



## Advice for Coping With CLL Treatment Side Effects

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**Andrew Schorr**

So we talked about all of those drugs, powerful anti-cancer medicines. But I like to say there's no free lunch. And so there are side effects of the different medicines. You had some side effects. What side effects did you have?

**Allen Melancon:**

I had joint pains and some night sweats.

**Andrew Schorr:**

And fatigue.

**Allen Melancon:**

Fatigue.

**Andrew Schorr:**

Okay. So how do we manage some of these side effects? Is it changing drugs, changing dose? Communication is basic. How are you doing? I'm really tired. I can't go up a flight of steps. Or my heart is racing or whatever. So let's talk about side effects with these CLL medicines and then what to do.

**Dr. Keating:**

One of the most common side effects of CLL is fatigue. And it's almost certainly due to high cytokine levels that are generated by the immune system. And we can do some research on symptom management with a drug that you've been on, with ruxolitinib (Jakafi), for example, that decreased the cytokine level. And we just published that it improves the fatigue in probably two-thirds of patients. The problem is that it costs \$100,000.00 a year, so I'd rather be tired.

But the other thing is to sort out the symptomatology from the disease and the symptomatology from the drugs is often very, very difficult. And you only get it from a lot of experience with the physician that's looking after you—and so to dissect those things out. You've seen it before, and you've seen it again before. And then, you begin to form there's a problem here. How do we handle it? Do you have to stay on the full dose of the drug? Is there any rationale for decreasing the dose of the drug? Are you going to do harm by decreasing the dose of the drug?

And then, oftentimes, there's not very much data out there to guide you. For example, with ibrutinib (Imbruvica), we had a whole bunch of little studies of 40 patients and 50 patients, etc. And that was spread among bunches of doctors. So any one doctor would probably only see three or four patients on a study and not enough to get experience.

So you don't gather that, unless you're seeing a lot of patients with one drug and one disease, etc. So it's a lot easier for people like Nicole and me to dissect it out. And it's led to some clinical trials, as I said. The Jakafi trial, we found, serendipitously, that some people, particularly women, do spectacularly well on relatively low doses of methylphenidate (Ritalin) for their fatigue. Men, not so much. And so that some people are screaming down the phone, "I haven't got my prescription." And it's not drug-addictive or drug-seeking behavior. They just really can get on with the rest of their day. And they define it very clearly. It felt good, it felt not so good, I took that, this happened, finished my stuff, didn't have to have a nap.

**Andrew Schorr:**

Now, just related to side effects, so, Allen, you mentioned you've been on three different drugs at least. Now, you're on venetoclax or Venclexta is trade name. And it sounds like you're doing really well not experiencing side effects that you're aware of, is that right?

**Allen Melancon:**

No side effects.

**Andrew Schorr:**

But you had side effects before. So and these are going to vary by patient. So, for instance, my friend, Lisa Minkoff, in Seattle, she was on ibrutinib, and she developed muscle pain and things like that. Other people don't. So it varies. So it's not the same. Again, the side effect profile is not the same for every person. If you listen to the TV ads for some of the drugs and other conditions, they rattle off like 20 things that could happen, but you wouldn't take any medicine...

**Dr. Lamanna:**

You wouldn't take any of those.

**Andrew Schorr:**

You wouldn't take any of them. Brad, how about you? Any ongoing issues? You had the sinus infection.

**Brad Adams:**

That was during treatment. Since I finished FCR, I have had no side effects.

I continue to deal with fatigue. My fatigue is not bad. If I were to try to climb a set of stairs, I would be winded by the time I get to the top. But otherwise, I lead a completely normal life. And I try to walk every day.

**Andrew Schorr:**

Okay. And you're going to walk with your wife? Okay. That's the prescription. You got it? Okay. And, Jeff, how about you, side effects? You had a monoclonal antibody, ofatumumab (Arzerra). Side effects then or any after that?

**Jeff Folloder:**

The side effects during treatment, especially for the first couple of treatments, were fairly intense and not pleasant at all. I was told to expect that the first infusion would last about eight hours. At 22 hours, I was allowed to leave. A lot of side effects. My body had never seen that before, and it rebelled. Once I figured out the program, and my body started to get used to it, I could drive myself to treatment here at MD Anderson.

I could get the treatment, have my giant bag of saline solution. And I knew that I had about a 10-hour window to get my butt back home. And then, I'd spend the next couple of days being in the malaise. And we'd start all over again. And it worked out fine. But five years later, I'm not taking anything for maintenance. And I don't have any recognizable side effects. And I'm still in remission so two thumbs up.

**Andrew Schorr:**

Okay. And he was in a trial. Again, and we'll keep talking about the importance of that. So you have to communicate. So, Dr. Liu, so this importance of talking about how you're doing, that's integral to helping, right? The communication is really at the bottom line.

**Dr. Liu:**

It's really very, very important.

And like an event like this, for humans to really know what's going on with yourself, going on with other people, how do you feel, and how to get through. To know the knowledge is extremely helpful, as you said. I know I feel bad right after chemo. Then, I know what I'm going to do and make a determination to do it. I don't know the origin of why that patient or being called patient. And I always tell my patients to be really patient with yourself. Think about the treatment course, as long as it's not like tonight after dinner. The whole thing is going over. It's not like that. So it's really every day you determine what I'm going to do.

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