



Moving Past a Mid-Life CLL Diagnosis: Advice From Survivors

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Andrew Schorr:

What advice do each of you have that might help someone who is facing a diagnosis of CLL in midlife? What lessons have you learned along the way that helped you face it?

You know, just kind of giving somebody advice, what would that advice be? And maybe, Andrew, do you want to start?

Andrew Schorr:

Yeah. I will say first given what we know about CLL and the range of things going on how, your life is not over. I thought my life was over. Here we are. I was diagnosed in 1996, or 22 years. I mean, I had no idea that I'd make it 22 months, right? And if you read some of the old articles and stuff, you'd say, oh, life expectancy is not very long. So first of all, you're going to live a long life and thank God for the medical research and the array of things that are available.

And I think Michele said it too, right now, she's been in a trial, she continues to take the ibrutinib (Imbruvica), maybe there'll be something else that she'll need at some time, and we're confident that there will be. So, Esther, you remember that there was a guiding light, a patient advocate in CLL years ago when I was diagnosed, and she gave us two words as advice.

Chill out. And so that's what I'd say. I'd say chill out. I don't mean to be harsh. There's a lot of grieving that goes with a diagnosis. I've probably said it to my friend Jeff Brochstein when we met in Atlanta last year, to you and Olga, but I would say that, and that's based on evidence, that I'm living longer and people living a long time. And we get an eye into the research going on, and there's a lot. So I think—it's not perfect. There are side effects, there are expenses, and there are course corrections in your head as well as in your life, but you're going to live a long time. Believe me.

Esther Schorr:

Nice. Jeff B, any advice you would give to someone?

Jeff Brochstein:

Really along the same lines that Andrew just spoke and what Jeff had mentioned when he gave his intro.

When you get CLL, when you get a diagnosis of this kind, god forbid, but when it happens during these years just take the what-ifs out of your life. Take the projection out of your life because that will just make you grow worrisome and grow older and grow grayer. You really have to—just to take things by the day. Just do your best early on to do as much research as you can about it. Try to see a specialist early on. I think that would helped me out my first couple of years if I would have gone to see a specialist as well as have somebody local and community-based where I lived.

Reach out to people like Andrew, to groups like Patient Power. It's a different world now than it was 10 years ago in terms of technology and information that's out there. And I think most of all just keep tabs on the treatment landscape that's changing every month it seems like or every six months something is approved, something new, something better, something not chemo related. Really, just pay attention to those things and you'll be okay.

Esther Schorr:

Thank you. Jeff?

Jeff Folloder:

I would tell everyone that is recently diagnosed with CLL to do a couple of things. First, take a deep breath. I guess during pregnancy they would call that the cleansing breath, but you're going to need to do a couple of them. So remember, that, Jeff, cleansing breaths.

Second, everyone has said it again and again and again. See a CLL specialist. You don't have to see the specialist regularly, but you need to get a CLL specialist as part of your team. The landscape of medicine is changing not just monthly. It's changing weekly, daily and hourly. One of the things my doctors keep on telling me the longer we wait the more likely we come up with something even better to treat you with. When I was first diagnosed we never heard the word "cure."

Now we're hearing the word "cure" for some forms of CLL, and it's getting better for lots of people very, very fast.

Make a few goals. I want to do this. I want to do that. Esther, you guys just saw Bruno Mars. Well, you saw him in a coffee shop. I'm going to go see him in concert this weekend. Why not? This is not a death sentence. This is just a part of my life. So I'm going to go do the things that I want to do, and that's what I tell every single patient. At several of our town meetings I have made the point to remind people that statistics only look backwards. When you start looking at Dr. Google you're going to see that the average life expectancy of a CLL patient is about six years. Well, that's only looking backwards. I'm now nine years into it, so some people would say that I'm past my expiration date. I don't look at that way. I'm living a great life. Every minute that I'm kicking, I'm kicking it for real.

Esther Schorr:

Thank you, Jeff. And, Michele, any parting advice in this discussion?

Michele Nadeem-Baker:

That's a tough act to follow.

Jeff Folloder:

Sorry.

Michele Nadeem-Baker:

It's a kick in the butt.

Andrew Schorr:

And have a shelf life of 25 years, you know, I mean.

Michele Nadeem-Baker:

So I would say the number one thing is to educate yourself and not just with as Jeff calls it, Dr. Google. Because if so you will get frightened by what it says because it does look backwards. But I would say to educate yourself as much as you can through credible sources, through current information versus past. Otherwise, you'll get really frightened.

And the other thing is for those of you watching this, Patient Power generally has the leading doctors around the world for CLL on it. If you can get to one of those doctors that you see or one of the institutes, then that is a great source to go to to find out what is best for you to match you up.

If you do need treatment yet or not, projected time to treatment. And then if you can either go to whichever doctor that is, or in conjunction to what Jeff of Atlanta as opposed to Jeff of Texas is doing, pair that with your community doctor if at all possible so that you don't have to travel. But that way you can be confident that you're getting either in a clinical trial tomorrow's treatment today or the best in treatment there is today. And there are so many out there.

The other advice I'd give, and someone gave this to me in my first week of diagnosis. Stay as healthy as you can today, because there will be something to treat you tomorrow. And we're all proof of that, all of us here right now.

Jeff Folloder:

Excellent advice.

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