Six Life Lessons Living With Lupus Has Taught Me

by ANNA SCANLON

Life Lessons Learned from Lupus

There are many things I have learned through my lupus journey. While I would honestly rather not have lupus, there are some things I think I may not have known about myself, or others, if I hadn't developed the disease. Here's what lupus has taught me about life.

1. Setting Boundaries

Full disclosure, I'm still learning this one. I still find it difficult to say no to people or cancel plans if I'm not feeling well.

I have learned that sometimes you have to say no and can't ruminate on the consequences. This sometimes means being firm with your family and friends and letting them know that sometimes you need to rest, or there are things you are unable to fully participate in because you may not feel well.

Or, sometimes if friends and family want to see you, they will have to come to you instead of the other way around.

Although I'm still learning how to do this completely, even after almost 12 years of lupus, I don't think I would be able to do it at all if I didn't have lupus. The nature of my personality is to acquiesce to others, so lupus has, in a way, forced me to stand up for myself.

2. Knowing Who Your True Friends Are

This has, perhaps, been my most valuable lesson. When I first developed symptoms, right away it was easy to see who was sympathetic and who wasn't.

It was difficult at first, as some people I thought I could count on as friends had some pretty cruel things to say to me or tried to make me feel badly for not being able to do the things I used to. Most of the friends who have stuck by me are definitely true friends and like me for myself, and do not take my symptoms as a personal affront.

Still, every now and then you do meet people who are less than understanding. So, it's easy to see right away that they are not people to trust and won't be there for you when you're ill.

3. Taking Personal Risks

I don't think a nine-to-five type job would ever have suited me, but having lupus means it is totally out of the question. Having lupus has given the inspiration to work toward a career that I both love and can do around my symptoms, which is something I may not have had the courage to do previously.

Lupus has forced me to think outside the box and put all of my skills and interests together and do exactly what it is that I want to. At this point in time, I am lucky enough to work entirely from home while I finish my PhD, which has been a massive help for me as I've been suffering from flare after flare.

If I had a nine to five job, I may be more financially comfortable, but I am sure I would have been much more bored and less free to pursue other interests.

4. Listening to My Body

Many people without lupus have to learn to listen to their body. But since I've been forced to do it for so long, I am well aware of the cause and effect of certain situations.

For example, I know if I don't get enough sleep, I won't feel well in the morning and my joints will ache. I know if I do too much one day, I will pay for it the next.

In this way, I am more in tune with my physical self than many people and therefore know exactly what my body needs and how to take care of it to keep it as healthy as possible.

5. Empathy

This is a big one. A lot of people without lupus have never actually been sick or exhausted for weeks at a time.

I see memes all the time joking about how people without kids can't say they're tired because they don't know what it feels like. Because running around and keeping up with a busy, otherwise healthy, lifestyle is all many people know of being ill or run down, they have a hard time empathizing with me.

I've had people tell me to try and "get on with it" as if it were that simple.

But because I understand what it is like to chronically feel like crap, sometimes for months at a time, I find I am more understanding with family members and friends when they don't feel well.

If someone needs to leave early because they feel sick, I will never beg them to stay. If I get a call canceling plans I've been looking forward to because my friend feels under the weather, I may be disappointed, but I've never been angry.

In turn, this makes me someone a lot of people come to speak to when they are concerned about their health or symptoms or need someone to talk to, and I am more than happy to be that person for them.

6. Appreciating the Little Things

Many of us, especially young people, take our bodies for granted. Of course, I'm not immune to this, even with a lupus-riddled body.

However, when the good days are fewer and far between, being pain-free or fatigue-free feels like an amazing gift. I know at any time things can be much worse, and in comparison to the health of others, I can actually do a lot.

My legs work, my hands work and I can do most everything for myself. And no matter what abilities you have, it is important to stop and be thankful for them every once in a while.