



Top Tips for CLL Patients From CLL Patients

Carol Preston

Online Host, CLL Patient and Advocate

Sherry, Sue, Neal, Catherine and Dave

CLL Patients

Please remember the opinions expressed on Patient Power are not necessarily the views of our sponsors, contributors, partners or Patient Power. Our discussions are not a substitute for seeking medical advice or care from your own doctor. That's how you'll get care that's most appropriate for you.

Carol Preston:

So let's start with, Neal, If you had one tip to pass along to other patients what, would you say?

Neal:

I would—and other people have touched on this. I would say don't let the fatigue get you down and try to stay active as you can. Obviously, listen to your body and don't push, but don't let it turn you into an inactive person as well.

Carol Preston:

That's a great tip. And, Dave, how about you?

Dave:

Just that people with CLL, it's not the death sentence it used to be. There's too many great drugs out there coming along, and I consider CLL just like diabetes. It's something I do, I take. I put it in the back of my mind and go on. It—the more you read the more knowledge is power, you'll find that. It's not the death sentence it used to be.

Carol Preston:

And we have to remember the first word is chronic.

Dave:

Yes.

Carol Preston:

And the goal is to live with it and die from something else.

Dave:

Correct.

Carol Preston:

Old age, the infirmities of old age, in our 80s, 90s, our 100s. I have a dear friend of my mother who lived life to the fullest till 108, so that's my goal. I'm shooting for that.

Sherry, how about you? What's a tip that you can pass along?

Sherry:

Well, I plan for 107 myself, Carol.

Carol Preston:

Yea, okay. You don't want to live too long there.

Sherry:

You know, I think about the infrastructure structure of ourselves. If we can strengthen who we are as people then we will do better with CLL. And by that I mean eat well, exercise, hang out with good people in your life. Take bolt cutters to any relationships that aren't good for you. Pay attention to the spiritual component of your life, however that may manifest itself. And have fun. If we do these kinds of things, then the infrastructure will be strong and we can cope with all the vagaries of CLL better.

Carol Preston:

Well, we're wishing for you, obviously, many more triathlons. And I love that term bolt cutters to people who are not positive.

I just want to add we can't expect people to understand exactly what we're going through, but hopefully the people we do hang out with can say things like, listen, I can't imagine what you're going through but I can drive you. I can fix a meal for you. I can take a walk with you. I can go to the gym with you. We can go to a movie together. Boy, those are all the things that have helped me in my life and I suspect all of yours as well.

So let's round this out with Sue and Cathy with your tips for the day. Sue?

Sue:

Well, I'd have to say two things. One is you must be your own advocate. Absolutely. And probably the other thing is get a second opinion.

Carol Preston:

Absolutely.

Sue:

That's what I tell everybody.

Carol Preston:

Okay. Cathy, you get the last word here.

Cathy:

It's like Dave said, knowledge is power so you need to be educated. And the other thing I would say is if it doesn't sound right, if it doesn't feel right, don't be afraid to question it. Nobody has all the answers, and just because they have an MD or a D.O. behind their name doesn't make them all powerful, so don't be afraid to ask questions and to get the answers that you need.

Carol Preston:

That is a fantastic last tip from our Patient Cafe, nobody has all the answers. And please, please, please according to, definitely what Sue said is at least get a second opinion because a good oncologist locally will work with a major medical center to make sure it's the right treatment at the right before you—or no treatment. It may be watch and wait or worry and wait, but best not to get treatment until you absolutely need it.

Please remember the opinions expressed on Patient Power are not necessarily the views of our sponsors, contributors, partners or Patient Power. Our discussions are not a substitute for seeking medical advice or care from your own doctor. That's how you'll get care that's most appropriate for you.