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# The Man Who Redefined 'Survivor'

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*Q & A with Fitzhugh Mullan, MD*

Fitzhugh Mullan, MD, was diagnosed with cancer in 1975. A decade later, he published “Seasons of Survival: Reflections of a Physician with Cancer,” which defined the term “survivor” as anyone diagnosed with cancer—from the time of diagnosis through his or her life. The essay, which appeared in *The New England Journal of Medicine*, was a eureka moment for many and a building block for the National Coalition for Cancer Survivorship, an organization Dr. Mullan helped establish in 1986. Currently a pediatrician at an inner-city health clinic and Murdock Head Professor of Medicine and Health Policy at the George Washington University, Dr. Mullan talked to *CURE* about the role he played in making cancer survivorship an issue.

**Q: How did you come to realize the importance of survivorship care?**

A: In 1975, I took a chest X-ray of myself and discovered a mass that I knew instantly was cancer—a primary mediastinal seminoma as it turned out. I spent the first couple of years undergoing treatments and suffering complications and setbacks followed by a few years getting back on my feet. I began writing the book, *Vital Signs: A Young Doctor’s Struggle with Cancer*. It was almost an autobiographical travel log—the difficult journey of cancer. A lot takes place after treatment, and that is the recuperation phase. You’re dealing with uncertainty, your identity and vocation. That healing period is terribly important, but it’s relatively poorly attended to. There’s a long purgatory that all cancer patients go through, and my experience was far from atypical.

**Q: When you redefined the term “survivor” as anyone who has been diagnosed with cancer—regardless of stage of treatment or recuperation—it really struck a cord with a lot of people.**

A: I was asked to speak at the Cured Cancer Congress after *Vital Signs* was published in 1983. It was an effort to get people together to talk about the long-term challenges of cancer care. After the presentation, a woman approached me looking guilty. She said she didn’t belong at the conference. When I asked her why, she replied that she was only three months into her treatment. The palpable inequity of that sentiment—that she felt excluded because she wasn’t cured—floored me. How does anyone know they’re cured? Doctors say five-year survival or “I think we got it all”—that’s all arbitrary and uncertain. What’s real is the uncertainty of this new future of having cancer. It was what this woman said that made me think we had it wrong. She and I are both in the same place more or less—we’re both survivors, and we both have uncertainty in our lives for as

long as we live.

**Q: Can you describe the stages of survivorship you defined in “Seasons of Survival”?**

A: It is three different stages, or seasons to be poetic, because they don't have a precise beginning and end—acute, extended and permanent. The acute season is the treatment phase. It's a tough phase medically, but you get a lot of attention. Then there's an extended phase, where you're beyond the immediate treatment but there is the uncertainty of recurrence and a host of adjustments to living with cancer and its follow-up. Finally, for those who are fortunate to be spared recurrence, there is what I call permanent survival. Survivorship will continue for the rest of your life. You may have a compromised lung, amputated limb or scarred breast. You might have employment or insurance problems. You're on stable ground clinically, but you live within the shadow of cancer. You also live with the appreciation of life that the disease has given you. Survivorship—be it for a month, a year or decades—is cause for celebration of life.

**Q: You said your cancer journey was very typical of what most survivors go through. What issues or situations did you have during the three stages of survivorship?**

A: My treatment was physically tough. It lasted many months and turned my life upside down. Long-term survival was uncertain and the fear of recurrence was with me for many years. This is a road many others have traveled and are traveling. Some of us are fortunate enough to become long-term survivors, but the experiences we all have are, to a point, similar. This is what survivorship services and the NCCS are all about.

**Q: It has been 20 years since the founding of the NCCS, but the focus on survivorship in recent years has grown tremendously. What are your thoughts about the American Society of Clinical Oncology focusing on survivorship this year?**

A: It was a very important step historically. I think the rationale for many people that go into oncology work is to achieve cure. They want to pull people back from the brink, but it doesn't end there. The fact that ASCO is taking a step in the direction of both cure and maintenance is exciting. But there are other issues that will need to be addressed in the future, including insurance issues, employment discrimination and genetic testing for family members.

**Q: What does life after cancer and being a survivor mean to you personally?**

A: Obviously it was instrumental in founding the NCCS, and I became very active in the cancer advocacy movement. When I address cancer audiences I always start with the throwaway line, “I'm glad to be here.” But I really mean it. I say it as only a cancer survivor can say it. I am very glad to be here.