Being More Than Lupus

by BARBARA LEECH

We Are Not Defined by Lupus

Lupus warriors Anna Scanlon and Barbara Leech share how to separate yourself from this disease.

Barbara's Story: When Disease Invades Your Life

My eight-year-old son recently wrote a bio of himself for a school project, and the part about family really struck me hard. It read, “My dad is funny and makes me laugh. My mom has lupus.” I read it and my heart began to ache.

This is what my legacy sometimes is — disease and illness. I don’t want my children’s memories filled with disappointment because I was not there for them, or that I was present for them but no fun because I was ill. I want them to remember good times with me, but I fear that the wolf has set unreasonable limits to my “normal” moments.

As a mom of four with lupus, it is a daily battle between guilt and endurance. Both have had years of intense training with lupus serving as their relentless coach. Some days I endure well, others I fail miserably. I have tried to make peace with both, but I am only human and I feel like I am battling daily to be more than lupus.

Lupus presents unique parental challenges. Plain and simple, I cannot always do what I want, when I want to do it. The weather, temperature, sunshine, and the intensity of a flare all dictate if I can attend some of my children’s activities or simply jump in the car and go do something with them.

Even playtime is not the joy it should be and I often struggle to keep up. What should be fun becomes a test of strength, and it is exhausting. I see other parents and feel cheated of what they all seem to take for granted — laughter and fun without a price tag of pain.

My older children, ages 24 and 28, still need me. Honestly, all four have moments and occasions that I should unquestionably be present for. But, these demands with lupus mean I carry a load heavier than most in order to keep everyone supported as they should be, and I usually find myself so tired I can barely communicate my need to rest.

As a result, I ignore housework tasks then feel guilty until either disgust or a need for everyone to have clean underpants motivates me do what I must do. I live forever on a treadmill with guilt and endurance running beside me.

How I Battle to Be More Than Lupus

Though some days I feel lupus has won, I try to overcome and be more than just this disease. I hope my kids see that. I hope they realize how hard I fight — and that I do so mostly for them.

There are certain things, no matter what, I refuse to give up doing — things that matter. Hopefully my kids will remember me cheering them on, the amazing birthday parties I put together no matter what, all the crazy inventive cakes I create to go with their theme, the tasks I take on to make holidays, parties and everyday moments special for them.

I hope they treasure the small adventures I plan; like random scavenger hunts and picnics in the park followed by ice cream. I want to be known for these things, not my disease.

So many times this week I wanted to surrender and just go back to bed. I don't do it and I desperately want to be remembered for that strength as well. If they are going to think of lupus when they think of me, I want it to be focused on my endless endurance. I want to be thought of as a warrior, not a victim.

Tricks to Put Lupus in Its Place

I have found a few tricks in meeting my motherhood expectations:

- **Though I really do try not to complain too much, I do try to keep it real.** Mommy gets tired and is only human. I have limits and though they may be caused by lupus, they are a part of life for many people, not just me.
- **Sometimes you have to say no.** Simply put, children do not have to participate in every single sport, group or activity that exists. My kids pick their top interests, but moderation is key. I only help out at school for certain events; I must say no to some activities and commitments and not feel less of a person for doing so.
- **Eat for health.** I cook complete meals 95 percent of the time, even if it means using the crockpot. Real food is vital to avoid flares.

- **Plan ahead.** I always create a strategy to help me endure. If it is cold, I utilize chemical hand-warmer packs (found at home improvement stores) tucked into my coat pockets, gloves and boots. For events or parades, I secure a viewing spot near a store, café or my car, so I can escape inside if the pain becomes too severe.

I am certain my kids do not think about lupus most of the time. I try very hard not to make it a topic of conversation every day or focus on the challenges, but I know they are aware it has impacted who I am and how much I can do sometimes. That is our reality.

The positive side of this is they have learned compassion from seeing someone struggle and persevere. I hope that I am making the impact I wish to, and in the long-run will be remembered for what I do for them, not what lupus has done to me.

Next page: Anna's advice for not letting lupus define you.

Anna's Advice: Don't Let Your Lupus Define You

Being chronically ill, no matter the illness, can fast become your identity. This can especially happen during really long lupus flares or other related illnesses that require spending quite a long time in recovery. And the longer you have lupus, the more susceptible you are to feeling as though lupus defines you as a person.

Just as other people are good at certain skills, you may feel as though lupus is your defining feature. However, it is essential to your mental and physical health that you do not let your entire existence become defined by this illness.

Personally, this has been a struggle of mine, especially when I am feeling really ill. Although I still have several major hobbies I can participate in since being diagnosed with lupus, it has taken away some hobbies and limited others.

Before being diagnosed with lupus, although I wasn't an amazing actor, I had a lot of fun performing in semi-professional and amateur productions. This also afforded me an amazing social life and I ended up meeting some lifelong friends. Additionally, I competed in Irish step dancing – not very seriously, but it was a lot of fun to travel, meet new people and dress up.

Because of my lupus, I have become incredibly unreliable, since my illness and exhaustion seem to be so unpredictable. I still Irish step dance occasionally, but performing is totally out of the question as I am never sure if I can make it to rehearsals or performances. As such, after my diagnosis I felt like a large part of my identity took a hit and I became someone who was simply sickly. I've even had people say they think of me as a particularly sickly person, meaning that this has, unfortunately, become one of my identifying features.

The Mental Health Impact

If you constantly focus on the things that made you 'you' before your diagnosis that you've had to give up, lupus will rapidly become your identity. As a result, you will begin to alienate yourself and others, convinced that no one else understands you and spending all of your time either talking to other lupus patients or talking about your lupus.

After a time, you can even develop pretty serious anxiety over the state of your health, reading up about the serious complications of lupus and unnecessarily worrying that they've finally caught up to you.

This kind of vicious cycle is also very common in patients who have mental health issues, who are convinced that an eating disorder or depression are their identity and what they are good at. This can prevent a person from making a full recovery. And although maintaining a healthy life with lupus is both mental and physical, lupus becoming your identity can seriously make your mental health decline rapidly.

Depression and anxiety are both common with lupus patients, whether they be organic or situational. However, allowing lupus to completely take over your life (even more than it already has) can wholly exacerbate the situation and make you feel even worse. Like everything in life, maintaining your identity with lupus is about balance. You cannot completely ignore that you have lupus, but allowing it to become the focal point of your life makes things worse for everyone involved in your life – but mainly for you.

Learn to Compartmentalize

In order to keep your identity separate from lupus, it is important to learn to compartmentalize in a sense. Although there will be times when lupus does take over your life, you can try to "put it in a box" the other days so that it isn't the main focus.

You can do this by joining forums online to speak to other lupus patients or seeking out local lupus support groups. This will allow you to speak to other patients, compare notes and talk about what's going on in your life with people who actually get it. For me, this helped me feel both less alone and less like I was some sort of ill anomaly within my friendship group.

Getting to know other people with lupus and discussing your everyday struggles allows you to put your lupus "in a box" instead of letting it bleed over into everyday life when it doesn't actually need to.

I find that consciously limiting your discussion of lupus helps maintain a life and identity outside of the disease. Make no mistake, this doesn't mean that you shouldn't speak to people about it, especially to your partner and close friends, particularly when you are feeling overwhelmed and down. But consciously limiting your conversations can help you not focus on, or obsess over (especially if you have anxiety) symptoms and can actually lessen some of the pain in your body. Most of us with lupus are in pain on a daily basis, but I find if you try to take the mental focus off of it, you don't feel it as much, making your life much more tolerable.

Keep Up With Your Hobbies

Additionally, it is equally important to continue activities that you enjoyed before lupus. You may not be able to do them to the full extent you used to, but you'd be surprised at how you can still stay involved.

Although I am an unreliable actor, I stay involved in theatre by writing, working with dramaturges and sometimes helping out in various aspects of costuming, teaching and am always an enthusiastic audience member. Likewise, I no longer compete in Irish step dancing, but when I am able, I still take classes in order to keep fit and have fun.

Some of my other pre-lupus hobbies and passions are, thankfully, ones I can still participate in even when I am having a flare (except, of course, when I take medicine that makes it difficult to think). As a writer, keeping up with my work takes discipline, but it is entirely possible to do—and I have been successful with it. Writing also allows me to keep my mind off of lupus and any symptoms I am experiencing for hours at a time.

If lupus makes it impossible for you to keep up with any of your old hobbies, there are still many things you can do with lupus in order to retain an identity outside of it. Writing, reading, sewing and gentle exercise are all great ways to escape your lupus while being kind to your body. You can also take your new diagnosis as an opportunity to explore new things that you may not have had time to do before and discover facets of your personality you had hiding beneath the surface all along.

No matter what you choose to do in order to retain your identity, remember that it is important to keep a balance in life. If you allow your lupus to take over, it will only have a negative impact on everything else. Instead, remember who you were before lupus and keep that in mind at all times.

You are still that person and always will be, no matter what gets in the way. And lupus can never change that – unless you let it.