

Track 5: Living with Uncertainty/Changes in Roles (Psychosocial)

Narrator

We've talked about how CLL is diagnosed and treated, and we have also covered most of the symptoms and side effects. We now need to discuss some of the other changes that you may have to deal with because of your disease.

Having CLL 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:

Nancy (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?

Jim

It's funny you should ask that question today. 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. I never had a son – just daughters – and I've looked forward to these kinds of activities for a long time. But as the time to pack for the trip got closer, I realized that I didn't have my usual 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 and help my wife. She says she can manage fine. But it makes me feel embarrassed and useless when I sometimes can't help with even the small things around the house.

José

I can really relate to that. We have a woodstove, and every fall we get a load of wood and I spilt it and stack it. I've done this for 20 years, and it's something I love. 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 felt weak and I had some trouble with my balance when I was stacking the wood. 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 important to me to be able to do.

Jim

This story is a little different, and it's hard for me to talk about. Always before, I've been the strong one in our family. I was raised to control my emotions, and crying wasn't something a man did. In fact, I never saw my father cry. Since I've had this disease, I find myself feeling emotional all the time. I'm ashamed to admit it, but when the doctor told me last week that I might need to change my chemotherapy again, it was all I could do not to start crying in his office. I broke down in the car – in front of my wife Claire. She was the strong one that day. It seems like our roles have reversed, and I feel like I'm letting her down.

Stan

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.

Nancy (Social Worker)

Well, it sounds like all of you have had situations where your lives have had to change due to leukemia. 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 Jim became a grandfather or when someone plans for retirement. Other times, like with Stan 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. It makes us angry. It doesn't seem fair. Yet, when we look back on it later, the change might actually have had a positive side.

For example, maybe in Jim's situation, his brother got to know his great nephew better, and enjoyed spending some unexpected time with Jim. Also, maybe Jim's wife was relieved that he could finally express his emotions. Maybe it also freed her up a bit from trying to always appear strong for him and the family.

And Stan, 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. Much of it can be useful, even positive. What's hard is getting used to the change. Most of our roles are comfortable. We know what is expected of us and we know how to perform in our usual roles. 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. We don't like it and just want things to be the same as they were.

But a cancer diagnosis and treatment can bring about permanent changes, like Stan'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. We can't be certain about the economy, or about our jobs, or even about the weather. But cancer brings with it a heightened sense of uncertainty, and it may take years for you as a cancer survivor and 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 CLL, 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.