I Was Blindsided by Lupus, but I Am Adjusting

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I'll always remember the day I found out I have lupus. It sticks with me like the memory of where I was the day Elvis died. It is a dividing line between the former "normal" days and my "new normal." Everyone has different symptoms that lead them to make that first doctor's appointment. Mine came when I bought a treadmill and could only walk for three minutes before gasping for breath. I used to walk two miles a day so I knew something was wrong.

I made an appointment with my doctor. I already knew she would tell me I needed to lose weight. I was ready for that speech. But I wasn't expecting her to send me to the lab for two dozen blood tests.

Most people have never heard of lupus

Two weeks passed between the tests and my appointment to discuss the results. During that time, I dreamed up all kinds of things that could be causing my health issues, but I never considered lupus. Many people haven't heard of lupus, unless they already know someone who has it.

Most of my test results were either normal or negative, so when the antinuclear antibodies (ANA) test was positive, it really caught my attention. I thought a positive result was a good thing. As it turns out, it's a marker for lupus. I didn't realize those three letters, ANA, would change my life.

A lupus diagnosis increases vocabulary

It's natural to want to read everything possible when diagnosed with a chronic illness, to want to be proactive and understand what all those blood tests are for. Many specialized doctors are involved, including rheumatologists, pulmonologists, pain specialists, ophthalmologists, dermatologists, cardiologists, neurologists, ear, nose, and throat specialists, and gastroenterologists. It's essential to know what part each of these doctors plays in treatment.

Those with lupus also are prescribed various medications, including some that patients may not have heard of before. It's imperative to figure out what each doctor or therapy is supposed to do. Become a specialist in your own health. After all, nobody knows your own body better than you.

Remember the adage: Trust but verify

Lupus information is often just a few clicks away. Thanks to the internet, the sheer amount of reading material is overwhelming. Sometimes, though, it's outdated or just plain wrong. Be careful about which sources you trust. Pay attention to the background of a website or of the person writing an article.

Talk to your primary care physician. A good one will become your best source of information and will be open to listening to your concerns or when you want to try something new.

No one has ever wanted lupus, but I can think of many things that could be worse. Getting the right combination of meds has taken some trial and error. I have good days and bad days. But I'm learning to live with it. Like it or not, lupus is here to stay.

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