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## Transcript: Standing Up for Your Rights

**Narrator: Robert O’Gorman**

[Narrator]

Cancer survivorship represents the challenges faced by over 9 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 Program 6 in the Cancer Survival Toolbox, about 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.

[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 cancer survivorship is a continual and ongoing process rather than a stage or outcome of survival. It is NOT just about cure, or long-term survival, or living five years past your diagnosis. Instead, it is the experience or process of living with, through, and beyond cancer. From this perspective, we can say that from the time of discovery and for the balance of life, an individual diagnosed with cancer is a survivor. That means you are a cancer survivor no matter how long ago you were diagnosed or what stage of cancer you have.

[Narrator]

Years ago, the word cancer was linked to the word victim. People with cancer may have been thought of as powerless, and 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.

## Linda, oncology social worker: Part I

[Linda]

You can advocate or stand up for yourself for any or all of the following reasons: Advocacy gives you some stability and a feeling of regaining some control of your life. Advocacy builds confidence because it helps you face challenges that may have seemed too difficult to overcome. Advocacy is a way of reaching out to others. It can be as simple as asking your doctor or nurse for the name of someone to talk with who has survived your type of cancer. Advocating for yourself may make the difference that turns hopeless and helpless feelings into feelings of hope.

[Linda]

Cancer survivors often feel that self-advocacy and personal empowerment make it possible to meet their needs for information, intervention, and support. Speaking up for what you need when faced with a diagnosis of cancer, and knowing how to communicate those needs to family, friends, and caregivers are the first steps in self-advocacy.

[Narrator]

You may think that you do not have the skills to be a good self-advocate. Often people have a harder time being an advocate for themselves than they do for others. If you went with your child or partner to a doctor's appointment, would you leave without getting your questions answered? If you felt doubt about the treatment, wouldn't you take your child for a second opinion? If you felt that your partner's medication for pain control was not working, wouldn't you ask the doctor for something else? You can speak up for yourself in the same way that you would for a loved one.

[Narrator]

A basic key to standing up for yourself is to develop a plan of action with specific goals. Let's listen to the situations and decisions of some cancer survivors. First, Donna.

## Donna, in her 30s

[Donna]

During my monthly breast self-exam, I felt a definite lump. My first reaction was a fear so strong that I couldn't even think straight. But, once I calmed down, I decided on an immediate goal -- to get examined by my doctor. My plans were to get an appointment as soon as possible; to have my doctor check the lump; and, to call a friend to go to the clinic with me for support.

## **Ben, in his 40s**

[Narrator]

Next, Ben has a specific situation that he needs to address.

[Ben]

I was on my second course of chemotherapy for Hodgkin's disease. I had a terrible time with the nausea and vomiting after my first treatment. It was so bad, that I dreaded going back for more of the same. So, when I was feeling better, I decided my goal was to find a more comfortable treatment. My plan included talking to my doctor about my nausea and vomiting, getting better medication to control these problems, and, asking my support group members how they dealt with this problem.

## Leo, in his 40s

[Narrator]

And, now consider the situation Leo faces and the way he stands up for what he wants.

[Leo]

I was diagnosed with advanced pancreatic cancer. The surgeon wanted to perform a major operation. The cancer doctor wanted to try experimental chemotherapy. My family wanted to go for any treatment that might give us more time together. And, my family doctor simply wanted to make me more comfortable. With all the different opinions, I needed to decide for myself. My goal is simply to die with dignity and without pain. My plan includes a number of things -- telling my family and my doctors about my wishes, talking with all of my doctors about my medical needs, making sure I have enough pain medicine, taking care of my legal and financial responsibilities, and, asking for assistance from my spiritual counselor.

[Narrator]

Successful plans begin with finding information and then developing clear ways to communicate with those who can help you most: your health-care team, family and friends, and other cancer survivors. In short, you can become your own best advocate by learning how to set goals and make plans to achieve these goals.

[Narrator]

You can learn or strengthen your self-advocacy skills in a variety of ways. One way is by listening to these programs and practicing the exercises until you feel you have increased your skill level in your weaker areas. Another way to become a better self-advocate is by going to support groups. These groups can provide education about cancer, help you understand that what you are experiencing is normal, share how to find needed information, and give you many tips about managing your illness, your relationships, and the health-care system.

[Narrator]

There are other types of support, such as poetry or art-therapy groups, that can help you use your own creativity to become a better self-advocate. If you feel uncomfortable in a group setting, you may benefit from seeing a counselor who specializes in cancer-related issues.

[Narrator]

A variety of pamphlets and booklets is available on cancer-related topics. You can get these at your doctor's office, or through your hospital's cancer resource center. Visit your local bookstore for books about how other people have managed their cancer experience, and on such topics as assertiveness training. You'll find some suggested resources in the booklet that is part of this Cancer Survival Toolbox.

## Linda, oncology social worker: Part II

[Linda]

When I work with cancer survivors, I always point out that another way to be a self-advocate is to ask for what you need. You cannot always assume that family members, friends, or even your health-care team knows what you think, feel, or need. Too often, you may feel hurt when people close to you don't recognize your needs or fears. But they may be just as confused as you are about what to do or even how to talk about your cancer. Probably the worst thing you can do is to avoid talking about your cancer or about the changes that will need to take place while you are undergoing treatment. You and your family may need help in putting your cancer in perspective. Often your cancer nurse or social worker can help in these areas.

[Linda]

If family responsibilities need to shift during the course of your illness, be direct about asking for assistance. Family and friends are usually eager to help in any way they can. Self-advocacy may mean allowing yourself to depend on others for awhile. Also, ask a family member or friend to help you if you feel you cannot deal with some aspect of your care or decision making.

[Narrator]

The following is an example of how one woman, Mildred, dealt with her inability to ask her doctor for a second opinion.

## Mildred, in her 30s

[Mildred]

I had been diagnosed with multiple myeloma a number of years ago. My initial diagnosis was a complete surprise. I never had any problems with my back before, but all of a sudden I had severe back pain. My doctor found a tumor in my spine. After emergency surgery, radiation therapy, and two years of chemotherapy, I finally went into remission of my disease. I was able to return to work, and my life pretty much became normal again. But, I was very surprised when I went for a routine three-month checkup after that and my cancer doctor said he wanted to begin an intensive round of chemotherapy the following Monday. I was confused ... all of my tests appeared normal. When I asked why I needed the chemotherapy and why so suddenly, my doctor said that he felt certain that I would come out of remission shortly and he wanted to get the "chemo" started.

[Mildred]

Well, I didn't want to offend my doctor. After all, he had taken good care of me, and I felt that I did not have the knowledge to challenge his decision. But, an inner voice was telling me to get a second opinion; I just didn't know how to ask for one.

[Mildred]

I had never had any type of serious illness before my cancer. To tell the truth, I was kind of frightened by the health-care system. But, I wanted to stick up for myself and get a second opinion. I called a cousin of mine who works in healthcare as a physical therapist, and described the situation to her. I asked if she would go with me to the doctor's office on Monday to help me talk about getting a second opinion. She said "yes," she would be glad to help me. When we arrived at the doctor's office, the chemo medicine was already prepared, which made it even harder for me to ask for a delay. But my cousin did not have to worry about offending my doctor. She simply explained why I wanted a second opinion. My cancer doctor appeared angry at first, but he did agree to send me to a nearby medical center for another evaluation.

[Mildred]

The team of doctors at the medical center felt that chemotherapy was not necessary at this time. So, I talked with my own cancer doctor again, and we agreed to wait on the chemotherapy until my tests showed that I was definitely coming out of remission. And as it turned out, I still haven't needed it yet. I sure am glad that I listened to that inner voice, and that my cousin agreed to help me ask for a second opinion.

[Narrator]

The point of this example is that there are different ways to be your own best advocate. Asking others for help when you need it is a strength, not a weakness. Can you think of other ways that Mildred might have handled the situation? Suppose she did not have a cousin in healthcare? What could she have done then? Just as some examples, Mildred could have found friends to talk with about her concerns; joined a support group to talk about different options; or contacted national cancer organizations for information about her specific disease.

[Narrator]

What would you have done? Remember that we all need different kinds of information and make very different decisions depending on our styles of learning and our personal situations. There are many ways to solve problems.

[Narrator]

One final area of self-advocacy is important for almost everyone who must deal with cancer, including family and friends. And that is the need for you to maintain a sense of hope. Maintaining hope in the face of cancer is not always easy, especially when the situation seems hopeless. But feeling hopeless leads to feeling helpless. What really matters is how we handle the situation, which can lead to feelings of hopefulness. Let's listen to how this applies to another situation, as described by Kathleen.

## Kathleen, 70 years old

[Kathleen]

My husband, Michael, comes from a large Irish-American family that prides itself on looking out for each other. When Michael was diagnosed with advanced lung cancer after he turned 71, all of the relatives got together to talk about how to handle this family crisis. Some of them were determined to act like everything would be all right. Others felt like there was nothing they could do for him. There was a great feeling of sadness throughout our house.

[Kathleen]

But, I looked at it another way. I believed that Michael's future was in God's hands, and so I would make the best of whatever time he had left. I realized that there were things to be hopeful for. While he still felt well enough, I could hope that we'd enjoy our daily walks together. When he didn't feel up to going outside, I could hope that he'd still enjoy his favorite meals. If he does become bedridden, I could hope that he'd still be able to enjoy visits from our children and grandchildren. And when his end is near, I hope that he will be free of pain and at peace.

[Narrator]

As a family member, Kathleen did not feel hopeless or helpless. You may never have thought much about what role hope plays in your life, or about how you hope, or even about how you learned to hope. Yet research tells us that people hope very differently, and that the way we hope is affected by family experiences. We learned how to hope from our family of origin -- that is, parents, brothers and sisters -- and from our current families as well.

[Narrator]

Families have well-established ways of hoping, which are called family-hope patterns. They contain your family's values and standards regarding hope, and ways to maintain hope. For example, some families use a religious or spiritual basis for their hope. As a result, statistics and medical facts may not be as important to those families because they believe God will determine the outcome. These family members may draw great strength from attending religious services, from prayer, and from talking with their clergy.

[Narrator]

Another family may use information as the basis for their hope. Their hoping leans more toward fact gathering. They use cancer information services and medical libraries. Information gives them a sense of control and hope.

[Narrator]

No one family pattern of hoping is the best or most useful. What is important is that you think about your own way of hoping, and that you be direct with family, friends, and your health-care team about what is most helpful to you about using and maintaining hope. You don't have to accept it if someone tells you there is nothing to hope for or that there is no hope. As we heard from Kathleen, there is always something to hope for, and you and your family have the right to determine for what, when, and how you hope.

[Narrator]

Try to think about something someone said or did in the past week that increased your hope. Go back even further and try to think of the most helpful thing someone said to you since you were diagnosed with cancer. What made the statement so helpful? Did it have anything to do with your maintaining hope?

[Narrator]

Another useful exercise is to keep a journal of hope. All you need is a notebook or several sheets of paper. Your hope journal should have several headings:

- The date,
- A column for people's names or the source of your hope entry, and
- A section for writing what was said or what you found that was hopeful and helpful to you.

[Narrator]

Hope comes in different forms. It may be something someone says. It may be a passage you read in a book or in the Bible, or it may be something you hear on television or the radio or at a support group. Or it may simply be some thought or memory that makes you feel more positive. The most important part of keeping your hope journal is to review it often.

[Narrator]

In cancer survivorship, advocacy does not stop with standing up for yourself. While it begins with you, it may broaden to include advocacy on behalf of others. As you become a "veteran" cancer survivor, you may find that you want to give something back, to share some of the wisdom that you have gained from your experience to help other cancer survivors.

[Narrator]

For example, when people find out you have had cancer, they may call you and ask you to speak to a family member or friend who has been diagnosed recently. If you are comfortable speaking on a personal level, talking with the newly diagnosed person can be an act of advocacy.

[Narrator]

Other ways that you may want to use your personal experience to help others include: Starting a support group in your community. Speaking about your cancer experience to community groups. Making sure your library has up-to-date resources on cancer. Speaking to medical, nursing and social work students and to employers and employees about your cancer experience. Telling your story publicly to the media or your congressional representatives to help change public opinion and policy about cancer.

[Narrator]

While the cancer experience is not unique, your individual experience with it is. Your age, your previous experience with illness, your cultural background, your job and resources, and many other circumstances affect how you respond to having cancer. As a cancer survivor, you need to become your own best advocate. In order to do that, you can develop survival skills that will help you maintain the highest quality of life possible after your cancer diagnosis.

[Narrator]

So in summary, learning and practicing the six basic survival skills covered in these programs will help you be better able to communicate so that you can ask the right questions, get answers that you understand and convey your needs to the right people. To find information so that you can gather the best resources for you and your situation; to make decisions so that you can make choices that seem best for you. To solve problems so that you know your options through careful and thoughtful planning; to negotiate so that you can agree on decisions that affect your life, and to be your own best advocate. Nobody is prepared for a cancer diagnosis and there is nothing easy about dealing with cancer, but if you or a loved one has received a cancer diagnosis you need not give up. Use the skills we have explored in this Toolbox. As you do you will see them as sources of stability, strength, and hope. Our best wishes go with you.

[Narrator]

This ends the cancer survival toolbox program funded by an unrestricted educational grant from our sponsors. This program has been developed by three national cancer organizations: The National Coalition for Cancer Survivorship, The Oncology Nursing Society, and The Association of Oncology Social Work. If you need more information about cancer survivorship issues feel free to call the National Coalition for Cancer Survivorship toll free at 1-888-650-9127 that toll free number again is 1-888-650-9127.