



How Changing Providers Led One CLL Patient to Better Care

Carol Preston

Host, CLL Patient and Advocate

Catherine

CLL Patient

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Carol Preston:

We want to hear how you were able to take a step back and figure it out. And you're living in a relatively small town. Doesn't mean you don't have access to major cities, but Harrisburg isn't that close to Penn, and you actually started out locally or more locally, did you not?

Catherine:

Right. I was referred to my local oncologist, and, like I said, I had a really bad experience with him. Number one, the day he told me what my diagnosis was he berated me for being upset. That was my start with him. So it all went downhill from there, and I started looking for another physician almost immediately because of some other should I said unprofessional-type things that happened with him.

But I—I was working in Pottstown at the time, which is about an hour outside of Philadelphia, and I was a nurse manager of a kidney dialysis unit, so I had my colleagues who were the managers of the cancer center, and I picked their brains. They gave me a lot of—back then there wasn't as much on the internet as there is now. It wasn't quite what it is today, so I relied more on written materials.

And everything I read said that CLL was a diagnosis or a disease of older men, and I was 38 and a female. So I was like—and everything I read said from diagnosis to death is like 10 to 12 years. And the physician I spoke to at the hospital that I was working at said, you have to realize that if you're diagnosed when you're 75 or 80 and they give you 10 to 12 years, you know, that could be just your normal life expectancy. So he said, you're 38. He said, you can't go by what that says.

So I took that and ran with it. You know, I said, okay. I'm only 38, so 10 to 12 years is not acceptable to me, so I got as much...

Carol Preston:

...thank goodness.

Catherine:

I got as much information as I could. You know, I went through the medical library in the hospital and had the librarian there help me do some research, things like that, and found out as much as I could. And like Sherry said, I wanted to fix it, you know. Okay, you have this problem. Who do we do about it? Let's fix it.

So watch and wait for me was a totally foreign concept. I want to fix this because that's just what we do. And I knew nothing about leukemia. It wasn't my field. I was a kidney specialist nurse, so I had a lot of where I just figured, you have leukemia, they give you a bone marrow transplant and away you go. So I had a lot to learn, and I've learned a lot over the last 21 years.

Carol Preston:

But I'm wondering if—we've talked a lot about the relationship that you have with your current healthcare teams, but I suspect that you have had discussions with other people who are newbies to all of this, and maybe you've had to calm them down. So how have you handled people coming to you and saying what should I do? Where should I go? How do I handle this? Shouldn't I—to your point, Cathy, can't I just get this fixed? Get this cancer out of me as quickly as I can.

What's been your experience with other people who have actually come to you for guidance?

Catherine:

Well, I have a friend that was just recently diagnosed, like I'd say maybe a year or two ago. And he goes to the physician that I went to initially, and I keep telling him he needs to get out of there, like you need to go somewhere else. But he just doesn't want to go anywhere but local. It's more important to him to be in close proximity than to get what I consider quality care.

Now, he's not to the point where he needs treatment yet, but I've been trying to work with his wife to try to convince him. I think she just about has him convinced to at least—to go down to Penn and get a second opinion.

Carol Preston:

You can be treated locally. A good oncologist not only will work with but should encourage all of us to seek second opinions from the experts in the field, major medical centers, because these are the men and women who are on the cutting edge. And the treatment options from those major medical centers could be a year or two in advance of what the community oncologist or the local oncologist is prescribing. Some of you have experienced that firsthand.

So, again, we want to emphasize, at the very least, be comfortable working locally but get that second opinion from a topnotch expert in the field, and increasingly they are spread around the country. If you go to the CLL forum on ACOR, for example, A-C-O-R, at the end of every discussion they have a list of CLL specialists. So there are lots of places to find CLL specialists at least to get that second opinion.

And then coordinate having that specialist work with your community oncologist. We don't want to discourage people from working locally. We need our community oncologists. The good ones will coordinate, work with the experts at the major medical centers.

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