

## Introduction

[Narrator]

Welcome to the *Cancer Survival Toolbox*<sup>®</sup>, an award-winning audio program brought to you by the National Coalition for Cancer Survivorship, or NCCS for short. , we've created this special module focused on multiple myeloma – what it is, how it's controlled, and ways to cope with a chronic illness that, while not yet curable, has many treatment options. You can listen to this single module, or you can use it along with the original *Cancer Survival Toolbox*. You can also refer to the resource booklet that comes with this CD for more information.

Multiple myeloma is cancer of the bone marrow and the second most common type of blood cancer. It affects men more than women. The highest rate occurs in African-Americans.

Multiple myeloma is difficult to understand. Let's begin by listening to survivors describe their disease.

[Renee]

I have cancer in my bone marrow, and this causes pain in my bones, especially my back. Also, my bones can break easily; I'm not sure why.

[Ari]

Although the cancer is in my bones, it's called a blood cancer. It's like a cousin to leukemia, but it isn't leukemia.

[Jose]

I have protein in my blood – whatever that means. I don't understand how this relates to cancer in my bones. And why am I so thirsty all the time?

[Sam]

After 5 years, I still don't fully understand what type of cancer I have. It's hard to explain. I often feel depressed.

[Paul]

My cancer's been described as an explosion of cells within my bone marrow. These cells aren't controlled. Could this explain why I'm always so tired?

[Charlene]

I thought I had bone cancer, but the doctor said that isn't exactly right. So I really don't understand what's going on.

[Narrator]

Each of these survivors is describing the cancer called "myeloma" or "multiple myeloma." Let me explain it further. You may want to take out the diagram that appears in the booklet that comes with this CD. That may help you visualize the process.

Imagine your bones as long, hollow tubes – hard on the outside, with space for a more liquid or spongy substance inside. With multiple myeloma, we're interested in the inside spongy space in the center of the bone, where blood cells are formed. This is the "marrow." All BLOOD cells begin there as STEM cells, before entering the bloodstream. These STEM cells turn into RED cells, WHITE cells, and PLATELETS. RED cells carry oxygen, giving us energy and keeping us from becoming anemic. WHITE cells protect us from disease and fight infection. PLATELETS prevent bleeding. In addition to these cells, the blood also contains PLASMA, which is mostly water but also contains proteins and other substances.

Let's focus on WHITE cells – the ones that fight infection – because this is where multiple myeloma begins. White cells in the marrow make different types of cells, called

LYMPHOCYTES. One of these is a “B” LYMPHOCYTE. In healthy bone, B LYMPHOCYTES turn into PLASMA cells. PLASMA cells then produce substances that fight disease and infection. If the B LYMPHOCYTES are genetically damaged, they can turn healthy plasma cells into malignant multiple myeloma cells that are unable to fight infection. These abnormal cells reproduce and make large amounts of protein, thus taking up space and crowding out normal cells in the marrow. The abnormal cells can then attack and weaken the solid part of the bone, causing soft spots, or “osteolytic lesions.” In an X-ray, these lesions look like holes in the bone, and can lead to fractures. So, while multiple myeloma can eventually attack the hard part of the bone, it begins in the marrow.

Let’s hear from a long-term survivor, Toni, about what it’s like to live with multiple myeloma, and what effects it’s had on her life.

[Toni]

Multiple myeloma’s a cancer of the bone marrow; however, it’s often mistaken for bone cancer. It’s a blood cancer for which there’s no cure at this time, but it is treatable. It’s part of a family of three blood cancers – leukemia, lymphoma, and multiple myeloma. Doctors often refer to these blood cancers as cousins. But, multiple myeloma is the most difficult to treat.

Having been diagnosed with multiple myeloma in 1998, I continue to deal with this chronic illness. I’m thankful for the great care I’ve received, and lucky I’m in remission. I haven’t had a bone marrow or stem cell transplant. My treatment is monthly oral medications and intravenous drugs. The side effects can be worse than the treatments, but the treatments keep me alive. Along with treatment, I credit much of my success to complementary therapies – like, acupuncture and Chinese herbs. And without proper rest, nutrition, and balance in my life, I feel worse and my immune system weakens, making me more likely to get to infections.

I'll probably require treatment for the rest of my life. Anyone faced with a chronic illness such as multiple myeloma must not only manage normal everyday duties, but also coordinate doctor visits, drug refills, insurance claims, and other responsibilities.

[Narrator]

Toni's a long-term cancer survivor. She'll always have multiple myeloma, yet she lives with periods of remission when the disease is not active.

Many of our listeners may question the term "cancer survivor." At NCCS, we feel everyone diagnosed with cancer is a survivor – from the moment they're diagnosed until the day they die. While there are many types of cancer, such as multiple myeloma, that cannot be cured but are treatable, there are also many resources to help support you and your loved ones.

Now let's learn about diagnosis and treatment.