Lupus Support Groups: More Than Just a Meeting?

by AVA MEENA

Should You Try a Lupus Support Group?

I have often wondered if the time and energy required to attend a support group was worth the exertion. One meeting takes nearly three hours of my time, and the process of going is strenuous enough that it's usually the only thing I can accomplish that day.

However, it only took one lupus support group meeting for me to realize that the right group is certainly worth it! My group has quickly become one of the most valued things in my life.

Here are a few reasons why I've found joining a lupus support group worthwhile and why I encourage you to make going to a support group one of your top priorities.

What Is a Support Group?

Support groups are usually organized by professionals with experience of the condition to which the group is focused on; someone such as a lupus nurse. However, a growing amount of support groups are being set-up by the very same people who are living with a chronic condition — people like you and me!

Some support groups can take place on a regular basis; either weekly, monthly or several times throughout the year. Depending on the size of the group, meetings can happen in a set place, such as a community center or a church hall. If the group is small, some people meet at a member's home.

What Do They Offer You?

Support groups offer:

- **A safe space.** Within the privacy and comfort of a support group, you are able to build relationships with other members who can understand what you are experiencing.
- **Shared experience.** The majority of those in attendance at a support group will be just like you. You can share your day-to-day challenges — for example, your daily medication list!
- **An opportunity to be yourself.** Support group members are able to empathize with you, something family and friends cannot always do. The space to be yourself can be both a tremendous relief and also extremely emotional.
- **A place to obtain and share information**. A support group is a great place to give and receive relevant information on your condition and/or associated conditions and medications.
- **A place to find out if you are eligible for external financial aid/support.** Who better to ask what is available than people going through the same thing as you?

Support Groups Bring Solidarity

Dealing with a disease like lupus isn't something you should try to do on your own. Life with lupus can be difficult –even scary–and you'll benefit immensely from meeting people who have first-hand experience with what you are going through.

When I attended my first support group meeting, I was stunned and relieved to realize that other people were facing the same challenges. Even though I had read other people's stories online, it was hard for me to believe that someone could be as sick as I was until I spoke with them in person.

After connecting with other lupies, I no longer felt as isolated when my lupus symptoms appeared. I knew I belonged somewhere and I could reach out to fellow group members when I needed compassion or advice. Having that camaraderie with others made my battle with lupus a little bit easier to fight.

Next page: what to expect from a support group, and looking at online support.

A Place to Share Experiences

Finding a support group is an important step for every person with lupus, but it's especially beneficial if you have recently been diagnosed. Someone new to lupus will likely find an intimidating amount of information available when they begin their search for answers.

There are lupus warriors in my support group that have been living with the disease for decades, and they have a wealth of knowledge to share. My first several meetings served as a much needed crash course on how to live well with lupus. I learned crucial details that I may not have discovered on my own for months or years.

For example, other members warned me about things that can potentially cause problems for people with lupus – such as routine dental cleanings and fluorescent lighting. They saved me from more than a few headaches by helping me figure out what to pay extra attention to or possibly avoid. They also shared tips with me, such as the fact that my state provides a medical exemption for car tinting, which can help with my lupus photosensitivity.

Finding a lupus support group means you'll have a pool of experience you can draw from each time a new or strange problem arrives. You can also share your expertise with other members; I've been filled with joy and a sense of purpose each time that I've been able to help another person with my suggestions.

Finding a Lupus Support Group

You can search for a lupus support group by state on the Lupus Foundation of America website. That is how I found my group and I've benefited from the group's connection to the Lupus Foundation.

Other places to check for local groups include Molly's Fund, Meetup.com, and your local news sources. Ask your rheumatologist if they know of any groups and be sure to try searching for "lupus support group in [your city or region]."

Don't settle for just any group, however. I had gone to support groups before that were unable to stay on topic, ran far over the allotted time, or were so cliquish that I didn't feel included. You want to find a cohesive group that has your best interests at heart.

What If There Isn't One?

Even though there are millions of people living with lupus, sometimes established support groups are spread a bit thin – especially if you don't live in a larger city. There are a few options to consider if you aren't able to find a lupus support group near you.

Start Your Own Support Group

Chances are other people with lupus probably live in your vicinity and would like to have a support group available to them. It may seem daunting to be in charge of a group, but you could start simply by having a cup of coffee and getting to know other lupies. The group can be as formal or informal as you would like it to be.

If you decide to lead your own group, be sure to prepare a topic, an icebreaker, or a few questions for your first meeting. If you want more guidance you can check out some tips from the University of Kansas Community Toolbox for creating and facilitating peer support groups.

Find Something Similar

If you aren't ready to start your own group, try looking for a less specific support group instead. Perhaps you can find a group that focuses on autoimmune diseases, chronic pain, or chronic illness in general.

Lupus tends to overlap with other diseases, and you will likely benefit from meeting a wider variety of people living with a chronic illness.

A chronic pain support group recently started in my area, and I've learned a lot from attending since lupus does cause me to have high pain levels frequently.

Look for Online Support Groups

While a more generic support group may be useful for having an in-person experience, they may not be able to help you with things that are unique to lupus. In that case you may want to consider finding an online support group.

The Lupus Foundation of America offers an online support group and Molly's Fund does as well. These groups are likely to have good facilitators, but if you decide to look elsewhere for online support be sure to proceed with caution.

Online groups can be rife with problems; some may ultimately bring you down with constant pessimism or be full of health shams. You can find some advice about what to look out for in an online group plus more online lupus support groups at Pain Doctor.

Are You Missing Out?

Support groups are missing out on you if you don't go to them! You are unique and with different talents and qualities that could benefit any group, especially a group/meeting that focuses on a condition that affects you directly.

Before lupus, you had goals and dreams. After lupus, these goals and dreams may take longer to achieve, or have had to change due to the amount you can do every day, but the essence of you still exists!

We all bring our individual experience to everything — and lupus is as individual as they come.

Your story could also inspire someone else. Many times you have gone through and survived much more than you give yourself credit for. Sharing your success in the comfort of a lupus support group could be just what you need!