



Patient Power

Coping With the Challenges of a Chronic Illness: MPN Patients Share Their Strategies

Julia Olff
MPN Patient Advocate

Samantha Trahan
MPN Patient Advocate

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.

Andrew Schorr:

So, Samantha, so you alluded to the fact you've had some low times. At some point, you had to say, "I am gonna live in the moment. I have today. I don't know where my MPN's going. It switched from ET to PD, and I don't know how I'm gonna feel tomorrow or next week."

So, how have you taken the little voice in your head, maybe the big voice in your head that was even shouting sometimes, and say, I've got my family, I've got my kid, I've got my dog, I've got my life. What did you...

Samantha Trahan:

...yeah. That was tough. I mean, so a couple of years ago—I mentioned I'm no longer really overproliferative. So, it threw me into this time period of uncertainty. And the first thing that I do, because I am involved in my own medical care, is I started flying around and seeing different doctors, and what do you think? And what do you think? And what's gonna happen, and where am I? And I need a new bone marrow biopsy. And that hamster in that wheel just started running and would not stop. And then that became what I focused on, so then every day, I was looking up research journals and then contacting authors to get full publications. And then I got to where I was no longer focusing on what was really important.

And I needed to spend more time with my family. I needed to really stop looking at research journals in the morning when I drank coffee, because it was not accomplishing anything but creating more time with that hamster on the wheel. So, I made a conscious effort. I'm going to stop. I don't know what's going to happen, and I don't know what's going on in my body right now. I'm somewhat of an anomaly. I've been over-proliferative for a long time, and now I'm not. How long is that gonna last? I asked every doctor I saw. No one knows, because this is not an exact science. This is something that we're all just working through, and there are frankly not that many of us, and not that many young patients to come up with a definitive answer.

Andrew Schorr:
Right.

Samantha Trahan:

And I had to set aside the fact that this – there was no answer. My doctors couldn't give me an answer. I couldn't find an answer, no matter how many research journals I looked at, how many ASH reports I read, and I just had to stop.

And so, what I do is I go see my doctor quarterly now, and I set aside time, whatever that week is going to be, and I review my symptoms. I do a little bit of research to see if there's anything new that I'm curious about. But other than that dedicated time that I set aside to focus on my health, I ignore. And I try to live the healthiest, best lifestyle that I can so that I strengthen and I feed my body. But other than that, I just have to turn it off, and I set aside dedicated time, and that's when I worry about it.

Andrew Schorr:

Julia, you've shared that you see a counselor to get some help. Tell us about that and how that helps you.

Julia Olff:

I think it's of tremendous benefit, and I'm one of those people that believes in therapy, particularly cognitive behavioral therapy, where you're learning to deal with problems. You're learning to cope. It's not necessarily about looking back into your past, but rather—Dr. Mesa spoke to it so well, essentially – sort of figuring out how to cope with challenges, how to get through the tough times, the adversity, I think it has helped me recognize that chronic illness does have an impact on one's life. And a therapist helps validate that. It also has helped me figure out in small ways how to allow myself the breaks or how to sort of pace myself. So, it has helped me have permission, as well as helped me persevere.

You know, I think I've practiced my own sort of mindfulness, if you will, at key times. Like when having a bone marrow biopsy, I sing or hum to sort of get through and distract my brain from the discomfort, pain, and sort of fear of the procedure. And I feel like going to therapy, or counseling, or thinking about how you think and reframing it, redirecting it, helps you just sort of get through those things that you have to deal with with this disease and the uncertainty. And Samantha and I are similar, I think, in that we've had a long time to learn how to do this. And I talk to people most often who are newly diagnosed, and I hear the fear. I hear the "why did this happen?"

They're not necessarily ready to embrace mindfulness, I think. And one of my questions is sort of when is it – I'm also a health educator, so I have to acknowledge that—is where in the experience would you benefit most from what we're talking about? Because I do think you also have to let yourself be sad and let yourself go through the emotion, that—it doesn't mean you'll stay there. So, when I've had acute episodes and have been hospitalized, I definitely get low—I mean, my mood changes. I start to think, oh my god, I'm dying. I'm ready for a bone marrow transplant. And then I get out of it. So, a long-winded way of saying I think therapy has helped me roll with all of that much better than I might have otherwise.

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.