

Track 3: Goals of therapy

Rick

I was just diagnosed, so my doctor and I are deciding on treatment. My doctor said there are several factors she'll use to decide what's best for me.

Dr. Griffin

Let's talk about making treatment decisions. Treatment goals often depend on the phase of CML.

There are three phases: the chronic phase, the accelerated phase, and the blast crisis phase. These are mainly based on the number of immature white blood cells – the myeloblasts - that are in the blood and bone marrow.

In the chronic phase, there are more white blood cells in the blood and bone marrow than usual. These mature cells may work normally, so people often don't notice any symptoms. Most people are in the chronic phase when CML is diagnosed. In the chronic phase, there are two main treatment goals: One: to destroy all cells with the *Bcr-Abl* gene; and two: to restore blood cell levels to normal so people can get back to day-to-day activities.

In the accelerated phase, there are increased numbers of blasts or immature white blood cells in the blood, bone marrow, liver and spleen. Because blasts cannot fight infection as well as normal white blood cells, a person may have more symptoms.

In the blast crisis phase, the number of blasts in the bloodstream increases rapidly. There are fewer normal blood cells and the symptoms a person has can become severe. When CML is in the blast phase, the disease acts like acute leukemia.

In the accelerated and blast crisis phases, the goals of treatment are to destroy all cells with the *Bcr-Abl* gene and return the disease to the chronic phase.

I need to stress how important it is to have the diagnostic workup and treatment planning done in a cancer center where the staff has a great deal of experience in the care of people with CML.

Besides the phase of CML, there are other factors that enter into forming treatment options. The main concerns are the person's age, general health, lifestyle and personal quality-of-life wishes, symptoms from the CML, and *co-morbidities* – conditions or chronic illnesses that limit safe treatment options.

Rick

Am I going to need a transplant?

Dr. Griffin

“Allogeneic” stem cell transplantation is used for some CML patients who relapse after good response to initial therapy, have a matched donor, and are relatively healthy. Stem cells are removed from a matched donor’s blood or bone marrow, processed and preserved. The patient goes through “conditioning treatment”—receiving either chemotherapy, radiation therapy, or both to eliminate any remaining disease from the blood and bone marrow, and suppress the immune system to prevent rejection of transplanted stem cells.

Dan

My chemotherapy is a pill I take daily. I’m careful about taking them, and as an extra reminder, my wife has it on her calendar to help me remember. We both know my life can depend on taking these pills exactly as prescribed. I’m so happy I don’t have to drive to the clinic every week! I can stay in my pajamas if I want; my wife doesn’t have to take time off work; and our lives just feel more normal.

Dr. Griffin

We’re making great strides in cancer treatments. Treatments for CML are now chemotherapy pills. But just because they’re pills doesn’t mean they aren’t powerful or don’t have side effects. And I must stress the importance of adherence – taking the pills at the correct times and doses.

Not adhering to the medication plan may result in treatment that doesn’t work as well as it could. It can also affect how your doctor views your illness. For example, your doctor may think the medication

isn't working well, when in fact you're missing doses. This might result in unnecessary changes to the treatment plan. It's also important your doctor know of any medicines, vitamins or supplements you're taking. These—and even foods—can cause unwanted interactions or side effects when taken with oral chemotherapy. You'll need to know what medicines and foods to avoid.

Cancer pills are convenient, in that they can be taken at home. But unlike IV treatment, which is closely supervised, taking cancer pills is largely a private matter. As a result, adherence has become very important in cancer treatment.

Dan

How will my doctor know if treatment is working?

Dr. Griffin

Your doctor will primarily assess three areas: (1) if the blood cell levels have returned to normal; (2) if the Philadelphia chromosome is now undetectable, and (3), if the *Bcr-Abl* gene is undetectable. This information helps your doctor determine if treatment is working.

Bruce

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

Rick – interrupting

What's a clinical trial?

Linda (social worker)

Rick, I'm glad you asked. Bruce, would you describe your experience for us?

Bruce

On the clinical trial, I took a new drug and it worked great! The study was what they call a "randomized controlled trial." There were two different treatments. One was standard therapy, the other a new drug plus standard therapy. I was selected at random (similar to flipping a coin), to get the new drug plus standard treatment. My doctor recently told me the new drug has since been approved

by the Food and Drug Administration or FDA, which means the drug was shown to be effective. It's helped—my CML's in remission now.

Dr. Griffin

Your stories are good examples of different treatment approaches. The decisions that are made about treatment and the possibilities of being in a clinical trial have to do with the exact kind of CML we're 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 we'll continue to see new forms of treatment for CML. We are very hopeful.

Linda (Social Worker)

Information about leukemia clinical trials is available from 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 helps you look for clinical trials. The *Cancer Survival Toolbox*® program, "First Steps" also provides more information about finding clinical trials.

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

Rick

I feel funny about this, but, sometimes, I don't think my doctor's being straight with me. Maybe I'm not communicating well—but I think I'm not getting enough information. My daughter thinks I ought to get a second opinion, but I don't want my doctor to be offended. I don't know what to do.

Linda (Social Worker)

It's important that you're able to talk to your doctor openly and honestly. One of the *Toolbox* programs focuses on communication. This could help you be more assertive about meeting your need

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

Evelyn

I have another suggestion for you, Rick. A couple 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/nationaled>). They have these and also webcasts, and you can get printed transcripts and audio recordings for an MP3 player. People all over the country were on the line, and we could ask questions of experts. I learned a lot about CML research, the newest drugs approved by the FDA, and some information that helps me be as healthy as I can be.

Linda (Social Worker)

What a great resource! Thanks, Evelyn. And, thanks to everyone for your helpful comments. Please know there are people to help you through this—the people in this support group, your oncology social workers and nurses and doctors, along with other members of your cancer care team. You only have to let someone know you need help.