Lupus and Winter Loneliness

by BARBARA LEECH

How to Survive Winter Loneliness

Lupus has changed me. I am much more isolated and disconnected from the rest of the world than I ever dreamed I would become.

Winter is usually worse for my lupus than other months of the year; it seems to ignite greater pain and exhaustion, flares are more intense, flu is in the air, and strep always seems to find me the second I leave my home. So, I am about to enter what I call lupus hibernation — it can be very lonely.

While friends and family are all planning get-togethers and fun outdoor winter activities, I have found I must hide from the chaos and germs in order to get through the winter with some shred of my health. The discomfort of cold weather has made me numb to those normal urges for human connections. I find interactions with others is often just too much on top of everything else I am dealing with.

This Is Not Who I Once Was

I once was the editor of two newspapers, and before that a beat reporter. I talked to dozens of people every day, attended meetings, and worked with many, many people as part of a newsroom team. My day was once filled with interactions with other people, often for 10 to 12 hours at a time.

Since lupus, and the birth of my third child, everything changed. I had to make some difficult changes. I had to reinvent myself and my career.

Today I work mainly from home. Even though I have an office 45 minutes away in a beautiful building in the city, I telecommute. It is just easier as a mom and especially as a mom with lupus.

But, that ease brings a downside: I am isolated. But, I know others with lupus feel this way too, so though I am isolated, I am not alone. If it were not for the connections I have on Facebook and lupus support websites, I am certain I could go weeks without connecting with anyone outside of work and family.

That is a depressing and lonely fact about lupus that nobody seems to realize, except those of us who have the disease.

Lupus can make you avoid social occasions, or even just getting together with old friends or exerting the effort it takes to make new ones. Often, I spend so much of my energy trying to cope and manage the pain and what my body is going through that I don’t want to go through what is required to be social.

Sometimes my words fail me, along with my memory. It is hard to articulate exactly what I am thinking or to hold a good conversation for any length of time. I find myself looking towards the door.

I am simply am in no condition to make small talk. So because of this, I can go days without conversational laughter of any kind. I am the Lone Wolf and I can tell you, it is not good for the body or the mind.

Breaking the Lonely Habit

With lupus it can feel like you are marooned on an island. It is not easy to break these habits and to force yourself to be social when you are battling pain and illness that nobody you encounter seems to understand. The only ways is to start bringing yourself back into life is through taking small, manageable steps.

At first it will feel awkward, and if you are like me, you will be longing for your yoga pants and the comfort of your sofa. But I assure you that breaking the isolation is important to your body and mind.

If you are ready to have a less isolated winter, here are a few tips to get you started:

- **Prepare for the cold.** Lupus and cold weather sends Raynaud's syndrome into overdrive. Plan for cold outings with layers and warm mittens (complete with hand warmers) because the more comfortable you stay, the better you will feel, and the more social you will become.
- **Join a few support groups online.** The best part about these new people is they will know exactly what you are going through. I have even found a few friends that are not that far away from where I live.
- **Find ways to heal and relax from stress and pain.** Try meditation, Reiki or yoga groups or classes. You will not only work on managing your condition, but you will also gain a connection with the people in class.
- **Join an organization and volunteer for small things.** I cannot always commit to ongoing volunteer work, but I will volunteer a few hours for a school party or in the classroom. It is something I can manage and it connects me to other mothers and teachers, even if it is only for a bit of small talk.
- **Join a gym.** That's right, I am suggesting exercise — but within reason. If you can walk for a little while on a treadmill in the comfort of a warm gym, the cold, dark winter months will not have the same effect on your mood or body.
- **Call a friend just to chat.** On days when you can't handle that, try texting friends or family. Sometimes you are so exhausted it is an effort to form words, so texting allows that connection with less work.

Lupus can steal so much of your life and who you once were. Do not let it totally isolate this winter. My social life may be altered by lupus, but I am fighting to create a new way to stay connected and to reach out to people while dealing with this condition.