The Hardest Parts of Having Lupus

by BARBARA LEECH

What the Hardest Parts of Having Lupus Teaches Us

When you have lupus you are constantly on a rollercoaster of emotions. Besides the obvious times where the wolf (aka lupus) poses a major threat to your life, there are so many other moments that stand out as some of the hardest situations to deal with. They seem etched into my memory, which is ironic since I often can't even remember why I entered a room. But there they are nevertheless.

Many of my hardest parts of having lupus moments are based upon what this disease has stolen from me, how I view myself, and how others treat me. I have learned many things about the true nature of people who love me, and in some cases that have not been easy.

Most People Will Disappoint You, but Some Will Surprise You

My husband said that to me once, regarding a dark, emotional moment of being let down by family in the most hurtful way. It has proven to be very true.

In my life, those who believe themselves to be there for me seem to fall short when it comes to simply listening, offering a gentle hug, and asking, "What can I do?" Instead, I have been preached at with such nonsense it feels like I have been attacked.

"If you think about a disease, you manifest it." No, I had lupus before I even knew I what it was — I did not "manifest" it. "If you just think positive, only positive things will happen." Again, no. Just no. I have had so many sudden unexpected attacks on my body when I was at my happiest and convinced I had it all beat.

Even more insulting was when, on several occasions, I was told by someone it was my karma to have lupus. Really? I am not perfect, but I consider myself a spiritual, praying, relatively moral person.

I give to those worse off than myself and offer to help others even when I am sick. I am also kind enough to watch what I say as to not hurt people with my words. What kind of karma does it cause to tell someone who is suffering daily that they are simply getting what they deserve?

Then there is the opposite side of the coin: my husband and children, who have surprised me with the love and support they continue to offer me. Thankfully, some people do surprise you in a good way, but the disappointment in most people and how they have reacted is one of the hardest things to deal with.

What Lupus Steals

Lupus steals important things from our lives. For me, it has been things like:

- **My hair.** I have lost so much hair I do not recognize myself.

- **My normal weight.** It is all over the place depending on my medications and how bad I feel.
- **The freedom to enjoy a day without pain.** Seriously, I don't know when I last had a day without pain.
- **My time.** It has been stolen by doctor's appointments and hospital stays.
- **The joy of waking feeling rested.** Lupus has stolen my ability to feel ready to tackle whatever comes my way.
- **The ability to go out into the sun.** I can't do this and not worry it will cause a rash or a flare.
- **Getting through a to-do list.** This is impossible without feeling overwhelmed by pain or exhaustion.
- **Doing activities with my kids with ease.** Things just aren't as easy as they used to be.
- **My job.** Working in my profession as a salaried manager, complete with title and nice benefits.
- **Being the fun person my husband married.** No matter what, in every situation it seems, I have new limits because of lupus.

Of all of these things, one of my hardest moments came the other night as I was putting my children to bed. I was so exhausted, I felt near tears.

As my two boys bickered a bit and delayed getting under the sheets, I said, "Please, mommy doesn't feel well, so can you just get into bed now?" The response hit me like a ton of bricks: "You never feel well."

It is important to know I try and hide the bulk of my illness from my kids. But, lately I guess I have been asking for cooperation by appealing to their sympathy. I guess that was wrong because hearing my child say that, like he is stating the obvious, was a very hard moment.

That is the last way I want them to think about me. Yet, there it is. And it is not untrue.

The Truth Is in These Moments

The hardest parts of having lupus also include having had to reinvent my career, which has taken so much of my self-esteem. I freelance full-time now, which is a huge blessing, but it has taken me seven years to develop enough work to be a real full-time income.

In the beginning years of working from home, I felt ashamed and worthless. Stripped of my title and salary I had no gauge to judge myself other that what others thought.

Facing myself in the mirror is hard as well. I know it may seem shallow, but I am not who I was before lupus. Seeing the visible results of this disease and what it has stolen from my body is hard on my soul.

I think each of us with lupus have our own hardest moments while battling the wolf. These are moments the outside world does not even consider when they think of our battle — if they actually think of our battle at all.

While the big struggles, like for survival and life, are obvious, these others linger beneath the surface for many of us. They are what ignite depression, despair, and feelings of anger and resentment. They are what we fail to speak about.

I hope sharing my experiences regarding difficult aspects of having lupus will help others feel less isolated and alone. There is safety in knowing this disease is hard on a person in many, many ways, even the ones less obvious.