concerns, call your health care facility and ask what systems are in place to ensure that you can safely receive the care you need.

Staying home doesn't mean staying still!

Even when restrictions are eased, many people are choosing to avoid gyms, crowded parks and trails, and other places where they could be active. "Physical activity is more important than ever," says Kathy Ruccione, PhD, RN, co-author of *Childhood Cancer Survivors: A Practical Guide to Your Future*.

"Don't sit on the couch or work at your kitchen table all day. Put on your mask, go outside, and walk around. Or do things inside your house. We all still have to move!"

Keeping calm during COVID-19

Anxiety, depression, and sleep issues often worsen when we're living with uncertainty and missing in-person contact with other people.

"Survivors may find it useful to explore some of the mindfulness websites and apps that are available. A good one to explore is HeadSpace (www.headspace.com). I also like Calm (www.calm.com)," Kathy says. "And if you're struggling, reach out for support, either from family, a friend, or a professional."



Kathy Ruccione, PhD, RN, is a member of the LTFU Study's Education Committee.

Resources

Resources on COVID-19 and survivorship are available by logging into your [myLTFU portal](https://myLTFU.org) and on our website ltfu.stjude.org

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Getting through & moving forward

My mother made sure I had a normal childhood. I didn't lose my hair, so most people didn't know what was happening. Mom would put me into a lawn chair in the sun and say, "Fresh air and sunshine are going to make you better." She loved the outdoors, so we went for lots of hikes. She didn't dwell on what could happen. Her attitude was, "We're getting through this and moving forward."

I married my high school sweetheart. Today, 43 years later, we're still married with three grown kids.

I didn't know if I'd be able to have children—there wasn't a lot of information available about the effects of treatment back then. But I had my first child right before finals of my college sophomore year and my second child two weeks after I graduated. I had to get an extra-large graduation gown, I was so big!

After graduation, I got a full-time job and two years later had my third child. I had a great career in computer programming and over the last 15 years was the VP of software development for three different companies, recently retiring.

The importance of resilience

When I was 44, my mother was going through chemotherapy for an aggressive cancer, and I found a lump in my breast—but I was so stressed about her that I didn't do anything about it. Two weeks after she passed away, I went to my doctor. I had a lumpectomy and was told it was cancer again, but they weren't able to remove all of it. I could have had a single mastectomy, but decided I wanted the whole works done. Given my family's history, there was no point in not being aggressive. And that was the right decision—even though the MRI showed my other breast was clear, when they did the pathology, they found cancer so small it hadn't shown up.

Going through chemo again was tough. I lost all my hair, and I was sick and weak. As an adult, I understood the risks more clearly. When I looked in the mirror, I had no hair and no breasts. What got me through was the same resilience my mom drilled into me when I had Ewings: "Keep putting one foot after the other. I will have hair again, I will be around to see my kids graduate." And it's been 16 years now!

I have some health limitations. I've had amputations in my rib cage, and one of my lungs is not as strong as the other. When I go hiking, I can't quite keep up with the others, but I'm slow and steady, and it's something I'm used to.

Getting over guilt, giving back through LTFU

My challenges now are more emotional than physical. I've always felt some guilt. I know it's not my fault I got cancer, but because of the financial hit, my parents sold their car and our home. My brother and sister had to change schools, move away from their friends, and miss out on a lot of our parents' attention. My teenage kids had to deal with my cancer right after seeing their grandmother go through chemo and pass away.

I'm a big believer in the LTFU Study. Maybe it's just me trying to get over my guilt, but I need to know I'm doing my part. I love getting the surveys, and I've done just about all of them. I'm thrilled with the myLTFU portal! I'm a former web developer, and I found it really nice to use. I like reading about the results—once we have results, we are armed with information that is helpful.

This is a banner year. I've retired, and I hit the 50-year survivorship mark. It feels fantastic to not need to get up to an alarm clock, though I still get up early. My husband and I make and sell dove houses through our small business, Lovey Dovey Birdhouses.

Sometimes I wonder, why me and not others? I know I can't answer that question, but to honor everyone who has had cancer and the incredible efforts of all the medical personnel who fought to save me, I know I must keep living the best life I can, each and every day.



Nancy Getsi was 10 years old when she was diagnosed with Ewing sarcoma 50 years ago.

Enjoying retirement, Nancy keeps busy creating and selling birdhouses with her husband, Jean.



Photo: Jenna Getsi