

Track 4: Symptom and Side-effect Management

Narrator

Many people fear treatment side effects. Let's listen in on another CML support group as they talk about managing problems related to treatment. This group is led by an oncology clinical nurse specialist.

Joan (Oncology Nurse)

My name's Joan and I'm an oncology clinical nurse specialist. Today we're going to talk about symptoms and side effects. Most CML survivors need some form of treatment throughout their lives. It's important to know about common symptoms and side effects and how to control and manage them. Knowing and describing what you're feeling is helpful to your healthcare team so they can change your therapy if needed, help you feel better, and decrease problems affecting your quality of life.

Our guest tonight is Dr. Mark Smith, an oncology clinical pharmacist.

Mark (Oncology Clinical Pharmacist)

Thank you for inviting me. I know this disease can be trying. I want to help by talking about what to expect in terms of symptoms, side effects of medicines used in treatment, and ways to use medicines to deal with some of these problems. There's a lot of good information out there about how treatments affect your disease, but remember to ask your oncologist or nurse about side effects of your treatments and how they might be managed.

Joan (Oncology Nurse)

During one of our earlier sessions, we talked about CML symptoms and noted it's often these symptoms that lead people to see a doctor in the first place—symptoms like shortness of breath or feeling very tired. Other symptoms occur because of treatment—the most common being drops in blood cell counts, nausea, and edema, or swelling in the face, hands or legs. In regards to blood cell counts, decreases in white blood cells increase the risk of infection, while decreases in red blood cells

may be a sign of anemia, which can cause tiredness and shortness of breath. A low platelet count can cause easy bruising, bleeding of the gums, and bleeding from minor cuts and scrapes.

Other slightly less common side effects are severe fatigue, diarrhea, muscle cramps and rashes.

If we don't talk about the side effects you're having, or if you want to know more, your doctor and nurse can help you manage treatment-related problems. The National Cancer Institute's website also has a link to "chronic leukemia" (<http://www.cancer.gov/cancertopics/types/leukemia>), and treatment-related side effects are described there and more fully in the section called "Cancer Topics: Coping with Cancer" (www.cancer.gov/cancertopics/coping). Likewise, websites sponsored by The Leukemia and Lymphoma Society (www.lls.org), and the National Comprehensive Cancer Network (www.nccn.com) include information about CML, its treatment, and side effects.

I also want to mention side effects and symptoms may respond to complementary approaches. 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 are useful for many people. Ask your healthcare team to help you find local resources and experts for adding complementary therapies like these and others to a full plan for dealing with side effects and symptoms.

Side effects differ from person to person, and can change from one treatment session to the next. Before you begin treatment, talk with your doctor, nurse, social worker, nutritionist or dietician, or other people on your healthcare team about possible side effects and ways you and your family can deal with changes you could face. One caregiver correctly said the battle against CML is "too hard to fight alone, you need support to fight." That's been the intent of the group—to make sure no one's dealing with this alone.

Mark (Oncology Clinical Pharmacist)

Probably the most common, and most serious, side effect of treatment is damage to the immune system—specifically, white blood cells. Because of this, people treated for CML 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 ways to minimize chances of infection. Young children are likely to bring home infections. During times when your white blood cell count is especially low, it's a good idea to avoid being around children and crowds of people if you can, and to wash your hands frequently.

Joan (Oncology Nurse)

In our clinic, we ask people to avoid using rectal thermometers, suppositories and enemas—any of which can injure the rectal area and allow harmful bacteria to enter the body. Although we don't suggest special diets during times when the white blood cell count is low, we do suggest meats be cooked thoroughly and fresh fruits and vegetables washed well.

Many 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 to get them.

For our patients, I've made instruction cards that describe early signs of infection. It's important you have your doctor's telephone number, and another number to call when the office is closed. We want patients to notify us right away if they have fever over 100.4 (F) or 38 (C), chills, or other signs of infection like redness and pain around incisions or wounds, or painful mouth sores or sore throat. We may be able to do an assessment in our office, though sometimes, patients go to clinics or emergency rooms. We try to find the source of the infection and treat it as quickly as possible.

Mark (Oncology Clinical Pharmacist)

Many medicines used for treatment also decrease number and function of red blood cells and platelets. Fatigue sometimes relates to anemia caused by low red blood cell levels—less oxygen in the blood can

cause fatigue, dizziness, and shortness of breath, especially with activity. One treatment for anemia is red blood cell transfusions.

Dan

I think I've been dealing with CML longer than anyone here. The last few months have been rough, as I've needed quite a few transfusions. I've been surprised how tired and moody I get right before I need another transfusion.

Darcy (Dan's Wife)

It hits Dan like a brick. He gets so irritable. We almost know without lab tests he's due for another transfusion.

Dan

I feel like a different person. I don't have energy for anything.

Mark (Oncology Clinical Pharmacist)

Let's talk about that. With transfusions, the doctors are monitoring your blood counts and making decisions about when a transfusion is needed. Being anxious about having blood drawn and what the results might say, are common feelings. Low counts can increase tiredness, depression, loss of appetite, and just generally feeling "blah". Concern about how often and for how long someone can have transfusions can also affect day-to-day activities and relationships.

Rick

I started transfusions when I was diagnosed, and I've had some anxious feelings, but thought it was "all in my head" (laughs)—that I was depressed and upset about having this disease. I didn't think about it being related to low counts.

Joan (Oncology Nurse)

In addition to red blood cells, platelets are another concern. Low platelet levels interfere with blood clotting and cause easy bruising and bleeding. Protecting yourself from injury is important. Things

you can do include brushing your teeth with a soft toothbrush, using an electric shaver instead of a razor, blowing your nose gently and wearing shoes, even inside your home. It's important to avoid aspirin or other medicines that can cause bleeding problems, unless they're prescribed by your doctor. And, avoid sports or other activities that can result in bruises or bleeding. Use of tampons, rectal thermometers, enemas, and rectal suppositories is also discouraged.

Talk with your doctor and nurse about ways to protect yourself when your blood counts are low, and put a list of emergency telephone numbers in a place that's easy to find.

Mark (Oncology Clinical Pharmacist)

Another common side effect of some types of CML chemotherapy is swelling or edema—the buildup of fluid in the body most often affecting the face, especially around the eyes, and the hands and legs. A few easy things can help manage edema: Take frequent breaks to get off your feet and sit or lie down with feet and legs raised above heart level. When seated, avoid crossing your legs. It may also help to decrease the salt in your diet if leg or foot swelling is present. Common sources of salt are potato chips, bacon, ham, tomato juice, canned soups, soy sauce, and table salt. Your doctor may prescribe a diuretic or “water pill” to help the kidneys remove extra fluid. It's important to take diuretics exactly as the doctor orders. If edema is severe, your doctor may stop chemotherapy for a short time, and resume treatment when the swelling subsides.

Let's talk about nausea and vomiting. The digestive system is affected by some chemotherapies and, in the past, these problems have been hard to manage. These days, nausea and vomiting are fairly well managed with medicines called “antiemetics” used along with steroids and anti-anxiety medicines. Anti-emetics are given before treatment, and continue during, and for a limited time, after treatment if needed.

Diarrhea can also occur. The risk of diarrhea 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. When diarrhea occurs, checking for infection is a first step, and if present, the infection is treated. Managing diarrhea involves keeping track of fluid intake and output, replacing lost fluids, diet changes, and use of medicines to control and stop diarrhea. Diarrhea can sometimes be prevented with anti-diarrhea medications.

We try to ensure patients get enough fluids so dehydration doesn't become a problem. The nutritionist or dietician helps patients make sure their diets have proper nutrients, too. We try to prevent, or at least minimize, problems up front, and avoid more serious problems.

Darcy

Don't forget about constipation. Dan had a terrible time because we didn't know about constipation until it was already a big problem.

Joan (Oncology Nurse)

Thank you, Darcy. Strangely enough, both constipation and diarrhea can be side effects of CML treatment. People often take these things lightly, but they can cause major problems. It's important to be pro-active to prevent them—or to manage them before they get more serious.

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

Dan

Something I struggled with was muscle cramps in my hands and feet and thighs and calves. It bothered me most during the night—it was hard to get a good night's sleep. When I mentioned the cramps to my doctor, he said it was a side effect of chemotherapy that many people experience. After he did a few blood tests, he advised me to take calcium pills I could get over the counter at the drug store. Taking calcium made a big difference – I don't have cramps any more. I'm sleeping much better too.

Mark

Dan, I'm glad you mentioned muscle cramps. They can affect everyone a little differently, especially which muscles are affected and what triggers the cramping. Often, people say their cramps are worse at night or with activity or exercise. Another simple remedy that could help is tonic water. But, if you have muscle cramps, talk with your doctor or nurse about it – don't just start taking calcium or drinking tonic water. That may not be the best treatment for you.

Dan

My counselor, Linda, helped with these concerns. My anxiety and stress were bad, but from her I learned coping strategies—deep breathing, muscle relaxation exercises, and something called guided imagery—that have really worked. She gave me the “Living Beyond Cancer” CD from the *Cancer Survival Toolbox*[®], which has instructions for these strategies. I use it once, twice or more times every week – depending on how I'm feeling. It also helped a lot with the stressed out feelings I got when my next bone marrow biopsies were coming up and I couldn't sleep. Linda said these strategies are part of a proven therapy called Cognitive Behavioral Therapy. Instead of thinking, “Everything's out of my control,” I stop myself, and instead think, “There are self-care tactics I can do on my own, that work for me, and give me back some control.” Changes in my thinking and using these tools have helped me feel calmer. I'm going to be treated off and on, maybe for the rest of my life, so now I've got some strategies to manage my stress levels that I can use regularly, too.

Kim

I want to bring up something that was a problem for Rick and me early on. He might not like that I talk about this, but I'm gonna bring up—S-E-X! Because we're retired, I think sex isn't something doctors and nurses think folks our age are concerned about, but it is. And, it isn't just the sex act, it's also about being close and intimate—things like hugging, holding hands, cuddling, even

communication. When Rick was diagnosed, I was almost afraid to touch him. We never talked about sex or intimacy much before, so this was hard for us to handle.

Rick

Hhumpf...it's hard for me to talk about this stuff, especially with ladies present. When I was diagnosed I was tired, depressed and angry. I wasn't talking to Kim about what I was feeling and our relationship was suffering. My doctor or nurse didn't bring up sex, so I figured they didn't want to talk about it either.

Kim

I saw an article about a weekend workshop on sexuality for cancer survivors. I don't know how, but I got Rick to go. We both learned so much. At first, the workshop topics and discussions were embarrassing for me—but everyone was going through similar things—and as the weekend went on, we started having a good time. We talked about ways to find time together as a couple, changes in the ways we express our sexuality depending on what's going on—like finding bedding, pillows, and other things to support positions that make sex more comfortable and safe. And I learned about using lubricants to deal with the vaginal dryness that's been a problem ever since menopause.

Joan(Oncology Nurse)

Thanks Kim, for bringing this up. You're so right—sexuality's important to all of us. Bottom line...there are lots of resources, including caring professionals, to help. The American Cancer Society's website (www.cancer.org, keyword sexuality) has sections on sexuality, and The Leukemia and Lymphoma Society has a fact sheet on sexuality and intimacy (www.leukemia-lymphoma.org/attachments/National/br_1243042774.pdf). There's also an American Cancer Society book, *Couples Confronting Cancer*, that's available from local American Cancer Society units, and may also be on local library shelves. Two other books, *Man Cancer Sex*, and *Woman Cancer Sex*, explore the impact cancer can have.

One other thought: if sexuality hasn't been brought up by your doctor or nurse, it may be they expect you to raise these issues if they're important to you. They may also lack the knowledge to offer you what you need. In this case, ask for a referral to another professional who is prepared and willing to offer this kind of expertise.

Bruce

Another thing that's bothered me is how tired and weak I feel. Why does this happen? Is there a way to deal with it? I don't want it taking over my life.

Joan (Oncology Nurse)

Bruce, you're not alone. Fatigue and weakness are very common, and can greatly affect your life. No one knows what exactly causes fatigue—but most likely it relates to several things—reduced physical strength and levels of activity, decreased appetite and intake of food, changes in sleep/wake patterns, low blood counts, pain, stress, infection, and anemia are just some of the factors related to fatigue. Dealing with fatigue can include medicines and exercise, reducing stress and worry, conserving energy, and promoting more normal sleep/wake cycles. Mark, would you talk a little about medicines used to treat fatigue?

Mark (Oncology Clinical Pharmacist)

The first thing is to figure out if there's something causing the fatigue that can be treated. We would check for anemia, depression, anxiety, insomnia, and find ways to deal with those problems when they occur.

Rick

I saw an article telling cancer patients to hit the gym! It seemed odd—to use exercise to deal with fatigue. But, I talked to my doctor and she told me research shows low to moderate exercise can help during and after cancer treatments. I learned it's best to start exercise before fatigue really sets in. Even in my small town, I found the local fitness center has a program designed for cancer patients to

speed recovery and reduce the fatigue of chemotherapy and radiation. I went to this program—and started swimming again. I sleep better, and it’s definitely decreased my fatigue.

Evelyn

I was feeling so tired, stressed, and worried all the time. My girlfriend offered to take me to a yoga center for a class. I talked to my doctor—he didn’t know much about it, but looked at the pictures in a yoga book, and marked “O.K.” on the poses he thought would be safe. My nurse said to explain my situation to the instructor—what I could do and what I should avoid. Between yoga and the meditation that’s part of the class, my stress levels have really improved. And, I don’t feel nearly as tired.

Joan (Oncology Nurse)

Simple walking—especially in a favorite place—can keep bones healthy and muscles strong and often helps people cope with 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 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 websites of the American Cancer Society, the YWCA, and the Cancer Support Community.

Dan

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 that went along with my diagnosis and treatment, messed up my sleeping. I was talking with the nutritionist about my diet and mentioned my sleep problem. She suggested ways to reduce caffeine—drinking decaffeinated coffee and tea, drinking water instead of soft drinks, avoiding chocolate, especially in the late afternoon and evening. Also I don’t drink too much after dinner so I don’t have to get up to go to the bathroom during the night. And almost every day, Darcy and I go for a walk. These things have helped me sleep better.

Joan (Oncology Nurse)

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

Evelyn

I'm not sure this is important, but since I started treatment, I've noticed a rash all over. It doesn't itch, but I'm worried I'm allergic to my medicine. The chemotherapy's pills are helping, and I don't want to stop taking them.

Mark (Pharmacist)

Several oral chemotherapy medicines can cause skin reactions such as a rash, dry skin or a darkening of areas of the skin, which is called hyperpigmentation. These reactions are not from an allergy, so you won't need to stop taking your pills. Unfortunately, these side effects can't be prevented, but simple treatments such as a steroid cream for the skin or steroid medicine may help improve the rash. Your oncology nurse or doctor can give you recommendations.

Rick

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

Joan (Oncology Nurse)

Having and being treated for CML presents each of you with your own set of needs. Right up front I suggest you ask for and keep copies of your 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 if and when side effects occur. A journal can help keep track of how you're feeling, how long a symptom lasts, and what makes it better or worse. You might want to set up a system on a computer for all this—if you need help, a friend, child, or grandchild might be able to assist you. They would enjoy helping you, too.

It's important to have summaries of your treatments so you can give your primary care provider and other specialists that information. You may find The Leukemia & Lymphoma Society's CML

Tracker useful

(www.lls.org/diseaseinformation/leukemia/chronicmyeloidleukemia/treatment/measuringresponse/).

It can help you record and organize your treatment information.

You may also be given a thorough plan for follow-up, or what we call a survivorship care plan. I like to work with each patient to develop his or her survivorship care plan together – so it's tailored to the survivor's unique and special needs. It can include tips about safe exercise, healthy eating, stress reduction, and community resources. It can also map out the 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.

CML may not be curable, but there are many treatments available to help control the disease and improve the quality of your life.