What It’s Like Being a Lupus Mom

by BARBARA LEECH

Lupus Mom: The Struggles Are Real

My children know I have lupus. What on earth would be the point of hiding it and having them just think I am *choosing* to cancel plans or avoiding doing fun summer activities with them? That would be worse than them knowing the truth and dealing with it.

Lupus is a part of our lives. I fight this battle every day, and some days are simply better than others.

This is what my legacy sometimes is: disease and illness. I don’t want my children’s memory banks filled with deposits of disappointment because I was not there for them, or that I was present, but no fun because I was ill. But much of that is out of my control.

So, my kids know the basics of what lupus is. I stop short of anything that might be scary or too worrisome.

They know that some days I endure well, others I fail miserably. They know I have pain and that I get very tired and the sun makes lupus angry. Living with lupus seems to offer a lesson each day for all of us.

Is Mom in Control? Not Always

Lupus presents unique parental challenges. Plain and simple, I cannot always do what I want, when I want to do it.

My kids need to know this so they don’t take it personally. The weather, the temperature, the 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.

Challenges include:

- **Playing ball or riding bikes with my kids is sometimes beyond my energy level.** I feel like I am a horrible parent for saying, “No, I can’t today.” I worry this is what they will remember. 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.
- **Active schedules with children mean dinner can be delayed until nearly 8 p.m. on some nights.** While other parents may just grab some fast food, for me, lupus eliminates that option. Lupus triggers like fast food can increase a flare drastically, so eating the right lupus foods is crucial. My kids see how careful I must be to eat healthy and I think this sets a good example, but it also reminds them I have a very pressing health reason behind my caution.
- **Being a baseball or soccer mom can be extra challenging.** I want to be sitting on the sidelines, but it can mean being at a ball field in 50-degree temperatures or roasting in the sun in 90 degrees.

- **My joints hurt so bad that simple tasks can be horrible to endure.** Being mom's taxi service means holding a steering wheel to drive even when the pain is more than I can bear. I try to hide it, but my kids know the difference in my mood and personality when I am in pain.

I have two older children, ages 25 and 29, who still need me — in different ways of course.

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.

The result is that I push through most of the time. I do it for them. I ignore what I can, like housework tasks, then feel guilty about it.

Next page: the struggle as a lupus mom.

The Struggle as a Lupus Mom

Somedays I lose the battle to push on through. I hate those days. I end up lying around thinking any moment I will revive enough to keep going, but I don't.

There are some very bad, painful hours spent hating my condition and myself. I hope my kids know I am fighting to be better. I hope they realize how hard I fight — and that I do so mostly for them.

I struggle to make the memories with them that I hope outshine the bad days. Hopefully my kids will remember me cheering them on, the amazing birthday parties I put together no matter what, and 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.

Recently, I have been in a lot of pain. I have gotten too much sun (this is where a sun protection kit comes in handy) and it shows. I have been doing too much as I try to keep up.

I confess, I have wanted to surrender more than once in the last week. But I didn't. I desperately want to be remembered by my kids for that strength as well. If they are going to think of lupus, I want to be thought of as a warrior, not a victim.

Lupus Mom Survival Tips

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

- **Eat healthy.** I cook complete meals 95 percent of the time, even if it means using the crockpot. Real food is vital to avoid flares.
- **Lupus moms are people too.** Though I really do try not to complain too much, typically hiding most of what I endure each day, I do try to keep it real. Mommy gets tired. Sometimes everyone, even I, needs to take a break. I have limits and though they may be caused by lupus, they are a part of life for many people, not just me.
- **I must say no sometimes.** Simply put, children do not have to participate in every single sport, group or activity that exists. I am not "super mom." My kids pick their top interests, but moderation is key. I must say no to some activities and commitments and not feel less of a person for doing so.

- **Plan for everything.** 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.

My kids don’t focus on my lupus. They simply have an understanding of what is happening when I can’t do something with them.

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. They have learned to support me and be there for each other too, and that is not such a bad lesson for them to learn.