

A NOTE FROM US

As 2021 begins with the roll out of an effective vaccine against COVID-19, we can finally see a glimmer of light at the end of the tunnel. The pandemic has impacted our lives, work, relationships, and mental health. As a childhood cancer survivor, you may have been challenged by worries about becoming sick, difficulties in seeing health care providers, and isolation from your usual support systems.

During this stressful period, completing your LTFU survey may not feel like a pressing priority. But your survey response, amidst a global health crisis, is critically important to help us learn how the pandemic is affecting the health and wellbeing of childhood cancer survivors.

The information you provide will advance clinicians' and researchers' understanding of the pandemic's effect on all aspects of your health, including your physical, emotional, and social wellbeing.

This is a unique opportunity to "give back" to the survivorship community and help others at a time when we have all, at times, felt helpless.

Please complete your survey, if you have not done so. If you didn't receive the survey or need another copy, please contact us at 1-800-775-2167 or ltfu@stjude.org.

For those of you who have already completed it, know that we are grateful. Your responses will continue to support childhood cancer survivorship research and our efforts to keep survivors healthy.

Greg Armstrong, MD
Principal investigator


RESEARCH RESULTS**Pain and survivorship**

Nearly one-third of LTFU Study participants reported moderate to severe pain more than 10 years after completing treatment. For many, pain significantly affects their daily life.

Pain is a serious medical concern that can affect relationships, work, and everyday experiences. Many options are available to help manage pain, but often survivors are not aware of them. "We conducted this study because, up until now, we lacked data on pain among survivors," says Cynthia W. Karlson, PhD, University of Mississippi Medical Center, who led the research team.

Comparing responses from 10,012 survivors and 3,173 of their siblings from the 2002 and 2007 LTFU Study surveys, researchers found that more than 10 years after treatment:

- 29% of survivors reported moderate to severe pain
- 20% of survivors reported that pain significantly interferes with their daily activities

The study also identified factors that were associated with pain in daily life, such as:

- Demographic: Female sex, minority race/ethnicity, older age at diagnosis
- Cancer-related: Sarcomas/bone tumors, platinum-based chemotherapy, amputation surgery
- Medical: Chronic conditions
- Psychological: Depression, anxiety, fatigue

Predictors of pain

"Although some of these predictors, like a survivor's sex or cancer diagnosis, can't be changed, the study highlights lifestyle factors that are very effective for reducing and managing pain," Dr. Karlson says. "We can manage pain by decreasing stress and anxiety, and getting good sleep. When we're more stressed or not sleeping well, our pain is worse."



This is the first longitudinal study of pain among childhood cancer survivors. Thanks to the LTFU Study, researchers can keep moving the field forward.

Cynthia Karlson, PhD, is a pediatric psychologist at University of Mississippi and a childhood cancer survivor.

LTFU Study: Year in review

2020 will be remembered as the year in which the world grappled with a new health crisis—the COVID-19 pandemic. But thanks to the dedication of LTFU Study participants, we have continued to make important contributions to what is known about survivorship and health.

Advancing the science

In 2020, the LTFU Study published 33 new studies and presented 20 abstracts at virtual scientific conferences.

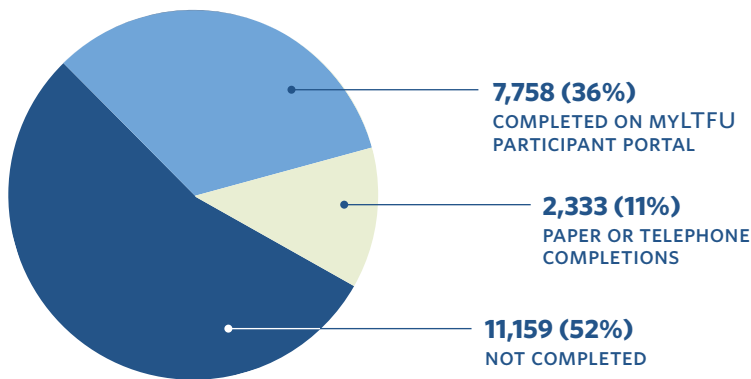
DID YOU KNOW? Survivors and their siblings have contributed to a total of 387 publications since the LTFU Study launched in 1996. Search them by topic on the LTFU Study website (in the Resources section): ltfu.stjude.org

LTFU Study Follow-up Survey

We began rolling out the most recent follow-up survey in August 2019 with an initial focus on the myLTFU portal. Mailing print versions was delayed because of COVID-19, but is currently underway.

As of December 30, 2020 the response rate for the current survey was 48%. Here's the breakdown:

SURVEY RESPONSE (TOTAL OF 21,546 PARTICIPANTS)

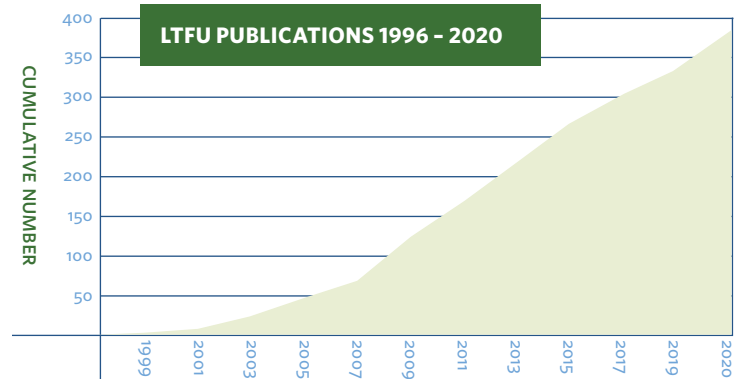


We need to hear from everyone. That's why the 13 staff working in our Coordinating Center and 14 Survey Interviewers make such an effort to follow up with every participant if we don't receive their completed survey.

Here's how often we many times we reached out to participants in 2020:

- 29,146 phone calls
- 216,953 emails
- 36,011 text messages

DID YOU KNOW? If you haven't completed your survey, it's not too late. Please contact us and let us know how we can help: Email: ltfu@stjude.org Phone: 1-800-775-2167



First myLTFU study completed

We recently completed the first study conducted through the myLTFU portal. In the study, titled “Symptom Assessment and Management using mHealth (SAM),” more than 40 participants used the portal to rate the presence and severity of 20 symptoms and their quality of life.

At the end of the study, the participants, who completed 90% of their reports (which is considered excellent!), reported that it was easy to provide data using the portal. What we learned will help us further integrate myLTFU in survivorship research.



DID YOU KNOW? If you have not yet activated your myLTFU portal, it's easy to do. Start here (ltfu.stjude.org/myltfu) and complete a few brief steps.

Participant Advisory Council (PAC)

Last year we put out the call to participants: “We need your input!” and 121 people volunteered to be part of a new Participant Advisory Council. In 2020, PAC volunteers:

- Provided feedback on how to enhance the study experience
- Helped test the myLTFU participant portal before we launched it with the whole cohort
- Contributed to the design of a colorectal cancer screening study and creation of educational materials for a new genetic counseling study

DID YOU KNOW? We still welcome new PAC members. There's no time commitment. To join, email us at ltfu@stjude.org.

Pain and survivorship continued from page 1

Implications for survivors

The study is important because it confirms that many adult survivors are affected by moderate to severe pain more than 10 years after their diagnosis. Screening for pain among survivors can help address it.

“Survivors who experience pain after treatment should talk to their medical providers about treatments that we know are effective,” says Dr. Karlson. “These options include both medical and lifestyle approaches, like physical therapy, relaxation training, and cognitive-behavioral pain management.”

Shout-out to survivors and their siblings

Dr. Karlson is a survivor of childhood cancer. She didn’t originally plan on cancer becoming the focus of her career, however. “I started in rheumatology,” she says, “Then I fell into cancer during internship. My personal experience makes me passionate about trying to improve evidence-based care and provide the highest quality support to survivors.”

“As a researcher, I am deeply grateful to everyone who is part of the LTFU Study. Because you take the

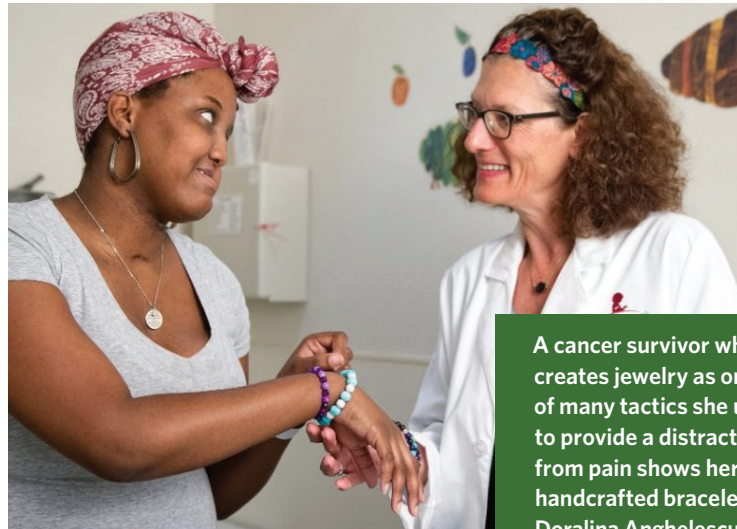


Photo courtesy
St. Jude Children's Research Hospital

A cancer survivor who creates jewelry as one of many tactics she uses to provide a distraction from pain shows her handcrafted bracelets to Doralina Anghelescu, MD.

time to answer all those questions, year after year, we can keep moving the survivorship field forward.”

Cancer

Citation: “Longitudinal Pain and Pain Interference in Long-Term Survivors of Childhood Cancer: A Report from the Childhood Cancer Survivor Study.” *Cancer*, June 2020.

Understanding pain and ways to address it

The brain plays an important role in our experience of pain, and is key to helping us manage it. Signals from the source of pain travel along pathways in the nervous system to the brain. If those signals send the message, “Yikes, that’s hot and it hurts!” we are prompted to move our hand away from the stove.

Pain signals then make a return trip from the brain to the original source. Pain management strategies can affect the signals in either direction and ease the pain.

Pain is not just physical—it has psychological and social components that can increase or reduce the way we experience pain. Managing pain requires an approach called “biopsychosocial” because it includes all of these areas.

“Biopsychosocial”: Breaking it down

“The biopsychosocial model looks at pain holistically and considers each person’s medical, emotional, and social situation,” says Doralina Anghelescu, MD, who directs the Pain Management Service at St. Jude Children’s Research Hospital.

Biological factors that cause pain include nerves, bones, and scarring. “Sometimes medications like acetaminophen or anti-inflammatories can help,” Dr. Anghelescu says, “But I always prefer to encourage non-medical approaches—physical therapy, yoga, stretching, swimming, or any comfortable and enjoyable physical activity.”

Psychological approaches, particularly cognitive-behavioral therapy (CBT), can help patients “reframe” pain and focus on their abilities rather than their limitations. Meditation and deep breathing exercises can promote relaxation and lower stress.

Social factors can affect how we feel pain by promoting a positive or negative mental attitude. “Supportive, reassuring relationships help us feel good about ourselves,” says Dr. Anghelescu. “On the other hand, if the people around us are anxious or overly focused on our pain, that can make the pain feel worse or prevent us from doing things that help pain improve.”

You don’t need to put up with pain

This study confirms that pain is common among childhood cancer survivors, who may not realize that they don’t need to accept it as part of their lives. Survivors experiencing pain are encouraged to explore available options with their primary care providers, who can help them find solutions.

Resources

For survivors: Chronic Pain after Childhood Cancer Health Link (Children’s Oncology Group): bit.ly/3ocA7oj

Understanding pain (How Stuff Works): bit.ly/3dM6obo

For health care providers: Guidelines for Survivors of Childhood, Adolescent and Young Adult Cancers (Children’s Oncology Group): www.survivorshipguidelines.org