

Survivors' Experience with Survivorship Care Plans

MORE THAN 14 MILLION CANCER SURVIVORS live in the United States—and the number is rising. To provide support to this growing population, care coordination resources are essential. Key stakeholders, including the Commission on Cancer and the Institute of Medicine, have proposed survivorship care plans as a way to extend support. To date, however, limited research has been conducted on care plans.

In 2011, the LIVESTRONG Foundation (LIVESTRONG) held the LIVESTRONG Essential Elements of Survivorship Care Meeting. More than 150 experts and stakeholders in the field developed a prioritized list of elements that any effective cancer survivorship clinician must provide (directly or via referral) to post-treatment cancer survivors. Number one on this list was survivorship care plans.

WHAT IS A SURVIVORSHIP CARE PLAN?

A survivorship care plan, developed from a patient-specific treatment summary, includes medical and psychosocial components and records information for both the survivor and the providers involved in the care of the survivor. Important components of the survivorship care plan include information about treatment exposures and potential long-term or late effects, such as medical and psychosocial complications and their signs and symptoms.

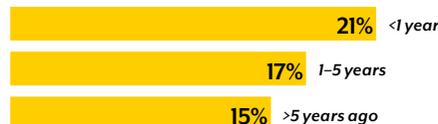
A care plan provides survivors with a long-term strategy for monitoring their health. At the most basic level, a care plan should include

- › Recommendations about tests that help detect recurrence or second cancers
- › Potential long-term effects of cancer and treatment
- › How often they should see specific health care providers
- › Recommendations for healthy lifestyle behaviors that are important to recovery
- › Information about reducing health risks, and
- › Community resources that can support cancer survivors.

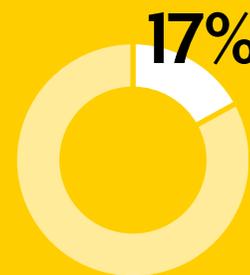
WHO RECEIVED CARE PLANS IN THE LIVESTRONG SURVEY?

Of the 5,315 survivors in the LIVESTRONG Survey who completed treatment or were living with cancer as a chronic condition, only 17% had a survivorship care plan. The more recently survivors had completed treatment, the more likely they were to have received a care plan (Figure 1) ($p < 0.001$). Only 14% of survivors who were living with cancer as a chronic condition had a survivorship care plan.

Figure 1. Percentage of Respondents Who Received a Care Plan by Length of Time Since Treatment Completed



In 2012, only 17% of cancer survivors had a survivorship care plan.



The LIVESTRONG Foundation provides free cancer support services to help people cope with the financial, emotional, and practical challenges that accompany the disease.

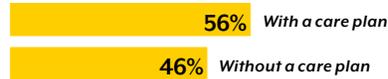
Created in 1997 by cancer survivor and philanthropist Lance Armstrong, the Foundation is known for its powerful brand—LIVESTRONG—and for its advocacy on behalf of survivors and their families.

With its iconic yellow LIVESTRONG wristband, the Foundation has become a symbol of hope and inspiration around the world. Since its inception, the Foundation has raised nearly \$500 million to support cancer survivors and has served 2.5 million people affected by the disease. For more information, visit LIVESTRONG.org.

SURVIVORSHIP CARE PLANS CAN HELP TO OPEN AND STRENGTHEN PATIENT PROVIDER COMMUNICATION

Survivorship care plans can help to open and strengthen patient-provider communication. Compared with survivors without care plans, survivors with care plans felt very confident that they could openly discuss problems related to their cancer diagnosis with their doctor ($p < 0.001$) (Figure 2). Survivors with care plans were more likely to discuss long-term side effects of cancer treatment, emotional or social needs, and lifestyle and health recommendations than survivors without care plans ($p < 0.001$).

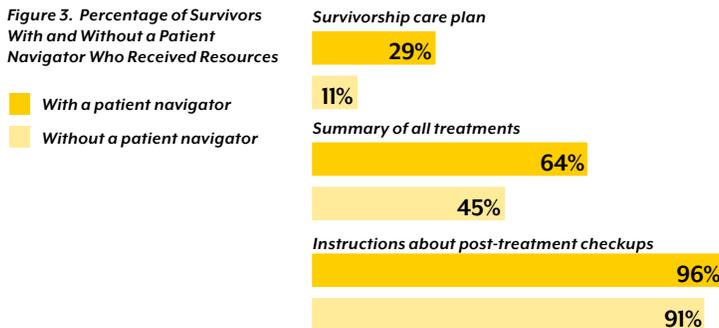
Figure 2. Percentage of Survivors Who Felt “Very Confident” They Could Discuss Problems with Their Doctor



PATIENT NAVIGATORS PLAY AN IMPORTANT ROLE.

Survivors who had a patient navigator were significantly more likely to receive a survivorship care plan than survivors who did not have a navigator ($p < 0.001$). Those with a navigator were also more likely to have a summary of all of their treatments and be given instructions about returning for routine cancer checkups after completing treatment than those without a navigator ($p < 0.001$) (Figure 3).

Figure 3. Percentage of Survivors With and Without a Patient Navigator Who Received Resources



HOW CARE PLANS CAN INFORM YOUR WORK

Tell your health care team about the importance of care plans.

Learn how to use a care plan in your practice: www.LIVESTRONGcareplan.org/faq-hcp.cfm.

Refer patients to LIVESTRONG’s navigation services: www.LIVESTRONG.org/gethelp or 1.855.220.7777.

Provide patients with information from LIVESTRONG that will help them on their new journey as survivors:

- › *The Survivorship Care Plan, powered by Penn Medicine’s OncoLink, is a free survivorship care plan available in English and Spanish at www.livestrongcareplan.org*
- › *The Living After Cancer Treatment Brochure Series*
- › *The Guidebook and Planner Set*
- › *The Cancer Guide and Tracker App*

The LIVESTRONG Survey

In 2012, the LIVESTRONG Foundation (LIVESTRONG) conducted the third iteration of the LIVESTRONG Survey, an online survey that explores cancer survivors’ needs and experiences before, during, and after a cancer diagnosis.

Participants were recruited through LIVESTRONG’s website, email, and social media as well as through LIVESTRONG’s partners. The survey was completed by 6,383 survivors. Of those respondents, 5,315 had completed treatment or were living with cancer as a chronic condition. Results from this brief are based on the analysis of these data.

For more information about the LIVESTRONG Surveys, visit www.LIVESTRONG.org/What-We-Do/Our-Approach/Reports-Findings.