

Study shows survivorship care plans empower cancer patients

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In 2005, the Institute of Medicine, surveying the outlook for the growing number of American cancer survivors, first described the idea of a survivorship care plan: a roadmap for the group of patients, today numbering nearly 12 million, who are beginning new lives as cancer survivors.

Care plans aims to arm [cancer survivors](#) with a customized road map for their lives as cancer survivors: tips for follow-up screenings, information about possible late effects of their therapies, and pointers on fertility or financial issues they may face in the future. The plans also seek to enhance communication between [health care](#) providers and cancer survivors, many of who return to care from internal medicine physicians after finishing their treatment. The concept is now recognized as a key part of ensuring the continued health of cancer survivors: Beginning in 2015, the Commission on Cancer will require cancer centers seeking accreditation to provide care plans to patients once they complete their treatment.

Now, a group of Penn Medicine researchers have published the first study to assess the effectiveness of care plans at equipping patients to meet these goals. In a study published online in the journal *Cancer* this month, the team details their findings about the effects of use the most widely used care plan tool – the online, Penn-developed LIVESTRONG Care Plan—on patients' health care knowledge and communication, [lifestyle behaviors](#), and emotions. More than 29,000 patients and health care providers have used this personalized tool since it launched on [Penn](#)

[Medicine's OncoLink](#) in 2007.

Despite the close watch from health care providers [cancer patients](#) receive during their treatment, it's often not clear who – an [oncologist](#), a primary care physician, or another type of specialty physician – is responsible for mechanizing the disparate aspects of a survivor's health, from monitoring for and managing late effects of therapy to ordering routine preventive health exams such as [bone density](#) tests and colonoscopies. Consequently, important health needs among cancer survivors needs may go unmet, the authors say.

"The one constant in the care of cancer survivors is the survivor him or herself," says Christine Hill-Kayer, MD, an assistant professor of Radiation Oncology in Penn's Abramson Cancer Center and the lead author of the new study. "By providing the survivor with the resources to know which tests need to be ordered in the form of a written document, a survivorship care plan enables the survivor to take more control of his or her care, and to participate in minimizing the 'slip through the cracks' phenomenon."

The research team studied 298 cancer survivors who used the LIVESTRONG Care Plan between May 2010 and January 2013 – culled from a group of 8,690 patients who completed plans during that timeframe – each of whom completed a survey about their experience using the site one month after completing their plan. Each user received a care plan after inputting demographic information and data about their diagnosis and types of treatments received.

Ninety-three percent of users reported that the information provided through the care plans was excellent, very good, or good. Importantly, the findings reveal that the care plans fill a knowledge gap: 65 percent of patients said the information received was new to them and had not been previously provided by [health care providers](#). Ninety four percent of

patients felt they would recommend it to others. Eighty percent shared or planned to share it with their health care team, and of those who had already done so, 80 percent reported that it improved communication. More than 60 percent felt that the survivorship care plan changed their health care participation, and over half of users reported that they had made or planned to make a lifestyle change in response to information they obtained from the care plan, most commonly dietary modification and increased exercise.

"Our results show that care plans are empowering patients to become more active participants in their own health care," Hill-Kayser said.

"This is an important tool that provides [patients](#) with greater education and prompts them to be more proactive about their care and more likely to discuss concerns with their providers."

Provided by University of Pennsylvania School of Medicine

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