

FEATURE STORY

Seasons of Survivorship

In 1985, cancer survivor Fitzhugh Mullan, MD, published an article about his own cancer experience called “Seasons of Survival: Reflections of a Physician with Cancer” in *The New England Journal of Medicine*.

Mullan identified what he called the “seasons” of cancer survivorship: acute survivorship, which involves diagnosis and initial treatment; extended survivorship, a time of watchful waiting with celebration, uncertainty, and transition; and permanent survivorship, the season of gradual confidence that there would be a future free of cancer.

“Seasons of Survival” became the foundation for recognizing the stages of the cancer journey, and the next year Mullan was instrumental in the creation of the National Coalition for Cancer Survivorship (NCCS), which advocates for cancer survivors. In 1996, the Office of Cancer Survivorship was established at the National Cancer Institute to focus on research into the issues facing those with cancer from the day of diagnosis and for the remainder of life.

In 2004, the NCCS, the NCI Office of Cancer Survivorship, the Centers for Disease Control and Prevention, and the Lance Armstrong Foundation collaborated to publish *A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies* with the goal of identifying and prioritizing cancer survivorship needs within public health to improve the quality of life for millions of Americans who are living with, through, and beyond cancer. The document expanded the description of “survivor” to include not only individuals living with cancer but also their families and caregivers.

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—Kenneth Miller, MD

In 2005, 20 years after Mullan’s landmark piece, came “From Cancer Patient to Cancer Survivor: Lost In Transition,” a milestone publication from the Institute of Medicine. The executive summary stated that “psychological distress, sexual dysfunction, infertility, impaired organ function, cosmetic changes, and limitation in mobility, communication, and cognition are among the problems faced by

some cancer patients. The good news is that there is much that can be done to avoid, ameliorate, or arrest these late effects of cancer.”

Based on research gathered for the report, the authors made 10 recommendations that included recognizing survivorship as a distinct phase of cancer care, ensuring the delivery of appropriate survivorship care, expanding research efforts in survivorship, eliminating discrimination and adverse effects of cancer on employment, and ensuring access to good health insurance.

Cancer survivors had finally been officially recognized.

Today, cancer survivorship remains a new area of research. Around the country, a number of specialized programs have been established to provide support and information.

In December 2008, Kenneth Miller, MD, director of the Lance Armstrong Foundation Cancer Survivorship Program at Dana-Farber Cancer Institute and a leading survivorship researcher, revisited Mullan’s original piece in “Seasons of Survivorship Revisited,” an article in *The Cancer Journal*.

“Many things have changed during the 20 years since Mullan described the ‘seasons of survival,’ ” Miller explains. “Earlier diagnosis and better treatment have resulted in more people living through and beyond cancer, though more are able to live with cancer as a chronic disease. And although the intensity of treatment may result in an improved chance of survival, it can leave some survivors with late and long-term side effects.”

Miller identifies the time immediately after treatment ends as **transitional survivorship**, when celebration is blended with worry and loss as the patient pulls away from the treatment team. After the transition period, Miller says patients move to **extended survivorship**, which includes those who are living with cancer as a chronic disease as well as those in remission because of ongoing treatment.

The final stage, **permanent survivorship**, includes not only those who are in remission and asymptomatic, but also those who are “cancer-free but not free of cancer” because of chronic late and long-term health or psychosocial problems. This group also includes those who develop second cancers unrelated to the first or those who develop new cancers as a result of initial treatment.

Transitional Survivorship: Finding the New Normal

It’s the day you have been waiting for—your cancer treatment has ended. Perhaps you celebrated in the infusion room or radiology suite. All you know is you can’t wait to get back to your “real” life and put cancer behind you, a thought that comes with a nagging anxiety about leaving the medical system where you were watched closely—where everyone was focused on you getting well. What will take its place? Who is watching you now?

You may be aware of other new feelings. You really want to forget about what you have just gone through, but somehow you find yourself wanting to talk about it over and over. Or you don’t want to talk about it at all.

Transition is that time when what has happened to you becomes reality. During the intensity of treatment there may not have been the opportunity to absorb the reality that cancer has become part of your life. Now is the time.

Indeed, the fact that you had cancer may not even sink in for months, and then when it does, you may experience anxiety and feelings that are hard to explain since everyone around you thought you were back to your old self.

Julia Rowland, PhD, director of the Office of Cancer Survivorship at the National Cancer Institute, says that at the same time that the patient is trying to adjust to new family roles and emotions, everything shifts again. Everyone, Rowland says, has to adjust to the “new normal.”

Finding your footing, Rowland says, depends on the length of your “acute” cancer stage, meaning that the longer the cancer experience—from the first suspicious symptom to the final treatment appointment—the longer you will need to recover from the physical and emotional ripple effects.

The medical and emotional issues of transition, also referred to as re-entry, are addressed in the next section of this guide. During this time you may be cancer-free but you are not free of cancer’s effects as you adjust to body changes brought on by surgery or treatment that impacted your physical and cognitive abilities. There may be chronic pain, fatigue, weight loss, or weight gain.

There is no right or wrong way to “do” survivorship, but you can be aware of the pitfalls of those who have gone before you.

Or, while your physical self may not have been significantly impacted, you may have emotional, relationship, or community issues to resolve.

Fear of recurrence, anxiety, and sleep disorders may plague cancer survivors, sometimes for years. Financial issues may impact the family—even those who have insurance. Add to that the new family dynamics for caregivers, employment stress, and other practical concerns. Without help, the aftermath of cancer treatment can be as devastating as the cancer itself.

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Each person is unique in how they navigate the stages of survivorship depending on a number of factors that may be out of your control, such as your age, family circumstances, gender, insurance coverage, and job status. If you are older, the fear of recurrence can be more difficult if there are other symptoms or conditions related to aging or to minor, unrelated illnesses that feel like recurrence but are not.

On the positive side, many survivors say that life after treatment provides an opportunity to re-examine priorities, resulting in a new awareness for survivors who choose to redirect their energy toward a different, perhaps more fulfilling, life as they move to permanent survivorship.

Extended Survivorship: The New Survivors

The need for understanding and research into survivorship has come about primarily because cancer survivors began demanding that the medical profession understand that the cancer experience does not end the day treatment ends. At the same time, new treatments and new drugs have led not only to increasing numbers of cancer survivors living in permanent remission, but also to those living as extended survivors, the “new survivors,” whose cancer has become a chronic condition or those who have active lives while either receiving ongoing treatment or episodic treatment for recurrent disease.

These are survivors such as Fran DiGiacomo, Erin Zammett Ruddy, and Wendy Harpham, MD, all of whom live with cancer.

Wendy Harpham, MD, is approaching her 20th anniversary of living with cancer. Diagnosed initially in 1990 with stage 3 non-Hodgkin lymphoma, Harpham has had seven recurrences of her cancer and suffers from cancer-related fatigue. While living with cancer she has authored seven books on cancer survivorship, written for medical professionals in a cancer journal, and spoken nationally.



"My cancer has encouraged me to know both the fragilities and the hopes of life and with this knowledge to live most fully," Harpham says.

Fran DiGiacomo often says she wasn't even surprised when she was diagnosed with breast cancer in her early 40s in 1984 because she had grown up in a family where everyone died young of cancer. She survived breast cancer only to be diagnosed in 1998 with stage 3C ovarian cancer. The award-winning artist has undergone 11 surgeries and had multiple recurrences of her ovarian cancer. She describes herself as working hard at surviving by exercising, keeping up with research about new findings in her cancer, and staying busy in her art studio.

"You quickly learn to treasure every day, and how much precious time and energy can be lost in tears and self-pity," says DiGiacomo.

☒ It never ceases to amaze me that my life with cancer is not much different than my life without it. ☒

—Erin Zammett Ruddy

In 2001, **Erin Zammett Ruddy** was diagnosed with chronic myeloid leukemia at age 23, only six months after the Food and Drug Administration approved Gleevec (imatinib), a targeted therapy for CML that replaced bone marrow transplantation as the treatment of choice. After five years on the drug, Ruddy, a features editor at Glamour magazine at the time, stopped the drug to become

pregnant, giving birth to her son in September 2007. Ruddy, who left the magazine to become a freelance writer and mother, announced in early 2009 that she was pregnant with her second child. Her cancer remains in remission with daily Gleevec.

Permanent Survivorship: Being Healed

While the authors of “Lost in Transition” see permanent survivorship as comparable with cure, Miller says it can also be a time when the survivor may face physical or psychosocial issues related to treatment that they were unaware of previously.

This group may also include those who develop second cancers unrelated to the first or those who develop new cancers as a result of their initial treatment.

Although assessing the survivor’s quality of life during this time remains difficult, there is recognition that a survivor’s physical and mental state during permanent survivorship depends on myriad physical, emotional, and social issues that will be continually impacted as time progresses. It is also a time when the existential aspects of cancer may surface as the survivor tries to understand the deeper meaning of the cancer journey for themselves, their family, and their future.

- ☒ Whether good or bad, life changing situations often give people the chance to grow, learn, and appreciate what’s important to them. ☒

—National Cancer Institute's booklet, *Facing Forward: Life After Cancer Treatment*

These qualities include the spiritual and emotional aspects of the survivor experience that, when integrated, offer the survivor a level of peace with the experience that goes beyond being cured to being healed. Or as one survivor says: “To be well is to be cured, but to be whole is to be healed.”

During permanent survivorship, individuals often reflect on the experience and how it has changed or is changing them. Some move toward becoming advocates for the newly diagnosed or active in cancer policy, while others find a renewed sense of purpose for life. On the other hand, some survivors choose to put the experience away emotionally and return to activities and interests from before cancer. There is no right or wrong way to move forward.

In its booklet, *Facing Forward: Life After Cancer Treatment*, the National Cancer Institute refers to permanent survivorship as a time of reflection, saying:

“Whether good or bad, life changing situations often give people the chance to grow, learn, and appreciate what’s important to them. Many people with cancer describe their experience as a journey. It’s not necessarily a journey they would have chosen for themselves. But it sometimes presents the opportunity to look at things in a different way.”

The Survivorship Care Plan

A primary finding of the Institute of Medicine report “Lost in Transition” was that “oncologists should provide every patient with a treatment summary and follow-up plan to monitor for long-term and late effects, recurrence, and new cancers.”

Survivors will be assessed for a period of time after treatment ends by their medical oncologist, radiation oncologist, or surgeon, who will be looking for specific issues related to cancer treatment and possible recurrence. But as survivors move into the future, they will resume seeing a family practitioner, internist, or other health care provider for health issues and potential chronic illnesses that are unrelated to cancer, such as osteoporosis, heart disease, and diabetes.

Surviving cancer adds a complex set of medical needs to that list beyond normal screenings and annual checkups. With this in mind, cancer survivors need to have a survivorship care plan and be aware of potential medical conditions and the risks that follow cancer and its treatments so they can implement strategies to reduce their risks—meaning survivors will have more responsibility than ever to be partners in their care.

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—Kenneth Miller, MD

Since patients see their oncologists during the transition from active treatment to survivorship, Miller says this is the time to get a care plan, before returning to primary care doctors.

“It’s really sort of saying where have you been, where are you now, where are you going, and how can we help you,” he says.

Miller encourages patients to ask for a summary that includes the diagnosis, treatment, and specifics as to what they should do next and in the years ahead. Another option is for the patient to request a copy of his or her medical records, which may have a fee attached but will give detail on drugs, dosages, and specifics about diagnosis. Patients can download and print off any of a number of survivorship plans created by various organizations, including the American Society of Clinical Oncology’s web-based plan.

A care plan may also include issues outside those of possible future physical issues. For example, Patricia Ganz, MD, an oncologist at the Jonsson Comprehensive Cancer Center at the University of California, Los Angeles, who specializes in long-term and late effects, has recommended genetic counseling in specific situations that suggest a possible genetic link that may put a survivor’s

family at risk.

According to Brad Zebrack, PhD, a professor of social work and public health at the University of Michigan and 23-year Hodgkin disease survivor, there are also psychological and social components that need to be included in a care plan. He says that studies suggest upwards of 30 percent of childhood cancer survivors experience symptoms of post-traumatic stress or depression.

A number of cancer organizations have created survivorship plans, including the Lance Armstrong Foundation (LAF), which released the LIVESTRONG Care Plan in early June. The web-based tool offers cancer survivors, their families, and physicians the ability to create an individualized plan using up-to-date treatment information based on Institute of Medicine recommendations.

Caroline Huffman, director of patient navigation services at LAF, explains that their interest in providing a state-of-the-art care plan began in 2006 with the first meeting of the LIVESTRONG Survivorship Center of Excellence network, comprising eight regional Centers of Excellence in Cancer Survivorship, which are recognized for their research, patient care, training, communications, and outreach.

Huffman says one of the most exciting aspects of the network is bringing together researchers who are used to working in relative isolation and in competition for funding.

“We’ve developed a way for them to communicate with one another to really figure out what it is that they’re strategically going to do that is going to change the field,” she says.

Huffman says those who have been working on how to follow survivors for years have collaborated to create the new plan.

“All the network centers are continually assessing what population of survivors needs to be seen, at what junctures they need to be seen, and what’s involved in a survivorship follow-up visit,” Huffman says.