



A CLL Expert's Advice to Patients

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Andrew Schorr:

Andrew Schorr in Niagara Falls at the CLL Live conference. I'm with Dr. Nicole Lamanna, a CLL specialist at Columbia University in New York. And, Dr. Lamanna, one of the things that people wonder as they hear about new treatments, the range of treatments, the research, they want to get the best for themselves. How do you counsel people? Maybe they don't go to a subspecialist like you, they're at community oncology. How do they advocate for themselves? What do you recommend?

And also should they also in this time of change necessarily be seeking an opinion from someone like you?

Dr. Lamanna:

All right. How much time do we have?

Andrew Schorr:

Well, let's start. Go ahead.

Dr. Lamanna:

I think it's—that's a really important question. I think it's—reading is important, although albeit the Internet can be a very—either a very good advocate or a very poor advocate, because CLL happens to be such a heterogeneous disease that it's really—you really need to sort of seek advice. So it's fine to get online and read patient advocacy groups. The Leukemia & Lymphoma Society lends a lot of information about the diseases, which is great—but I still think...

Andrew Schorr:

And Patient Power.

Dr. Lamanna:

...and Patient Power, but I think it's important to write down a list of questions. When somebody first hears about CLL or their diagnosis, oftentimes they can't even remember half the things that their physician might have told them, so going back and sitting down and sort of recollecting about them, you know, what it means and writing questions. And then I

actually think they should seek perhaps a second opinion, because sometimes it helps clarify a lot of the questions they had.

Some physicians, oftentimes one of the biggest complaints I hear from patients is the physicians don't spend a lot of time with them, because they'll go, oh, you have CLL. That's a good cancer. You don't need anything right now. I'll see you in X amount of time. And that can be dissatisfying. I mean, the physician may be all well intended, but for a patient with a new diagnosis even if they're in that watch and wait group it's sort of dissatisfying because they actually want to go over a list of things and understand what it means to have a blood cancer and so on and so forth. Of course, obviously if they're getting treatment it's a little bit of a different implication.

But I think it's really important that patients need to be comfortable with what their learning about themselves and their disease, and so reading, writing down lists of questions, perhaps seeking a second consultation with somebody who does leukemia or CLL specifically just to answer some of those questions.

Because of the new drugs—that's a whole thing you sort of tag on to the end of your question—there's a whole new era of what we're doing and how we're strategizing these new drugs with the old drugs, so there [are] a lot of open-ended questions, even for people who do leukemia research. So it's important to I think, you know, speak to somebody who is at least knowing about all these different issues.

Andrew Schorr:

Sometimes when someone is diagnosed it's overwhelming, and they feel like they're drinking from the fire hose. You've seen hundreds, if not thousands, of patients. Is it your view that in most cases, it being chronic, that they have time to learn?

Dr. Lamanna:

Oh, absolutely. Oh, yes. So I think one of the benefits—if there's a benefit to having any disorder, particularly CLL—one of the benefits is it's very rare that somebody needs treatment tomorrow. It is rare in my clinic for me to go, oh, you need treatment tomorrow, so this is a big deal. So patients do have time and a little leeway to step back and think about what they've heard or what they're reading or what they're absorbing and then make those lists of questions and sort of take your time. So I think it's—absolutely, I think there's no doubt that you have extra time on your hands.

Andrew Schorr:

One other question about family members. Do you welcome people coming with family members? Because if I go, I get home, my wife, Esther, says, what did he say, what did she say? What about this? So is that okay?

Dr. Lamanna:

Yes, absolutely. And, in fact, obviously family members, if they're too overwhelmed, friends, close friends. In my practice, I typically will actually write things, write the whole dialogue down for them, so they can actually take it home. Because everybody is usually scrambling, and they're usually writing things down and I say, you're not listening. Stop writing. I will write for you. You can still have questions, but at least you have this on a piece of paper what we've discussed, because they can't hear everything.

So you're exactly correct. So if they can bring family members or friends with them to hear and be a third ear, fourth ear, or fifth ear, but if not that, they can go away with something. Then truly that helps, and they can come back with other questions.

Andrew Schorr:

And it would seem in this age of now for some people oral therapy where you have to remember to take it and understand it and maybe report side effects, that that collaboration of the people around you is helpful.

Dr. Lamanna:

Yeah. It's—I think we're facing, because of these new—the era of these new agents that are oral I think one of the big mistakes that I hope is not happening but I fear might be is that people will get started on these oral agents. And then be, oh, I'll see you in several months versus, no—yes, you're still on an oral agent and it's easy to take at home, but you still need to be seen. And the side effect issues are new.

And so I actually bring people in quite quickly after they're starting on a new agent to go over those potential side effects that they might have even though it's an oral therapy. So I think those things are very important.

Andrew Schorr:

Okay. All right. We'll be talking more, but we're here in Niagara Falls, and Dr. Lamanna will be with us in Houston, Texas, at a town meeting we're doing, which is at the end of October with Dr. Keating. So you'll be seeing her again. She'll be a regular on Patient Power. Always send in your questions.

Dr. Lamanna:

Absolutely.

Andrew Schorr:

Dr. Lamanna, thank you so much for being with us.

Dr. Lamanna:

Thank you, thank you, thank you. Absolutely.

Andrew Schorr:

Andrew Schorr, reminding you that knowledge can be the best medicine of all.

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