

Winter 2020

Your Survivorship Care Plan

An important tool for you and your providers

A Survivorship Care Plan, sometimes called an SCP, is a concise and complete record of your cancer treatment and how your treatment might affect specific organs and tissues in your body—from ear wax buildup to risk of other cancers later in life.

SCPs also identify recommended health screenings based on your specific treatment exposures. This may include early cancer screening, organ function testing, and advice about behaviors to help keep you healthy.

Survivorship Care Plans are usually created for survivors by their oncology providers, after treatment has been completed, to help guide follow-up care. Give a copy of your SCP to everyone on your healthcare team, including your primary care doctor, subspecialists like your eye doctor or neurologist, dentist, counselor or therapist, and chiropractor.

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Melissa Hudson, MD, Director of Cancer Survivorship at St. Jude Children's Research Hospital, reviews a Survivorship Care Plan with a patient

Happy 2020, LTFU participants!

As we enter the new year, we are excited to let you know about a new feature we have added to the myLTFU study portal. Participants who complete their surveys now can see, in real time, how other participants who have completed the survey answered selected survey questions. This is one way that we are trying to “give back” to the LTFU Study community.

Survey update

By the end of 2019, we had sent myLTFU portal invitations to nearly 17,000 survivor

participants. Our sibling participants will be invited in early 2020. I'm happy to report that over 5,700 (34%) of you have activated your myLTFU portal and over 4,100 (25%) have completed your current follow-up surveys. We look forward to seeing these rates increase as we continue to email, text, and call with reminders.

In January 2020 we started mailing print versions to people who had not yet completed their surveys. If possible, though, we hope you'll help us save dollars, time, and trees by choosing the portal option.

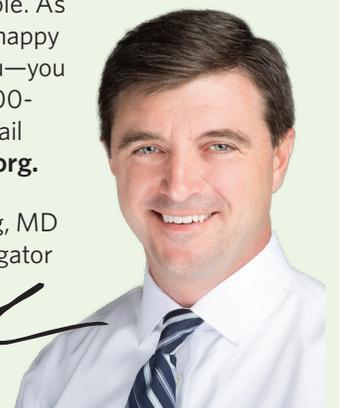
First smart watch winners announced

Congratulations to Carter, April, and Kelly for winning smart watches in our first drawing!

Participants who complete their surveys through the portal are eligible for upcoming drawings, so please submit your survey!

Thanks to everyone who makes this research possible. As always, we are happy to hear from you—you can call us at 800-775-2167 or email LTFU@stjude.org.

Greg Armstrong, MD
Principal investigator

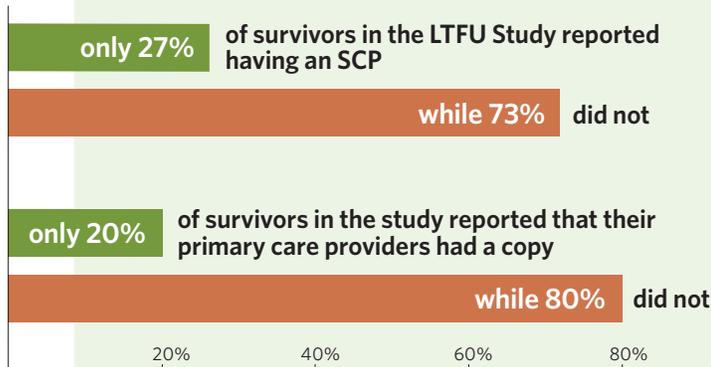


A NOTE FROM US

The LTFU Study Community

How many LTFU participants have SCPs?

Survivorship Care Plans can help protect survivors' health, but:



The research that identified this missed opportunity looked at responses from 10,791 LTFU Study participants who completed follow-up surveys between 2014-2016.¹

The same research showed that a majority of survivors are not receiving the follow-up care recommended by survivorship guidelines. **Less than 50%** of those at risk of breast cancer reported receiving a mammogram. Among survivors at risk for skin cancer, **only 22%** had received a skin exam.

The good news: SCPs increase screening

The study showed that survivors who have SCPs are more likely to have had their heart function monitored, and that providers with a copy of the SCP were more likely to perform skin cancer checks.

If you don't have an SCP

First, look back through your personal files. Many survivors don't remember receiving a Survivorship Care Plan.

If you have your complete treatment history, you can create your own SCP online by entering the information into Passport to Care (<https://cancersurvivor.passportforcare.org>), which will produce a plan for you based on the screening recommendations of the Children's Oncology Group.

¹"Impact of Survivorship Care Plans (SCPs) on Adherence to Surveillance for Second Malignant Neoplasms (SMNs) and Cardiac Dysfunction in the Childhood Cancer Survivor Study (CCSS)." *Journal of Clinical Oncology*. May 20, 2018.

Survivorship Care Plan continued from cover

Most non-oncology health care providers care for very few adult survivors of childhood cancer. Your SCP will help your doctor understand your health history and your unique needs. Some survivors view their SCP as a tool that helps them advocate for the special care they need after childhood cancer.

FEATURED RESOURCE

Matched mentors provide survivor support

Diana Merino, a member of the Education Committee that produces the LTFU Study newsletters, understands the challenges of survivorship—she's a survivor herself and a cancer researcher.

Diana also volunteers with Imerman Angels, a nonprofit organization that provides free support by matching survivors with mentors. These one-on-one relationships (by phone, email, or video chat) offer the chance to talk about personal challenges and get support from someone who shares the survivor experience.

"Some things you just can't learn from your doctors or from loved ones who haven't gone through the same experiences," she says.

Shared experiences, unique understanding

Based on her own experience, Diana notes, "Survivors from racial/ethnic or other minority groups may not always see themselves reflected in the available survivorship resources. People's concerns can vary based on their family, race, or even the food they ate growing up. Imerman Angels allows people to reach out to other survivors across the continent, increasing the chances of finding a mentor who shares the same culture and beliefs."

Finding a purpose in cancer's "crazy things"

Diana also suggests that survivors may want to consider volunteering as mentors. "It's amazing to be able to help others who are experiencing what I did. It helps me find a purpose in all the crazy things I went through, by simply listening and sharing my own feelings or advice," she explains. "Mentees aren't the only ones who benefit. Mentors do, too!"

Imerman Angels has supported cancer patients, survivors, and caregivers in 97 countries (www.imermanangels.org).



Diana Merino, PhD, is the Director of Research Partnerships at Friends of Cancer Research, a cancer research nonprofit in Washington, DC.

Racial and ethnic disparities in survivors of childhood cancer

The LTFU Study is leading the way to investigate the role of race and ethnicity in survivorship outcomes. In this Q&A with Stephanie Dixon, MD, we learn about a recent one-of-a-kind research project.

Stephanie Dixon, MD, led the LTFU Study team that published “Racial and Ethnic Disparities in Neurocognitive, Emotional, and Quality-of-Life Outcomes in Survivors of Childhood Cancer,” which looked at data from 13,708 five-year survivors and 3,055 siblings. Race/ethnicity were self-reported as white (non-Hispanic), Black (non-Hispanic), and Hispanic.

Why is this study significant?

“Very little research has compared the outcomes of childhood cancer within different racial and ethnic groups. Our study has more minority participants than any other similar study. There is a great deal of interest in this type of research.”

What did you learn?

“The good news is that, among survivors, we did not find differences in neurocognitive (thinking skills) outcomes affecting memory and organization by race or ethnic groups.

“We also measured the difference (or ‘gap’) between the responses of survivors and siblings of the same racial/ethnic group. The survivor-sibling difference for depression was greater in Hispanics than in whites. Blacks and Hispanics had greater survivor-sibling differences in health-related quality of life than whites for mental health and social function.”

What are the implications for survivors?

“It’s reassuring that thinking skills outcomes did not differ in racial and ethnic groups, but there were differences in quality of life. These differences suggest that some

survivors are not getting the support or resources they need during treatment, or after going back home. Support services like those offered by Imerman Angels (see page 2) can help.

“This study identifies important issues we need to explore and understand, so we can develop new and effective ways of promoting survivor health and wellbeing.”

Citation: *Racial and Ethnic Disparities in Neurocognitive, Emotional, and Quality-of-Life Outcomes in Survivors of Childhood Cancer: A Report From the Childhood Cancer Survivor Study. Published in Cancer, Volume 125, Issue 20*



Stephanie Dixon, MD, St. Jude Children’s Research Hospital, was a 2019 Conquer Cancer Foundation ASCO Merit Award recipient.

Suggestions for survivors

Quality-of-life means different things to different people. If a survivor is struggling emotionally or socially, here are some of Dr. Dixon’s recommendations:



Try to keep a close community, whether through church, school, friends, families, or work.



Stay physically active—it’s important for your emotional health and how you perceive yourself.



Find a support group by calling your local cancer treatment center or search for one online.

Take your feelings seriously. If you are experiencing difficulty in any area of your life, seek out support and discuss your concerns with someone you trust. (Read about the mentor matching services available from Imerman Angels on page 2.)

