



Patient Café: Coping With the Ups and Downs of Chronic Blood Cancer

Andrea

Patient Advocate & MPN Support Group Leader

Denise

Care Partner

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Carol Preston:

But do you sometimes feel you're either on a merry-go-round, or it's like an EKG going up and down. You feel like things are fairly stable at this point, because you're grounded in what you know and how you can find what you don't know?

Andrea:

Well, I think that there was a short period of time where MPN research was very popular, and a lot of drugs came out, and a lot of clinical trials were introduced. I'm finding lately, and this is just personally with my limited amount of research, that the wheels seem to have slowed down. Whether the diseases are more difficult than the doctors—the researchers thought they would be, or not. So I feel a little bit on the downward trend right now as far as emotionally. I'm looking, looking, looking, and I can't find very much that's new out there.

Certainly when I'm on a trial and I'm feeling good, the sky's the limit. But when I'm looking for other things and not seeing too much, I feel like I'm a little bit on that downward trend right now.

Carol Preston:

Yeah, and I think that's true with all of these diseases. I remember in I think it was 2014, it was an explosion of new oral medications for chronic lymphocytic leukemia. Then in 2015, suddenly after stability and really nothing percolating for multiple myeloma, five new drugs came on the market. And so it's been with MPN and pretty much for all of these cancers. So I think all of us as patients have to hope that the pendulum will swing in the other direction and that we have medications and treatments to keep us going. The bridges that we need to get us to the next medication, if and until there is a cure.

Denise, Andrea just mentioned about the vicissitudes—the ups and downs when there's innovation, and there are new drugs on the market, the sky's the limit, but then things get very quiet, and it pulls her down. How does that impact you?

Denise:

Well, it does. It does impact me. You have to be honest about it. But you know, we're both very optimistic and one of the key things that we try to do is as you get older, you're not 20 anymore and while you still have the mindset to do the 20-year-old things that you used to do, you're physically unable to.

And so we make adjustments. Andrea is an avid cyclist, and so the question is—one of the things we decided on recently was how does she continue to ride, because that is extremely important to her not only mentally and emotionally but also physically. So how does she ride, and how does she still maximize and still go out and enjoy what she wants to do? And we searched—she researched, and we said electric bike. This is important for you. So she researched, we found an electric bike, and she continues to ride now. And so we make adjustments, and that's what's important in the day-to-day ongoing of her life.

Carol Preston:

Boy, that is such an important message. And I hope everybody takes away the point that Denise just made. We all have things that we love to do.

Andrea, I know that you love not only bike rides, but you love theater, you love movies, and there are always ways to find what we love to do—different ways of doing it. It may not be what we did five years ago or 10 years ago, but that's such an important takeaway message. Before we end this, I just want to ask you, Andrea, what would you like to leave our viewing and listening audience with? If they take away one message from you today, what would you like that to be?

Andrea:

Don't give up. Don't give up. Keep fighting, because new treatments are coming out of MD Anderson, Mayo, all over. And don't stop doing what you love. Just to Denise's point—find other ways to do it. Keep a good, good attitude because if your mind is positive, your body will respond.

Carol Preston:

Words of wisdom. Can't say it any better. Andrea and Denise, from the Dallas, Texas area, I want to thank you so much for joining us for our coffee klatch in the Patient Café today. Again, we want to thank the Patient Empowerment Network for helping us make this program possible. And we want to thank all of you for tuning in and continuing to pepper not just us but your physicians and your partners with the questions that are really going to make a difference in your life.

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