
INTRODUCTION

Lauren Berger, MPH

Hello, I'm Lauren Berger, Senior Director of Professional Education and Engagement at The Leukemia & Lymphoma Society. In this program, we will introduce you to two individuals living with chronic lymphocytic leukemia. Each will share their experience of navigating their path as a CLL patient and survivor. Dr. Jennifer Brown and Jeffrey Hellman of the Dana-Farber Cancer Institute will share information on diagnosis, treatment, side effect management and the importance of communicating with your healthcare team.

DIAGNOSIS

Suzanne

I was diagnosed about 13 years ago. I had these swollen glands in my neck that were going up and down. So I didn't think that it was really anything, but my daughter noticed them because they were, they had gotten bigger. So she said, "Mom I think you need to see a doctor." So I called my doctor and he had me come right in. He said, "I don't like the looks of this." So, he said, "We need to do a biopsy." So, they did the biopsy, and the next morning he called me and said, "I'm sorry to tell you, but you have CLL."

John

I was originally diagnosed with CLL when I was 35 years old, about 10 years ago, during a routine physical. So I was going for my annual physical exam, and my doctor, my primary care physician, came back and said I had an elevated white blood cell count. I didn't know what that meant at the time. So I asked, "What does that mean?" He said, "Well it could mean various things. You could have a virus, or you could be coming down with something, or it could be something more significant. So I want you to see an oncologist." At that point when my doctor said that, I knew what an oncologist was, and I became quite concerned. But I went to the visit with the oncologist and sure enough the diagnosis was CLL. I would say, I'm a pretty optimistic, positive individual but that day, it was a tough day.

I think probably the hardest thing anybody could ever hear is that they have cancer.

Suzanne

I wanted to find out as much as I could about the illness. So when I went in, they gave me a brochure. It's an illness that affects your immune system. So if you get a cold you have to be careful. You don't want to be around sick people. You kind of have to adjust your lifestyle.

Jennifer R. Brown, MD, PhD

CLL, or chronic lymphocytic leukemia, is a type of chronic blood cancer. All cancers arise from some normal cell that goes haywire to become the cancer. In the case of CLL, this is a normal cell of the immune system, which we call a B lymphocyte. B lymphocytes are the cells that make antibodies to fight infections, normally.

John

When I was first diagnosed I had no symptoms. In fact, I was so shocked about my doctor telling me that there was a problem with my blood. I thought it was cholesterol. I had zero symptoms. I felt fine.

Jeffrey Hellman, PA-C

Often, when patients are first diagnosed they don't have many symptoms of the CLL. It's usually incidentally noted on a blood test at the regular doctor's office whether it be for a physical or a pre-operative type test. So, a lot of people don't have any symptoms at first and that continues for often quite a while.

Jennifer R. Brown, MD, PhD

Most typically, CLL is diagnosed when someone goes to their primary care doctor for a routine visit and happens to have a blood count drawn. Typically, it's noted that the white blood cells, which are a subtype of the blood count, are elevated compared to normal and that this is due to an increase in the subtype of the white blood cells, which are called lymphocytes.

A special test called flow cytometry is usually sent in order to establish a diagnosis of CLL, as compared to a couple other diseases that can sometimes look similar to CLL. People can also present sometimes with a small lump in their neck, which is a lymph node, and that is a common way for people also to present with CLL.

Typically, no biopsies are required to make the diagnosis of CLL if the lymphocyte count or the white blood cell count is elevated. Then we can just send the test, the flow cytometry test, on the blood. If, however, the white blood cell count is not high, but the lump in the neck is present, the lymph node is present, then we may need to do a lymph node biopsy to establish the diagnosis.

In addition to the flow cytometry test to diagnose CLL, another very important test to have, early in the disease course, is what we call FISH testing, or cytogenetic testing. This is also done on peripheral blood—a very simple blood test—and it consists of a panel of markers of chromosome changes that are common in CLL.

The reason that it's important to do it early on is because there are two higher-risk chromosome abnormalities that we usually like to know about relatively early on so that we can monitor people more closely. Down the line, these could potentially influence treatment choice.

Staging in CLL is based on traditional criteria that are now fairly old. What I always tell people about staging in CLL though, is that the staging in CLL is not as important as it is in some other types of cancer, because even stage IV disease can respond extremely well to treatment and go into a complete remission for many years. So, it's really more a marker of where the disease is than it is as prognostically significant.

John

I was put on what is known as watch and wait, which is they want to see what stage your disease is and how aggressive your disease is. So, I had several blood tests and I stayed on watch and wait for a couple of years. But at that point, two years into my disease, it continued to progress and became more aggressive.

Jennifer R. Brown, MD, PhD

Most patients who are initially diagnosed with CLL do not require any treatment and go into what we call watch and wait, or what the patients sometimes call watch and worry.

Jeffrey Hellman, PA-C

CLL can be managed so there's a good quality of life for people in the sense that in for a large proportion of the patients we observe them, they're on observation. It's one of the few cancers that we diagnose and we don't treat immediately. So, people can continue to live their life and they're feeling well and they don't have those symptoms such as the fevers, sweats, chills and they can live a normal life.

Jennifer R. Brown, MD, PhD

I do find that some people may report some fatigue, although sometimes this is associated with anxiety around the initial diagnosis and can settle down over time. Another common report that I hear from patients is that they may feel warmer and may have low-level night sweats on the upper body, but these are not progressive over time like the night sweats that we typically worry about.

Some people may continue to feel perfectly well, even though their blood counts may reach a point where we think it's time to initiate treatment. Other people may start to have more frequent infections, be more tired, develop more sweating, and this can sometimes herald that the disease is progressing toward treatment.

The genetic or cytogenetic FISH testing does not play a role in the decision to initiate treatment, which is typically based on clinical parameters, namely how a person is feeling, how their blood counts are, whether they have lymph nodes that are bothering them. However, once the decision to initiate treatment has been made, the presence of the higher-risk cytogenetic abnormalities, in particular the deletion of the short arm of chromosome 17, so-called 17p deletion, does influence our selection of treatment.

TREATMENT

Suzanne

I was on watch and wait, and when my white blood cell [count] went very high and my spleen was starting to get bigger, that's when we did treatment and we did the FCR, fludarabine, Cytosan and Rituxan. So, we did that and it was scary to have that.

Jennifer R. Brown, MD, PhD

So, the first-line therapy for CLL typically involves what we call chemoimmunotherapy. This involves chemotherapy drugs combined with an antibody drug, most typically rituximab. These regimens have been developed over the last 10 to 15 years and found to result in deep remissions. One regimen called FCR, fludarabine, cyclophosphamide and rituximab, is common for our younger and fitter patients. Another regimen called bendamustine, or rituximab, is often used in the intermediate ages or fitness, as well as to older patients.

There's a new regimen, which is a combination of a very old drug called chlorambucil, but in combination with a new antibody called obinutuzumab, which has been recently found to be quite beneficial for older patients who have some medical problems. So, typically one of these regimens would be a first-line therapy for a CLL patient who does not have high-risk cytogenetics.

John

So, when I became symptomatic I started doing further research because I knew the treatment was near and I was going to require treatment. So, that led me to the path of FCR treatment, which was at the time in 2007, the gold standard for the best remission. Actually, I responded well to that treatment, and that led me to three-year remission, which puts you back on kind of a watch-and-wait pattern.

Jennifer R. Brown, MD, PhD

So, remission periods after first-line therapy are very variable and do depend on the intensity of the therapy. After FCR chemoimmunotherapy, the average remission is approaching five years, four-and-a-half to five years, whereas, for example, after bendamustine and rituximab, it's about three-and-a-half to four years.

Jeffrey Hellman, PA-C

Once there's an indication to treat the CLL, some of the treatments do have side effects. A lot of the front-line standard-of-care treatments can cause things like nausea, vomiting, constipation. Those are some common side effects that we manage with medicines: anti-nausea pills and constipation medication. And people generally, we have a system down that people tend to do very well with those problems.

John

When I was going through active treatment, your life changes quite a bit in terms of you just don't feel well. Part of it's your disease, certainly, you're not well to begin with and you need the treatment. But secondarily, the chemo itself, it gives you side effects when you're going through it and you have to kind of deal with that. Trying to maintain some sense of normalcy, and trying to work and be a dad. All those things kind of compiled. It wears on you mentally and emotionally when you don't feel well.

I could go to work when I felt lousy, and I tended to do that, and for me, it was almost like a distraction. It gave me a sense that I wasn't losing to the disease. That I was fighting the disease. But there were days where I did need to rest and I tried to take that into account.

Suzanne

You kind of have to adjust your lifestyle, and I found that to be pretty hard.

Jeffrey Hellman, PA-C

I think that patients should really feel comfortable talking to their doctors and clinical staff and asking whatever question they can think of that comes to mind about their disease, treatment options, and side effects. We always encourage people to ask questions.

Suzanne

I was doing good for a while, and then my numbers started to creep back up again after about a year. My doctor said that he wasn't sure what we should do. So, he recommended that we see a CLL expert, and I was totally for that.

She did my DNA and when we got the results back, they weren't good. It was a more aggressive cancer. So I said, "Well what are we going to do about it?" So, she found a clinical trial for me. I had a shorter remission and then we did a lot of clinical trials until we reached this one that I'm on right now. I've been on this one for five years.

John

At the end of the three years, I didn't feel sick, but my counts started to show that my disease was coming back and I was going to become sick. So, Dr. Brown indicated that my remission was ending, and I was going to have to require more treatment. And luckily, I did qualify for that trial. Because I was on top of the disease in terms of being proactive, seeking my medical attention and getting counts, that helped a lot because I was ahead of my disease.

Jeffrey Hellman, PA-C

I do like to tell people that are sometimes they're doing well, but they have the question of what if this stops working or if that medication appears that it's sort of borderline not working anymore, I do tell people that we have a lot of options, be it through clinical trials or standard care options that they haven't had before. Then also that just in the past few years we've had many, many newer options for people that are very promising and would likely help them.

Jennifer R. Brown, MD, PhD

The simplest reason why I offer patients clinical trials is that we don't yet have a curative therapy for CLL and so that means that we can always do better. The way that we do better is by adding to what's previously known with some new drugs, new targets that are coming into the clinic and the way that we learn about those and study those is through clinical trials.

I find that our patients on clinical trials do extremely well. They typically are offered something that we consider to be better than what we could offer them outside of a clinical trial. They get a large amount of attention from extra team members, extra nursing attention, for example, as well as our research staff. Patients like that, and we like that.

Jeffrey Hellman, PA-C

A lot of the newer drugs are in some ways better than the older drugs. So, I think that a lot of people hear that they're going to go on a clinical trial and they think that it's a last ditch effort or something like that. Whereas, with CLL a lot of these new drugs are so promising that you likely want to be on a clinical trial if you could be with CLL.

Jennifer R. Brown, MD, PhD

But perhaps the greatest excitement has been around some of the oral targeted inhibitors, two of which received FDA approval last year. Ibrutinib, which hits a target that we call BTK, or Bruton's tyrosine kinase, and idelalisib, which hits a target called PI3-kinase. Both of these targets are important to the growth and development of the CLL cells. These pill drugs block them, and that leads to killing of the CLL cells and reduction of the disease. These drugs are generally quite well-tolerated, and so they are moving very rapidly into certainly second-line therapy after first-line chemoimmunotherapy, and trials are ongoing to potentially move them even to front-line therapy.

Now, one thing that's very interesting about them that you should be aware of when you start on them is that the pattern of response is different than what we see with traditional chemotherapy. Instead of the white count going down initially, it usually goes up.

This, we think, is because the CLL cells come out of the bone marrow and the lymph nodes into the blood, because the drugs block the signals that normally hold the CLL cells in those sites. So, you shouldn't be afraid of that or worried that this means the disease is progressing. This is just normal. It may keep going up for even a month or two before it levels off, and then it may or may not come down in the short term. Sometimes the white count can remain high for an extended period. But nonetheless, we see that people feel really well.

COMMUNICATION & SUPPORT

Jennifer R. Brown, MD, PhD

So, it's very important for patients to share whatever is going on with them with their physician and their healthcare team, because all of this information goes into how we think about their situation and how we choose treatment—how we plan what would work best for them. We need to know what they're thinking, what their goals are for their treatment, what issues may have developed that are not being met. Sometimes, for example, there may be a whole variety of treatment options and if there's a side effect that's particularly troublesome with the current one, there may be a variety of other options to try. But you may not know if you don't tell your doctor what you're experiencing. So, I would just encourage you to just always share whatever's going on with you and that will undoubtedly, I think, give the best opportunity for the best options for you.

Suzanne

I could call them anytime and the doctor would call me right back. I'm so glad that I went. It was the best thing I ever did.

John

The communication I have with Dr. Brown is really a solid two-way communication where I try to come to her with what's going on with my disease in terms of what I feel, and then have good solid questions. I never feel rushed and that's one thing that I feel is extremely important—that she spends the time, listens to my questions, gives me answers about what I'm going through and what my disease is.

Jennifer R. Brown, MD, PhD

So, the fact that two of our new medications are oral and that we see a potential paradigm shift toward more oral therapy going forward in CLL has raised some new issues for us and for patients.

One issue that comes up is that oral medications sometimes require high co-payments or may be more difficult to get coverage from insurance companies. So, that's an issue that always needs to be worked out. If you are prescribed such a medication and you find that your copayment is astronomically high or your insurance company doesn't want to cover the medication, be sure to tell your doctor and your healthcare team, and everyone can work together to try and take care of this for you.

Jeffrey Hellman, PA-C

Patients feel pretty comfortable asking any question and it doesn't necessarily have to be medical. We get to know these patients so well. We get to know their family or hear about their family, so we sort of understand where they're coming from—the socioeconomic situation. So, we always feel comfortable with having people talk to us about that and ask questions.

John

We have a solid communication through email, which has been really good. I'll email her anything that's going on. I've actually sent her pictures of when I was having a certain rash that was breaking out during treatment.

The way I always looked at it, I owed that to her—like I'm expecting her to help me beat this disease or at least keep it at bay. But how can she do that if she doesn't know what I'm going through? So, you really need to be open, honest about what you're going through as a patient and make sure that your doctor has all the information.

Jennifer R. Brown, MD, PhD

I would suggest that patients ask their healthcare team about anything that's bothering them or that they're curious about in CLL. Certainly, patients ask me a variety of questions relating to symptoms, relating to how the disease behaves over time, relating to what causes it, relating to how we treat it. Over time, we can cover a large amount of ground. I think the more questions that people can get answered, the more comfortable they are with living with the disease over time and managing it.

Another issue that comes up is that you are on your own recognizance to take the pills at home and to remember them. For some people that's harder than for other people.

Suzanne

I have a pill box now. I put all my pills in there for the day, so that I don't forget. It's very important, because I do take other medicines so that I don't get viruses or pneumonia.

Jeffrey Hellman, PA-C

People shouldn't be scared if they missed a dose for whatever reason. It's definitely good to let us know. Depending on the situation, we might see something different about their labs or whatnot that might be easily explained by some missed doses or if people stop taking their medication. So, it's always important to be as honest as you can with your healthcare team.

Suzanne

When I first came to the infusion room years ago it was such a scary place. Now when I go, I see faces that are filled with hope. It's not as scary as it used to be.

Now I'm taking this drug in this clinical trial that has made such a difference in my life. It gave my life back.

John

You really get a reality check when somebody tells you have cancer.

I was worried about being a dad. I think that probably was the hardest thing: wanting to be there for my kids.

I think I appreciate life a lot more. I try to appreciate what's been given to me in terms of a second chance.

Living With CLL

Chronic Lymphocytic Leukemia



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Suzanne

I'm very, very happy to be here. I enjoy every day. Try to stay positive, happy, eat well.

John

If you are going through it, know that you can get better. You can fight this disease and get better, and that's something—you got to hang on to the hope that there's going to be brighter days.

Suzanne

This illness can knock me down but it won't keep me from getting back up.

Lauren

The Leukemia & Lymphoma Society, as well as your healthcare team, are valuable resources for information and support. If you would like more information on what you've heard, or for other education materials or support, we encourage you to contact an Information Specialist at The Leukemia & Lymphoma Society by calling 800-955-4572, or email us at infocenter@LLS.org.

We would like to acknowledge and thank Genentech and Biogen Idec, Gilead, and Pharmacyclics and Janssen for their support, which helps LLS to bring you this information.

Please click on the link in the description below to complete the evaluation (www.LLS.org/CLLeval). We will use your feedback to plan programs and services to meet your needs.

On behalf of The Leukemia & Lymphoma Society, thank you for joining us today. We wish you well.