

[TRACK 11: SURVIVOR STORIES: SIDE EFFECTS]

Joe, in his early 70s

[Nurse]

A patient who came to our pain clinic recently, Joe, has prostate cancer that has spread - or metastasized -- to the bones in his hip. He has had a chronic pain problem relating to arthritis for the past two years. But, the spread of cancer to his hip made the pain much worse. So, Joe asked his cancer doctor if he could get something more than Tylenol to help his pain. The doctor didn't pay much attention to Joe's request, saying, "With your pain, there isn't very much I can do. And besides, at your age, everybody has a little pain." Joe didn't feel comfortable arguing with his doctor and he didn't want to seem like he couldn't take it. But, his pain was making his life miserable.

[Joe]

I heard about a pain clinic at the hospital that specializes in treating hard-to-control pain. I decided to call them to see if they could help me. The receptionist there asked which doctor had referred me, and I told her that I was referring myself - that my doctor did not seem to be able to deal with my pain. The receptionist explained that my insurance might not pay for their services unless a doctor referred me. That made me think about how I could find other ways to pay for the service, or maybe another way to get a referral to the pain clinic.

[Joe]

Even though I have not seen my family doctor since my cancer started, I called her and told her my problem. She was very sympathetic and explained that sometimes pain problems are difficult to handle and that not all doctors or nurses know how to manage cancer pain. She seemed to feel that the pain clinic could really help me and was eager to help me see a doctor there. With her referral, I got an appointment with a cancer pain specialist the next day. This doctor told me that I did not have to live in pain, regardless of my age or my cancer. He said there are many things we can try but that the first thing is to find out exactly what is causing my pain. He looked at my X-rays and thought that I could be helped by having a short course of radiation therapy to those places in my bones where the cancer has spread. He explained that it might take a few days for the radiation to work and, until then, I would get pain relief from using both prescription and over-the-counter medicines.

[Joe]

I was afraid of taking strong pain medicines. I didn't want to be all "drugged up" and lose control - I need to stay alert. The doctor and nurse assured me that they would help me find a pain control plan that would help me stay alert and keep my pain under control. The nurse showed me how to use a pain assessment journal that would help them understand my pain situation better. I got regular appointments so that they can check how well my pain plan is working. They even have a 24-hour telephone "hot-line" so that if I do have problems, there's always someone for me to call. I understand my pain problem better now. I know how to use the medicines so that they control my pain. And, I feel like I can do a better job of taking care of myself. It is such a relief.

[Narrator]

This example has characteristics of what we will call "ageism" or "age discrimination." This is when someone discriminates against another person solely on the basis of their age. Like racism or sexism, ageism is a negative view that some people have that the desires, fears, or concerns of older people are somehow different from, and not as important as those of younger people.

This can mean that the needs of older people don't get the same attention. It can also mean you might have to work harder to carry out your plans.

[Narrator]

Joe found a way to get his needs met. He stood up for his rights. He realized he didn't have to keep seeing a doctor who wouldn't listen to him. He found someone to assist him with getting his pain under control.

[Narrator]

Maintaining a healthy lifestyle is another type of self-advocacy. This means eating right, exercising, and getting enough rest. All of these activities are made more important when you have cancer. If you have difficulty eating due to mouth sores or nausea, talk with a nurse in your doctor's office about medications. The nurse may also suggest that you see a dietitian who specializes in working with people who have cancer. Cancer-related fatigue is another serious problem for people with cancer. Once again, others may think your fatigue is related to the fact that you're getting older.

[Narrator]

Health-care professionals have recently recognized that cancer-related fatigue can be severe and that it can limit many of your usual activities. Fatigue is very common among cancer survivors. Yet, it is hard for doctors and nurses to observe and evaluate fatigue during a short office visit. Therefore, you may have to find a way to describe to your health-care team what your fatigue feels like and how it affects your life. In cancer-related fatigue, it's not just a matter of feeling tired - no amount of rest will help you overcome this fatigue. Listen to how Bessie got her health-care team to hear her concerns.

Bessie, in her late 60s

[Bessie]

I've been undergoing chemotherapy for several months now. I go to see my doctor every four weeks, and it seemed that each month I was getting more and more exhausted. When I tried to talk to him about this, he suggested I get more rest. "Just take it easy," he said, "at your age, it's normal to be slowing down some." I have to tell you, I was a little offended by the casual way he said this. I've always been an energetic person, but I found I was even too exhausted to do things I have always liked to do. Then one week, I was so tired, I started staying in bed. That made me feel very depressed. My niece came to visit me, and seemed alarmed that I was doing so poorly. I told her I was just too tired to get up. She called and made an appointment with my doctor and said she would drive me there the next day. Before going I thought about my fatigue. It had started right after I finished my first round of chemotherapy. It had gotten worse every month. I made a list of all the things I could do and enjoyed doing before I started my treatment. Then I made a list, a very short list, of what I could do now. I took those two lists with me and told the doctor that I wanted to be able to do those things again -- I wanted my life back. This time, he heard me and ordered some additional tests to help understand my fatigue.

[Bessie]

The nurse came in and did what she called a "fatigue assessment." She not only went over what I could and could not do, but she also asked a lot of things, like how I felt emotionally, how much stress I was under, what I was eating, and how I slept at night. Then she asked me about my support system, did I have people who could help me if I needed help? People who could take me places or get me to appointments? I told her my niece is my biggest support, but that I also

have friends at the church and senior center.

[Bessie]

The nurse said that I was a little anemic, and that that could be part of my fatigue, although fatigue can be very complicated. I did get a prescription to help with my anemia, but just as importantly, the nurse helped me develop an exercise schedule so that I could build up my physical activity level. She told me I might want to try some dietary supplements to maintain my nutrition, and she suggested that I might want to talk to someone, a therapist, about my depression. While talking with her, I realized that I had been depressed ever since my cancer was diagnosed. While my outlook is good, I do find it hard to go for my chemotherapy each month. Instead of seeing a therapist, I decided to join a cancer support group at the community center. It's a special kind of group that uses journal writing to help people cope. I really enjoy it, and I'm back to attending a few other social events and having friends over for lunch. I'm beginning to feel like my old self again.

[Narrator]

Physical problems can lead to emotional problems. When you are in pain or overly fatigued, you may become depressed. This seems to increase your pain and fatigue even more. There are some clues for telling if you are depressed. For example, you may be feeling sad. You may be unable to concentrate. You may lose interest in your usual activities -- stop going places, reading the newspaper, or watching your favorite shows on television. You may find that you're sleeping a lot more or that you don't feel like getting up and getting dressed during the day. Or, you may have difficulty sleeping at night. You may also have changes in your eating habits -- maybe you just aren't interested in food or maybe you're eating all the time. You might start feeling helpless or hopeless or begin thinking that life no longer has much meaning for you. Some people even begin wishing they would die, or think about taking their own lives. They fear that no one is listening to their needs, that they are becoming a burden on their families. If you are feeling this way, call your doctor, nurse, or social worker and make an appointment. Tell them how you're feeling. They can help you get your pain, fatigue, and depression under control.

[Narrator]

If you have signs of depression, don't wait to get help. In addition to making you feel more miserable, depression can actually interfere with the healing process, which is the last thing you need when you are trying to recover from cancer. It might also help to remember that hope changes as situations change, and there is always something to hope for. Try this exercise. Take out a sheet of paper and start a list numbered from 1 to 10. Write down 10 things that you are hoping for this week. These hopes may be general, like having a better quality of life, or specific, like feeling well enough to go to church on Sunday. Review and update your list once a week. Check off hopes that you have achieved. Look at the remaining hopes and ask yourself if each item is still important to you. If it is, keep it on your list. If not, replace it with a new hope. Remember, that a hopeless person becomes a helpless person, so it is very important to always have something to hope for.