

## [TRACK 3: SURVIVOR STORIES: MAKING TREATMENT DECISIONS]

### Anna, 45 years old: Part I

[Anna]

I read a lot about a new treatment, called biologic therapy, that seems like a good option for my type of cancer, non-Hodgkin's lymphoma. So, at my next appointment with my cancer doctor, I asked him about the new treatment. He said that he didn't know a lot about biologic therapy. But, from what he did know, he didn't think that it might help me. And besides, he said he doesn't feel comfortable with new treatments until doctors have been using them for some time. I trust my doctor to look out for my best interests, but I couldn't help feeling disappointed with his response. I thought this new treatment might be worth a try.

[Anna]

I decided to get more information about biologic therapy on my own and then see if I could convince my doctor to consider it. I went to the library and read through current magazines and health sections of newspapers. I found out which company makes the drug used in the treatment. I even got the names of research doctors who have used this drug and think it is worthwhile. I also found an article about a doctor who works in a hospital in a nearby city who has used the treatment for my type of cancer. I copied the story and made an appointment with my own cancer doctor to see if he could refer me to this other doctor.

[Anna]

My cancer doctor was surprised and impressed by my ability to find good information. But, he was still skeptical. He also asked an important question: would my insurance company pay for a second opinion that involves biologic therapy? So, I left his office this time feeling disappointed and somewhat discouraged.

[Anna]

But, that wasn't going to stop me. The next day, I called my insurance company. I found out that the other doctor is part of my company's plan. But, I would have to get a referral from my own cancer doctor in order for the insurance to cover a visit to the other doctor.

[Anna]

I felt like I was going around in circles. I brought my problem up at my next support group meeting to see what other people said. A man in the group, who had a similar experience, suggested that I ask the doctors to arrange a telephone meeting. He also recommended that I collect all the information I can from the most reliable and up-to-date sources possible that support biologic therapy and give it to my cancer doctor before he talks with the other doctor.

[Anna]

I took his advice and it worked. My cancer doctor knew some of the names I collected of research doctors who support biologic therapy. In fact, they are people he really respects. So, he called the other doctor to get a sense of how he would handle my treatment. The next day, my cancer doctor called me to say, that though he's still somewhat skeptical, he would give me a referral to see the other doctor.

[Narrator]

As Anna's story shows, sometimes negotiation takes more than one or two conversations. If you feel strongly about something you want to try but your doctor disagrees, follow Anna's example. Find good information and talk it over with your doctor. If your doctor doesn't agree, keep digging

for better information and continue to discuss what you find with your doctor.

[Narrator]

Another point that Anna's case shows is that you have control of your healthcare. Seeking second opinions is common and should not upset your doctors. Usually, a second opinion will reassure you that you are doing the right thing. But, it could turn out that the second opinion is different from the first doctor's. You may find this both confusing and difficult. If this happens, it is often best to be honest and ask both doctors why there is a difference. Rarely is one doctor completely right and the other completely wrong. Because cancer is such a complicated disease, you may have several treatment choices. Just make sure you clearly understand the choices your doctors offer.

[Narrator]

If you think you want to follow the advice of the second doctor but also want to continue under the care of the first doctor, find out if the first doctor is willing and able to follow the second opinion. Some doctors may lack the training, understanding, or confidence to do so. This may be like asking a French chef to make Chinese noodles, or asking a modern artist to paint the Mona Lisa. You need to know this and not demand that health-care professionals work in ways they are not trained or comfortable with. After all, you would not want to feel pressured to accept a treatment you don't want. But, you do have the right to make the final decisions about your own treatment, and about the doctors you prefer to provide it. If your doctor feels strongly that a treatment will not help you, listen carefully to his or her reasons, so that you can make a thoughtful, informed choice about your treatment plan. You may also want to listen to the Cancer Survival Toolbox program entitled "Making Decisions."

[Narrator]

While Anna was interested in a new cancer treatment that was being tested by medical researchers, other cancer survivors are interested in using non-conventional cancer treatments. You may also hear these treatments called "alternative" or "complementary" medicine. This can include anything from vitamins and herbs to treatments given only outside the United States.

## **Anna, 45 years old: Part II**

[Joan]

I've worked with many cancer survivors who did not want to ask about non-traditional treatments out of fear that this question would offend people on their health-care team. Some were even afraid that their cancer doctors would not take care of them any more if they mentioned it at all. I find that the strength of a good health-care team comes from trust in each other, respect, and truthfulness. You can only expect the best care if you have given all the important facts about yourself and your health to your doctor and asked the questions on your mind. Some doctors may not share your interest or excitement for non-conventional or alternative cancer treatments. But, if you are seriously thinking about these kinds of treatments -- and certainly if you are taking any other kind of treatment -- your doctor needs to know. Otherwise, you could be creating serious medical problems for yourself.