

[TRACK 1: INTRODUCTION]

[Ellen Stovall, Cancer Survivor]

Hello, everyone. My name is Ellen Stovall, and I, too, am a cancer survivor. Yes, a cancer...survivor. That powerful phrase describes all of us who have been diagnosed with cancer at some time in our lives. There are now about 12 million of us who have or had cancer. About half of that number—or around 6 million people—have survived more than 5 years after a cancer diagnosis, while approximately 14% of us—or slightly less than 1,700,000 survivors—have lived more than 20 years beyond our diagnosis. That means that there are many of us who are surviving and living relatively normal lives years after our original diagnosis of cancer. Encouraging news, for sure. The end of the story? Not exactly.

[Ellen Stovall, Cancer Survivor]

Welcome to the *Cancer Survival Toolbox*[®] program entitled “Living Beyond Cancer.” This is just one of a series of Cancer Survival Toolbox programs. There are also programs on communicating, finding information, making decisions, solving problems, negotiating, and ways to stand up for your rights. In addition, there are other “special topics” programs like ones on finding ways to pay for care and topics for older persons, as well as programs on different types of cancers. You can listen to or read these programs online at www.canceradvocacy.org/toolbox; you can also download the audio files from iTunes.

The Cancer Survival Toolbox comes with a free Resource Booklet, also available at www.canceradvocacy.org/toolbox. Resources and organizations related to each Cancer Survival Toolbox topic are included.

Now, let’s talk more about the topic of this program, living beyond cancer.

If you have been treated for cancer, you probably have clear memories of the day you received your last treatment. Maybe you remember putting on a happy or brave face as the staff brought out balloons, or a cake, or a graduation certificate to celebrate your last treatment. After all, this was the end of your cancer therapy that you were looking forward to for so long, right? Treatment was difficult, to say the least, but now it was finally over! That moment may have filled many of us with joy—we were ready to celebrate and get on with our lives. Others of us, though, weren’t quite so sure just how we were feeling. Were we happy and relieved to be finished with treatment? Or, anxious and afraid that we were now on our own? Were we feeling insecure about not seeing our health-care team so often? Or, were we ready to bolt out the door and never return? Maybe we were feeling a combination of all these feelings. That would only be natural, since we still had questions that nobody could answer for us. What would happen to us now that our treatments were over? Will we be able to keep the cancer from coming back? What does life beyond cancer look like?

[Ellen Stovall, Cancer Survivor]

In this *Cancer Survival Toolbox* program, we will talk about a number of important issues that are specific to life beyond the diagnosis and initial treatment of cancer. While support and resources are increasingly available to help people who are being treated for cancer or suffering from the side effects of these treatments, much less attention is focused on what happens AFTER our initial treatments are done. The reality is that we don’t simply change from being a “sick patient” one day to being a “well survivor” the next day. Cancer survivorship is a day-to-day, on-going process that begins with your diagnosis and continues through the rest of your life. The people on your health-care team—your doctors, nurses,

social workers and mental health professionals—are some of your best allies in addressing your physical and emotional needs as a cancer survivor. Keep in mind that survivorship does not look or feel the same for each of us. Here are some examples of how different our needs might be.

[Narrator]

Survivorship may extend for months, years, and even decades. Some survivors continue on maintenance therapy, which is similar to long-term treatments for other chronic diseases, like diabetes and heart disease. Other survivors will live for many years with metastatic cancer, while others will never experience their cancer again.

[Narrator]

Some survivors may have completed treatment within the past few months or even the past few years, while others were treated decades ago. Obviously, day-to-day survival issues will depend on your own individual situation.

[Narrator]

Some survivors may experience a recurrence of their original cancer, or they may be diagnosed with a second malignancy. Others may discover that their cancer treatments have damaged parts of their bodies, such as their heart, lungs, or kidneys.

[Narrator]

Some survivors recover from the effects of treatments with little difficulty and feel almost normal within a few short months. Other survivors take much more time to recover physically from the trauma of treatment.

[Narrator]

And, finally, while many survivors will recover physically, they may still have difficulty recovering from the emotional or social traumas that can result from cancer and cancer treatment. These challenges can be more difficult to deal with than the medical problems. Linda is an oncology social worker who's seen a spectrum of cancer survivorship.

[Linda]

Surviving cancer is more complicated than simply being sick or well...having cancer, or being cancer-free. Instead, it's a continual process of survival that's constantly changing. There may be times when the joy you feel about survival far outweighs any anxieties you may have. Then, there will be times when your fears and uncertainties seem to take over your life, and you wonder if you'll ever feel normal again. These changes might involve family and friends who are trying to adjust to your experiences after cancer, but often don't—or can't—understand what you're feeling. Many survivors face challenges in school or at

work. You may have to fight **against** discrimination and fight **for** the chance to recover at your own pace. And, you may need to deal with intense feelings, like anxiety, anger, uncertainty, unresolved grief, and loss.

[Linda]

On the positive side, many survivors find themselves reevaluating their lives and changing their priorities. They might experience a new zest and appreciation for life, and try to make sense out of painful experiences. Many survivors have done this by getting involved in volunteer work and cancer advocacy in their communities, and by helping other cancer survivors directly.

[Narrator]

We hope that this *Cancer Survival Toolbox* program will introduce you to some new skills that will help you adapt to your life after cancer. The goal is to help **you**, a cancer survivor, be as healthy as possible within your personal circumstances.

[Narrator]

This program contains 6 sections on issues that are important to survivors.

Section 1 is Living With After Effects, in which we will look at the physical effects of cancer and its treatment, and what kind of records you need to keep.

In Section 2, Intimacy, we will explore the important topics of sexuality and fertility, and how close relationships might be affected.

In Section 3, Family Communication, we will talk about the experiences and challenges of survivorship that affect more than the survivor alone.

Section 4 focuses on the Emotional Aspects of Cancer, specifically in recognizing and dealing with anxiety, depression, grief, and distress.

Section 5 provides helpful information on Getting Your House in Order through health directives, wills and trusts, power of attorney, and financial planning.

Our program will conclude with Section 6, Living With Hope While Dealing With Uncertainty, with thoughts about advocacy, getting involved, giving back, and maintaining.

Many people find it helpful to follow along with written material while listening to each program. If you would like a transcript please visit the toolbox website at www.cancersurvivaltoolbox.org.

Let's begin by looking at how life beyond cancer can affect our bodies physically.