

Track 6: Coping Styles – Adapting to Your Illness

Narrator

As we learned from the men's support group, many factors play an important part in the decisions and adjustments you need to make after a cancer diagnosis. For example, these include your age, whether you're employed or retired, or whether you are living alone or are caring for children or other relatives. They also include health issues and financial concerns. Many of these needed changes can be difficult to accept. You may hate to depend on others and aren't used to talking about private issues. You don't want people feeling sorry for you or talking about you. In addition, your treatments may make you anxious or depressed or emotional. These all stress the importance of finding support and talking with the people in your life you are closest to or going back to people who have helped you with problems in the past. The following exchange between a long-term survivor and one recently diagnosed is an example of this type of help.

Renee

It's been several months since I was diagnosed, but as I said, my CLL is at an early stage so I am not taking chemotherapy now. I've been learning a lot, and I know its best to watch and wait, but the hardest part is waiting and not knowing if or when this CLL will become something that has to be treated.

Another hard part about the watching and waiting is that I didn't know exactly what to say to people; especially my son who has other stress in his life. His company downsized and since he's been unemployed, he and his wife had some trouble in their marriage. I know there might be many years before treatment is needed so I thought that telling him would be an unnecessary burden. But we are very close, and it didn't feel comfortable to keep it from him either. I talked with a really helpful social worker at the clinic. She gave me the *Cancer Survival Toolbox*[®] "Basic Skills" and my sister and I listened to the part on "Communicating" in the car on the way home. She also listened to the "Caring

for the Caregiver” on her own. In our next meeting with the social worker, Nancy helped me rehearse what I would say to my son when the time seemed right. The more we practiced, the more comfortable I got with what to say. She also gave us the website of The Leukemia and Lymphoma Society, where there is a lot of useful and hopeful information. I thought this was good since our son uses the internet a lot. We came up with saying first that I have a chronic blood condition, but that I might not need any medication or treatment for many years. I’m waiting for the right time to talk with him, hopefully in the next couple of months, and it feels better to know how I’ll begin the conversation.

Narrator

It's good to remember that although CLL is not as common as some other types of cancer, you are not alone. There are thousands of others, who like you, are figuring out how to live and cope with CLL and its symptoms, side effects and uncertainties.

There are also many different types of help and support that your doctor or nurse or social worker can suggest. We've already learned that support groups are one way to find others who can help you understand the many ways leukemia affects your life, but support groups aren't for everyone. Some people don't like being in, or talking in, groups and need something different. Let's listen to how Charlene found the help she needed.

Charlene

I'm a pretty private person. I've always lived alone and have been able to take care of myself and my home just fine. I don't talk about my personal life or feelings with people I don't know. And I certainly don't want to talk to people who don't understand this thing called CLL. My best friend is a talker and she keeps telling me I should go to a support group, but that's just not for me. I do talk to her, but while she tries hard, even she can't really understand what I'm going through with all these meds. The fear that I have about how I might not be able to stay in my home and take care of myself

because of this illness. The nurse at the clinic suggested I keep a daily journal – put my feelings down on paper just to get them out. I've tried that, but it doesn't seem to help very much.

Then Nancy, the social worker at the treatment center, told me about a program at The Leukemia and Lymphoma Society that would match me with another person with a similar diagnosis. (http://www.leukemia-lymphoma.org/all_page?item_id=4582). They found a woman named Carrie who is almost my age, single, and she's been battling this disease for over three years. The first time Carrie called me on the phone, we knew we had a lot in common.

Talking to Carrie gave me a lot of hope. When I first heard my diagnosis, I admit I thought it was a death sentence. So it gave me hope to hear that Carrie was doing so well three years later. I can talk to Carrie about anything. She's become a good friend to me. I also looked at something called Life Mosaic on the LLS website (<http://www.llslifemosaic.com/>) and that really was hopeful.

The other person who has helped me is the priest at my parish. I have always had faith and I find comfort in prayer. But I didn't quite know how to explain my situation to Father Chris. One day after church, he said he had heard that I haven't been feeling too well lately, and he asked if he could come and visit me at home, and I quickly agreed. Once I talked to Father Chris, I was surprised that he knew so much about cancer. He said that he is a part of a national group of faith leaders who are trained to understand the problems and struggles that people with cancer face. He understood the language and the terms. But most of all, he understood my fears. He also asked if I would allow him to suggest ways other parish members could help. I agreed, so now I feel like I have a bigger family, but they aren't intrusive. They only help when I want help.

Nancy (Social Worker)

With all of the different treatment choices and resources available, it's important for you to tell your health care team what kinds of services and supports you find most helpful. Clinics and doctors' offices can seem really busy, but if you ask, someone will sit down with you and go over your

treatment plan and support resources. Some cancer care teams also have nurse and social worker oncology navigators – staff members whose job is to help people with cancer navigate through the complicated aspects of dealing with cancer. It saves time in the long run the cancer care team members can get to know you and understand the best way to help you make decisions and cope better with your illness. We work as a team in the clinic or office, so if you just let one of us know what you need, we can find a way to work together. The better you know yourself and what helps you to cope, the better the people caring for you are able to help you. But you must be a self-advocate – and when you aren't feeling up to it, recruit a family member or friend to be your advocate. You need to be direct in asking for what you need and you need to stand up for your rights to good care and support.

Charlene

It's taken me awhile to figure out that I don't always have to do everything for myself, even though I have taken that route in the past. I still go to work every day and that is important to me – along with taking care of my home – and I don't plan to give that up any time soon. It took me ending up in the hospital to realize that when I have a problem, I have to call the clinic before things get too serious. My church family has been like a rock. I know that all I have to do is ask – actually I don't even have to ask, I just have to say ok, and they'll be there. CLL is a serious illness, but it doesn't have to be the end of my life, just a turn in path with some outstretched helping hands that I can grab onto along the way.