Why You Should Make Friends With Fellow Lupus Warriors

by BARBARA LEECH

The Support of Lupus Friends

Walk a mile in my shoes. Sometimes I wish my friends could do this, if not for a mile than for just a few yards, in order for them to have some semblance of an idea of what I am going through with lupus.

The fact is, walking is not required. They could just stand there and still soak in all the pain, fatigue and the weight of it all.

There are days I swear I can feel gravity. The fatigue is so strong I might as well be trying to walk through quicksand, and the pain so severe I fight back tears because I know if I let the first one fall, it will open the gates to a full breakdown.

It is on this type of day when one of my healthy friends, one who runs 10 kms for fun and thinks I just feel “a little sick sometimes” can give me a moment of pause as I try and make that connection I so desperately seek. In fairness to her, she does not live with what I do and though she tries to offer a wealth of compassion, I feel a distance form as she listens to me tell her about my week.

She feels sympathy for my struggles, but she does not understand — not really. She and I both feel that we have less and less in common now, and that hurts deeply.

I have found that friendships with fellow lupus survivors — my "lupus friends" or "fellow lupies" — can fill a void left by my other friendships, however. You can never have too many friends!

And no, I did not already have a group of friends that had lupus. Some I have sought out through support groups, others were people I have recently encountered, as if they were placed in my path for a reason.

One friend I've known for the last few years and she suddenly is in the process of diagnosis. My suggestion is if you feel a disconnect with your regular circle of friends, expand your circle to include a few who have lupus.

Finding Fellow Lupies

Friendship with others who have lupus can be an amazing comfort, but how do you find them?

Join Lupus Support Groups

This can be on Facebook or through the actual websites and blogs of other lupus warriors. In most cases if you do a search on Facebook (just type “lupus” in the search menu), a list of suggestions will appear. These are people from all over the country and the world, but chances are, there are a few that live near you.

Even if they are not local, online friendships can offer amazing support.

Find Local Chapters

Contact the Lupus Foundation of America about local chapters of support groups near you. There are some across the country and they are often held at clinics or in hospital meeting rooms and can be led by either a fellow lupus survivor or even a nurse.

It is mainly a way to connect and gain support, but it can lead to great friendships with local people.

Start a Group of Your Own

You can be a true warrior by starting your own lupus group, maybe include similar autoimmune diseases — fibromyalgia and crohn's for example — so your group can grow, but still contain people who relate to each other. Meet at a park or at the local coffee shop or public library.

There is a saying, "There is safety in numbers," and perhaps that is why I felt safer in my own skin once I developed friendships with people going through the same struggles.