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Podcast Transcript:

Dr. Ron Falk

Living with ANCA: Managing the rollercoaster of flares and remission

Dr. Falk: You've stayed in remission for a period of time, and then despite the medicines, a flare occurs. The problem with ANCA small vessel vasculitis is the worry and then the reality of the rollercoaster of relapses and remission. How do you manage that rollercoaster?

Dianne: It's very hard. It's not a ticket to ride that you want to buy, but you've bought it. I think that managing flares—first of all, knowing when one is coming. I think that takes a certain level of self-knowledge that you develop as a patient, knowing your body and knowing that this is happening. Sometimes, in my case, the symptoms show up about a month before the numbers show anything. You learn over time. You can say "I don't know if I'm having a flare, but I am having these symptoms and they're concerning me. What should we do?"

I think this is where your notebook comes in. You say, "Yeah, I had one of these a couple of years ago, and it took about this long and I got through it, and then I had 2 years where I was fine, and now we're at it again." One patient said that now she just kind of laughs, she said "I've been through a lot of these and I'll get through this one." Another patient tells herself "This isn't going to last forever. It's going to last for a period of time and then I'll feel better again." So those are some ways to cope with it.

Dr. Falk: The reality that I think patients are most worried about is that when they're not sure that a flare is occurring, their ability to discuss that worry with their physician. A certain number of those times, there won't be a flare. On the other hand, there certainly can be. It's that concern of the patient that they might be "crying wolf", that it isn't a real event. I would encourage patients to make sure that they have a physician who's not going to hide if the patient has repetitive needs about whether or not a flare is or is not taking place. A

neurotic patient and a neurotic physician seem to do best and help patients get through flares.

I worry about those interactions where the physician finds it a burden if a patient has called too many times about one of these events. That's almost a moment to try to find a new physician. But that rollercoaster is very hard for both sides, both the patient and the physician.

Dianne: I remember one time, when I didn't know that I could call you when I was having a flare. And you had a "spy" in the hospital and she saw me limping around because I was having bad joint pain. Which I had written off as "Oh I just exercised too hard". And you called me and said, "I hear that you're limping around. Are you having joint pain?" And I said, "Maybe." And you said, "Well, we need to talk about this!" And a light went off in my head—Oh, okay, I guess I *can* call him when I might be concerned. I don't have to be Cleopatra, Queen of Denial.



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