

[TRACK 3: SURVIVOR STORIES: COMMUNICATING]

Joanne, in her early 70s: Part I

[Joanne]

I had surgery and radiation therapy to treat my cancer of the uterus. My husband and I have been married for 52 years, and lovemaking has always been a good part of our marriage. After my surgery and treatments, I thought someone would talk to me about this, but no one did. I think they thought I was too old to be interested in sex. I kept wanting to ask my doctor when my husband and I could have relations again, but I was too embarrassed. Last week, we decided to try again anyway, but it was painful for me. My husband said it felt different to him, too. This made me even more determined to ask about it.

[Joanne]

I had a doctor's appointment this week. I was just going to come out and ask. I felt I had a right to know the answer -- they should have talked to me about it. I practiced what I was going to say, and wrote down questions I wanted to have answered. I thought that if I had them written down, I would be more assertive. But, it is so hard to talk about such private things.

[Joanne]

Well, I got to my appointment and when the nurse was asking me if I was having any problems, I got up all my nerve and told her about my discomfort during sex. She could sense how uncomfortable I was and right away put me at ease. She said she thought someone else had discussed that with me earlier, and apologized so sincerely for not having brought this up earlier. She also gave me a booklet on the problem and recommended a certain cream.

[Narrator]

Joanne reminds us that your needs, both medical and personal, are very important. If something doesn't seem right or if you have questions about your health or how your body is responding to treatment, communication can be the key to finding a solution.

[Nurse]

As a nurse, I'm in a good position to see problems that cancer survivors are having and to help them. I offer them several tips about communicating with their health care team. First, writing down your questions or concerns is an excellent way of making sure you get answers. It's also helpful to have an extra copy of your questions. That way, you can give one copy to your doctor or nurse to read and you can write the answers down on your copy as you discuss each question. Sometimes, the doctor may seem to be in a hurry, but if you have a list, that helps to make it go all the more smoothly. If you have a lot of questions, you may want to let the office staff know that ahead of time, when you make your appointment. That way, they can schedule you for a little more time.

[Nurse]

Another useful tip is to bring a family member or close friend with you. It frequently helps to have two people listening to what the doctor or nurse says. If you wish, your family member or friend can wait outside when you are examined, and you can ask that they be sent in when the physical exam is over. You also might want to ask the doctor if you can bring a small tape recorder along and record what he or she says. This is particularly useful if you have a hearing problem and don't always catch what is said.

[Nurse]

If you do have a hearing problem or vision problem or some other barrier to communication, tell your doctor and nurse about it. Your treatment is too important not to understand what is going on.

[Narrator]

Your health care team also needs to know if there might be anything else that could get in the way of good communication. They need to know how to communicate with you in a way that you can understand.

[Social Worker]

It's a very good idea to let the health care team know if you have difficulty reading or if you've never learned to read. In my job as a social worker, I've seen that many older people may not have had the opportunity to get formal schooling, and some very intelligent people never learned how to read. Or, perhaps English is not your native language. It may take a lot of courage to tell your nurse that you can't read, but the doctor cannot legally give you treatment if you're unable to understand a consent form for treatment. So, it's important to tell your nurse if you're unable to read, and ask that your nurse or doctor read you any form that you need to sign.

Joanne, in her early 70s: Part II

[Narrator]

You may find that you can communicate with your health care team, but don't know how to talk to your family and friends about your cancer. Maybe you haven't told them because you think it's best not to worry them. Or, maybe you're very worried about what their reaction might be. Yet, cancer is a family problem, and you need the support of your loved ones and friends to get through the treatments and help you cope. Try the following exercises to help you talk to your loved ones and close friends.

[Social Worker]

First, get out a pencil and paper and write down all of the reasons you think you should tell them about your cancer, and all of the reasons you think you should not tell them. Look at each reason and try to decide if it really is a good reason, or if you're just making excuses because you don't know how to tell them or are afraid of how they will react. Next, think of the three most important things about your illness that you want your family to know. Write them down, too. For example, you may want to say: "I have cancer, but I'm very hopeful about it being cured or controlled. I want you to be hopeful, too." Or, "It's my life, and I need to be the decision maker." Or, "I want to be able to ask for help when I need it." Once you have decided what exactly you want to communicate, it usually seems easier.

[Social Worker]

Other communication tips include using the word "cancer." Remember cancer is a disease like any other disease. Cancer can be cured, it can be controlled, and many people live for decades with cancer as a chronic illness. Set a specific time that you want to tell your family and friends. It might be helpful to tell one person in advance and ask them to help you tell the others. Address your emotions honestly. It's okay to say, "I'm scared but hopeful" or "I'm relieved to finally know what's wrong." Set the ground rules for your family's involvement. You might need to insist that they not call your doctor without your permission. Or, that you're quite confident in the surgeon you have selected and that you do not want to travel to a medical center in a distant place for a

second opinion. Or, that they respect your privacy and not discuss your condition with people outside the family. You might want to tell them that you value their input, but that you'll need to make your own decisions about your treatment.

[Social Worker]

Dealing with acquaintances may be harder. Too often, news of someone's illness does become known publicly. And sometimes, the effects of cancer treatment can be hard to hide. Therefore, it might be useful to think about, and practice, a couple of responses to well-meaning, but perhaps nosy neighbors. You may find everyone wants to tell you a cancer story -- about someone they knew who had cancer and died from it, or who had a terrible time with the treatment, or who had your kind of cancer and did very well. With negative stories, you may need to be abrupt, and simply say something like, "As part of my treatment, my doctor has recommended that I only listen to positive stories." Depending on the situation, you may need to be a little short with that person and ask if he or she is trying to scare you. As you experience some of these situations, you will develop easier responses. You may want to write a few down and practice using them before they are needed.

[Narrator]

What's important to remember is that each person is different and each person's cancer is different. Cancer is not one disease, but many. There are over 100 different kinds of cancer. For example, there are numerous types of breast cancer, different kinds of leukemia, and so on. The experience of others with cancer should not be taken as an example of what will happen to you.

[Social Worker]

You may also want to talk to a Pastor, Priest, or Rabbi about your cancer. You may have questions about what meaning cancer has for your life. It is important to remember that some members of the clergy don't know very much about cancer as a disease, and that their responses may be similar to those of well-meaning friends. They may also tell you about others who died or suffered. Again, you should ask for what you need. You may need to communicate that you want to discuss religious or spiritual issues, not your disease or treatment.

Joanne, in her early 70s: Part III

[Social Worker]

If you don't have someone you can talk about your spiritual concerns with, there are several resources available to you. You can ask to speak with a pastoral counselor at your local community hospital. He or she will be able to help you directly, or make a referral for you. Or, if you live near a religiously-affiliated college or university, you could call and ask if they have a counseling service. Also, some communities have parish nurse programs, whereby churches have support programs organized by a specially trained nurse, called a parish nurse. Other congregations have visitor programs or programs that will assist you with transportation or in other ways. Also, spiritual counseling is a part of all hospice programs.

[Social Worker]

What if you don't have family or close friends in your area? It may take a little time looking, but there are good services available in most communities for persons with cancer. Your local division of the American Cancer Society may be able to help you find somebody you can talk to about your cancer. Or, your local hospital or senior center may host a support group for persons

with cancer. If you would like more information, ask your nurse for some resources when you go for your next appointment.

[Narrator]

In summing up this section on communication, you are in control of your life and you need to maintain control of your illness. For these things to happen, you'll need to become a good communicator. If you have not yet listened to the Cancer Survival Toolbox program entitled "Communicating," you may want to do so to help improve your communication skills.