

[TRACK 3: SURVIVOR STORIES: ADVOCACY SKILLS]

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 what I wanted to do and what was right for me. 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. I also need to have a conversation with hospice.

[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 the Cancer Survival Toolbox basic skills programs, including "Communicating" and "Negotiating," 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 journaling, 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 or spiritual advisor who specializes in cancer-related issues.

[Narrator]

There are also many pamphlets, booklets multi-media and online resources available on cancer-related topics. You can get these at your doctor's office, through your hospital's cancer resource center, from community support organizations, from bookstores, or over the internet. Just be careful to get current, updated information, and to access reputable sources when using the internet. You'll find some suggested resources in the resource booklet that is part of this Cancer Survival Toolbox. You may also want to listen to the program entitled "Finding information."

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, Felicia, dealt with her inability to ask her doctor for a second opinion.