

## **Karen Kell Hartman, LCSW-R, OSW-C**

It's really important for any cancer patient, myeloma patients included, to speak with their teams about what side effects they might experience. Because, I think, most people think of cancer: chemo-nausea-vomiting. But the reality is those types of side effects are usually managed, and the ones people don't expect or don't know about are the ones they need to hear about so that they're not taken by surprise, so that they'll know that it's normal. They also need to know when to call the treatment team if it is not an expected side effect. And the fatigue is the biggest side effect and I think the people don't know to expect that. An awful lot of cancer patients in general, myeloma in particular, experience a lot of fatigue and that's quite debilitating.

## **Scott**

When I was first diagnosed, my doctor did tell me what to expect. What multiple myeloma was doing to me specifically, all the different treatment options, and also the side effects.

## **Ruthee-Lu Bayer, MD**

Steroids are the mainstay of treatment for multiple myeloma. These drugs can often make patients more anxious. They can affect sleep for patients. They can affect mood and these drugs can also affect blood sugar.

## **Dr. Bayer**

Patients who have multiple myeloma may also have issues with their kidneys both from the disease and from the medications that we use to treat the disease. So we often are vigilant in terms of other medications that we use to be sure that we're not causing any more damage to the kidneys.

Hyperviscosity syndrome is a side effect of the disease multiple myeloma itself. And essentially, what happens is when the body is overproducing this abnormal protein; the blood actually becomes more viscous or thick. And what can happen is people can have strokes, people can have actually bleeding from this process.

Patients who are receiving IMiDs and proteasome inhibitors can be more susceptible to infectious complications. And many of these patients, we monitor very closely. Many of them may be on a preventative antiviral medication to help protect from the shingles. We try to stress to our patients that they receive flu vaccines and pneumococcal vaccines.

Patients can also have issues with bone pain from the bisphosphonate drugs that we utilize. These drugs help strengthen the bones. These drugs also are believed to prevent the growth of myeloma cells, and patients who are taking bisphosphonates regularly can have bone pain. Patients who receive bisphosphonates may also have issues with healing after major dental work. So, we often try to remind these patients when they see their dentist that they need to make the dentist aware that they are taking the drug and if they should ever need major dental work, we will actually give them a drug holiday.

## **Karen**

People often realize once they've started treatment that the cancer itself may not be causing them any pain or discomfort or anything but the side effects of whatever treatment they're on are usually pretty significant and people will say to me, "The doctor gave me this huge list when I started on – whatever drug – and it was terrifying so I didn't know which ones to expect which not and it all kind of went out of my head and I went home and then I started to experience... whatever, fatigue or nausea or like pains in my legs and I didn't know if it was normal." And – but we try to encourage people to do is always to understand that side effects are normal and expected, but also to feel free to call the doctor. And people are often reluctant to do that. They're reluctant for a lot of reasons. They want to be a good patient and a good patient in many people's estimation is that person who goes to the doctor and everything is fine.

# Multiple Myeloma Side Effect Management

People are sometimes afraid if they report a certain effect that they'll be taken off the clinical trial or the drug or whatever that they're on. When in reality most of the times, that kind of a drug is – that kind of a side effect is something that's expected. It might be unusual. They might not have heard about it but it's something that can be managed. Most of the time.

## **Scott**

Since being diagnosed with multiple myeloma. It's been... I've been... multiple side effects from the multiple myeloma or even from the treatments. Anywhere from neuropathy, to chemo brain.

## **Diane**

Chemo brain is a side effect that you don't hear a lot about. You hear a lot about people throwing up from chemo. You hear a lot about people losing hair from chemo. You hear a lot about people getting nauseous from chemo and... He gets chemo brain and a lot of people get this. He's forgetful. The chemo brain can be a little unnerving sometimes.

## **Karen**

Cancer is such a mysterious disease that I think people don't always know what to expect. And so whether they're feeling a pain or some kind of discomfort, especially with something like multiple myeloma that people really often don't understand because it is so complicated. It's hard to know whether what they're experiencing is from the cancer itself or from the medication and people fear progression of cancer. They really fear that it's going to go somewhere else. "It showed up here but now if I tell the doctor I have a pain somewhere else, does that mean that now the cancer is somewhere else? And if I don't talk about it maybe it won't be real."

What I will say to people often when they're concerned about the issue of is the cancer spreading is this is a side effect? What is going on? I'll say, "Well what do you think – what's the worst that's going to happen if say it is the cancer for the worst-case scenario?" And then they'll say, "Well I guess the doctor will come up with a treatment plan." Yeah, that's exactly what will happen. Usually the doctor will figure out a different drug to take, a different treatment. It's very rare that the doctors going to say, "Okay, that's it. You're done." There's going to be a plan. So you just need a plan. The anxiety comes from not knowing. Knowing really resolves a lot of this concern if you could just bring yourself to ask the doctor. There will be – usually there is an answer.

## **Diane**

You've got to take the good with the bad. When we go on vacation, we plan it so we do everything in the morning so he can nap in the afternoon. You can find the good stuff also so you adjust, There's the new normal that a lot of cancer patients talk about.

## **Scott**

But even though you have these side effects and you realize it; you shift your priorities, you shift your life so this way you can continue to live your life... a full life even with all the side effects that you experience.