

Track 3: Goals of therapy

Charlie: I was just diagnosed with CLL, so my doctor and I are now in the process of deciding what treatment I'll have. My doctor told me there are several factors she will use to decide which treatment is best for me.

Dr. Griffin:

Let's talk about treatment decisions. Although at this time, there is no cure, with standard therapies new forms of therapy and supportive care increasingly allow people with CLL to live with good quality of life for years. Given what is known about CLL, there are currently three major goals for the treatment of people who have CLL. First, we aim to slow the growth of CLL cells. Second, we want to give patients long periods of remission – time without signs and symptoms disease during which they feel well enough for normal day-to-day activities. The third goal of therapy is to prevent or at least quickly detect and treat the distressing problems that are common among people with CLL – for example - extreme tiredness or fatigue, and infection.

First of all, I have to stress how important it is to have the diagnostic workup and treatment planning done in a cancer center where doctors, nurses, and other staff members have a great deal of experience in the care of patients with CLL.

Factors used to consider possible treatment options include the stage of CLL, findings from the physical exam, blood and other laboratory tests, the **person's** overall health, and the person's age. There are two staging systems – Rai (pronounced *Rye*) and Binet (pronounced *Bin-ay'*). Both staging systems describe the extent of disease and provide some clues to potential survival time. The staging process combines the findings from a person's exam and laboratory tests to arrive at a grouping or stage for each person with the disease. The Rai system places patients in categories ranging from zero (0) to four (IV). A person who is stage 0 CLL has the longest predicted survival time and a person with

stage IV would be predicted to have the shortest survival time. The Binet system uses categories of risk – low risk is stage A and is similar to the Rai stage 0; Binet intermediate risk, stage B, is like Rai stage I or II; Binet stage C indicates high risk and is similar to Rai stage III or IV.

Besides the specific type and stage of CLL, other factors that are important to consider in forming treatment options include the person’s age, general health, life-style and personal quality-of-life wishes, symptoms of the CLL and *co-morbidities* – those conditions or chronic illnesses that may limit what can safely be used for treatment.

Charlie: Am I going to need a stem cell transplant?

Dr. Griffin:

Some people with CLL may be treated with “allogeneic” stem cell transplantation. Stem cell transplantation is used for some CLL patients who relapse after having a good response to initial or “first-line” therapy, have a matched donor, and are healthy enough to go through this type of therapy. For allogeneic stem cell transplants, stem cells are removed from a matched donor’s blood or bone marrow, processed and preserved for later use. The patient goes through “conditioning treatment” – receiving either chemotherapy or radiation therapy or a combination of both, to prepare the body to receive transplanted stem cells. The goal of conditioning treatment is to eliminate any remaining disease from the circulating blood and bone marrow, and to suppress the immune system to prevent rejection of transplanted stem cells.

Dr. Griffin:

Some people with CLL may be treated with “allogeneic” stem cell transplants. Stem cell transplants are most often used for CLL patients who relapse after initial or “first-line” therapy, have a matched donor, and are healthy enough to go through this type of therapy. For allogeneic stem cell transplants, stem cells are removed from a matched donor’s blood or bone marrow, processed and preserved for later use. The patient goes through “conditioning treatment” – receiving either chemotherapy or

radiation therapy or a combination of both, to prepare the body to receive transplanted stem cells. The goal of conditioning treatment is to suppress the immune system to prevent rejection of transplanted stem cells, and may also be used eliminate remaining disease from the patient's circulating blood and bone marrow.

Renee

When I learned that I had CLL I was shocked! I had been feeling a little more tired than usual but when my doctor ran blood tests for my annual physical and called me to say I had CLL, I just couldn't believe it. I panicked, of course thinking I might die very soon. But, when my sister and I met with the hematologist, he said that based on my blood tests, there was no need for chemotherapy or other treatment right now. He said I would be monitored closely and if tests in the future showed I needed active treatment he would start treating me with chemotherapy. He says there are many treatment options. That's reassuring because if one treatment is not what I need we can change to another.

Dr. Griffin

Renee, you are right! If a person with CLL has no symptoms, regular monitoring by your hematologist or oncologist may be all that is needed for the time being. For people who have a higher stage of CLL, treatment with oral or intravenous chemotherapy, and possibly other types of drugs, is usually called for. Often CLL is treated with two, three, and even four chemotherapy medicines and also a type of drug monoclonal antibody, a form of targeted therapy. A person's health, and the extent of their disease affect which medicines are used. Sometimes the person's age is also a factor, but people of any age can be treated. There are many treatments available now, and we tailor the treatment plan for each and every patient, using medicines that work together to get the best results.

Jim

My doctor said I needed to have chemotherapy, but mine was in pill form that I take every day. I'm very careful about taking them, and as an extra reminder, my wife has it on her calendar to help me

remember. We both know that my life can depend on taking these pills exactly as they are prescribed. And I am so happy that I don't have to drive to the clinic every week! If the driving and traffic aren't stressful enough, we would then have to sit in that waiting room and hope that I don't catch a cold or infection from the other people there. Then we would spend more time in the treatment room hooked up to the chemo. I am so much more comfortable taking my pills at home. I can stay in my pajamas if I want; my wife does not have to take time off work; and our lives just feel more normal.

Sam

When I was diagnosed five years ago, my doctor suggested I enroll in a clinical trial.

Charlie – interrupting

Excuse me . . . What's a clinical trial? My doctor talked with me about enrolling in a clinical trial, but I'm not sure I understand what it is. It makes me a little nervous.

Nancy (social worker)

Charlie, I'm glad you asked that question. Sam, would you describe your experience for us, and maybe Dr. Griffin can add some information, too.

Sam

On the clinical trial, I took a new drug and it worked great! The study was what they call a "randomized controlled trial." On the study, there were two different treatment options that were being compared. One option was standard therapy for CLL, and the other option was a new drug plus standard therapy. I was selected at random (similar to flipping a coin), to get the new drug in addition to standard treatment. My doctor recently told me the new drug I was taking has since been approved by the Food and Drug Administration or FDA, – which means the clinical trials to study its effects are finished and it was shown to be effective. It has helped – my doctor says my CLL is in remission now.

Dr. Griffin

Your stories are good examples of some of the different treatment needs of CLL patients. The decisions that are made about treatment and the possibilities of being in a clinical trial, have to do with the exact kind of CLL we are dealing with – and by that I mean, what we know about the cell biology - including the changes in the cancer cells’ genes - - that are specific to a person’s diagnosis, and the stage of the disease. There are many clinical trials in progress now, and many drug therapies and vaccines being studied – all good signs that we will continue to see new forms of treatment for CLL. We are very hopeful.

Nancy (Social Worker)

There is a lot of good information about CLL clinical trials on web sites offered by the National Cancer Institute (<http://www.cancer.gov> 1-800-422-6237) and The Leukemia and Lymphoma Society (www.lls.org/clinicaltrials 1-800-955-4572). Each has a Clinical Trial Information Service that will help you search for clinical trials for your type of leukemia. Additionally, the *Cancer Survival Toolbox*[®] program, “First Steps” provides more information about finding clinical trials.

Charlie, you are still trying to understand your illness and make decisions about your treatment. Do you have questions or concerns that we can talk about tonight?

Charlie

Well, yes, actually. I feel sort of funny about this. But, sometimes, I don’t think my doctor is being straight with me. Maybe I’m not communicating with him very well – but sometimes I think that I’m not getting enough information from him. My daughter thinks I ought to get a second opinion, but I don’t want my doctor to be offended either. I don’t know what to do.

Nancy (Social Worker)

It is important that you are able to talk to your doctor – whoever it is – openly and honestly. We can help you improve your communications skills – and again, one of the *Toolbox* programs focuses on communication. This could help you be more assertive about meeting your own needs for information,

and your relationship with the doctor could work much better for you. As for a second opinion, it's almost always a good idea – even if the second opinion turns out to be exactly the same as the first. And, the *Toolbox's* “First Steps” program suggests ways to go about setting up second opinions. At least you may feel more comfortable with the treatment recommendations. Or, it may turn out that you could have a better relationship with another doctor, and that is very important, too. You and your doctor will have an ongoing relationship – and it's in your best interest that the two of you work well together.

Renee

I have one more suggestion for you, Charlie. Well, really, it's something we can all use, I think. A couple of weeks ago, I took part in a Leukemia Education Series telephone/web education program provided by The Leukemia and Lymphoma Society (<http://www/lls.org/nationalead>). They have these and also webcasts, and on the computer, you can get printed transcripts and audio recordings for an MP3 player. People from all over the country were on the line just like I was, and we could ask questions of experts. I learned a lot about what's going on in CLL research, the newest drugs that have been approved by the FDA, and some information that helps me be as healthy as I can be.

Nancy (Social Worker)

What a great resource! Thank you, Renee. And, thanks to everyone for your helpful comments. Please know that there are people all around to help you through this – the people in this support group continually reach out to help each other. It's sort of like the “veteran” helping the “rookie.” The oncology social workers and oncology nurses and doctors, too, are here to help you, along with other members of cancer care team. You only have to let someone know you need help. As Renee says, we all want to help you to be as healthy as you can be.