

[TRACK 1: INTRODUCTION]

Transcript: Standing Up for Your Rights

Narrator: Robert O'Gorman

[Narrator]

Cancer survivorship is a challenge faced by about 12 million people living today who have been diagnosed with cancer. It is about the quality of your life when faced with this frightening disease; about how you can learn to communicate, gather information, and make decisions; and, about how you can negotiate and solve specific problems. It is, indeed, about how you speak up or advocate for yourself from the moment you were diagnosed onward.

[Narrator]

The luxury of thinking about cancer along survivorship terms is fairly new. As therapies became available to manage this disease, some cancers became curable. Others changed from brief and severe forms to chronic illnesses. The hopes and expectations for surviving cancer have greatly increased.

[Narrator]

Before this decade, doctors planned the course of care for people with cancer. Doctors rarely gave choices about what they felt was best for these people as individuals. Eventually, however, people like you began to take more control over all aspects of care that affected their lives. Many wanted to be partners in their own care and began talking with each other. They developed support groups, hotlines, resource materials, and networks. As people with cancer became more vocal, the idea of survivorship emerged.

[Narrator]

Welcome to the Cancer Survival Toolbox program entitled "Standing Up for Your Rights." The topic of this program is self-advocacy. Advocacy means giving support to a cause. At the conclusion of this program, you will better understand what cancer survivorship means, and how you can become your own best advocate.

"Standing Up for Your Rights" is just one of a series of Cancer Survival Toolbox programs designed to help you learn the basic skills essential to self-advocacy. There are also programs on communicating, finding information, making decisions, solving problems, and negotiating. In addition, there are programs on special topics like finding ways to pay for care and living beyond cancer, 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, standing up for your rights.

[Narrator]

What does survivorship mean? How can it be defined? How do you know if you are a survivor? It is important to understand that for this program cancer survivorship is defined as a continual and

ongoing process rather than a stage or outcome of survival. NCCS believes that survivorship is NOT just about cure, or long-term survival, or living five years past your diagnosis. Instead, the NCCS Charter reads “that from the time of discovery and for the balance of life, an individual diagnosed with cancer is a survivor.” Simply put, this means that you are a cancer survivor no matter how long ago you were diagnosed or what stage of cancer you have, Survivorship can then be defined as the experience or process of living with, through, and beyond cancer.

[Narrator]

Years ago, the word cancer was linked to the word victim. People with cancer may have been thought of as powerless—that they could do nothing to help themselves once cancer had struck. See how you feel about the power of certain words. Repeat the following statements after me and notice how different they feel: "I am a cancer victim." (Pause) "I am a cancer patient." (Pause) "I am a cancer survivor." (Pause)

[Narrator]

Other terms that people with cancer use to describe themselves, include victor, triumpher, veteran, thriver, activist and warrior. All of these words describe someone who has choices and control. They show that you are not powerless, and that you can do much to maintain a high quality of life after cancer. Defining yourself, instead of letting other people label you in a certain way, is an act of self-advocacy. This may seem like a small point, but the words we use to describe ourselves make a big difference in how others see us, how we see ourselves, and how we act. This is also called empowerment.

[Narrator]

We often hear the term empowerment. Does it really have any meaning for you as a cancer survivor? Empowerment refers to any process that helps you influence other people and organizations that affect your life. More simply, it is about taking control. As such, empowerment is an important part of cancer survivorship. Empowerment assumes that you usually understand your own needs better than anyone else. It also assumes that it is best for you to have the greatest possible control in shaping your life, and in making your own informed decisions about actions that will affect the quality of your life. Empowerment and self-advocacy go together.

[Narrator]

In the classical sense, advocacy means summoning to one's assistance or calling to one's aid. For example, you practice self-advocacy when you seek a second opinion to learn the best options for your diagnosis or treatment. Instead of doing nothing or worrying about what your doctor might think about your asking for a second opinion, you actively do something in your own best interest. Let's hear the perspectives on self-advocacy of an oncology social worker, Linda, based on her experiences working with cancer survivors.