Managing Stress After a CLL Diagnosis

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Andrew Schorr:
Let’s talk more about the managing stress after diagnosis. So, Paul, you obviously have studied it, but now you’re living with it, so you’re in this one-year, watch-and-wait situation. You were told you probably have this condition you never heard of, CLL. How have you used what you know to minimize stress?

Paul Salmon:
I think there are several parts to it. I guess in one way, the initial diagnosis, of course, came as a surprise, because after all, I had just gone in for a routine workup, and in every other respect, everything else was great; all my other numbers were fine. Then, it was kind of like, “Well, we just have this one number that seems to be out of the ordinary, and maybe we should look into it.” That was my first inkling, and maybe something that I wondered about a little bit.

And, I should mention that my father probably—may have had CLL. We don’t know, but he had an elevated white blood cell count for years. So, that’s kind of—and, there are cancers in the family. I take really good care of myself. I work out, I meditate, and do all the right things, and of course, people who are diagnosed with conditions like this often go through an initial phase where they say, “Why me? I do everything right. I follow all the rules. I eat well.”

And, in a certain way, what’s helped me is to become real curious about this and to look for interesting connections that I can make. I can see where people—you could get into a sense of blame or feeling like somehow, you’re responsible for what happens, but really, the foundation of the meditation practice of mindfulness—which is based in Buddhism—I think there’s a view of the world and of how things are that certainly helps me keep things in perspective.

Andrew Schorr:
You seem calm. You seem pretty calm.

Paul Salmon:
I just take great joy and pleasure in what’s happening on a moment-by-moment basis, and I think a really important element is I can find my mind—I’ve been meditating for years, but the essence for me of mindfulness is that paying attention to what’s going on in the moment, and then noticing when you’re not in the moment. That’s kind of a critical thing because you get off wondering about things, predicting, and trying to make projections, but when I find myself doing that, I say, “Okay, back to the breath, back to the moment, and let’s just go with that.” So, that’s very helpful.
Andrew Schorr:
Mark, you were nodding your head there a minute ago when he was talking about living in the moment. So, you’ve had a rollercoaster with CLL.

Mark Silverstein:
Absolutely. Often, CLL is my moment to be living in, but yeah. I absolutely agree with everything Paul said.

Andrew Schorr:
So, how do you do it? Because you’re a man who’s lived with tremendous uncertainty. We all have uncertainty, and I’m gonna ask Barbara about this in a minute. The thing that weighs over me as a cancer patient—two blood cancers, because I have myelofibrosis as well—is uncertainty. But, what I know is the now. What about you? With this rollercoaster, you’re on new treatments now after the transplant, which you hoped could be curative. How do you manage that?

Mark Silverstein:
It is often challenging at times. Honestly, I probably went through a bit of a grieving process after relapsing after the transplant. There was some hope that there was a cure in there. And so, I think both my wife and I actually went through a bit of a grieving process through it, and part of it is allowing yourself to go through these things and experience them as opposed to suppressing them.

But, as Paul said, the mindfulness—I’ve taken mindfulness courses, walking—all these things help. Our emotions—I like to believe that we are not our emotions. They don’t control us. We can control them. If we understand ourselves well enough, we can make different choices. As mindfulness teaches you, something comes into your head, you put it up there for now, say, “I’ll come back to it later,” and come back to the present moment, and that’s really the most important thing.

The existential challenge of CLL especially—what I’ve gone through is 17p, and all the treatments, and all the relapsing—it is challenging, and it’s challenging to stay in the moment, and I’m not gonna lie: There are times that I’m not in the moment, I’m in the hell of CLL world, so to speak, but it’s bringing yourself back as quickly as possible to what matters. You can’t live in the future too much. You can’t live in the past, because then, you’re not in the present, and really, the present is all I have because I don’t know what’s gonna happen next. And so, my need or my motivation to stay in the present is huge, and so, anything I can do to manage that is where I focus on.

Andrew Schorr:
Right. I remind myself, “I don’t know about tomorrow, but right now, I know about today. I’ve got a great cup of coffee with my family on it, and that’s what I know.”.