

## **Track 4: Symptom and Side-effect Management**

### **Narrator**

We have now learned about how chronic lymphocytic leukemia is diagnosed and how treatment decisions are made. We learned that there are different stages of CLL and, therefore, different kinds of treatment. Many people fear treatment because of side effects. Let's listen to another support group for CLL survivors as they talk about how they manage problems they have had with treatment. This group is led by an oncology clinical nurse specialist.

### **Emily (Oncology Nurse)**

Welcome to another program for people dealing with CLL. My name is Emily and I am an oncology clinical nurse specialist in the Cancer Clinic. What we are going to talk about today are the symptoms and side effects that people with CLL often have. Most people with this illness need some form of treatment throughout their lives. It's important for you to know about common symptoms and side effects of the disease and treatment and how to control and manage them. Being able to know and describe what you are feeling is helpful to your health care team so that they can change your therapy if needed, help you feel better, and decrease problems that affect your quality of life.

Our guest expert tonight is Dr. Mark Smith, an oncology clinical pharmacist. He can help us sort through the effects of medicines used in treatment and ways to manage symptoms and side effects.

### **Mark (Oncology Clinical Pharmacist)**

Hello, and thank you for inviting me. I know that having this disease may cause trying times. I want to help you by talking about what you can expect in terms of symptoms of CLL, side effects of the many medicines used in treatment, and ways to use medicines to deal with some of these problems in the best ways possible. There is a lot of good information about how treatments affect the disease you have, but remember to ask your oncologist or nurse about possible side effects of the treatments and how they might be managed.

## **Emily (Oncology Nurse)**

During one of our earlier sessions, we talked about the symptoms of CLL and noted that it is 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 as a result of treatment. The most common problems that occur during treatment for CLL are lowered blood cell counts. Other side effects of treatment are fatigue, neuropathies, loss of appetite, nausea, diarrhea and constipation. If we don't get to talk about the side effects you are having, or if you want to know more than we have time for now, your own doctor and nurse can help you manage treatment-related problems, too. The National Cancer Institute's website has a link to "chronic leukemia" (<http://www.cancer.gov/cancertopics/types/leukemia>), and treatment-related side effects are described there more fully in the section called "Cancer Topics: Coping with Cancer" ([www.cancer.gov/cancertopics/coping](http://www.cancer.gov/cancertopics/coping)). Likewise, websites sponsored by The Leukemia and Lymphoma Society ([www.lls.org](http://www.lls.org)), and the National Comprehensive Cancer Network ([www.nccn.com](http://www.nccn.com)) include information about CLL, its treatment, and common side effects.

I also want to make sure to mention that side effects and symptoms may respond to other forms of treatment and coping skills. For some time now, it's been known that exercise can help relieve fatigue, nausea, constipation and improve appetite and mood. Yoga, Qigong, progressive muscle relaxation, meditation, guided imagery, and other stress reduction practices are useful for many people, too. Ask your doctor, nurse, social worker, or physical therapist 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 from treatment may differ from one person to another, 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 health care team about possible side effects and ways

you and your family members can deal with the changes you could face along the way. One wife and caregiver correctly said that the battle of CLL is “too hard to fight alone, you need support to fight.” That’s been the intent of the group - to make sure no one is alone in dealing with this illness.

**Mark**

One issue that I especially want to bring up early in our time together has to do with fertility. I apologize – because I don’t know all of you personally, so I really can’t say if fertility is something that concerns you. Often, just because CLL tends to affect people after what are considered the “child-bearing years” – 60 and older, we tend to forget that once in a while, people in their 30’s and 40’s are diagnosed with CLL. Without delving into this topic at great length, I’ll just say that if you are concerned about fertility – and this goes for both men and women – please talk with your doctor or nurse about fertility issues and the possibility of sperm banking. This discussion has to happen before the start of any treatment because many of the chemotherapy drugs and sometimes, radiation therapy used to treat CLL can result in permanent infertility.

Probably the most common, and also the most serious, side effect of treatment is damage to the body’s immune system – specifically, the white blood cells. Because of this, people being treated for CLL are at risk for developing infections caused by bacteria and viruses. As a routine, blood cell counts are checked often as patients go through chemotherapy. Thorough hand-washing techniques and good oral care are simple but very effective ways for all of us to minimize chances of getting infections. Young children – our children or grandchildren – are likely to bring home infections – colds, flu, and skin infections. During the 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 wash your hands frequently.

**Emily (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 that all meats we eat be cooked thoroughly and fresh fruits and vegetables are washed well. Many people ask me about getting vaccinations before treatment starts – and that is a complicated question. So, please 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 is important that you have the doctor's office 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) or chills, or other signs of infection like redness and pain around incisions and other wounds, or painful mouth sores or sore throat. We may be able to do the proper assessment in our office, though sometimes, patients go to clinics or emergency rooms. We try to find the source of the infection and begin treatment for the infection as quickly as possible.

### **Mark**

Many of the medicines used to treat leukemia also decrease the number and function of red blood cells and platelets. Fatigue sometimes relates to anemia caused by low levels of red blood cells. This results in less oxygen in the blood and can cause symptoms including fatigue, dizziness, and shortness of breath, especially with activity. One of the treatments for anemia is red blood cell transfusions.

### **Sam**

When I was diagnosed, my doctor said I would need chemotherapy. The nurse in the infusion center suggested I ask the doctor about having a special IV line – a central catheter, - inserted into a large vein close to my heart. I learned that the central catheter would be used when I have chemotherapy and other medicines, fluids and blood, and is also used to draw blood samples. A vascular access nurse inserted the catheter and helped me learn to take proper care of it. I had the central catheter in place for

the entire time of my treatment. There were things I had to learn to take care of it, and potential problems to watch for, and I could never forget that it was there. But, I think having the central catheter saved me from having a lot of needle sticks throughout my time in treatment. Is this something that you would suggest to people starting treatment?

**Emily**

The decision to have a central catheter inserted is like so many other treatment decisions – it depends. Whether a person can benefit from having a central catheter – also called a “vascular access device”, depends on a number of factors. For example - “How often and for how long will the patient need IV medicines or have blood samples taken?” “Is the patient or caregiver able to take care of the catheter safely on their own and in doing so, reduce chances of infection related to the catheter?” There are many types of catheters and vascular access devices, so it’s important to have a talk with the doctor or nurse to decide if a central access device would be helpful, explain the types of devices, and how the choice for the best device for each patient is made.

**Jim**

I think I’ve been dealing with CLL longer than anyone here. The last few months have been rough as I have needed quite a few transfusions. One of the things I experienced with the transfusions was how tired and moody I would get right before I needed another transfusion.

**Claire (Jim’s Wife)**

It seemed to hit Jim like a brick. He would get so tired and irritable. We could almost know without the lab tests that he was due for another transfusion. At least once we realized what was happening, then it all made more sense.

**Jim**

Yes—I have to admit it, that’s true. At those times I felt like a different person. I didn’t have energy for anything. If we didn’t plan just right, it would be very disappointing to Claire and my family.

**Mark**

Let's talk about that. With transfusions, the doctors are monitoring your blood counts and making decisions about when you need to have a transfusion, and how often. Being anxious about having blood drawn and what the results might say, are common feelings to have. Low counts can increase feelings of 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.

**Charlie**

You know, I just started transfusions a short time ago – right when I was diagnosed, and I've had some anxious feelings, too, but just 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 the low counts.

**Emily**

In addition to red blood cells, platelets are another concern. 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. Several things you can do are to brush your teeth with a soft toothbrush, use an electric shaver instead of a razor, blow your nose gently and wear shoes, even inside your home. It is also important to avoid using aspirin or other medicines that can cause bleeding problems unless they are prescribed by your doctor. And, avoid sports or other activities with high risk of injury that can result in bruises or bleeding. Again, the use of tampons, rectal thermometers, enemas, and rectal suppositories is also discouraged. 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 telephone numbers in a place that's easy to find.

**Mark**

Even without a diagnosis of cancer, most people have heard about nausea and vomiting caused by chemotherapy. It is true that the digestive system is affected by some types of chemotherapy and, in the past, these problems have been very hard to manage. These days, nausea and vomiting are fairly well managed with effective medicines—called “antiemetics” used along with steroids and anti-anxiety medicines. Anti-emetic medicines are given before treatment, and continue during, and for a limited time, after treatment if needed.

Diarrhea can also occur as a side effect of disease and treatment. The risk of developing 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 as a cause is usually 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 as well as managed with anti-diarrhea medications.

We try to make sure that patients get enough fluids so that dehydration does not become a problem. The nutritionist or dietician helps patients make sure that their diets have proper nutrients, too. So, you see, we try to prevent, or at least minimize, problems right up front, and avoid more serious problems.

**Claire**

Don't forget to remind everyone about constipation. Jim had a terrible time with that because we didn't know about constipation until it was already a big problem.

**Emily (Oncology Nurse)**

Thank you for that reminder, Claire. Strangely enough, both constipation and diarrhea can be side effects of CLL treatment. I know that people often take constipation and diarrhea lightly, but they can

cause major problems. 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, lack of physical activity, and use of pain and anti-nausea medicines. Ask your oncology nurse to help you come up with a plan to prevent constipation.

### **Larry**

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 using my 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.

### **Mark**

Yes, peripheral neuropathy can be caused by several of the drugs used in CLL treatment. 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. Treatments for peripheral neuropathy include Vitamin B<sub>6</sub> and nutritional supplements with amino acids, pain medicines, anti-depressants, non-steroidal anti-inflammatory drugs – sometimes called NSAIDs – 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 that physical therapy, relaxation, and acupuncture can help.

**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.

**Sarah**

I have friends and relatives who've had hair loss from chemotherapy, and I guess that I always thought they made a big deal out of something that was not all that important. After all, what's more important: losing hair and maybe wearing a wig for a short time, or getting the right kind of treatment for cancer? But, when it started to happen to me, all of a sudden I understood. One of my secret vanities has always been my hair – it was sort of like my identity, and made me feel attractive and feminine. For me, the hair loss was really devastating. Maybe it's different for the guys: they can just wear a baseball hat and look pretty normal. But, you see, my hair's all grown back now.

**Sam**

Well, I disagree: hair loss **was** a major issue for me. For most of my life, I've had what my friends call a "flowing mane" of hair, along with a full beard, and, um, lots of body hair. I lost all of that, even my eyelashes and pubic hair, and now, when friends saw me for the first time, they knew I was very sick, and maybe thought, too, that I was dying. I would say that this was the most distressing side effect of treatment for me – even more so than the episodes of nausea and vomiting. Those things would come and go, and could be managed quite well, but my hair loss was with me for the entire time I was being treated. I couldn't hide or disguise this at all.

**Emily**

Over the years, there have been many attempts made to find ways to prevent or diminish hair loss. Cold caps, ice caps, and even tourniquets applied to the head have been used and studied. Unfortunately, so far, nothing has really worked very well, if at all. Most of my patients end up shaving their heads rather than deal with their hair falling out gradually and in clumps that they found a lot more distressing. I've seen many friends, relatives, and even co-workers band together, with everyone shaving their heads too, in support of someone who loses hair from cancer treatment. I guess it's a way of making the best of a difficult situation. I do know that it is important for people to know that hair loss is likely to occur, and to prepare for this as much as possible. Getting a wig or hairpiece before hair loss begins helps in matching a person's normal hair color and style. The American Cancer Society and other community resources do offer help for people wanting to use wigs and hairpieces, and there are many stores and catalogs that supply fun and interesting hats and scarves. The "Look Good, Feel Better" program – a free, community-based service was founded and developed by the Personal Care Products Council, supported by the cosmetic industry, the National Cosmetology Association, and the American Cancer Society. Oncology nurses and social workers can help you find these useful resources. Programs for female cancer patients offer beauty tips, group workshops to address makeup, skin and nail care, and ways to deal with hair loss with wigs, turbans, and scarves. Salon consultations with volunteer cosmetologists are available in some areas, for women who are unable to attend group workshops. "Look Good... Feel Better" resources for men are a bit more limited, but include a free self-help brochure available at a toll free number (1-800-395-LOOK / 1-800-395-5665) or at a local American Cancer Society office. Additional information is included on the "Look Good...Feel Better" page of the ACS website ([www.cancer.org](http://www.cancer.org)).

### **Jim**

One of the medicines I've been on, the steroid called dexamethasone, really affected my memory and mood.

**Claire (Jim’s wife)**

Jim 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.

**Jim:** 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.

**Mark**

Let’s talk about that. Dexamethasone, prednisone, and/or prednisolone, all steroids, may be a part of your treatment. 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 blood glucose levels; 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.

**Jim**

I keep singing the praises of my counselor Nancy for helping me with these concerns. I didn’t think I needed counseling but the anxiety and stress were really bad. She taught me some specific ways to manage or reduce the stress and anxiety — deep breathing, a muscle relaxation exercise, and something called guided imagery that have really worked for me. She gave me the “Living Beyond Cancer” CD from the *Cancer Survival Toolbox*<sup>®</sup> with instructions for these strategies on it and I use it once, twice or more times every week – depending on how I’m fee. 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.

She said these are part of a proven therapy called Cognitive Behavioral Therapy. Instead of thinking, “Everything is out of my control,” I stop myself, and instead I think, “There are definitely some self-care tactics that I can do on my own, that work for me, and give me back some control” and I use them. Changes in my thinking and using some of these new tools I’ve learned have helped me feel calmer. I know I’m going to be having treatment 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.

### **Sarah**

Well, before time gets away from us, I want to bring up something that was a problem for Charlie and me early on. He might not like that I talk about this, but I think it’s important – especially for people here who have just been diagnosed and are starting treatment. 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 Charlie 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.

### **Charlie**

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. I didn’t talk with Sarah about what I was really feeling. 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.

### **Sarah**

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 Charlie to go – I guess, we had a lot of the same concerns. We both learned so much – about sexuality and about each

other. At first, the workshop topics and discussions were embarrassing for me – but everyone there was going through similar things – and as the weekend went on, we started to have a good time. 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 Sarah, for bringing up this important and sensitive topic. And 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 quality of life issues around sexuality. The American Cancer Society’s web site ([www.cancer.org](http://www.cancer.org), keyword sexuality) has sections on sexuality for men and their partners, and women and their partners and The Leukemia and Lymphoma Society has a fact sheet on sexuality and intimacy ([www.leukemia-lymphoma.org/attachments/National/br\\_1243042774.pdf](http://www.leukemia-lymphoma.org/attachments/National/br_1243042774.pdf)). There is also an American Cancer Society book, *Couples Confronting Cancer*, that is available from local American Cancer Society units, and may also be on local library shelves. There are two books that I’ve recently discovered – one is *Man Cancer Sex*, and the other is *Woman Cancer Sex*, both written by a nurse expert in sexuality. (both referenced in the Resource Booklet) Both explore the impact that cancer can have on the lives of men and women.

One other thought: just because sexuality has 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 and weak I feel all the time. I know I'm not alone either – seems like everyone I talk to while I'm in my doctor's office is affected by this, in one way or another. 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? I don't want it to totally take over my life.

**Emily (Oncology Nurse)**

Sam, you are not alone, and fatigue and weakness are important things 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, low blood counts, 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. Mark, would you talk a little about using medicines to treat fatigue?

**Mark**

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 occur. .

**Charlie**

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 take 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 – in fact, I feel so much stronger.

**Emily (Oncology Nurse)**

While we are on the subject of exercise, I can add that simple walking – especially in a favorite place - can help keep bones healthy and muscles strong and often helps 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 Cancer Support Community. These groups and organizations in your local communities can be contacted by phone.

**Jim**

I think my fatigue is related to lack of sleep. 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. Almost every day, Claire and I go for walks down by the river or out on fairly easy hiking trails. I think all of those things have helped me sleep better.

**Emily (Oncology Nurse)**

All of these things are helpful. 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.

**Charlie**

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 CLL 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. You might want 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. If you need help, a friend, son, daughter, or grandchild might be able to assist you. They would enjoy helping you, too.

It is important that you get and keep summaries of your treatments 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. 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. CLL may not be curable, but there are many treatments available to help control the disease and improve the quality of your life.