Understanding Your Treatment Options

[Narrator]

Many people with multiple myeloma have found taking part in a support group can be helpful. Support groups take many forms: some meet the needs of people with all kinds of cancers; others focus on one type of cancer. Some provide information while others offer emotional support. Some are led by nurses or social workers, others by peers – people who've had health problems like yours.

One group for people with multiple myeloma and their loved ones has been running for years. Some of its members have been living with their disease for a while, and then there are new members – people who've recently been diagnosed. Let's listen in on this group's discussion.

[Carletta (Social Worker)]

Hello, everyone. I'm Carletta, an oncology social worker. Tonight, our focus is on how the diagnosis of myeloma is confirmed, and how it is treated. Dr. Griffin, a medical oncologist, is here to help us understand diagnosis, and how treatment options are chosen.

[Dr. Griffin]

I'll start with a couple of comments about diagnosing myeloma – often, it's not simple. One thing that makes myeloma hard to diagnose is symptoms can vary and because of this, myeloma can look like several other diseases. The symptoms that usually bring people to their doctor include bone pain, often in the lower back, ribs, and/or breastbone; low red blood count and symptoms of anemia like tiredness or fatigue; and frequent infections. Sometimes a person has no symptoms and myeloma is discovered by accident during a routine check-up.

[Laurence]

That sounds like me. I was in for a check-up after I retired. My doctor noticed my red blood count was low, and there were some other odd things in my blood and urine tests. I was not eager to go through more tests. I was a little tired, but other than that, I felt fine. I was shocked when it turned out to be cancer! The first thing, my doctor talked to a hematologist – a doctor who specializes in blood problems – and they agreed I needed more blood tests and a 24-hour urine collection to check for protein in my urine. The urine showed something called the Bence-Jones protein often found with multiple myeloma. My blood tests showed the presence of the M-protein, another sign of myeloma. The hematologist took over my case. He ordered more exams and X-rays and other studies to look for damage in my bones. I had to have a bone marrow biopsy. It was scary. The information I found at the start was discouraging. My future looked bleak. But, here I am – seven years later!

[Renee]

The back pain I thought was related to a car accident was from a collapsed vertebrae caused by the cancer. That started the whole medical workup I now know is what happens at the diagnosis stage.

[Dr. Griffin]

After we know the diagnosis is myeloma, we need to find out the exact kind of myeloma – there are at least seven kinds – and its stage. The most telling exam involves a bone marrow biopsy – marrow cells are removed – usually from the hipbone. Besides testing for presence of protein, blood and urine chemistries can reveal increased calcium levels, decreased red blood cells, and signs of kidney damage. X-rays and CT scans are done to look for damage to bones. MRI and PET scans look for other possible problems. The results of these tests help us figure out the extent of the myeloma. These tests are repeated from time-to-time, to monitor your disease.

You might hear your doctor talk about the “stage” of your myeloma. The stage of myeloma helps us decide which treatment is best for each patient. You can find more information about stages in the resource booklet included with this module, and also on the International Myeloma Foundation website at www.myeloma.org.

[Ari]

I was just diagnosed, so my doctor and I are in the process of deciding what treatment I’ll have. My doctor told me there are a number of factors used to decide which treatment options are best. He said my heart problem would be important in his decisions about my treatment.

[Dr. Griffin]

That’s right. Other factors that will be considered include your age, general health, lifestyle, personal wishes, symptoms and *co-morbidities* – other conditions or chronic illnesses that may limit treatment.

Most often, patients are treated in ways that combine chemotherapy, steroids, and radiation therapy, in different doses and different sequences. Some patients get a stem cell transplant – in which stem cells are removed from the patient’s blood, or sometimes from a donor’s blood. It’s too much to go into all the treatments available – we try to use medicines and procedures that work together to achieve the best results, and these are tailored for each patient. There are also hundreds of clinical trials in progress, a good sign we’ll continue to see new treatments for myeloma.

[Laurence]

When I was diagnosed seven years ago, my doctor ordered Melphalan, a chemotherapy drug, and prednisone. That worked for several years and then my M protein started to rise. So he changed my treatment and I took a drug called Thalidomide along with the prednisone. This worked until two years ago when the myeloma came back. Now I’m taking Lenalidomide – also called

Revlimid – along with the prednisone. When one treatment plan stops working, we change to another. My myeloma is back in remission, and I hope it stays that way.

[Renee]

My story's a little different. Because I had a collapsed vertebrae, my doctor suggested I have a vertebroplasty (ver-TE'-bro-plasty), where a kind of cement was injected into the damaged vertebrae to stabilize it, which decreased the pain in my spine. I also had radiation treatment to that part of my back, and that eased my pain. My doctor also thought I should go through a stem cell transplant since I was only 50 when I was diagnosed and my health was good. I had the transplant a year ago, and so far I'm doing fine.

[Dr. Griffin]

Everything in the myeloma picture is changing so fast right now. Over the past five-to-ten years, there's been an explosion of new drugs and combinations. Researchers are looking at gene therapy and vaccines, too, and all these advances will likely change how we treat myeloma. We're very hopeful.

[Sam]

When I was diagnosed five years ago, my doctor suggested I enroll in a clinical trial.

[Ari – interrupting]

What's a clinical trial? My doctor talked with me about enrolling, but I don't understand what it is. It makes me nervous.

[Carletta]

A clinical trial is a study you can participate in, in which you could receive an experimental drug. Sam, would you describe your experience for us? And Dr. Griffin, maybe you could add some information?

[Sam]

As part of a clinical trial, I took a drug along with prednisone and it worked great! My study was a "blind study" – meaning neither my doctor nor I knew which treatment I was getting – but it had to be at least standard therapy. I found out after the study ended that I was on the experimental drug, and what it was. Three years ago, I also had a stem cell transplant. My myeloma was in remission for over a year, but then scans showed some disease in my back. My doctor suggested I take a drug that had just been approved by the FDA – which means the clinical trials to study its effects were finished, and the drug was shown to be effective. It's helped –my myeloma is stable now.

[Dr. Griffin]

There's a lot of good information about clinical trials on websites such as the National Cancer Institute (www.cancer.gov), the Multiple Myeloma Research Foundation (www.myelomatrials.org), and the International Myeloma Foundation (www.myeloma.org). The *Cancer Survival Toolbox* module, "First Steps", provides more information about clinical trials. But, briefly, clinical trials are done to test the effects – good and bad – of new drugs or study agents before they can be approved by the FDA. The goal of clinical trials is to find better ways to treat cancer.

[Carletta]

Ari, you're still trying to understand your illness and make decisions about treatment. Do you have questions or concerns we can talk about tonight?

[Ari]

Yes. I feel funny about this. But sometimes, I don't think my doctor's being straight with me. Maybe I'm not communicating with him very well – but sometimes I think I'm not getting enough

information from him. My daughter thinks I ought to get a second opinion, but I don't want to offend my doctor. I don't know what to do.

[Carletta]

It's important you're able to talk with your doctor openly and honestly. We can help you improve your communications skills – there's a *Toolbox* module focused specifically on communication. This information could help your relationship with your doctor. As for a second opinion, it's almost always a good idea – even if the second opinion turns out to be the same as the first. The *Toolbox's* "First Steps" module suggests ways to go about setting up second opinions. This may help you feel more comfortable with treatment recommendations. Also, it may turn out you could have a better relationship with another doctor, and that's important. You and your doctor will have an ongoing relationship – it's in your best interest that you work well together.

[Renee]

I have one more suggestion for you, Ari. Well, it's something we can all use. A couple weeks ago, I took part in a Myeloma Education Series teleconference provided by the Leukemia and Lymphoma Society (their website is www.lls.org). They have patient education teleconferences and webcasts, and on the computer, you can get printed transcripts and audio recordings. People from all over the country were on the line, and we could pose questions to a panel of myeloma experts. I learned a lot about what's going on in myeloma research, the newest anti-myeloma drugs, and other information that helps me be as healthy as I can be.

[Carletta]

What a great resource! Thank you, Renee. Please know there are people all around to help you through this – the people in this support group continually reach out to help each other. The social

workers and nurses and doctors, too, are here to help you. You only have to let someone know you need help. As Renee says, we all want to help you be as healthy as you can be.