

Track 6: Coping Styles – Adapting to Your Illness

Narrator

As we learned from the men's support group, many factors play a part in decisions and adjustments needed after a cancer diagnosis. These include your age, whether you're employed or retired, whether you're living alone or caring for children or other relatives, and health issues and financial concerns.

Needed changes can be difficult to accept. You may hate to depend on others or not be 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. Because of all these factors, it's important to find support—talk with the people you're closest to or go back to people who've helped you with problems in the past.

Let's listen to Evelyn talk about getting the help she needs.

Evelyn

It's been several months since I was diagnosed and started treatment. One hard part is not knowing if or when the CML will no longer respond to the medicine I'm taking, and I'll have to try something different.

Also, I didn't know 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 thought telling him would be an unnecessary burden. But we're close, and I didn't feel comfortable keeping it from him.

I talked with a social worker. She gave me the *Cancer Survival Toolbox*[®] program on “Communicating” and in our next meeting she helped me rehearse what I'd say to my son. The more we practiced, the more comfortable I got. She also gave me the web address for The Leukemia and Lymphoma Society, where there's a lot of useful and hopeful information. I thought this was good

since my son uses the internet a lot. Now I'm just waiting for the right time to talk with him. It feels better knowing how I'll begin the conversation.

Narrator

Although CML is not as common as some other cancers, you're not alone. There are thousands of others, who like you, are figuring out how to live and cope with CML and its symptoms, side effects and uncertainties.

There are many different types of help and support your doctor or nurse or social worker can suggest. Support groups are one option, but they're not for everyone. Let's listen to how Ayana found the help she needed.

Ayana

I'm a private person. I've always lived alone and taken care of myself and my home just fine. I don't talk about my personal life with people I don't know. And I certainly don't want to talk to people who don't understand CML. My best friend's a talker and she says I should go to a support group, but that's not for me. I talk to her, but she can't really understand what I'm going through—the fears I have about how I might not be able to stay in my home and take care of myself. My nurse suggested I keep a journal—I've tried that, but it doesn't help much.

Then a social worker at my 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.lls.org/diseaseinformation/getinformationsupport/supportgroups/peersupport/>). They found Carrie, who's almost my age, single, and she's been battling CML for over three years. The first time Carrie called, we knew we had lots in common.

When I first heard that I had relapsed, I thought it was a death sentence. It gave me hope to hear Carrie was doing so well three years after her cancer relapsed. I can talk to Carrie about anything. She's become a good friend. I also looked at something called Stories of Hope on the LLS website

www.lls.org/diseaseinformation/getinformationsupport/storiesofhope/). It has some simple stories of people who have lived with leukemia and other blood disorders and had success. I find it helpful to read hopeful stories, because lots of the information about my diagnosis can be frightening. The priest at my parish also helped. I've always had faith and found comfort in prayer. One day after church, Father Chris said he'd heard I haven't been feeling well, and asked if he could visit me in my home. I agreed. Once I talked to him, I was surprised he knew so much about cancer. He said he's a part of a national group of faith leaders trained to understand the problems and struggles people with cancer face. He asked if I'd allow him to suggest ways other parish members could help. Now I feel like I have a bigger family, but they aren't intrusive. They only help when I want help.

Linda (Social Worker)

It's important to tell your healthcare team what types of services and support you need. Clinics and doctors' offices can seem busy, but if you ask, someone will sit with you and go over your treatment plan and support resources. Some cancer care teams have nurse and social worker oncology navigators whose job is to help people navigate through the complicated aspects of dealing with cancer. They can get to know you and help you make decisions and cope better with your illness.

The better you know yourself and what helps you cope, the better the people caring for you can help. But you must be a self-advocate, or find a friend who can advocate on your behalf. Asking for what you need can be difficult, but people are better able to respond if they know what you need.

Ayana

It's taken me a while to figure out I don't have to do everything myself. My church family's been like a rock. All I have to do is ask—actually I don't even ask, I just say O.K., and they're there. CML is serious, but it's not the end of my life, just a turn in the path with some outstretched helping hands I can grab onto along the way.