

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) 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), and the National Comprehensive Cancer Network (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]

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.

[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 B₆ 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?

[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 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.

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.

[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 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.

[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. 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.