

[TRACK 3: SURVIVOR STORIES: COMMUNICATING]

John, Part I

[John]

When my wife, Susan, was diagnosed with breast cancer we both went into shock. I felt angry and scared all at once, but I didn't think I should tell her. I didn't want her to worry about my feelings, too. The whole thing has taken a lot out of both of us. But, we've found out that it really does help to talk about it.

[Narrator]

Communicating, which involves sharing information and sharing feelings, is an important skill for everyone dealing with cancer. Yet, many studies confirm what people often say: Communication can be difficult for many cancer survivors and their caregivers. Those who care about each other may not want to share the strong feelings that come with a diagnosis of cancer, and these feelings may make it hard to talk about the questions and concerns they have with doctors, friends - even their own family members. The "Communicating" program in the Cancer Survival Toolbox teaches the communication skills of being assertive, using "I" statements, active listening, and expressing feelings. In that program, we review how you can use communication skills to improve your well-being, because when your well-being is maintained, you can do a better job of helping to maintain the well-being of those you care for. Let's hear how John used the communications skill, assertiveness, to solve a problem.

[John]

When Susan first got cancer and we were figuring out what we needed to do to keep our family going, I tried to avoid telling people at work about it. I was trying to keep my night shift job and stay awake all day to get everything done for Susan and our two kids. When my in-laws offered to help, I really didn't want to accept it. I guess I didn't want to have to admit that I wasn't in control of everything. But, I was getting exhausted and the treatments were taking everything out of Susan. So, I finally decided I had to tell my boss so I could get time off if I needed it. It was hard to say, "I need this because my wife is sick." But, when I put it that way, he didn't give me trouble. In fact, he was really good about it. Turns out his mother-in-law had the same thing. He told me to take the time when I needed it and that he would work it out with my supervisors.

[Narrator]

Being assertive is important for everyone affected by cancer. Being assertive means stating what you think or what you need in a way that clearly lets the other person know that you are serious. In today's world, being a caretaker often demands that we be assertive to be sure that our needs are met.

[Narrator]

Using "I" statements is another important communication skill. This means making statements such as "I" feel or "I need" instead of "you did this" or "you need to do that". "I" statements are usually received better by listeners because they don't put people on the defensive. John used an "I" statement when he said to his boss, "I need to be able to take some time off to help my wife with her cancer treatments".

[John]

One of the hardest things for me when I did take time off to go with Susan to her treatments was making sure I was hearing what the doctors and nurses were trying to explain, especially when they would use the names of medications or medical terms I never heard of before. The first time they would explain something, I had to stop them and say, "I'm not really sure I understand what you mean. Could you explain it to me again." I had to be sure I understood because I was the one watching out for Susan at home.

[Narrator]

What John is describing is another important communication skill- active listening. This means showing the person who is speaking that you are listening and checking to make sure what you heard is really what they were trying to say. When you use active listening, you are much more likely to get the message that others are trying to tell you.

[John]

For awhile, I tried to put my own feelings aside, especially in front of my wife. I was afraid that if I let myself feel sad or angry, I'd lose control. I didn't want her or anyone to know about my feelings. But it was really hard sometimes because we were going through tough times and I had a lot of strong feelings about it. After a couple of months, I got to the point where I started to blow up at everybody. I'd start yelling at the kids for little things and I even yelled at Susan. Well, she yelled right back at me. Then, I felt really guilty- after all, Susan was the one who was sick and here I was yelling at her and our kids. I realized then I had to admit how angry I was that this was happening to her - and that I couldn't change it.

John, Part II

[John]

I finally found a time when the two of us could be alone together and we both agreed we needed to talk. The first time I said out loud, "I'm mad at the cancer - not you," I felt a lot of relief. I was surprised Susan could actually listen to my feelings without getting upset. When she heard me say that, she told me she understood how I felt because she was angry about the cancer, too. Since then we've been able to fight the cancer - not each other. It actually brought us close together again.

[Narrator]

It is natural for caregivers to feel a range of emotions when someone they care about is ill. Studies tell us that the emotions in people close to those with cancer are very similar to those that the person with cancer is feeling - at times caregivers might be even more depressed or anxious. Because of this, it is just as important for caregivers to express how they feel as it is for those diagnosed with cancer.

[Linda]

From a social worker's perspective, I know that when feelings about cancer are expressed, it gives people an opportunity to support each other and reduce the stress associated with anger or sadness. Families often find it helpful to share their feelings with each other as a way of getting and giving support.

[John]

I guess you could say I've gone through just about every feeling there is during this cancer

treatment. I've been really scared at times, afraid of losing Susan, afraid of my family falling apart - I have to say I was even afraid of being physically close at first. After her mastectomy, I was worried that I'd hurt her if I touched her in the wrong way, or that our physical relationship would end. Susan was the one who brought it up the first time, not that long after she came home from the hospital. She had talked to the nurse and social worker at the hospital, and I guess they helped her figure out that we needed to talk about it. I was relieved because I knew I needed to show her how much I loved her, but I wasn't sure how to handle physical closeness. It was actually one of the first times we'd really talked straight out about her cancer and how it might affect us. We both ended up feeling like there were a lot of ways to physically show our caring for each other and our relationship has changed - for the better in some ways.

[Narrator]

There are many changes in relationships and family life that cancer and cancer treatment can cause. Good communication helps family members adjust to these changes. Good communication can help with the decision making that is needed during cancer treatment, and with the other important skills of finding information, negotiating, and problem solving. Communication does not make problems go away, but it can help you gain support and understanding so you can manage cancer and its treatment more effectively.

[Linda]

And remember, everyone can benefit from support, and it can come from many places - from other family members and friends, from cancer professionals, and from others who are going through cancer, too. Some caregivers find it helpful to attend support groups or counseling sessions where they can express their feelings. Even difficult feelings are easier to deal with if you have support.

[John]

It took me a while to go to a support group. Maybe it's part of being a guy - I didn't see myself sitting in a group of people and talking about my problems. But we heard from a friend about a group for husbands. The first time I went, it was helpful to meet other men going through the same thing I was. You know, I found out I could just go and listen if I don't want to discuss my own feelings. I've gotten some really useful information about how other people are dealing with cancer in their families. The group is a place where I can say how I feel to people who understand because they're going through it, too. Sometimes, I am more comfortable talking after I've heard what other people in the group are feeling.

[Narrator]

John's story is common. The group for husbands that he went to is sponsored by the Breast Cancer Network of Strength. It can be challenging for caregivers to ask for what they need. But good communication can lead to better care. Before you continue, or at some point when you have the time, you may want to try the following exercise to help you with communication.

[Narrator]

On a blank sheet of paper, draw a large square. Draw one line down the middle - from top to bottom - to divide the square in half. Now, draw a line across the middle - from side to side - to divide the square into four equal boxes. In one box, write a thought or feeling about cancer that you have not told anyone. In a second box, write something you feel very good about in your life. In the third box, write a question you have about cancer. In the fourth box, write down something that gives you hope. Now, look at each box and what you have written in it. Think about the communications skills - using "I" statements, being assertive, active listening to check the

message, and sharing feelings. Next, choose one box and practice how you might communicate what you have written. After you have practiced, try out your skills with someone you trust. The more you practice, the more skilled at communication you will become.