

[TRACK 10: SURVIVOR STORIES: MEDICAL EXPENSES]

Cynthia, in her 30s

[Narrator]

Cynthia's story is a common one: she discovered she has a cancer that most cancer experts believe needs very specialized care. She has insurance but the insurance company was not prepared to pay for Cynthia to go to a specialist or to a cancer center aside from those facilities or doctors that the company has contracted to provide care for a certain cost. Let's hear how Cynthia handled her problem:

[Cynthia]

From the information I found when I was first diagnosed, I knew that melanoma can be a deadly disease - and melanoma treatment is complex. I was surprised and upset that my managed care provider would not authorize - or pay for - treatment at the Cancer Center. They said I had to go to the local hospital's cancer clinic, but this clinic does not even have a melanoma specialist! I really believed the treatment plan my managed care provider offered me would not give me the best chance for cure. At about this same time, I read a story in the newspaper that described another woman in my situation. She described her view of the Cancer Center: She said: 'You know what excited me about the Cancer Center? All the patients who were looking at their wristwatches. They had cancer and they wanted to get back to work, on with their lives. They had hope.' Well, I want to live - I want to have that kind of hope - of getting on with my life." I have insurance - my husband's job offers insurance as a job benefit. Our insurance is part of a plan offered by a managed care company. When my husband and I read the benefits booklet, we felt like we were reading a new language - so many new words that we didn't understand. It was hard for me to tell what they would pay or would NOT pay for. I found a helpful booklet called "What Cancer Survivors Need to Know About Health Insurance" published by The National Coalition for Cancer Survivorship. This booklet describes types of health insurance, the basics of Medicare, protections under the law, and suggestions for what to do when an insurance claim is denied. It was just what I needed to start my "Finding Information" process. I got my copy of this booklet by calling the NCCS at their toll-free number - 1-888-650-9127. So, I went back to "Finding Information" all over again - just this time, a different kind of information. I needed to find out what my rights are where our insurance is concerned, and what the options are for the most effective kind of treatment for my cancer. My doctor and the melanoma specialist helped me too. They were ready to file an appeal with the managed care provider's medical director. If I had to, I was willing to hire a lawyer who is an expert in insurance law. Since my own diagnosis, I met a cancer survivor who got help from her congressman. I was surprised - I would not have guessed that a politician would get involved in this sort of personal problem - but now I realize that they can and do offer help like this. Fortunately for me, I did not have to go to these extremes. But, it is good to know this kind of help exists. I knew that I would have to be really assertive, and learn as much as I could about my cancer and the kind of treatment that would be most likely to work for me. I became a regular big pest to everyone at the managed care company. Finally, I went directly to the human resources department manager at my husband's company - this is the person who chooses the managed care plans that will be part of the employees' benefits package. The company ended up threatening the managed care company with losing the company's account unless it authorized my treatment at the cancer center. I am still in treatment now - and the managed care company is supporting my plan of care.

[Narrator]

Let's review how Cynthia used a number of basic skills from the Cancer Survival Toolbox. First, she looked for and found information that helped her understand their insurance situation. She researched and understood the treatment options for her type of cancer. She also learned her rights, and what to do when her request for a certain kind of procedure was denied. She

communicated with members of her health-care team to create a clear plan for her care. She made decisions about what to do and how to do it. Then, she used skills described in the "Standing Up For Your Rights" Toolbox program to advocate for the kind of care she knew she needed to have. She got others, like the Human Resources manager, the doctor, nurse, and social worker, to help her develop plans to get the care she needed. And, she succeeded.

A common problem for many cancer survivors, even those with insurance, is finding ways to pay for prescription medicines - the medicines that help control the side effects of cancer treatment, pain medicines, and sometimes, even chemotherapy and other medicines used to treat cancer. Many insurance plans do not pay for prescription medicines. Others require the insured person to pay a part of the costs - called a "co-payment". Some insurance policies offer prescription coverage only after a costly prescription plan is added to the regular insurance plan. Medicaid benefits vary from state to state, and may or may not cover out-patient prescription drugs. Even though prescription drugs are only one part of cancer care, the cost of medicines amounts to a large burden, particularly when the costs come directly from your own pocket. Expense is a problem that keeps many people from getting and taking needed medicines. Some people try to "save" on medicines or make the prescription last longer by taking only a small part of what is really needed and prescribed by the doctor or nurse. When forced to choose between prescription medications and buying groceries, clothes for the kids, and even rent, the family expenses often come first. Arlene describes the way she was able to find help to pay for her prescription medicines.