



A Patient Panel Shares Ways to Maintain Health After a CLL Diagnosis

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Andrew Schorr:

So, Adrian, this whole person thing. What can we do that makes sense for us, that's not harmful, and how do we partner with our doctors? How do you view it?

Adrian Warnock:

Well, for me, personally, when I was diagnosed, I was pretty fat. And I think, as a middle-aged guy, I think quite a few of us have a spare tire. And I resolved, straight away, I was gonna lose that. And I did, and that wasn't because of the CLL. We do have to be watchful about that. We don't want to be losing weight excessively fast.

So, I did change my diet, not as radically as Jay, but for me, I decided to cut down significantly on carbohydrates, and just to maybe do a little bit of intermittent fasting. And I managed, over a number of months, to lose the weight gradually. But what I would also do, was every now and then, I'd have a cheat week, just to make sure that if I lifted the foot off the accelerator of my diet, that I would actually regain the weight, because I didn't want it to be misconstrued that it was my illness. But if you look at my weight chart over those 60 months of watch and wait, it was gradually going down in a nice, smooth, controlled way. But unfortunately, that didn't seem to help, for me, personally. It does for some people, but it didn't for me.

The other thing I tried to do was physio. I've been seeing a physio now, most weeks, sometimes twice a week, since November of 2018, because I had this awful sense of the decline in my mobility. I was using sticks as a 46, 47-year-old, and I still do.

But the physio, I do think, helped a bit, and I think exercise definitely helps, but unfortunately, it's kinda like there's a weight pulling you down, and sometimes exercise isn't enough. But I tell you what, when I was stuck in my hospital bed, unable to get out, this was in November, after my first FCR, unable to get out safely, it was my physio that taught

me some bed-based exercises that I think helped me to get out. One of my doctors was saying, “You’re gonna end up in a nursing home, Adrian, if we’re not careful here,” because I was just so weak.

And I just did some very simple things, lifting my legs out of the bed, pushing my bottom off the bed, things like that. Things that my physio had taught me. And then, over a few weeks, I gradually started to regain my strength. And that’s where I am at the moment. My physio says to me now, I’m very badly deconditioned, from the last nearly two years now, of being ill. And I’ve got to gradually build myself up, not overdo it, not boom and bust, not do too much, so that I don’t do anything, but gradually try and regain my strength.

And that’s after treatment, but I think sometimes in watch and wait, if you can get as thin as you can, if you can get to an optimal weight, and if you are allergic to foods, certain foods seems to provoke your inflammation, then definitely cutting those out. All of those things, to me, seem to make perfect sense, again, provided you’re talking to your doctors about it.

Andrew Schorr:

Right. Boy, this is such great advice. So, Maggie, how are you staying in as good of shape as you could be, knowing that you may have treatment, but you’re trying to do what you can do? What are things you do?

Maggie Buckenmayer:

Right, yeah, so I think, and I do believe it’s the CLL, I do get tired in the afternoons. There’s an exhaustion level that I kinda never felt before. I’ve always been extremely fit and extremely active, so I made sure that I try to exercise every day, but I do it first thing in the morning. I’m a master swimmer and I play golf a lot. I do a lot of walking.

And when I was first diagnosed, I did notice that my times were dropping, as a master swimmer. And so, now I’m just not pushing myself as hard. But I’m still in the pool, I’m still working out. I’m still saying, “Hey, you’ve gotta push yourself a little bit, but don’t overdo it. Don’t way overdo it.” So, I stay active and that’s really important in my life.

Jay Blatt:

You have to take some responsibility for your general health. And I think it’s just really irrefutable, that if you do things like watch what you eat, you try not to be too stressed, you make an occasion to walk a few times a week, you’re just going to feel enabled. You’re going to feel healthy. And you can’t give up.

You have your CLL life, and you have your general health, and they can’t be separated. You can’t have one without—you can’t have good CLL health, I believe, unless your body is very strong. So, do the best you can and take it slowly, but every day, set a goal to do something that might make you feel healthier, might make you feel less depressed. Live life, enjoy life, but don’t equate taking personal action and responsibility for not enjoying your life. To the contrary, you’re helping yourself live a longer and healthier life. That’s what I would say.

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