



# “But You Don’t Look Sick”: Staying Positive While Living With a Chronic Illness

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**Andrew Schorr:**

Have any of you dealt with a situation where you tell somebody what's going on for you and they say, well, you don't look sick. What do you say? What do you do when somebody says that to you?

**Jeff Folloder:**

A lot of smiling and nodding. It is a very common response. I think the two most common responses that we as CLL patients hear is, one, you don't look sick, or two, oh, you've got the good cancer. Neither of these are acceptable. Yeah, I look good because I work at it. The whole concept of you don't look sick, well, there's a difference between looking sick and feeling sick, and as a CLL patient I take as much charge of my physical well-being as possible. Before I was diagnosed with cancer I was a couch potato. I never exercised.

I didn't need to. I was pretty lethargic and sedentary. Now I'm an avid power walker knocking out between 30 and 35 miles every week. I do it pretty fast, too. I'm trying to maintain my weight, and I'm trying to maintain my energy level. So, no, I don't look sick. Sometimes I feel sick. I just did a week and a half on the road. I missed a bunch of naps. I'm a little tired. Actually, I'm a lot tired, and I'm looking forward to a nap this afternoon. And I'm going to take one, and it's okay.

But this is part of my new normal. My new normal is the way I feel doesn't necessarily show. And my wife understands that. My family understands that. The people close to me understand that. My doctors understand that. So if people don't get it, that's their problem, not mine.

**Esther Schorr:**

Any other commentary on that? I think that's a great, very positive way of looking at it.

**Michele Nadeem-Baker:**

I have to say that I'm trying to look at the positives about people saying you don't look like you have cancer. In other words, I feel like they're trying to convince me I don't have it because I don't look it, but I guess I'd rather not look it than look it. That's what I keep trying to tell myself. And as Jeff just said, I do smile a lot, it's like, oh, yeah, you really don't know what you're talking about, but thank you. I know you mean it to be good and be nice. I also know people don't know what to say. So I try to put the little sarcastic bubble aside and just try to think of that.

But as Jeff said you do have to—you have to take charge. And I continue to, as Jeff was saying, I continue to work out in the way I do throughout even infusion. Continue to go to the gym and use weights and do cardio. And when the weather's good enough up here, which it's now turning to not be, do whatever I can outside as well as in the gym because you feel better.

And that is one way I felt I could take control when everything else was out of control health-wise. So it also helped me in that way, in that respect as well as to be healthier physically. So it's very important, I'd say.

**Esther Schorr:**

And really what you guys are all talking about is how do you stay empowered and positive. And for you, Jeff, it's everything from power walking to taking naps, and for you, Michelle, it's going to the gym and being an advocate. And Jeff, Jeff other Jeff, you've talked about some of the things that you do. And you're going to be a lot busier with a baby in the house.

**Jeff Brochstein:**

That's right.

**Esther Schorr:**

Anything else that helps you to stay positive in all of this?

**Jeff Brochstein:**

You know, I was always active for I don't know 20 years before I was diagnosed. I've always lifted weights, done CrossFit in recent years. So I spoke about this earlier, and this really kind of repeats some of the stuff that Michelle and Jeff were saying.

I've never appeared sick. I've always been physically fit. There was a time for about two years since I was diagnosed that I had some lymph nodes that went away once I started the ibrutinib. People never associated me with some sort of chronic or acute illness. And when I've told them what I have and I've told them about the condition, you know, I've also followed up with just trying to create awareness around this, send them some links, sending them some videos. Maybe sending them the original video I did at ASH last year, just to really create awareness around it. And it's really up to them if they want to absorb it, on Jeff's point.

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