Coping With a Lupus Diagnosis

by ANNA SCANLON

How to Cope After a Lupus Diagnosis

When I was asked to write about coping with a lupus diagnosis, I had to think about it long and hard. My particular story of finding out I have lupus might be a bit different than most lupus patients — and for me, being told I had SLE was actually a welcome relief. It was a name to a face; a way for doctors to finally take me seriously.

The Beginning

Before I was diagnosed with lupus in 2010, I vaguely knew about the illness due to the fact that my paternal grandfather suffered with it. He passed away when I was only nine, so I never really got to have any kind of adult conversation with him about his illness or his symptoms.

Lupus was always something the grown-ups discussed when I went to visit. I was more interested in the Rocky Road ice cream and goldfish crackers my grandmother always seemed to give me, and playing dentist with my brother on a reclining chair in their living room.

He was also pretty sick with lots of other illnesses, including a form of cancer and Parkinson's. For most of my childhood, lupus was "something that made Pop (what we called him) sick" and little more.

I began to develop my first lupus symptoms in 2005. It coincided with an emotional event in my life that everyone thought I was just reacting badly to. But I knew something was off.

I was going from living the life of a typical college student to simply sleeping all of the time. I think there were a couple of days in which I actually slept for 24 hours straight. At first, all of my bloods were normal and because I have a history of depression, doctors told me I was "just depressed" (as though it is a throwaway diagnosis, but I digress!).

Eventually, when antidepressants weren't helping me, I was given the diagnosis of chronic fatigue syndrome, which followed me on my medical charts for years. If anyone has had this CFS, you will know that most people, in the medical community and in life, don't really believe this is a "thing." They think it is depression, a poor diet, in some cases, "the yuppie flu" — meaning something only upper middle class people get to avoid going to work.

Just the name elicits responses from peers telling you that they are just as tired as you are or that everyone gets exhausted. You need to, they say, "suck it up."

Advocating for Myself

Not content with the CFS diagnosis, I went from doctor to doctor, some of which flat out told me they didn't believe I had all of the symptoms I presented to them when I tried to track them. "You're too young," they said. "I don't believe a woman in her early 20s would have all of this. Sorry."

Because lupus flares come and go and the activity of lupus comes and goes, this is, unfortunately, not an uncommon narrative for lupus patients. In fact, it becomes a vicious cycle.

You feel ill, go to a GP who either doesn't do a proper panel or refers you out to a rheumatologist. The rheumatologist doesn't have an appointment for several months out, and by the time you have the appointment, you're feeling better and the lupus antibodies have disappeared. Rinse and repeat ad naseum until you're ready to scream.

In 2010, I was finally diagnosed with SLE after a tentative diagnosis of undifferentiated connective tissue disorder. Knowing the symptoms and knowing my grandfather had lupus (aka knowing lupus heredity may be possible), I stuck to my guns and kept persisting.

Next page: it's okay to grieve and more on how to cope with a lupus diagnosis.

Advocating for Myself

I was never married to the idea of a lupus diagnosis, but it seemed like the most likely thing, especially after I finally received the diagnosis of UCTD and knew there was something wrong that the doctors could actually see. But the lupus diagnosis didn't come until I started seeing a rheumatologist that clearly cared about her patients.

She was passionate about helping them live well with their illnesses and even answered patient emails during her off hours. She was a gem and actually was the first person to treat my illness properly. Without her, I may still be struggling for answers to my constant pain and fatigue.

It's Okay to Grieve

This is a long-winded way to say that my lupus diagnosis was actually a pretty happy occasion. I was relieved that a medical professional finally believed me, that I could actually put something that wasn't contested by others down on my chart.

It was like finally solving a mystery, finally putting all of my questions to bed. And it also strengthened by trust in my own body as I basically diagnosed myself with it before I was able to get the doctors to agree!

But I recognize for some people being diagnosed with lupus isn't a relief, but more of a prison sentence. I have met other patients who were diagnosed fairly quickly after showing their first symptoms and went into fits of rage and depression before accepting their diagnosis.

It isn't easy to hear that you have a disease you'll never recover from, especially if you are a young person. In fact, it can be downright depressing or seem like the end of your life.

Although living day-to-day with lupus is a struggle for many, some are able to curb their symptoms well enough that they live a life free of many of the complications of lupus. Many people with the disease continue to live rich and full lives and are able to fulfill their dreams.

If you are diagnosed with lupus and are not relieved like I was, give yourself time to grieve. It is okay to feel upset or defeated by the diagnosis, especially if these crazy new symptoms are both uncomfortable and unfamiliar.

Even though I was relieved to be diagnosed with lupus, it doesn't mean I don't have days that absolutely suck and that sometimes I don't just feel sorry for myself all day. Know that, that is okay.

When you are diagnosed, especially if you haven't read up much on the illness, take this opportunity to educate yourself. While your doctors have their own wealth of knowledge from years of experience, they don't live in your body and you will ultimately be your own best advocate when it comes to living with lupus. You know your body best and don't be afraid to be "pushy" or "demanding" if you don't feel your treatment is up to par or being

taken seriously.

Lastly, I strongly suggest joining a lupus support group. For some people, this isn’t possible due to geographical constraints, but with the magic of the Internet, even those in far off corners of the world can connect with their peers. This will help you talk out what it is you’re feeling and it helps knowing you have a friend who can understand you.