Seven Things You Should Say to Someone With Lupus

by ANNA SCANLON

What to Say to Someone With Lupus

When you have a loved one with lupus, it may feel like you're hard-pressed to say anything right. To help you through it, I've come up with several things on what to say to someone with lupus in order to strengthen your relationship and help them feel more supported.

1. "I am sorry you had to miss the party..."

"Let's catch up another time. Maybe I can come over to your house or we can catch up over the phone if you don't feel like hosting?"

People with lupus will often miss social gatherings, either with friends or family members. People can easily take this personally, making the person with lupus feel guilty on top of feeling physically ill.

Many times, the person with lupus was actually looking forward to seeing their friends and catching up, but just wasn't feeling up to it. If you're genuinely interested in continuing the friendship and your friend isn't feeling well, instead, make arrangements to come to their house and see them.

If they're not feeling like hosting, you can always offer to chat with them via Skype, FaceTime or over the phone. This helps your friend feel like you do care and are there for them, even if it is just for a phone call, while they are feeling sick.

2. "I totally understand that you're fatigued. That absolutely sucks."

Don't try to compare apples and oranges by then telling them about how tired you are when they talk about their fatigue. You being tired as a result of working a full-time job and/or raising kids is completely different from being fatigued from lupus.

That doesn't mean you can't tell your friend about your daily struggles and feeling worn out due to day-to-day life, but be aware not to do it in the context of comparing your tiredness to their lupus fatigue.

3. "How are you feeling?"

People often ask each other this and don't really mean it. A lot of the time, lupus patients feel glossed over, or like their friends don't exactly care how they feel, or are getting bored of their talking about their illness.

Instead, listen with open ears. Remember, however, that lupus does not define your friend, so be careful not to place too much focus on their condition.

4. "Is that convenient for you?"

Lupus can be an extremely fickle disease, meaning your friend might be able to do one thing one week and completely unable to do it the next. That means sometimes they may be able to drive to a restaurant across town and meet you for lunch and sometimes it is just too difficult for them to get there.

You can ask if your plans work for your friend and simply listen to them without getting angry or offended if they need to change something to suit their health needs better. Remember, they can only do what they can do.

5. "Can I help you with anything?"

Coming over and helping a friend who has lupus is the mark of a true friend. This doesn't mean you need to be used by the person or become their personal maid, but if they are sick, fixing them meals or helping with cleaning or caring for their pets once in a while is a great way to show your friendship.

Most lupus patients will be extremely grateful (I know I would be) and will likely repay you in a way they are able.

6. "You know you can talk to me about it if you need to."

This is always really helpful to hear, especially if the person with lupus is having a hard time with their health or feeling like they are a burden on others. Knowing they have a soft place to fall is invaluable.

7. "I've read up on lupus…"

When I hear someone has done this, I really appreciate it. It means they took the time to educate themselves, if only a little bit.

Reading up on the disease gives you a bit more insight and understanding into it and allows you to really "get" the symptoms of lupus or why certain accommodations need to me made. Reading up on the disease will also help your understanding and make it easier for you to not feel as upset or take it personally when your friend or family member with lupus doesn't do everything you want them to do.

The Bottom Line

All of these things don't mean you should play the role of a doormat to your friend, only that you should be accommodating and understanding if plans change at the last minute or they keep missing things because they don't feel well.

It also means generally trying to say and do the right thing to make them feel comfortable or that they can talk to you if they need to. If the relationship is all take and no give, even if the person does have lupus, you need to re-evaluate it.

But that means you need to be reasonable when it comes to evaluating your relationship and not expecting them to do things they physically are not capable of due to their lupus.

However, having high expectations of someone with lupus to do lots of things at once or to stick to an action-packed schedule, especially if they don't feel well, only results in anger on both sides.

If someone you know is visiting you from out of town and they have lupus, be aware that the journey over to your house may have really taken a lot out of them. You can make some plans, but scheduling action-packed day after action-packed day can often lead to disappointment and resentment.

This has happened to me on several occasions and has lead to some pretty heated arguments with family members who have, in all good intentions, tried to plan lots of fun days out for us together.

For Anna's thoughts on comments to avoid, check out our article What Not to Say to Someone With Lupus.