

## PEOPLE

# Defining Survivorship

BY MELISSA WEBER

Julia Rowland, PhD, director of the National Cancer Institute's Office of Cancer Survivorship ([survivorship.cancer.gov](http://survivorship.cancer.gov)), talked with *CURE* editorial director and managing editor Melissa Weber about the condition of survivorship care today and what's to come.

## What attracted you to the field of survivorship?

In graduate school, I was instantly intrigued by the issues that so many patients talked about in the context of their cancer experience and that these didn't end when treatment ends. They were having to deal with concerns which at that time, 30 years ago, were largely unrecognized, not only in the medical community but also socially. These were not diseases you talked about. Much of that suffering was going on in silence.

**You recently co-authored an article called “Cancer Survivorship: A New Challenge in Delivering Quality Cancer Care,” published in the *Journal of Clinical Oncology*, in which you immediately reference the definition of “survivor” as beginning at the moment of diagnosis. That definition has become popular, but there still seems to be a disconnect in communicating that message to newly diagnosed patients. Why is that?**

Let me step back because I think this is such an important message. The transformation of the definition goes back to 1986, when a group of 24 individuals got together in Albuquerque, New Mexico, [to create the National Coalition for Cancer Survivorship], and challenged the medical definition of a cancer survivor, which at that time held that only someone who had remained disease-free for five years could be called a survivor. They recognized the need to transform or broaden how people think about individuals who are diagnosed with cancer for two reasons. One, it's a message of hope that there is life after cancer. But more importantly, it would oblige the health care provider system—doctors, nurses, all the people who come in contact with the patient—to be thinking about that person in a context. You're not just a breast, colon, kidney. You're an individual who comes with life aspirations, dreams, goals, and achievements and things you want to do in your life after this illness. And you can't wait for five years before you begin to acknowledge or address these issues. So philosophically, that shift in language is important because it mandated a conversation and it forced the medical community to think differently about what was going to occur, what the decision process needed to be, and how to engage patients in that to say, 'We need to make treatment decisions that are going to be meaningful to you and relevant to you and the life you wish to lead.' If you look over time, survivorship may not be in everybody's lexicon, but it's certainly

changed the philosophy in the medical setting.

**There's a lot of discussion in the medical community about achieving optimal survivorship. How would you define optimal survivorship?**

It would be comprehensive. Optimal care is care that allows you to minimize the costs of survival (physical, emotional, social, economic), maximize your health outcomes and enable you to be as successful as possible in achieving your goals in the context of this illness. It makes available to you the resources you need to do this, and gives you hope and meaning for a life beyond your illness and treatment.

**Do you think we're there yet?**

I think we're getting there. One of the interesting issues is that we in the larger medical and research communities have only really just become securely anchored in what we call the survivorship experience on the larger cancer-control trajectory.

We think of cancer control as primary prevention, early detection, treatment, and then it used to go right to end of life. Now, we realize there are a whole set of needs and experiences that people have after the completion of active treatment and before they either die of their disease or something else. We realize this piece of the trajectory is important and has special demands attached to it—being disease-free does not mean being free of your disease. Or, as my esteemed colleague Patti Ganz says, 'It's not over when it's over.'

Many people struggle with the residual effects of the experience. Some are things that will get better over time, some are changes that will have to be accommodated over time because they linger, or in some cases are permanent, and some of cancer's effects may not show up for months or years later. We always want to be on the lookout.

And then there's the art, or manner, in which you deliver optimal care. It's not just the knowledge that you have; it's how you deliver that and how you relate to individuals and support them. Some of that art is in the language used and attitudes reflected, in particular words and behavior that honor each survivor as a unique individual with particular needs, desires, and care demands and the capacity to be a partner in his or her future health.

**There are so many issues to address whether you're at the end of treatment or 20 years out dealing with long-term effects. If you had to pinpoint the most critical time in the trajectory, what would that be?**

It's really the day of diagnosis. Right from the outset, you want to be working with a set of health care providers who are going to treat you as a whole person. It's not only focusing on the disease and the impact this is going to have on your physical well-being but [also focusing] on your emotional health, your cognitive functioning, your social well-being, your economic status—all of that should be considered. Being an active participant is going to be very important in optimal outcomes. It doesn't mean you have to make all the decisions yourself, but you have to be engaged in the process.

Another critical point in time, we are quickly realizing, is making that transition from active treatment to post-treatment. In the past, people just used to say:

“Congratulations, you got through chemotherapy. We’ll see you back in three months. Good luck.” And then people fell into the black hole. No information, no knowledge, no support. There are a lot of reasons why that transition is traumatic for a lot of people. We’re still not doing what we need to do for people after they finish treatment. And we don’t yet have the best models or evidence base for who needs to be providing what information, how and when.

### **Within these transition areas, what’s the weakest and what’s the strongest?**

We know what the treatment exposures were, so we just need someone to collate that information for survivors and their future health care providers alike. Less well-known, because we don’t have the necessary research data, is who may be at risk for what kinds of late effects. And what we don’t do very well at all is tell survivors how to keep this disease from coming back. While we don’t necessarily know the answer to that, survivors are asking us for health-promoting interventions, and ... we really need to be thinking about what we can do to take advantage of this teachable moment when people may be willing to make lifestyle changes they were unable to make or had not considered making prior to this event in their lives.

### **What is the Office of Cancer Survivorship doing to address these questions?**

The big gap area we had when the office was created was studies of long-term survivors, so our first major initiative was to request the investigator community to conduct studies among survivors who were five years or more post-diagnosis. Even though more than 60 percent of our survivor population is five years or more out from diagnosis, and 14 percent of them were diagnosed 20 or more years ago, we don’t have a lot of data on what their lives are like as a consequence of having cancer. An important new finding of this emerging area of research is that while survivors are living longer, which is obviously good news, the bad news is that with longer survival has come a higher risk for late complications, like a new, second cancer. While some of these will be related to the earlier cancer, many will simply be due to getting older. As a result, researchers are beginning to look at models for care ... to best optimize outcomes for survivors.

### **What’s the most exciting thing about where cancer survivorship is heading?**

It’s the visibility and recognition of cancer survivorship issues at a national level that is particularly exciting. In some ways, if we’re going to take a really big-picture view, some of the things that cancer survivors have been wonderful at championing are not unique to cancer. It’s about how we all need to be regarding our health and well-being. We need to partner with our health care providers, we need to be proactive in our care and attentive to our health behaviors, we need to have access to high-quality care. And cancer survivors are really teaching us how to do this. They are the leaders out here championing what needs to happen to improve not only their own health, but potentially that of the rest of us along the way.

### **Expanding on that, what role do you think survivors play in pushing the survivorship movement forward?**

We wouldn’t be where we are today without survivors’ articulate and vocal advocacy. They’re coming to the table saying, “You need to pay attention to us.”

It's not enough to focus on cure. Cure is not enough because there are no benign treatments; treatment comes at a human cost. We have to understand that and what the trade-offs are. Nobody listens better to an appeal for action than when it comes from someone who has been there. Having gone and testified in front of Congress I know ... that, no matter how convincing the science, there's nothing more compelling than when you hear a personal testimony — this is what it's like, this is why you have to change things.

### **Do high-profile cancer survivors like Lance Armstrong make your job easier?**

There is no question that being able to give a 'face' to survivorship has been incredibly powerful. And Lance has certainly done that and been an inspiration to millions—and globally. As he would probably agree, timing and teamwork are critical. He was able to build on the momentum that had been slowly growing since the coalition [NCCS] was formed, supported by an emerging body of research among cancer survivors, to literally propel (or perhaps I should say fast-pedal) survivorship issues to the level of national awareness. Survivors have the spotlight right now. It's something we want to be able to use to our advantage but not take for granted.