Coping With Lupus and Isolation

by BARBARA LEECH

Lupus and Isolation

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 is the ultimate foe of social occasions, getting together with old friends and making new ones. I spend so much time dealing with what my body is going through that I don't want to go through everything that is required in being social. Showers are sometimes my main mission for the day. I am often in no condition to make small talk. I can go days without conversational laughter of any kind. Feeling sick and lonely together is not a great combination. I am the Lone Wolf and I can tell you, it is not good for the body or the mind.

I thankfully work from home, but this further isolates me. Basically, unless I have a meeting scheduled, I don't see anyone face-to-face other than my immediate family or strangers at the grocery store. To top it off, I moved to my husband's home-state a few years ago and lupus went into a full-blown flare, so I have not gotten to know my new community or anyone who lives here. It feels like I am a sole survivor on Lupus Island.

Breaking the Isolation

It is not easy to force yourself to be social when you are battling pain and illness that nobody you encounter could possible understand. I recently started with baby steps in getting back out there socially, because this isolation I found myself in had to be broken before it broke my spirit. Here a few things I did to get 'back in the game':

- I joined several support groups online for Lupus and began to welcome the connections and friend requests to chat. This gave me a connection to new people who know exactly what I am going through and I have learned that some are not that far away from where I live.

- I committed myself to attending a healing group once per week. I am a Reiki Practitioner, so I chose a group where each attendee receives Reiki treatment for the healing of whatever their ailment. I have met people who have a variety of challenges, from arthritis to cancer, and there is a feeling of community in this group. I was recently asked to provide Reiki treatments as well as receive treatment and my connections to these amazing people has grown.
- I volunteer for small things. I cannot always commit to ongoing volunteer work. I never know when Lupus will take me down for the count and I will leave a large void for others to fill. (Enter Lupus guilt). But I will volunteer a few hours of my time 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.
- Texting friends and family. Sometimes you just don't want to talk. I get so exhausted it is an effort to form words, so I text. It keeps me connected, answers questions and seems to be easier for me than holding up my end of a conversation.

Lupus steals so much of our lives. I refuse to allow it to totally isolate me any longer. I refuse to allow myself to feel both sick and lonely. 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 lupus. It is time to live, love and laugh despite the lupus.