How to Help Someone With Lupus

by BARBARA LEECH

Offering to Help Someone With Lupus

Often the greatest form of support is simply the art of listening. Most of the time the things that actually help and support me are so very small, yet they bolster me up and keep me going.

Those of us with lupus often find ourselves in the awkward position of being offered help that is anything but helpful. We have well-meaning friends, family, or even spouses who just do not understand what we are going through.

Other times it goes beyond a general lack of lupus understanding to outright judgment of our condition and whether we are somehow perpetuating our illness.

Those who combine “help” with judgment tend to try to fix us by telling us the ways we would surely cure ourselves if only we focused solely on the positive, exercised more, took this new supplement they heard about, cleansed our body of all the supplements we are taking, got on certain medication, got off certain medication, and (my favorite) manifested a remission.

Most of the help that is offered to me is actually well-intended, even if its basis is slightly skewed. When a friend offers to get me out of the house on a day that is bitterly cold, she does not realize that I will actually feel a painful lingering reaction to being out in the weather that day.

When family invites us to come stay with them, they don’t realize that packing, unpacking, not sleeping well in uncomfortable bed, and eating meals of nothing but meat containing nitrates and served up hours past normal meal times will not make me feel rested or rejuvenated. It actually makes me feel horribly worse for the next two weeks.

Most people say they want to help but they don’t understand the criteria of what actually will help me.

Considerate Invitations

Offer to include me in activities focused on good weather, or make plans for inside. A person without lupus does not give this a second thought, but weather affects me. It is not a personal preference or choice; cold temperatures, snow, rain, or even extreme heat and too much sun affect what activities I can do.

This past winter was horrible for me. Invites to go sledding make me feel like an outcast, and taking an early morning walk in 20-degree weather is not going to help me. Attending a spring or fall barbeque dinner means sitting outside in cold air that settles deep inside my muscles and joints and hurts me for days.

Instead, helpful ways to get me out of the house include grabbing a coffee at a nice warm coffee shop or asking to meet me at the gym to put in a mile walk on the treadmill. Ask to come over to my house and watch a movie or

work on a craft.

Offer to Help With the Small Things

I don't want to feel like an invalid, but there are times that the small things seem huge to me. I will run out of eggs and milk and the thought of getting myself down to store to fetch them is just too much for me to handle that day.

My husband is amazing at these small, meaningful ways to help me. He has made it a habit to call me before heading home from work and asking if I need him to pick anything up on the way. I know I can count on this small thing, which means everything to me when I don't have the energy or I am in too much pain to tackle it myself.

This goes for other small things too. For example, running a small errand is an amazing way to help someone with lupus who is in pain or struggling to get through a day with no energy.

Really Listen

Really listen to what I am saying. This is huge. Nothing makes me feel loved and nurtured more than feeling that what I am saying matters to someone.

If I tell you about my lupus or a recent flare or issue with one of my organs, I am completely crushed when a week later you have no idea what I am going through or anything I already told you.

Then there are "helpful" people who listen and nod, and try and relate everything they hear back to something in their own life. Don't be this person. I would rather have someone listen to me vent about lupus or life and then say, "Wow, this just sucks for you. I am so sorry." I don't want you to say you know just how I feel unless you really truly have had the same experience.

I find comfort in simply knowing someone else agrees that what I am going through sucks and wishes me hope and improved health. Basically, when you listen to someone suffering and desperate, do not turn it around somehow into a story about you.

Never Assign Blame

I have been told that I have lupus because of karma coming back to me. Apparently I was very bad in a past life. I have been told that since I talk about my health issues, I am manifesting them into reality — which of course does not make any sense. I have been told that if I thought only positive thoughts, it would attract only positive things, including health.

First, it is hard to be positive when going through dire struggles and extreme amounts of pain. Second, everything I worry about does not tend to happen, yet every time I am feeling happy and positive, something unexpected and horrible occurs. The positive theory has not held up for me.

Whatever your beliefs, do not tell someone they are to blame for having a disease and suffering from it. Even in cases where the person's actions might have caused a disease, like a person who smokes who gets lung cancer, don't ever say something like that! Help never comes in the form of blame.

If you want to help someone with lupus you need to understand and empathize with what it physically feels like to have this disease. Remembering how things as simple as cold weather can impact us, listening with a compassionate ear, and offering us assistance in small ways that ease our burdens can make all the difference in the world.