Coping With a Lack of Lupus Understanding

by ANNA SCANLON

Building a Foundation of Lupus Understanding

Lupus SLE can be a tricky disease because it is, by its very nature, both an imitator and invisible. You likely don't tell people every time you're in pain (as that would probably be all you'd talk about) and therefore people don't really know how much lupus impacts your daily life.

SLE is also extremely fickle, meaning that you may feel like you're on death's door one day and then feel absolutely fine the next. Because of the nature of the illness, it can create lots of tension between you and your family and friends, especially if people are unable to understand.

The Rocky Road to Diagnosis

For me, I had the worst time with people understanding my illness before I was diagnosed. Like many lupus patients, it took me several years to get a diagnosis. During this time, I was told I had several different health issues, including depression, vitamin deficiency and chronic fatigue syndrome (CFS).

The latter, although a real disease, is still controversial in the medical community and the name doesn't lend itself to a very believable cadence. As I developed the disease in college, many people told me they were tired as well and I should get on with it.

One of my old college roommates was also kind enough to tell me the her father, who was a doctor, didn't believe in CFS and therefore I was probably just using the label to both get sympathy and get out of my obligations.

All of the doubt from others made me start to doubt myself, something I struggle with to this day. Sometimes I would convince myself I was going crazy and was actually just faking and trying to get sympathy, and would then push myself to the limit to try and "overcome" whatever was making me feel physically ill. If I just pushed myself, I said, I would be able to overcome what was making me so sick.

During this time, I also had a boyfriend leave me because he thought I was being lazy. Because he valued physical activity, he said he felt my periods of inactivity were bringing him down. Due to this, I began to convince myself that I would never find someone who would accept all of me.

This was reinforced by family members who would tell me to downplay or hide my illness from potential partners. It actually took me several years of soul-searching, therapy, ruining the next serious relationship I was in because I was terrified of losing him and even trying to cope by starving myself before I was finally able to accept that I was lovable even with lupus.

More Doubts Post-Diagnosis

After receiving a diagnosis, things have seemed to calm down as far as people not believing me. Last year, however, I did end up having a very hurtful fight with a close family member who thought I was using the disease as an excuse to get out of seeing her because I secretly disliked her.

This person is one of the most important people in the world to me, and having them accuse me of this made it feel like I had nowhere to turn and had no one on my side. This person had been there and seen the first-hand effects the disease has had on me and my life since day one, so these feelings took me by surprise and really hurt me.

The thing with a lupus diagnosis is that you can't really compare one person's lupus to another, which is what often happens when people don't accept your lupus. Either they are unfamiliar with the disease and its nature (i.e. "Why don't you just drink caffeine and get on with your day?" or "Why don't you just ignore it and keep going?") or they know someone else with lupus who is affected in a different way.

Sure, some people with lupus are able to hold down extremely stressful full-time jobs. Other people can barely make it out of bed most days. It all depends on how the disease affects you.

Helping People Understand

My first big tip for helping people understand the disease is to explain it. A lot of the time, people have never even heard of lupus, so simply saying you have it doesn't make people automatically understand.

Instead, explain what it is and how it affects you. Tell this to the person upfront so they will know in the future that you are not making things up to try and get out of an obligation.

In my experience, trying to explain things as they come up can make you look a bit flaky and a bit less believable. Most people will appreciate the upfront honesty.

Avoid people who make things all about themselves. Lupus will show you exactly who your true friends are. If people (yes, even family members!) make your struggle all about how it affects them, it is time to cut them out of your life.

This doesn't mean a one-off crying session isn't acceptable, as those who are very close to you are bound to be affected by your illness. Your partner, parents or children may very well have their lives impacted by your lupus and it may be very stressful to them — they are allowed to have their feelings about how it impacts their lives.

However, if someone repeatedly makes it all about them and makes comments regularly, i.e. "You're ruining my life," or "I don't understand why you're always sick when it's convenient for you," then it may be time to think about cutting them out of your life.

If you have people in your life you want to keep close to you, but they are having trouble understanding your illness, consider bringing them along to a doctor's appointment or to a lupus support group. This can enlighten them on what exactly it is you're going through. Having a doctor or medical professional explain the disease to them may also help them understand in a way they were unable to before.

Even though it may be difficult, true friends will always understand and be gentle with you. Don't shut yourself off from everyone who makes a silly comment — we all do it every once in a while — and give people a chance to get used to your lupus. Make sure people have a chance to be a good friend — and most will!