

Track 4: Living with Uncertainty/Changes in Roles (Psychosocial)

[Narrator]

We now need to discuss some of the other changes that you may have to deal with because of your disease.

Having lymphoma requires making some difficult life changes. Some of these changes are temporary, others are ongoing. Let's listen to a conversation of a for-men-only session of the support group as they respond to the social worker who has just asked them about life changes they have had to make since their diagnosis:

[Carlotta: (Social Worker)]

Sometimes cancer causes other problems in our lives, and many of these changes are hard to accept. Can anyone give an example of a life change brought about by their disease?

[Carlos]

I had a disappointment just last weekend. It was the opening of trout season, and my nine-year old grandson and I have been planning for months to go to a cabin on the lake to fish. Well, my last chemo was done almost a month ago. I was sure I'd be back to my usual activity level by fishing season. But as the time to pack for the trip got closer, I realized that I didn't have my strength or energy back yet. I started to worry about being responsible for an energetic little boy and how long I'd be able to fish, and whether or not he would even be safe with me. I finally asked my brother Joe to go with us and he agreed. He and my grandson had a great time together, but I felt like a third wheel. At least I didn't have to cancel the trip and disappoint my grandson. But I wonder if I'll ever be able to do all the things with him that I had planned.

[Sam]

What I hate is not being able to do some of the daily things. Like help carry in the groceries for my wife. She says she can manage fine. But it makes me feel embarrassed and useless when I can't help with even small things around the house.

[Paul]

I had the same problem with cutting the grass. We have a big yard, and I really love keeping the lawn looking nice. But, when I am on treatment, it's pretty hard for me. We finally settled on buying a riding lawnmower and that's been ok so far. I have to admit that using the push mower had gotten pretty hard for me, but I hate not being able to do something that is so routine.

[Jose]

We have a woodstove, and every fall we get a load of wood and I spilt it and stack it. Well, last fall I was feeling pretty good and I was sure I could pace myself to get the job done by working on it some every day. But on the second day, I had some trouble with my balance when I was stacking the wood. I also had some tingling in my thigh muscles from some nerve damage and peripheral neuropathy that's probably caused by the vincristine. Now we have the wood brought already split and the man who brings it stacks it for us. I feel a little cheated by not being able to do it myself, but it's also good to save my energy for things that are really fun and healthy for me to do.

[Carlos]

This story's a little different. Always before I've been the strong one in our family. Since I've had this disease, I feel emotional all the time. When the doctor told me I might need chemo again, I broke down in the car – in front of my wife Tanesha. She was the strong one that day. Our roles have reversed, and I feel like I'm letting her down.

[Jerome]

That's how I've felt since I had to take early retirement. You know I was a truck driver – drove a big rig. Well, it got so that I simply couldn't do it physically after my diagnosis. So I retired five years earlier than I planned. That leaves my wife as the family breadwinner. She's been great about it, but I feel like I'm not holding up my end of the bargain. And it's caused some financial issues for us, too.

[Carlotta (Social Worker)]

Well, it sounds like all of you have had situations where your lives have had to change due to non-Hodgkin lymphoma. I think I heard two major themes. One was what we call "role change" or "role reversal." The other might be termed "living with uncertainty" – not being able to know enough about the future to be able to plan for it the way you would like.

In families, and in the workplace, each of us assumes certain roles and some change more frequently than others. Some of these roles are fixed – like the role of father or husband. Other roles can change – like when you get a promotion, or when you change jobs. Sometimes we can plan for these role changes and are happy when they occur – like when Carlos became a grandfather or when someone plans for retirement. Other times, like with Jerome having to take early retirement, the change seems out of our control – it is forced on us in some way. We almost always resist forced change. Yet, when we look back on it later, the change might actually have had a positive side.

For example, maybe in Carlos's situation, his brother got to know his great nephew better, and enjoyed spending some unexpected time with Carlos. Also, maybe Carlos's wife was relieved that he could finally express his emotions.

And Jerome, maybe your wife likes the fact that you're home more and that you are able to help her around the house or just keep her company in the evenings.

[Narrator]

Not all change is bad. What's hard is getting used to the change. Most of our roles are comfortable. So role change brings with it uncertainty. And role reversal – when someone else takes our role, and maybe we take theirs – can feel like it doesn't fit.

But a cancer diagnosis and treatment can bring about permanent changes, like Jerome's stopping working. The goal after a cancer diagnosis is to get back to normal, but most often a "new normal" must evolve so you and your loved ones can move forward.

We always have to live with some uncertainty. But cancer brings with it a heightened sense of uncertainty, and it may take years for you as a cancer survivor or your family to feel safe again, to be able to plan for the future with confidence.

Living with such uncertainty can have a negative impact on family communication and on family functioning. If you feel you or your family are having trouble talking about your problems, you might find it helpful to listen to the program about "Communicating" on the basic *Cancer Survival Toolbox*[®] and the program called "First Steps." It also might be useful to seek assistance from your health care team or from a social worker or other mental health professional. Similarly, if you are feeling depressed or anxious due to the changes you must make in your life because of cancer, seek some help. Try a support group or a specific cancer-related community activity or program. Or look for individual or family counseling. A few meetings with someone skilled in counseling people with cancer will help you link your cancer experience to the problem-solving skills you have always used. They will help you remember how you successfully dealt with change and challenges during other times in your life. And they will help you use the skills and strengths you already have to move beyond the current situation.

If your cancer is causing financial problems, seek some help there, too. A meeting with a financial advisor can go a long way. There is also a program in the *Toolbox* on "Finding Ways to Pay for Care."

You can't alter the fact that you have been diagnosed with lymphoma, but you can learn to adapt to it and to manage the necessary life changes required to live as fully as possible after your diagnosis.