Making Everyday Life With Lupus Easier

by BARBARA LEECH

How to Manage Your Everyday Living With Lupus

The word “chronic” says it all. Living with lupus is ongoing, relentless, and at times it feels I will never get a break to simply catch my breath.

In fact, as I write this, a period of pleurisy makes it painfully difficult to breathe at all. But I must. Life, work, all those daily tasks just keep demanding for me to push on through.

You probably know what I mean; lupus warriors are known for their strength and courage to persevere, but what others without this horrible disease define as strength is often simply not having any other choice.

Days like today, when the pain is constant and I have a foreboding shadow hanging over me warning me that this flare may intensify, I become the great pretender. I pretend all is fine and I can do whatever is required.

Truth be told, I do far more than what is comfortable or what I probably should. Being a mom of four requires a special level of resilience that does not allow me to cater to how I really feel. The truth behind the smile is that I am struggling.

I think we all do this. We push to accomplish more than what lupus wants to allow us, because not doing so would be letting the illness win. We devise strategies, which somehow get us through those tasks that must get done.

Sometimes it is my strategy — not my strength — that makes me *seem* like a superhero to my family.

Here are some strategies for taking on everyday tasks while living with lupus — superhero cape optional!

Focus On Your Top Priorities

You cannot be all things to all people even when you are healthy. In a lupus flare, it is vital to pick the most important tasks you need to do and focus on what matters the most.

This means saying “no” to some things. Will your kids remember you taking them to all their soccer practices and cheering for them, or will they remember how all the laundry was neatly folded and put away?

When I think about what matters — what *really* matters — housework falls to the bottom of my list. Some things can wait, some things I can ask for help with, some things simply will not matter in the end — like how neat your husband’s sock drawer is.

Admit When You Need Help

I do not like to ask for anything — it makes me feel weak. So, I am in a battle with my ego on this one quite often.

But, there are times when I must admit I need a little help. If I am struggling to make dinner, I ask my husband to help chop or do some of the reaching and lifting required to get a pot roast in the oven.

I ask the kids to help with things like fetching me ingredients or stirring a pot of soup. They often set the table and — here is the remarkable part — they seem to sense when help is needed, even if I have been hiding it.

Accepting help means everyone is working together and pitching in, so asking for it should be a guilt-free request.

Break up Your Tasks Into Manageable Amounts of Activity

This is hard when you are a mom. Grocery shopping can be strenuous; I often will go and buy all the smaller items, then my husband will pick up the few heavy objects on his way home from work.

If you have nobody you can ask to do this, try breaking up the shopping trips for yourself, so the heavy items are not bought the same day as the mass quantity of items. It is easier to handle bringing in a large package of 24 water bottles if you are not also hauling in several bags of groceries from the same shopping trip.

Clean, but Don't Choose Sparkle Over Health

I am a bit of a clean freak. It makes me nuts when the kitchen is dirty and there is clutter everywhere.

But, I often cannot keep up with the housecleaning because my children and my job seem to require whatever energy lupus has left me with. My strategy is to just do the basics, prevent the spread of salmonella, and take comfort in the fact that nobody in my family notices if I have cleaned or if we are living in a sticky mess.

They do not notice. So, I clean the counter and sink. I buy anti-bacterial wipes and get the mystery crust off of the refrigerator door handle.

Some days I just do the bare minimum required to keep the kitchen safe for food preparation. Take my advice and save the big clean up until there is a day where you feel you can tackle it — and survive it.

Rest When You Can

I need to follow this advice more. When rested, you can tackle more of your everyday tasks. If you can, squeeze in a nap before you head out with your must-do list.

Go to bed earlier than normal if you are very fatigued. Drink herbal sleepy-time tea (look at ingredients and avoid melatonin, which can aggravate flares) to help promote good sleep or ask your doctor for something to help you get the solid sleep you need.

There are days when we all feel we are struggling to keep up, and are failing miserably. Remind yourself that you are doing the best you can — this disease is not easy to live with, and your best is good enough.

Also, do not compare how many tasks you accomplished on any given day with anyone else. We all can feel competitive and our healthy friends on social media always seem to be accomplishing so much.

Don’t compare. If they do not live with lupus, they have a totally different reality than you.

You my friend, who is living with lupus, are the warrior. Take pride in all that you *do* accomplish, the adjustments you must make to simply get through the day, and your strength to persevere — even when you do not want to.