

INTRODUCTION

Lauren Berger, MPH

Hello, I'm Lauren Berger, Senior Director, Patient Services Programs at The Leukemia & Lymphoma Society. The Leukemia & Lymphoma Society, as well as many healthcare professionals, encourages you to seek information to help you make informed treatment decisions. Today we will be talking about how personalized discussions with your healthcare team about non-Hodgkin lymphoma (NHL) and chronic lymphocytic leukemia (CLL) will be helpful to you.

I am pleased to welcome Dr. Christopher Flowers, Associate Professor of Hematology and Medical Oncology at Winship Cancer Institute, Emory University School of Medicine. Also with us today is Ms. Barbara McCullough, a follicular non-Hodgkin lymphoma survivor. And in addition, Ms. Lizette Figueroa, an Information Specialist with The Leukemia & Lymphoma Society. Together, we will talk about making NHL and CLL treatment decisions.

Barbara, as a follicular lymphoma survivor, I'm sure you had many questions and concerns when you were first diagnosed. Can you talk about those a little?

Barbara McCullough

Absolutely. I was diagnosed by my primary care physician in 2011, I had an abnormal mammogram resulting in a biopsy. I was expecting a diagnosis of breast cancer, since it took a while to get the results back and I was shocked when I was told I had follicular lymphoma. My doctor told me that it was slow-growing lymphoma and may not require chemotherapy. She offered to refer me to a hematologist. However, since I recently retired as a nurse from Emory Healthcare, I wanted to be treated at Emory. Since my diagnosis did not require treatment right away, I was able to take the time and focus on getting into the Emory system. Then once accepted, I knew I would have to have staging studies before seeing a hematologist/oncologist. Even though I am a nurse, it's so different being on this side of an illness, and I had many questions. But at that time, I just wanted to get the results of all the staging studies and then I felt I would be ready to ask those questions and learn more about the disease.

Dr. Flowers is my hematologist/oncologist and he really helped me through my treatment journey.

OVERVIEW OF NHL & CLL

Lauren

It is important to learn as much as possible about your disease. Dr. Flowers, will you please provide a brief overview of CLL and NHL, including some treatment options?

Dr. Flowers

Sure, Lauren, I'd be happy to. When we think about the non-Hodgkin lymphomas there are many different subtypes of those lymphomas but in general, they can be broken down into two major categories. What we call the low-grade or indolent or more slow-growing lymphomas, like follicular lymphoma, are often the types of lymphomas where you can make a diagnosis of lymphoma and not necessarily need treatment right away. Another disease that falls into this same category is chronic lymphocytic leukemia, which also is very similar to a type of lymphoma called small lymphocytic lymphoma. Like follicular lymphoma, it is also slow-growing. The aggressive lymphomas, on the other hand, are diseases that can behave, as the category implies, very aggressively. These are the types of lymphomas that typically need to be treated immediately at the time when they are diagnosed. The most common type of aggressive lymphoma, however, diffuse large B-cell lymphoma is the type of lymphoma that is typically cured with standard therapies.

I think the most important thing to know though is that everyone's situation is different. Sometimes patients need treatment right away, sometimes they do not. There are lots of questions that arise because the disease is so different in everyone. And these treatment options can range from "watchful waiting" – or observation – for the low-grade lymphomas, to very aggressive treatments. And I think it's important to include clinical trials in the discussion of treatment for all patients.

COMMUNICATING WITH YOUR HEALTHCARE TEAM

Dr. Flowers

Most hematologists and oncologists are open to having questions from their patients. Yes, the physician's time is limited, but it's important for patients to come to each visit with questions to ask.

Barbara

I wasn't sure which questions to ask. I was hesitant to ask questions at first because I wasn't sure where to start. I think the first thing patients need to determine and perhaps get help with is to figure out which questions to ask.

Lizette Figueroa, MA

Sure, Barbara. And every patient's journey is different. To help patients figure out the right questions to ask and make informed decisions, The Leukemia & Lymphoma Society's Information Specialists offer "one-to-one" support to help patients create a personalized treatment decision "action plan." We provide you with the latest information on treatment options, taking into consideration your unique situation. We answer questions about the diagnosis and treatment, as well as questions regarding clinical trials, financial assistance and, of course, support services. We also answer other questions patients may have, so they can collaborate and communicate with their treatment team to select the most appropriate treatment for them.

Barbara

When I did an Internet search for “lymphoma” the information that was displayed was overwhelming. It was difficult to weed through everything and to understand how the information related to my personal situation. That's where the Information Resource Center can come in.

Lizette

One tip I'd like to give is to prioritize the top three questions, and be sure to ask those during your visit. There are other ways to get the rest of your questions answered, even if there is not enough time during the appointment with your doctor.

Dr. Flowers

Healthcare teams often have many different styles and patterns of communication. It is important for you to discuss and determine the patterns of interaction that work best for you and your personal healthcare team. Some teams prefer that you interact with the nurse or nurse practitioner for most questions. In other settings, you can email questions to your doctor, or leave a message on their voicemail. You can also ask for a time to speak by telephone, by email, with the nurse, or the social worker, or other members of the healthcare team. Each team and each patient is different. It is important for the patient to feel empowered to ask questions and to know when and how best to ask those questions.

Lizette

Sure, Dr. Flowers. And also family members and caregivers have questions too. They don't always feel comfortable jumping in during an appointment and asking their own questions, or they may be hesitant to ask questions while the patient is there. So, most healthcare providers welcome family input and are happy to answer their questions. But also by reaching out to a resource such as The Leukemia & Lymphoma Society's Information Specialists, we can help caregivers get some of the answers that they're looking for without feeling like they are taking the doctor's time away from the patient.

Dr. Flowers

Barbara, can you tell us about some of the concerns that you had when you were first diagnosed?

Barbara

My concern was that I be treated as a patient who happened to be a retired nurse. I needed my treating doctor and nurse to tell me what I might expect and what issues to report. They shouldn't assume patients will know what issues and concerns to report and how urgent these issues might be.

I was concerned about my side effects, and how my life would be affected by this, including my energy level. Lisa, Dr. Flowers' nurse, and Amanda, my research nurse, helped me set up my first treatment schedule. During my staging studies, my mother died after an extended illness. They were

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very helpful in setting it up so I could safely travel to her memorial service after my counts recovered and still avoid any delay in my treatment schedule.

Lisa and Amanda gave me written materials on side effects and how to manage. They were a constant resource whom I could email or call when I had questions or issues.

Lizette

Right, and some questions that patients may want to ask their healthcare team at diagnosis and then at other junctions, including when considering trying a new therapy may be:

- What is the subtype of NHL that I have? Do I have an aggressive disease that has the potential not to return after treatment or do I have a chronic disease that will probably return?
- If you have CLL, you may want to inquire if you have any chromosomal abnormalities, as some of these abnormalities may give your physician an indication as to how your CLL will progress.
- Are there clinical trials that may be a treatment option for me at this time? There may be more than one type of appropriate therapy – so you really want to discuss those options with your treatment team.
- What are the possible side effects from each of the treatment options?
- How will one therapy be selected over another for me?
- How will I know if the treatment is working?

Lizette

We can help you develop individual questions for your physician.

Barbara

Dr. Flowers gave me the results of my staging studies and my stage of disease. Treatment options were then discussed: observation, also called, "watch and wait," chemotherapy, or clinical trial. Knowing my stage, Grade 1, Stage III follicular lymphoma, I declined observation and considered a clinical trial.

CLINICAL TRIALS

Lauren

So Barbara, when you considered a clinical trial for your treatment, I'm sure that you had a whole host of questions in addition to the questions that you had right at the beginning of your diagnosis.

Dr. Flowers, can you share some information about what a clinical trial is, what it does, and how it might benefit patients?

Dr. Flowers

Sure, I'd be happy to. Clinical trials are approaches to care that use new therapies that are not available widely in the marketplace, using new drugs that are first being tested in patients, or sometimes involve different combinations of drugs that are available in the marketplace but are being used in a new way. Clinical trials are appropriate for all patients at different ages and different stages of disease; not just those who are relapsed or refractory. There are a number of clinical trials for lymphoma patients that are available at diagnosis as well. These trials use these combinations in ways that hopefully improve upon what's available through the standard of care with existing treatments. Some of the approaches are aimed at reducing side effects, some are aimed at trying to extend remission or improve cure rates for patients with lymphomas. For treatments in clinical trials, we may not know the long-term success or know all of the side effects that may occur, but certain of these treatments may be more effective for you and your disease than the standard of care. The standard of care typically is the most widely accepted treatment for a specific diagnosis, but even in these situations, the standard of care therapy may have some limitations. Drugs now being used to treat patients as standard of care were used to treat patients on clinical trials previously. We tend to know more about the efficacy and the side effects as standard of care treatments as they have been around longer and more patients have utilized these treatments. And we continue to research other treatments in hope that they may be more effective for patients.

Barbara

I considered the clinical trial for the following reasons:

- I would be receiving the standard of care, plus another drug.
- By adding a drug to standard of care, the results could benefit future patients.
- Also, I would have a clinical research nurse added to my treatment team. I knew this would offer attention, support, and monitoring, and this made me more comfortable.

So I decided to participate in the clinical trial.

Lizette

All of the Information Specialists can help patients find information about a clinical trial that may be suitable for your diagnosis.

Our clinical trial searches are very individualized. Two patients with relapsed CLL would not necessarily get the same trial offerings because we take into consideration each person's needs or challenges – such as your present physical condition, your support network, or your financial situation.

GETTING INFORMATION & SUPPORT

Lauren

Absolutely. And communication is really key to getting the support that you need.

Barbara, can you share some tips about getting the information and support that you needed at various times in your cancer journey?

Barbara

Communication with the team was crucial. I had a notebook at each visit. Each time in between visits when I thought of questions or concerns, I would write them in my book and prioritize them to discuss at my next visit, as Lizette mentioned earlier. Too often patients on the way home recall questions they wished they had asked. It is important to prepare for each clinic visit. I had two notebooks to record data during my treatment journey. In one I filed my pathology reports, lab reports, and scan reports, as well as my treatment calendar and clinical trial protocol. The second book was a financial file; I filed my bills, claims, and payments. The bills included prescription expenses and bills for supplies that I needed on my treatment journey. That was a big help at income tax time the following year. Also, anytime I discussed an issue with the insurance company or business office, I noted the date, the time, the name, and the result of our conversation.

A very organized friend set up a Care Calendar so that friends could sign up to bring meals three times a week, as well as bring me to scan and treatment appointments. As my energy level did decrease, I appreciated this very much, for it was tasks that I did not have to address. There are similar websites which may be used to assist patients as well as emailing their good wishes to patients. Many friends do not know how to assist, and these websites offer a structured way to be on the care team.

Lizette

Dr. Flowers, have you found anything else to be effective when communicating with your patients and how do you encourage communication between your patients and yourself?

Dr. Flowers

That's an excellent question. Ongoing communication with your healthcare team is so important.

You should ask your doctor for your specific diagnosis, your stage, and any other clinical factors that have been evaluated that can provide you a sense of how your disease is behaving. It's important to ask about what the treatment options are and if there is any debate about what might be the best treatment for your situation. Then gather information about all of your treatment options, let your doctor and nurse know your needs, how you are feeling, and any questions that you may have.

Be sure to mention any side effects that you are experiencing. Patients often shy away from mentioning side effects because they are concerned that the doctor will take them off of their

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medication. But very often there are other medications available that can be just as effective, and may have fewer side effects for a particular patient.

Try to identify what information about treatment is most important to you and to feeling comfortable with the decision that will be made about your care. It's important also to seek a second opinion for diagnosis and for more treatment discussion. Ask questions to be sure that you understand the information from your healthcare team and take notes, as you've heard earlier on. As all of this is a lot to remember and take in, if you think that it might be helpful to ask, ask about recording conversations about treatment and ask for additional materials to read at home. Plus, it will help you to formulate additional questions. Also, bring a family member or friend to appointments to help take notes and for support.

Lizette

The Information Resource Center and cancer organizations like The Leukemia & Lymphoma Society have many resources for you. We have other helpful organizations listed on our website, as well as when you call The Leukemia & Lymphoma Society, we could provide you with those resources. We have one-on-one guidance for patients' unique challenges, including insurance and financial assistance. We offer suggested support. We also have "what to ask" question guides which are included in our booklets as well as on our website. And we can really create an action plan for patients. Following up with patients and caregivers is something that we can do just to see how you're doing as well as if you have any survivorship challenges.

Barbara

Written information such as booklets and a list of reliable websites is very helpful for patients. Younger patients may be more apt to use websites while others prefer booklets. I wanted to review information on my timeframe. I was not ready initially. My focus was to get treatment started, note my response, and then begin to study about the various aspects of my treatment journey.

The content on websites can be overwhelming. So I suggest patients ask their healthcare team and The Leukemia & Lymphoma Society Information Specialists for direction to reliable resources.

SUMMARY AND CLOSING

Dr. Flowers

You make some very key points. I think it's important to keep open lines of communication with the healthcare team at diagnosis and at other junctures. It's important to make a list of questions, report side effects, and seek a second opinion, both at diagnosis and for additional treatment options.

Lizette

From the moment your doctor tells you your diagnosis, and continuing throughout your treatment, you will receive information that you may have questions about that often requires a decision. Ask questions to make sure you're aware of any potential treatment side effects and how the treatment may affect your body. From choosing doctors, understanding and researching your diagnosis, and evaluating your treatment options to organize medical records, handling financial pressures, and talking with others about your cancer, The Leukemia & Lymphoma Society Information Resource Center is here to help you. We are committed to providing education, support, and guidance to people living with blood cancer.

Lauren

Thank you all for sharing your input and your expertise.

We hope this program will help guide your discussions about NHL and CLL treatment decisions.

The Leukemia & Lymphoma Society, as well as your healthcare team, are valuable resources for information and support. If you would like 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 you can visit us at www.LLS.org/NHLCLLdecisions. We would like to acknowledge and thank Celgene Corporation, Genentech Biogen Idec, and Spectrum Pharmaceuticals for their support, which helps LLS to bring you this information.

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