

Track 3: Symptom and Side-effect Management

[Narrator]

Many people fear treatment because of side effects. Let's listen to another group of survivors as they discuss problems associated with treatment.

[Emily (Oncology Nurse)]

Welcome. My name's Emily and I'm an oncology clinical nurse specialist. Today we're talking about symptoms and side effects people with lymphoma often have. While some lymphomas are curable, most people need treatment on an on-again/off-again basis throughout their lives. It's important to know about symptoms and side effects and how to manage them. Being able to identify and describe what you're feeling is helpful to your healthcare team, so they can change your therapy if possible, help you feel better, and decrease problems that affect quality of life.

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

[Rodney]

I know having this disease presents trying times. I want to help by talking about what you can expect in terms of symptoms and side effects, and ways to use medicines to deal with some of these problems.

[Emily (Oncology Nurse)]

We've talked before about symptoms that lead people to first see a doctor, like swollen lymph nodes, fever, and night sweats. These symptoms can diminish or disappear after treatment is started. Other symptoms occur as a result of treatment, the most common being an increased risk of infection, anemia, nausea, vomiting, diarrhea, dehydration, and nutrition issues. Temporary hair loss is very common, too. If we don't talk about the side effects you're having, or if you want more information, your healthcare team can share what they know. The National Cancer Institute's website has a link to "lymphoma" and side effects are described more fully in the section "Cancer Topics: Coping with Cancer." Websites for the Leukemia and Lymphoma Society, and the National Comprehensive Cancer

Network include information about side effects. You can also call these organizations using the phone numbers in the booklet accompanying this program.

Side effects and symptoms may respond to complimentary therapies and coping skills. Exercise can help relieve fatigue, nausea, and constipation and improve appetite and mood. Yoga, Qigong, progressive muscle relaxation, meditation, guided imagery, and other stress reduction practices can be useful. Ask your healthcare team to help you find local resources and experts who can help you add complementary therapies to your plan for dealing with side effects and symptoms.

Side effects may differ from one person to another, or from one treatment session to the next. Before beginning treatment, talk with your healthcare team about possible side effects and ways to deal with changes you and your family could face. One wife correctly said the battle of lymphoma is “too hard to fight alone, you need support to fight.”

[Rodney]

The most common and serious side effect of treatment is immune system damage — specifically, white blood cells. People being treated for lymphoma are at risk for developing infections. Blood cell counts are checked often as patients go through chemotherapy. Thorough hand-washing techniques and good oral care are simple but effective ways to minimize chances of infection. Young children are likely to bring home infections. When your white blood cell count is low, it’s a good idea to avoid children and crowds if you can.

[Emily (Oncology Nurse)]

In our clinic, we suggest avoiding rectal thermometers, suppositories and enemas which can injure the rectal area and allow bacteria in. Although we don’t suggest special diets, we do suggest meats be cooked thoroughly.

People ask about getting vaccinations before treatment starts. That’s a complicated question. Talk with your doctor about which vaccinations you should have, and when. Many treatment plans include medicines called “colony stimulating factors,” that stimulate production of white blood cells.

Also, I make instruction cards describing early signs of infection. It's important that you have the doctor's telephone number and another number to call when the office is closed. We have patients notify us right away if they have fever over 100.4 (F) or 38 (C), or other signs of infection — redness, pain, or drainage at the vascular access device site, around incisions and other wounds, skin rash or blisters, painful mouth sores or sore throat, or increased heart rate. We may do an assessment in our office, though sometimes, patients go to clinics or emergency rooms. We try to find the source of infection and begin treatment quickly. Talk with your healthcare team about protecting yourself from infection, and get information about what to do if you have signs of infection.

[Rodney]

Even before treatments are discussed, most people have heard about chemotherapy-related nausea and vomiting. It's true in the past, these problems have been hard to manage. But, these days, nausea and vomiting are fairly well managed with medicines called "anti-emetics" and steroids and anti-anxiety medicines. These medicines can be given the night before treatment, and continue during, and for a limited time, after treatment.

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 infections or bowel conditions such as irritable bowel syndrome, colitis, or diverticulitis. Diarrhea can occur after surgery involving the bowel or after stem cell transplant. When diarrhea occurs, checking for infection is usually a first step, and if present, the infection is treated. Managing diarrhea involves tracking fluid intake and output, replacing lost fluids, diet changes, and medicines to control and stop diarrhea.

Diarrhea can sometimes be prevented with medications.

We try to ensure patients get enough fluids so dehydration isn't problematic. Nutritionists and dieticians help patients ensure their diets have proper nutrients, too. We try to prevent or minimize problems up front, and avoid more serious problems.

[Carlos]

One of the medicines I've been on, I think it was a steroid, really affected my memory and my mood.

[Tanesha: (Carlos's wife)]

Carlos got irritable and moody after he started treatment for the lymphoma, and he was difficult to live with.

[Carlos]

Yes – I have to admit it, that's true. We didn't understand what was causing me to feel and act that way.

[Ari]

You know, I just started treatment a short time ago, and I've had some of these feelings, too, but just thought it was "all in my head" (laughs) – that I was depressed and upset about having this disease.

[Rodney]

Let's talk about that. It's likely that dexamethasone, prednisone, and prednisolone — all steroids — have been part of the treatment that each of you have or are having. In lymphoma treatment, steroids can trigger the death of cancer cells – which is a good thing - but people often have distressing side effects that can affect nearly all body systems. Besides the irritability and mood swings Carlos and Ari mentioned, steroids can cause depression, difficulty sleeping, weight gain, increased appetite and general body swelling, flushing and sweating, muscle cramping, digestive tract problems like heartburn, gas, and taste changes, changes in sexual functions, and a "let down" effect when steroids are stopped suddenly. When it is time to decrease the dose or stop taking a steroid medicine, talk with your doctor or nurse about ways to help "wean" off of the medicine gradually. Sometimes just adjusting your medicine schedule and adding other medicines can help – something like taking the steroid early in the morning, for example, and taking an over-the-counter or prescription medicine can help with digestion problems. Sometimes, seeing a specialist is helpful for the complex steroid-related side effects. We encourage patients to not make major life decisions while taking steroids.

[Carlos]

I keep singing the praises of Carlotta for helping. I didn't think I needed counseling but the mood swings were bad. She taught me strategies—deep breathing, a muscle relaxation exercise, guided imagery—that've really worked. She gave me the “Living Beyond Cancer” CD from the *Cancer Survival Toolbox*[®] with instructions for these strategies and I use it regularly.

[Renee]

Can we talk about hair loss for a minute? Before I got lymphoma, I knew people who'd had hair loss, and I always thought they made a big deal out of something that was not that important. But when it started to happen to me, I understood. One of my secret vanities has always been my hair. The hair loss was devastating. Maybe it's different for the guys...

[Sam]

I disagree: hair loss **was** a major issue for me. I lost all my hair, even my eyelashes and pubic hair. When friends saw me, they knew I was very sick. It was the most distressing side effect for me – even more so than nausea and vomiting. Those things came and went, but hair loss was with me the entire time

[Emily (Oncology Nurse)]

Over the years, there have been many attempts to find ways to prevent or diminish hair loss. Unfortunately, nothing has really worked. Most of my patients shave their heads rather than deal with their hair falling out gradually. I've seen friends, relatives, co-workers band together, with everyone shaving their heads too in support.

It's important to know hair loss is likely to occur, and to prepare. Getting a wig or hairpiece before hair loss begins helps match hair color and style. The American Cancer Society and other community resources offer help for people wanting to use wigs and hairpieces, and there are stores and catalogs with fun, interesting hats and scarves. The “Look Good, Feel Better” program is a free,

community-based service that oncology nurses and social workers can help you find. Programs for women offer beauty tips, and group workshops for makeup, skin and nail care, and ways to deal with hair loss. Salon consultations with volunteer cosmetologists are available in some areas. “Look Good... Feel Better” resources for men are more limited, but include a free brochure available at 1-800-395-LOOK / 1-800-395-5665 or at local American Cancer Society offices. Additional information is included on the “Look Good...Feel Better” page of the ACS website (www.cancer.org).

[Tanesha]

Don't forget to remind everyone about the constipation. Carlos

[Emily (Oncology Nurse)]

Thank you for that reminder, Tanesha. Strangely enough, both constipation and diarrhea can be side effects of lymphoma treatment. It's important to be pro-active to prevent these problems from happening – or to start to manage them before they get more serious.

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

Vincristine is used in several treatment plans for lymphoma, so it's worth mentioning that in addition to constipation other possible side effects of this chemotherapy include damage to the nervous system, causing balance problems and tingling and pain affecting hands and feet - this is called peripheral neuropathy.

[Jose]

Numbness in my hands has been a problem because I play the guitar.

[Rodney]

Yes, peripheral neuropathy is caused by some of the drugs used in lymphoma 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 severe pain that limits use of the legs,

feet, and hands. Regular check-ups with your doctor or nurse should include exams to check for early signs of neuropathy – things like decreased ability to detect hot and cold temperatures by touch, and slight 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 some of the medicines usually given to control convulsions. The oncology nurse is most likely going to be a good resource for information about early signs of peripheral neuropathy, and what symptoms you should report to the nurse and doctor.

[Tanesha]

Carlos I'm gonna bring up – S-E-X! Because we are retired, I think that sex isn't something that a lot of doctors and nurses think folks our age are concerned about, but it is. And, it isn't just about the sex act, it's also about being close and intimate – things like hugging, holding hands, cuddling, and even communication. When Carlos was first diagnosed, I was almost afraid to touch him. We never talked about sex or intimacy much in our marriage, so this was hard for us to handle.

[Carlos]

Hhumpf... it's really hard for me to talk about this stuff, especially with ladies present. But, at that time, I was so darned tired all the time. And, I was depressed and angry, too. Our relationship was suffering. My doctor or nurse didn't bring up anything about sex, so I just figured they didn't want to talk about it either.

[Tanesha]

Well, I saw an article in the newspaper about a psychologist who was going to do a weekend workshop on sexuality for cancer survivors at the local senior center. I don't know how, but I got Carlos to go – I guess, we had a lot of the same concerns. We both learned so much – about sexuality and about each other. We talked about ways for us to find time together as a couple, changes in the ways that we express our sexuality depending on what's going on with our health issues – like finding bedding, pillows, and other things to support positions that make having sex more comfortable and safe. I

learned about using lubricants to deal with vaginal dryness that's been a problem for me ever since menopause.

[Emily (Oncology Nurse)]

Thanks Tanesha, for bringing up this important and sensitive topic. Bottom line...there are lots of resources, including caring professionals, to help people with quality of life issues around sexuality. The American Cancer Society's web site (www.cancer.org, keyword sexuality) has sections on sexuality for men and their partners, and women and their partners. An American Cancer Society book, *Couples Confronting Cancer*, is available from local cancer society units, and may also be on local library shelves.

One related issue is fertility – especially for younger people. If fertility is a concern for you, talk to your oncology doctor or nurse about what options you might have to preserve your fertility.

One other thought: just because fertility issues and sexuality have not been brought up by your doctor or nurse, it may be that they expect you to start talking about these issues if they are important to you. They may also lack knowledge to offer you what you want and need to know. If this is the case, ask for a referral to another professional who is prepared and willing to offer this kind of expertise.

[Sam]

I guess one other thing that has bothered me has been how tired I feel all the time. People who have not had cancer treatment just have no idea what it's like. Why does this happen? And, have any of you figured out a way to deal with it?

[Emily (Oncology Nurse)]

Sam, you are not alone, and fatigue is an important thing for us to talk about here. It's the most common side effect of cancer and cancer treatment, and can greatly affect your quality of life. No one knows what exactly causes fatigue – but most likely it relates to several things going on at once – reduced physical strength and levels of activity, decreased appetite and intake of food, changes in

sleep-wake patterns, pain, stress, infection, and anemia are just some of the factors that are often related to fatigue. Ways of dealing with fatigue can include medicines and exercise, reducing stress and worry, conserving energy, and promoting more normal sleep/wake cycles. Rodney

[Rodney]

The first thing that should happen is to try to figure out if there is something causing the fatigue that can be treated. So, we would check for anemia, depression, anxiety, insomnia, and energy levels and decide ways to deal with those problems when they are present.

[Ari]

I saw an article in the newspaper telling cancer patients to hit the gym! It seemed so odd – to use exercise as a way to deal with fatigue. But, I talked to my nurse and doctor and they told me that research shows that low to moderate exercise can reduce fatigue – and that it can help during and after cancer treatments. I learned that it's best to start an exercise program before the fatigue really sets in. So, even in my small town, I found out that the local fitness center has a program designed for cancer patients to speed up the recovery process and also to reduce the fatigue of chemotherapy and radiation. I went to a regular exercise program – and started swimming again, and it made me remember how much I used to love being in the water. Now, I look forward to going to the gym, I do sleep better, and it has definitely decreased my level of fatigue.

[Renee]

I was feeling so tired, stressed, and worried all the time. My girlfriend offered to go with me to her yoga center. First, I talked to my doctor about whether or not I could do yoga. He didn't know much about yoga, but he looked at the pictures in a yoga book I have, and marked "O.K." on the poses that he thought would be safe for me. My nurse was already doing yoga, and she said to explain my situation to the instructor – what I could do and what I should avoid. Between the yoga and the meditation that is sometimes part of the class, I think my stress levels have really improved. And, I don't feel nearly as tired as I did before – and I feel so much stronger.

[Emily (Oncology Nurse)]

While we are on the subject of exercise, I can add that simple walking can help keep bones healthy and muscles strong. Exercise can help people cope with other 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 local offices or exploring internet web sites of the American Cancer Society, the YWCA, and the Wellness Community. These groups and organizations in your local communities can be contacted by phone.

[Carlos]

I'd never thought too much about it, but in my "before cancer" life, I used to have several cups of coffee every day, and sometimes some tea at night while I watch the nightly news. Well, those things, plus the stress that went along with my diagnosis and treatment, really messed up my sleeping. I was having a talk with the nutritionist about my diet and just mentioned my sleep problem. She asked about caffeine in my diet and suggested ways to reduce caffeine – drinking decaffeinated coffee and tea, drinking water instead of soft drinks, avoiding chocolate – especially later in the afternoon and during the evening. I don't drink too much after dinner so that I don't have to get up to go to the bathroom during the night. Tanesha and I think all of those things have helped me sleep better.

[Emily (Oncology Nurse)]

Doctors and nurses have begun to see that cancer-related fatigue is important, and many record and track levels of patients' 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 to some people, too.

[Rodney]

Many of the drugs used to treat lymphoma decrease the number and function of red blood cells, white blood cells, and platelets. We already talked about decreased white cells and the risk of infection. But, fatigue sometimes relates to anemia caused by low levels of red blood cells. Anemia caused by chemotherapy is sometimes treated with injections of colony stimulating factors to increase red cell production. Other times, red cell transfusions are used to treat severe anemia. Platelets are needed to form blood clots, and low platelet levels interfere with blood clotting and cause easy bruising and bleeding. Protecting yourself from injury is an important aspect of self-care. Avoid using aspirin or other medicines that can cause clotting problems unless they are prescribed by your doctor. And, avoid activities that can result in bruises or bleeding, including body piercing, tattooing, contact sports, use of rectal thermometers, enemas, rectal suppositories, 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.

[Ari]

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

[Emily (Oncology Nurse)]

For sure, having and being treated for lymphoma presents each of you with your own set of needs. So, right up front I suggest that you ask for and keep copies of your hospital and clinic reports. It is easy to put together a 3-ring binder or accordion file to help you organize your records. You can also use one calendar to keep track of your appointments, and also to note if and when side effects occur. A journal can help you keep track of how you are feeling, how long a symptom lasts, and what makes it better or worse. A friend, son, daughter, or grandchild might be able to set up a system with a computer to help you keep track of appointments, note side effects, and get and keep your records in order.

Once a treatment ends, it is important that you get a summary of your treatment so that your primary care provider and other specialists have the same information about your treatments that you do. You may also be given a thorough plan for follow-up, or what we call a survivorship care plan or Prescription for Living. This plan will be a guide for living beyond cancer. I like to work with each patient to develop his or her survivorship care plan together – so that it is tailored to his or her unique and special needs. It can include tips about safe exercise, healthy eating, stress reduction, and community resources. It can also map out your schedule of doctor appointments, diagnostic tests, ways to deal with lingering problems from treatment, and describe how to assess new symptoms that may need attention. Non-Hodgkin lymphoma may not always be curable, but there are many treatments available to help control the disease and improve the quality of your life.