

# The Cancer Survival Toolbox®: Living with Multiple Myeloma

## Table of Contents

Introduction

Understanding Your Treatment Options

Side Effects and Symptom Management

Coping with Change

Information for Caregivers

Conclusion

# The Cancer Survival Toolbox®: Living with Multiple Myeloma

## Transcript

### Introduction

[Narrator]

Welcome to the *Cancer Survival Toolbox*®, 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]

## The Cancer Survival Toolbox®: Living with Multiple Myeloma

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.

## **The Cancer Survival Toolbox®: Living with Multiple Myeloma**

[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.

## The Cancer Survival Toolbox®: Living with Multiple Myeloma

### Section 1: 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]

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.

## The Cancer Survival Toolbox®: Living with Multiple Myeloma

[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](http://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]

## The Cancer Survival Toolbox®: Living with Multiple Myeloma

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]

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](http://www.cancer.gov)), the Multiple Myeloma Research Foundation ([www.myelomatrials.org](http://www.myelomatrials.org)), and the International Myeloma Foundation ([www.myeloma.org](http://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

## The Cancer Survival Toolbox®: Living with Multiple Myeloma

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](http://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.

## The Cancer Survival Toolbox®: Living with Multiple Myeloma

### Section 2: Side Effects and Symptom Management

[Narrator]

We've learned a little about how multiple myeloma is diagnosed, and how treatment decisions are made. Many people fear treatment because of possible side effects. Let's listen to another group of survivors as they discuss how they manage side effects.

[Nurse Emily]

My name is Emily, and I'm an oncology clinical nurse specialist. What we're going to talk about today are the symptoms and side effects people with multiple myeloma often have. Most people with this illness need some form of treatment on an on-again/off-again basis through their lives, so it's important to know about symptoms and side effects and how to deal with them. Being able to identify and describe what you're feeling is helpful to your health care team. They can change your therapy if possible, helping you to feel better and decreasing problems.

Our guest tonight is Dr. Rodney Jackson, an oncology clinical pharmacist.

[Rodney]

Hello, and thank you for inviting me. I know having this disease presents many trying times. I want to help by talking about symptoms, side effects of medicines, and ways to use medicines to deal with problems. There's a lot of information about how treatments affect the disease, but there's not much information about how treatments might affect you.

[Nurse Emily]

Some common symptoms with multiple myeloma are fatigue or feeling tired much of the time, aches and pains in the bones, nausea, constipation, and numbness in different parts of the body. These are the symptoms that made you see your doctor in the first place, and are often caused by the disease. But, these same symptoms can also be side effects of treatment.

There are many possible side effects – some common, others not so common. If we don't talk today about the ones you're having, or if you want to know more, the National Cancer Institute's website ([www.cancer.gov](http://www.cancer.gov)) has a link to multiple myeloma, and side effects are described there more fully. You can also call them at 1-800-4CANCER. Websites sponsored by the Leukemia and Lymphoma Society ([www.lls.org](http://www.lls.org)), and the National Comprehensive Cancer Network ([www.nccn.org](http://www.nccn.org)) also include information about myeloma, its treatment, and side effects.

Side effects differ from one person to another, and can change from one treatment time to the next. Before you begin treatment, talk with your health care team about possible side effects and ways you and your family can deal with changes you might face along the way.

[Laurence]

## The Cancer Survival Toolbox®: Living with Multiple Myeloma

I think I've been dealing with this the longest of anyone here. I've lived through a number of these side effects. One of the medicines I've been on, the steroid called dexamethasone, really affected my memory and mood.

[Tanisha: (Laurence's wife)]

Laurence got irritable and moody after he started treatment. He was difficult to live with. I didn't know what I was going to do – what I could do.

[Laurence]

I have to admit that's true. I felt like a different person. We didn't understand what was causing me to feel and act that way.

[Ari]

I just started treatment a short time ago. I've had some of these feelings, too, but thought it was "all in my head" – that I was depressed and upset about having this disease. I didn't think about it being related to treatment.

[Rodney]

Let's talk about that. Most likely, dexamethasone, prednisone, and/or prednisolone, all steroids, have been part of your treatment. Myeloma experts call these steroids "the backbone" of myeloma therapy. Steroids cause cancer cell death – which is a good thing – but people often have side effects. Besides irritability and mood swings, steroids can cause depression; problems sleeping; weight gain; increased appetite; general body swelling, flushing, and sweating; muscle cramping; digestive problems like heartburn, gas, and taste changes; changes in sexual function; and a "let-down" effect when steroids are stopped suddenly. I suggest you talk with your oncologist and nurse about ways to minimize and manage these effects. Sometimes, just adjusting your medicine schedule and adding other medicines can help – something like taking steroids early in the morning, for example, and taking an over-the-counter or prescription drug, can help with digestion. Sometimes, seeing a specialist is helpful for the complex steroid-related side effects.

[Laurence]

A side effect I've had is peripheral neuropathy due to nerves damaged by my chemotherapy. It started with numbness and tingling in my fingers and toes, and, my doctor tells me, it can cause serious pain and problems with walking and use of the hands. Luckily, my nurse described this problem as something that might occur, and as soon as it started, I told her and my doctor. Since I wasn't in pain and the numbness and tingling weren't bad, and the treatment seemed to be working, one dose of treatment was skipped to give my nerves time to recover. The tingling and numbness got better, and I was able to get treatment when I had to start the next cycle. The doctor also gave me vitamins and a medicine normally used for depression. They worked. My nurse watched my symptoms closely. I was able to continue treatment with slightly lower doses, and the symptoms went away after a few months. But I know some people have to stop the medicine due to problems like this.

## The Cancer Survival Toolbox®: Living with Multiple Myeloma

[Rodney]

Yes, peripheral neuropathy is caused by many of the drugs used in myeloma treatment. Sometimes it appears even before treatment starts, and we don't really know why that happens. At best, it's an annoying problem. At worst, it causes muscle weakness, and pain that limits use of the legs, feet, and hands. Regular check-ups should include exams to check for early signs of neuropathy – things like decreased ability to detect hot and cold by touch, and signs of muscle weakness. Things used to treat it include Vitamin B<sub>6</sub> and nutritional supplements with amino acids, pain medicines, anti-depressants, non-steroidal anti-inflammatory drugs – sometimes called N-SAIDs – and medicines usually given to control convulsions (or seizures). Your nurse is probably a good resource for information about early signs of peripheral neuropathy, and what symptoms you should report that will help you avoid permanent damage.

[Renee]

I've also read physical therapy, relaxation, and acupuncture can help.

[Nurse Emily]

That's correct. And, sometimes just gentle massage of painful areas with cocoa butter is comforting – it's also something that's easy for caregivers to do.

[Renee]

Myeloma affected several vertebrae in my spine and caused back pain. I couldn't work and had trouble sleeping. My doctor reassured me the pain could be treated. She explained there were several options. First, we needed to treat the myeloma with chemotherapy and radiation therapy to my spine. She also prescribed pills to control pain. She explained it was important to take the pills regularly – around the clock – and to let her know if my pain wasn't getting better. I ended up having vertebroplasty, but even before that, taking pain pills made a big difference. I was able to go back to work.

[Nurse Emily]

Pain can be caused by your disease or sometimes it occurs as a result of treatment. It's important to tell your doctor or nurse right away if you have pain. The more information you can give, the more it will help your cancer care team find the best way to manage your pain. As you get ready to talk with your doctor or nurse about pain you're having, think about – and write down – answers to these questions:

- How bad is your pain? Give it a number from 0 to 10 – where 0 equals no pain and 10 is the worst pain imaginable. Also, describe changes in pain level during the day and night, and any pain you have with your usual activities.
- What does the pain feel like? Sharp, dull, stabbing, tingling or burning?
- Where is your pain?
- How much relief are you getting from pain pills? What other methods help you control the pain? Does heat or ice work? What makes the pain worse?

## The Cancer Survival Toolbox®: Living with Multiple Myeloma

[Rodney]

First, I want to let you know not everyone with myeloma has pain. In fact, one of the kinds of medicine often prescribed for people with myeloma is bisphosphonates (bis-fos'-fan-ātes). They decrease the chances of tumor growth in bone, and are used to try to reduce or delay development of bone pain and fractures. These medicines require special monitoring, so if one is prescribed, talk to your doctor and nurse about scheduling routine visits to check your progress.

The most common type of pain with myeloma is caused by myeloma's effects on bones. Radiation treatment usually reduces or gets rid of the pain. But, this can take a while, and in the meantime, medicines are used to control pain. It's important to understand how and when to take pain medicine. I know some people with pain decide NOT to take pills because of fear of becoming addicted. Or, people think they should save strong pain medicines for when pain becomes really bad. Both these beliefs are based on myths. When people have physical pain, the risk of true addiction is very, very small. And, severe, uncontrolled pain is much harder to get under control. The best way to get good pain control involves finding and treating the source of pain early, and using pain medicines in the right ways. Good pain control often requires two or three medicines that work together in an around-the-clock schedule as Carletta mentioned.

[Tanisha]

Don't forget about the constipation that happens with pain medicine! Laurence had a terrible time with that, because we didn't think about constipation until it was already a big problem.

[Nurse Emily]

Thank you for that reminder, Tanisha. Strangely enough, both constipation and diarrhea can be side effects of treatment. I know people often take constipation and diarrhea lightly, but they can cause major problems. It's important to be proactive to prevent these problems – or manage them before they get more serious.

Constipation is common among cancer patients because of decreased appetite, poor intake of food and fluids, and anti-pain and anti-nausea medicines. Ask your doctor or nurse to help you come up with a plan to prevent constipation.

[Rodney]

Diarrhea can also occur. The risk increases with the use of some herbal supplements, laxatives, antibiotics, antacids and other medicines, and in people who have infection or bowel conditions such as irritable bowel syndrome, colitis, or diverticulitis. Diarrhea can occur after surgery involving the bowel or after a transplant. When diarrhea occurs, checking for infection as a cause is usually the first step. Managing diarrhea involves keeping track of fluid intake and output, replacing lost fluids, diet changes, and use of medicines.

Other side effects can include nausea and vomiting. Too often, I talk with patients who think these things are bound to happen with cancer treatment. This isn't the case. These problems can often be

## The Cancer Survival Toolbox®: Living with Multiple Myeloma

prevented. Anti-nausea and anti-vomiting medicines can be given the night before treatment, and continue during and after treatment. If these problems occur, let your doctor and nurse know you need ways to manage them.

[Tanisha]

I want to bring up something that was a problem for Laurence and me. He might not like that I talk about this, but I think it's important. I'm gonna bring up – S-E-X! Because we're retired, sex isn't something a lot of doctors and nurses think folks our age are concerned about, but it is. And it isn't just about sex, it's also about being close and intimate – hugging, holding hands, cuddling, even communication. When Laurence was first diagnosed, I was almost afraid to touch him, he seemed so fragile. We never talked about sex much in our marriage, so this was hard to handle.

[Laurence]

Hhumpf...it's really hard for me to talk about this stuff, especially with ladies present. At that time, I was so tired all the time. I was depressed and angry, too. I didn't talk with Tanisha about what I was feeling. My doctor and nurse didn't bring up sex, so I figured they didn't want to talk about it either.

[Tanisha]

I saw an article in the paper about a psychologist who was doing a weekend workshop on sexuality for cancer survivors. I don't know how, but I got Laurence to go – I guess, we had a lot of the same concerns. We both learned so much – about sexuality and each other. At first, the discussions were embarrassing – but everyone was going through similar things – and as the weekend went on, we started having a good time. We talked about finding time together as a couple, and changing the ways we express our sexuality depending on what's going on with our health – like finding bedding, pillows, and other things to support positions that make sex more comfortable and safe.

[Nurse Emily]

Thanks Tanisha, for bringing up this important and sensitive topic. You're so right – sexuality is important to all of us. Bottom line...there are lots of resources, including caring professionals, to help people with issues around sexuality.

One related issue is fertility. While myeloma affects most people after their reproductive years, there may be times when myeloma affects women before menopause, or men who still want to father a child. If fertility's a concern, talk to your doctor or nurse about options to preserve your fertility. A good resource for cancer patients is the organization Fertile Hope – 888-994-HOPE or [www.fertilehope.org](http://www.fertilehope.org).

One other thought: if fertility and sexuality have not been brought up by your doctor or nurse, it may be they expect you to talk about these issues if they're important to you. They may also lack knowledge. If this is the case, ask for a referral to another professional who is able to offer this kind of help.

## The Cancer Survival Toolbox®: Living with Multiple Myeloma

[Sam]

The thing that's bothered me is how tired I feel all the time. People who haven't had cancer treatment have no idea what it's like. Why does this happen? Have any of you figured out how to deal with it? I don't want it to take over my life.

[Nurse Emily]

Sam, you're not alone. Fatigue is an important thing for us to talk about. It's the most common side effect of cancer and cancer treatment, and can greatly affect your life. No one knows what causes fatigue – most likely it relates to several things – reduced physical strength and levels of activity, decreased appetite and food intake, changes in sleep-wake patterns, pain, stress, infection, and anemia are just some of the factors related to fatigue. Ways of dealing with fatigue can include drugs and exercise, reducing stress and worry, conserving energy, and promoting more normal sleep/wake cycles. Rodney, would you talk about using drugs to treat fatigue?

[Rodney]

The first thing that should happen is to see if there's something causing the fatigue that can be treated with drugs. We would check for anemia, depression, and energy levels, and treat those problems if they're present.

[Ari]

I saw an article telling cancer patients to hit the gym! It seemed odd – to exercise to deal with fatigue. I talked to my nurse and doctor and they told me research shows low-to-moderate exercise can reduce fatigue during and after cancer treatments. I learned it's best to start an exercise program before fatigue really sets in. Even in my small town, I found the local fitness center has a program designed for cancer patients to help speed recovery and reduce the fatigue of chemotherapy and radiation. I started swimming again, and it made me remember how much I love the water. I look forward to the gym. It's definitely made me feel less tired.

[Renee]

I was so tired, stressed, and worried all the time. My friend offered to go with me to her yoga center. I talked to my doctor. He didn't know much about yoga, but he looked at the pictures in a yoga book I have, and marked "OK" on the poses he thought would be safe. My nurse was doing yoga, and said to explain my situation to the instructor – what I could do and what I should avoid. Between yoga and the meditation that's sometimes part of the class, my stress level has improved. I don't feel as tired – and I feel much stronger.

[Nurse Emily]

Simple walking can help keep bones healthy and muscles strong. Exercise can help people cope with side effects like nausea, fatigue, constipation, and depression. Being in an exercise program with other people offers social and emotional benefits, too. Talk with your doctor or nurse and

## The Cancer Survival Toolbox®: Living with Multiple Myeloma

maybe consult with a physical therapist or fitness instructor who knows about fitness programs for people with cancer. You can begin looking for an exercise program by calling the local offices or exploring websites for the American Cancer Society, the YWCA, and The Wellness Community. These groups can also be contacted by phone. Web addresses and phone numbers for all groups mentioned in this program are listed in the booklet that came with this module.

[Laurence]

My fatigue is related to lack of sleep. I used to have coffee every day, and sometimes tea at night. Those things, plus the stress of my diagnosis and treatment, messed up my sleeping. I was talking with the nutritionist about my diet and mentioned my sleep problem. She asked about caffeine and suggested ways to reduce caffeine – decaffeinated coffee and tea, drinking water instead of soft drinks, avoiding chocolate, especially in the afternoon and evening. Also, I don't drink much after dinner so I don't have to get up to go to the bathroom at night. And almost every day, Tanisha and I walk by the river or on easy hiking trails. All these things have helped me sleep better.

[Nurse Emily]

These things are helpful. For those of you who don't have companions or need support, you might find it helpful to get out for a walk in your local mall where you can take breaks, or go for a short stroll around the block.

Doctors and nurses have begun to see cancer-related fatigue as important, and many track fatigue at clinic visits. Sorting through factors that can disturb your sleep patterns is a first step toward solving this problem. Seeing a sleep specialist can be helpful, too.

[Rodney]

I want to bring up one last group of side effects. Many drugs used to treat myeloma decrease the number and function of red and white blood cells and platelets. Low white blood cell levels increase the risk for infection. Fatigue sometimes relates to anemia caused by low red blood cell levels. Low platelet levels interfere with blood clotting and cause easy bruising and bleeding. Protecting yourself from infection and injury are some of the most important actions you can take – and some are simple. For example, frequent washing of your hands and asking your caregivers to do the same is the best way to prevent infection. Tell your doctor right away – even at night or during weekends – if you develop a fever. Avoid using aspirin or other medicines that can cause clotting problems unless they're prescribed by your doctor. And, avoid activities that can result in bruises or bleeding, including body piercing, tattooing, contact sports, use of rectal thermometers, and anal sex. Talk with your doctor and nurse about ways to protect yourself during times when your blood counts are low, and put a list of emergency contact numbers in a place that's easy to find.

[Sam]

As long as we're talking about blood – I read people with myeloma are at risk for clotting in the lungs. I haven't had this happen, but I don't know how I would know if these things are going on.

## The Cancer Survival Toolbox®: Living with Multiple Myeloma

[Rodney]

People with cancer do have an increased risk for developing blood clots. Deep vein thrombosis – “DVT” – is a small blood clot in an arm, leg, hand, or foot. If this were happening, you’d probably notice swelling, feelings of tightness, aching, pain, and/or a lump in the affected area. Sometimes, the heartbeat speeds up, and veins are larger than usual. A pulmonary embolus – “PE” – is a blood clot that travels into the lungs. Symptoms are feelings of anxiety, fast heartbeat and breathing, shortness of breath, chest pain, and coughing up blood. A stroke can be caused by a blood clot that travels to the brain. Symptoms could include changes in behavior and confusion, severe headache, chest pain, sudden onset of numbness or weakness, and loss of coordination. These problems are medical emergencies and need to be treated right away.

[Nurse Emily]

Factors that increase your risk for blood clots include lack of activity, smoking, history of blood clots for you or in your family, lengthy airplane travel, recent surgery, and certain medicines. You can reduce your risk of by exercise – walking, and doing ankle circles and knee-to-chest lifts. If you’re overweight, you might talk with a nutritionist about ways to lose weight. If you smoke, a stop-smoking program will help you reduce your risk. Talk with your doctor and nurse about your risk, and ways to improve your chances of avoiding blood clots.

[Ari]

This all sounds pretty scary. There are so many things to think about, so many things I need to do. How can I keep it straight?

[Nurse Emily]

Right up front, I suggest you ask for and keep copies of your doctors, hospital and clinic reports. It’s easy to put together a 3-ring binder or accordion file to organize your records. You can also use a calendar to keep track of appointments, and to note side effects. A journal can help you track how you’re feeling, how long symptoms last, and what makes them better or worse. If you like computers and have internet access, you may want to use the Multiple Myeloma Personal Care Assistant™, available for free through the International Myeloma Foundation at [www.myeloma.org](http://www.myeloma.org). If you’re not comfortable with computers, a child or grandchild might be able to help with your records. It would give them a good way to help you, too.

Once a treatment ends, it’s important that you get a summary of your treatment so all your doctors can have the same information. You may also be given a plan for follow-up, or what we call a survivorship care plan or Prescription for Living. This plan is a guide for living beyond cancer. I work with each patient to develop the plan so it’s made for his or her unique needs. It can include tips about exercise, healthy eating, stress reduction and community resources. It can also map out your schedule of doctor appointments, tests, ways to deal with problems after treatment, and describe how to assess new symptoms that may need to be looked at.

## The Cancer Survival Toolbox®: Living with Multiple Myeloma

### Section 3: 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]

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

## The Cancer Survival Toolbox®: Living with Multiple Myeloma

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]

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.

## The Cancer Survival Toolbox®: Living with Multiple Myeloma

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

## The Cancer Survival Toolbox®: Living with Multiple Myeloma

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]

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.

## Section 4: Information for Caregivers

[Narrator]

Cancer affects the whole family, and it's important to talk about the stress and problems of family members and friends. If you're helping someone you love get through cancer treatment, you are a caregiver. A caregiver can be a family member or friend. Caregiving can involve many different activities. Helping with daily activities, personal care, coordinating care and services, and giving emotional and spiritual support are just a few of the ways you can give care.

What comes naturally for most caregivers is to put our own feelings and needs on hold and to focus on the person with cancer. This may work for a short time, but it can be hard to keep this up. It can be hard on you, and it can be hard for your loved one.

[Kaya]

My name is Kaya. My husband Sam and I were in to see his doctor for follow up and treatment planning. We were discussing his chemo scheduled for the next week and my husband laughingly said, "I guess I'm ready to turn everything over to Kaya for the next month. She has a hard time letting me do anything because I get tired. I wish she could let me push myself to do some things. I wouldn't feel like such a big lump." I laughed along with him, but I was a little upset. Our social worker noticed this and said several other women had coffee in an adjacent room while their partners got chemo. She suggested I join them, that it might help to talk to other caregivers.

One of the people there was a woman named Susan. We quickly learned we had a lot in common. Our husbands were both in treatment. We both struggled between addressing their every need and backing off and not saying anything when they pushed themselves to go to work or get out in the yard. We could see how tired they were, but didn't want to take away from them feeling they were doing what needed to be done.

Susan helped me to not feel alone. Once a week, I was able to talk to her and others who truly understood how I felt because they were in the same place. We talked about our feelings. Traded stories and advice. We were there for each other. When I'm struggling, I give Susan a call. It helps me get through hard times.

[Narrator]

Taking care of yourself as the caregiver can help you be a better caregiver. It's important in giving you the strength you need to do what needs to be done. Some ideas for taking care of yourself include:

- Give yourself an outlet for your thoughts and feelings.
- Find comfort. Think about what makes you happy or relaxed and do it.
- Join a support group or find a "buddy" who's in a similar situation.
- Talk to a counselor.
- Share special moments with your loved ones.
- Look for positive moments in every day.

## The Cancer Survival Toolbox®: Living with Multiple Myeloma

- Laugh.
- Be grateful.
- Write in a journal.
- Do regular activities as much as possible.
- Learn as much as you can about your loved one's medical condition.

[Kaya]

One thing Susan did that helped was to ask each week if I'd done something to take care of myself. These questions were like:

- Did I get my annual mammogram?
- Did I go to the dentist?
- Did I take my medications and vitamins?
- Did I eat healthy meals?
- Was I sleeping?
- Did I exercise?
- Did I relax with a book?

Susan helped me think about myself while still focusing on the most important person in my life, my husband.

[Narrator]

As a caregiver, remember to care for yourself. Your loved one will appreciate what you're doing. It will provide a balance to your relationship that will help keep it strong, especially during this difficult time.

Many caregivers find the experience changes them. Each is affected in a unique way. Each shows great courage in meeting the needs of their loved one, providing the support and comfort only they can provide.

[Kaya]

Caregiving means we also have to be successful problem solvers. Susan learned a five-step approach to problem solving that she shared. I tried it, and the steps helped me find better ways to care for my husband when he was dealing with fatigue. The steps are:

1. Identify and define the problem.
2. Gather information.
3. Plan your action.
4. Carry out your plan.
5. Evaluate your plan and make necessary changes.

Susan and I worked together on the fatigue problem, because both our husbands had it. We used the steps with our husbands and came up with ideas that really helped. One idea for my husband was including a nap in his day. He'd never been much of a nap taker, but once we tried it, we were really happy. We napped together and it gave us both energy to complete some extra things during

## **The Cancer Survival Toolbox®: Living with Multiple Myeloma**

the day. So it helped me to look at caregiving as problem solving. It was a positive approach for me and my husband.

## The Cancer Survival Toolbox®: Living with Multiple Myeloma

### Conclusion

[Narrator]

Myeloma is a complex and chronic disease. When first diagnosed, there's so much to learn and adjust to. Eventually, you and your family learn the language of myeloma, and you become an expert.

The resource booklet that accompanies this module contains tips and resources to help you manage life with myeloma. You'll find definitions for terms used in this program, and a list of resources including phone numbers and internet addresses. There are also references to articles and books you might find useful.

To live well with myeloma, you must become your own advocate. You know yourself and your body best. Ask for what you need. Let your health care team know if you need more information or support, or if you think you're developing a new problem. As time goes by, you'll learn to live fully with this chronic illness.

Let's review some important points we've learned:

- Everyone diagnosed with cancer is a survivor.
- Treatment for myeloma is complex. Most people will need treatment throughout their lives.
- It's important to know about symptoms and side effects, and how to deal with them.
- You can't change the fact you have multiple myeloma, but you can learn to adapt to it and manage the life changes required to live as fully as possible.
- You are not alone. There are thousands of others, who like you, are figuring out how to cope with myeloma.
- In terms of treatments, over the past five-to-ten years, there have been many new drugs and combinations. We are very hopeful.
- There are hundreds of clinical trials in progress, a good sign we'll continue to see new treatments.
- There's good information about myeloma clinical trials on the National Cancer Institute, the Multiple Myeloma Research Foundation, and the International Myeloma Foundation websites.
- The battle against myeloma is too hard to fight alone. One needs support to fight.
- There are people all around to help you through this. You only have to let someone know you need help.
- The goal after a cancer diagnosis is to get back to normal, but, most often, a "new normal" must evolve.
- You must be a self-advocate. You need to ask for what you need and stand up for your right to good care and support.
- Taking care of yourself as the caregiver can help you be a better caregiver.

This program from the National Coalition for Cancer Survivorship is one of many educational programs for cancer survivors. We invite you to listen to other programs contained in the *Cancer Survival Toolbox*®, available at [www.canceradvocacy.org/toolbox](http://www.canceradvocacy.org/toolbox) or 877-Tools-4U.