

Coping With Change

[Narrator]

We've talked about how myeloma is diagnosed and treated, as well as symptoms and side effects.

Now let's discuss other changes you may have to deal with.

Having multiple myeloma requires making difficult life changes. Some are temporary, others ongoing. Let's listen to a conversation of a men-only session of a support group, as the social worker asks about life changes they've had to make:

[Carletta (Social Worker)]

Sometimes cancer causes 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 cancer?

[Laurence]

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 to go to a cabin on the lake to fish. My last chemo was done a month ago; I was sure I'd be back to my usual activity level. But as the time for the trip got closer, I realized I didn't have my strength back. I started worrying about being responsible for an energetic 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 to go with us. 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. But I wonder if I'll be able to do all the things with my grandson that I'd planned.

[Sam]

I hate not being able to do daily things. I help carry in groceries for my wife. She says she can manage. She doesn't want me to take any risks with my back, but it makes me feel useless when I can't help with even small things.

[Paul]

I had the same problem with cutting the grass. That's always been my job. But, when the doctor found a "hot spot" on my arm, my wife suggested we hire someone to do the yard. We settled on buying a riding lawnmower and that's been OK. Using the push mower had gotten hard for me, but I hate not being able to do it.

[Jose]

We have a woodstove, and every fall we get a load of wood and I spilt and stack it. I've done this for 20 years. Last fall I was feeling good and I was sure I could pace myself by doing some every day. But on the second day, I had a sudden pain in my chest. Turns out, I'd broken two ribs – just by stacking wood. Now we have the wood split and the guy who brings it stacks it for us. I feel cheated not being able to do it myself.

[Laurence]

This story's a little different. It's hard to talk about. Always before I've been the strong one. I'm African American and was raised to control my emotions. Crying wasn't something a man did. But since I've had this disease, I feel emotional all the time. When the doctor told me last week I needed to start chemo again, it was all I could do not to cry in his office. I broke down in the car – in front of my wife Tanisha. She was the strong one that day. It seems like our roles have reversed. I feel like I'm letting her down.

[Jerome]

That's how I've felt since I had to take early retirement. I was a truck driver. It got so I couldn't do it physically. 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. And it's caused some financial issues, too.

[Carletta (social worker)]

It sounds like all of you have had situations where your lives have had to change. I hear two major themes. One is what we call "role change" or "role reversal." The other might be termed "living with uncertainty" – not knowing enough about the future to plan the way you'd like.

In families, and the workplace, each of us assumes roles. Some are fixed – like father or husband. Others change – like when you get a promotion, or change jobs. Sometimes we plan for these role changes and are happy when they occur – like when Laurence 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's forced on us. We almost always resist forced change. It makes us angry. It doesn't seem fair. Yet, when we look back later, the change might actually have had a positive side. For example, with Laurence, his brother got to know his great nephew better, and enjoyed spending some unexpected time with Laurence. Also, maybe Laurence's wife was relieved he could finally express his emotions. And Jerome, maybe your wife likes that you're home more and able to help around the house and 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 and how to perform. Role

change brings uncertainty. And role reversal – when someone else takes our role, and maybe we take theirs – can feel like it doesn't fit. We want things to be as they were.

Cancer diagnosis and treatment can bring about permanent changes. The goal is to get back to normal, but, most often a "new normal" must evolve.

We all have to live with uncertainty, but cancer brings a heightened sense of uncertainty. It may take years to feel safe again, and to be able to plan for the future with confidence.

Living with uncertainty can negatively impact family communication and functioning. If you feel you or your family are having trouble talking about problems, you might find it helpful to listen to the program about "Communicating" in the *Cancer Survival Toolbox*. It also might be useful to seek assistance from your health care team, or a social worker or other mental health professional. , If you're feeling depressed or anxious due to changes you must make because of cancer, seek help. Try a support group or a cancer-related community activity or program. Or seek individual or family counseling, or talk to your pastor. 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. Such people can help you remember how you've successfully dealt with change and challenges during other times in your life. They can help you use skills and strengths you already have to move beyond the current situation.

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

You can't change the fact you've been diagnosed with cancer, but you can learn to adapt to the life changes required to live as fully as possible after your diagnosis.

Many factors play a part in the decisions and adjustments you need to make after a cancer diagnosis. These include your age, whether you're employed or retired, whether you're planning a family or have grandchildren, and whether you're living alone or are caring for children or other relatives. They also include other health issues and financial concerns.

Needed changes can be difficult. You may hate depending 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, depressed, or emotional. These all stress the importance of finding support and talking with people close to you, or seeking out people who've helped you in the past.

It's good to remember that although multiple myeloma is not as common as some other cancers, you're not alone. There are thousands of others figuring out how to cope. There are many types of help and support that your doctor or nurse or social worker can suggest. We've already learned support groups are one way to find others who can help you. But support groups aren't for everyone. Some people need something different. Let's listen to how Charlene found the help she needed.

[Charlene]

I'm a private person. I've always lived alone and taken care of myself and my home. 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 multiple myeloma. My best friend is a talker and she keeps telling me I should go to a support group, but that's not for me. I do talk to her, but while she tries hard, even she can't understand what I'm going through. My nurse suggested I keep a journal – put my feelings down on paper to get them out. I've tried that, but it doesn't help much.

Then a social worker told me about a program that would match me with another person with a similar diagnosis. They found a woman named Carrie who's my age, single, and she's been battling this disease for over three years. The first time Carrie called, we knew we had a lot in common, even though she's gone through a bone marrow transplant, and that's not the plan for me. Talking to Carrie gave me hope. When I first heard my diagnosis, I thought it was a death sentence. It gave me hope to hear Carrie was doing well three years later. I can talk to Carrie about anything. She's become a good friend.

The other person who's helped is my pastor. I've always had faith and found comfort in prayer. But I didn't know how to explain my situation to Pastor White. One day after church, he said he'd heard I haven't been feeling well, and asked if he could visit me at 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 who are trained to understand the problems people with cancer face. He understood the language. But most of all, he understood my fears. He asked if he could suggest ways other church members could help. I agreed. Now I feel like I have a family, but they aren't intrusive. They only help when I want help.

[Carletta (social worker)]

With all the different resources available, it's important to tell your health care team what kinds of services and support you might find helpful. 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. The better you know yourself and what helps you, the better the people caring for you are able to support you. But you must be your own advocate. You need to ask for what you need, and you need to stand up for your right to good care and support.

[Charlene]

It took a while to figure out I don't have to do everything myself. I still work every day and that's important to me – along with taking care of my home – and I don't plan to give that up any time soon. My church family has been like a rock. I know 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. Multiple myeloma's a serious illness, but it doesn't have to be the end of my life, just a turn in the path with some outstretched helping hands I can grab onto along the way.