

*Cancer survivorship* implies that the cancer has been treated and the survivor can return to his or her precancer life. The term fails to acknowledge the radical change to the person's mind, body, and spirit, nor does it address the diminished quality of life that can occur secondary to treatment. The survivorship struggle is often overlooked as public interests lies only in "success stories."

# Survivorship

## How to survive cancer and still lose your life

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**S**urvivorship is a word that is interpreted differently among individuals. Like the old adage says, ask 10 different people the same question, and you will get 10 different answers. For me, survivorship implies that a terrible event has occurred and that event is over and you move on. If only that definition rang true for me as a cancer survivor. Some people identify with the title cancer survivor, but I do not. I am not sure what word I would use to describe my experience. I think of my life now in very black and white terms—life before cancer (BC) and life after cancer (AC), and nothing in between.

### Life Post-Treatment

In general, if someone gets diagnosed with cancer and is offered a treatment plan, no one really focuses on what happens once the treatment is over. You hear stories about patients feeling as if they are in a cocoon during treatment as appointments, infusions, and scans are focused on getting that patient to the finish line. The common goal is finishing treatment and getting rid of the cancer. Once treatment is completed, you seemingly are left on your own to pick up the pieces and go back to the life you had before. But now you have been changed. You are living a life AC.

In my case, no one mentioned that my life after treatment would include taking 29 pills per day, visiting doctors continuously, and experiencing ongoing symptoms such as chronic diarrhea, pain, and fatigue, nor how the treatments would alter not only my body, but also my mind and spirit. Most importantly, no one

mentioned how my life would be forever changed. This becomes the new normal. It is the ugly truth that no one wants to talk about.

The public only seems to be interested in the success stories. You often read about individuals running marathons, seemingly unscathed by their cancer experiences, or hear about people who manage to complete treatment while working full-time jobs. Everyone then expects you to be the same hero who goes on with life unaffected by this disease. These stories are often the exception, not the rule.

Other issues that are rarely discussed include social issues (losing friends because of your illness), financial burdens because of loss of health insurance or loss of employment, and disability insurance. All of these affect survivorship. Survivorship is not just keeping the cancer at "no evidence of disease," but also battling other issues that affect daily survival.

In retrospect, receiving a "cancer survivorship road map" would have been beneficial. This would have included meeting other providers, such as a nutritionist, physical therapist, social worker, and case manager prior to treatment. This designated team would be vital to me in restoring my health and well-being while working with me to design my individual road map.

### The Survivorship Struggle

If I go back to the term *cancer survivorship* and think about the meaning, I often ask, "Is it truly survivorship if you are faced with insurmountable odds of surviving?" If I am faced with a five-year survival rate of 8%–21% (depending on whose study you read), is this truly survival, or is it just beating the

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