

Track 5: 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 CML requires making some difficult life changes. Some are temporary, others ongoing. Let's listen to a conversation of a “for-men-only” support group session as they respond to a social worker asking them about life changes they've had to make since their diagnosis:

Linda (Social Worker)

Changes related to cancer can be hard to accept. Can anyone give an example of a life change brought about by their disease?

Dan

I had a disappointment just last weekend. My nine-year old grandson and I were planning to go to a cabin on the lake to fish. But as the trip got closer, I realized I didn't have my usual strength or energy. I worried about being responsible for an energetic little boy. I finally asked my brother Joe to go with us, and he agreed. He and my grandson had a great time, 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'd planned.

Bruce

What I hate is not being able to do things to help my wife. She says she can manage fine. But I feel embarrassed and useless when I can't help with even small things around the house.

Eduardo

I can really relate to that. We have a woodstove, and every fall we get a load of wood and I spilt and stack it. Last fall I was sure I could pace myself by doing some every day. But on the second day, I felt weak and off-balance. Now we have the wood brought already split, and the man who brings it

stacks it. I feel cheated not being able to do it, but it's good to save my energy for things that are really fun and important.

Dan

This story's a little different. I've always been the strong one in our family. I was raised to control my emotions, but since I've had this disease, I'm emotional all the time. When the doctor told me last week I might need to change my chemotherapy again, it was all I could do not to cry in his office. I broke down in the car—in front of my wife. She was the strong one that day. It seems like our roles have reversed, and I feel I'm letting her down.

Ken

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

Linda (Social Worker)

All of you have had situations where your lives have had to change. I heard two major themes. One was what we call "role change" or "role reversal." The other might be termed "living with uncertainty"—not knowing enough about the future to plan for it the way you'd like.

In families, and the workplace, each of us assumes roles. Some are fixed—like the role of father or husband. Others can change—like when you get a promotion, or change jobs. Sometimes we can plan for changes and are happy when they occur. Other times, like Ken having to take early retirement, the change seems out of our control—like it's forced on us. We almost always resist forced change. It makes us angry, doesn't seem fair. Yet, when we look back on it, the change might actually have had a positive side.

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

And Ken, maybe your wife likes that you're home and able to help around the house, or 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's expected of us and how to perform. Role change brings with it uncertainty. And role reversal—when someone takes our role, and maybe we take theirs—can feel like it doesn't fit. We don't like it and just want things the same as they were.

Cancer can bring about permanent changes, like Ken'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, our jobs, or even the weather. But cancer brings with it a heightened sense of uncertainty, and it may take years for you 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 communication and functioning. If you feel you or your family are having trouble talking about your problems, you might listen to the *Cancer Survival Toolbox*[®] program about "Communicating" and the program called "First Steps." It may also be useful to seek assistance from your healthcare team or a social worker or other mental health professional. Similarly, if you're feeling depressed or anxious due to changes you must make, seek help. Try a support group or a cancer-related community activity or program. Or look for individual or family counseling. A few meetings with someone skilled in counseling people with cancer can help you link your cancer experience to the problem-solving skills you've always used. He

or she can help you remember how you successfully dealt with change and challenges during other times in your life, and can help you use the skills and strengths you already have to move beyond the current situation.

If your cancer is causing financial problems, seek help there, too. A meeting with a financial advisor can go a long way. The *Toolbox* program “Finding Ways to Pay for Care” may also be helpful.

You can't alter the fact that you've been diagnosed with CML, but you can adapt to and manage the life changes required to live as fully as possible.