What Not to Say to Someone With Lupus

by ANNA SCANLON

Here's What Not to Say to Someone With Lupus

Lupus can be a difficult disease to understand, especially because it comes and goes. Those of us with lupus can look completely healthy one day and then be bedridden the next, which makes many people question us and our disease.

This can be very frustrating. As someone who has had lupus for 10 years now (yikes!), the comments others make can be really annoying. We know most people are just trying to help, but it can still put a damper on your entire day.

If you know someone with lupus, these are just a few things we've heard quite often —and that you should probably keep to yourself. Here's an exact list of what not to say to someone with lupus.

"But you don't look that sick..."

This one is so common that there is even a website dedicated to it. People with lupus may look totally healthy, or even healthier, than others. Some people even experience a natural glow on their skin when they are ill, making them look even healthier and almost a bit tan.

But looks can be totally deceiving and don't always match how a person feels on the inside. If someone with lupus says they feel ill, believe them and move on.

"If you just lost some weight and exercised, I bet you'd feel better."

Weight and exercise can be very sensitive topics among lupus patients, especially for those with pre-existing body image issues. Unfortunately, lupus treatments (especially steroids) can cause people to gain weight no matter how hard they fight it.

Additionally, when someone is in the middle of a flare-up, exercise is nearly impossible. Many people with lupus (myself included) do enjoy going to the gym and exercising, but there are periods in their lives when it just isn't possible. Respect that.

"Have you tried taking fish oil/gin soaked raisins/eating three oranges per day/putting a raw onion on your foot?"

These are all legitimate things people have asked me. People with lupus have likely heard and tried it all. Although these things may help alleviate some symptoms, they won't cure lupus.

And just because it worked on your best friend's sister's hairdresser's arthritis doesn't mean it is going to work

on the lupus sufferer in question.

"Why don't you try the paleo diet/go vegan/cut out gluten/cut out dairy?"

This one is perhaps the one comment people make that infuriates me the most. I could write (and I have) an entire article on this concept alone. Some people with lupus do find that eliminating certain foods is helpful for them, but suggesting a restrictive diet as a one-size fits all cure is misleading and dangerous.

If you are the guardian or a carer of someone with lupus, it may be worth it to visit a dietician and rule out certain foods that may aggravate symptoms, but diet does not cure lupus. I have tried several of these diets that promised me a cure and often times I ended up more tired and feeling even worse.

Just because someone is resistant to try a highly restrictive diet does not mean they do not want to get better, it just may mean they've tried these things before with minimal results. You don't hear the stories of people who got minimal results on the websites and in the books promoting these diets, do you?

"Everybody's tired — I work full time and have three kids, so I know how you feel."

If you don't have a condition that causes fatigue, then you don't know how we feel. Yes, you may be tired from your busy daily life, and that's totally normal. But unless you frequently have days when you need to nap after taking a shower, or preparing a meal is too overwhelming, then you don't really know how we feel.

There is a huge difference between normal tiredness from daily activities and fatigue. On a really bad day I don't even have the strength to watch Netflix, and I spend all day sleeping. That's fatigue.

"I work so hard at my 9–5 job. Your life is so easy/you're so lucky to sleep in/spend so much time in bed."

Most of us would love to have a 9–5 job. Spending so much time in bed means we lose out on income opportunities, are constantly worrying about money and miss out on gatherings and events with our job, school, friends and family. Not being able to get out of bed isn't at all glamorous or fun.

"Why don't you just push yourself a bit more?"

Remind us lupus patients to ask you that next time you're laid up in bed with the flu. Having lupus is like having the flu over and over again ad nauseum. Next time all of your joints ache, you're running a fever and you can't do much more than turn over in bed, we'll ask you to push yourself a bit more.

"You're STILL not better?"

No. It's called a chronic condition for a reason.

"I can't believe you missed my event — you went to Sally's event last week!"

Unfortunately lupus is unpredictable and it may work out that we feel well enough to show up at one person's event and get sick when another person holds an event. It isn't personal and believe us, we hate missing events just as much as it upsets you that we don't show.

We already feel bad enough that we had to miss your special day or event, so please don't make it worse. Understand that we are trying our best, and that day it just wasn't feasible.

"You're far too young to have all of these problems!"

Tell me about it! I wish that were the case, but unfortunately lupus doesn't care how old you are.

Reposting things on the Internet with no scientific basis

For a while, there was a chain letter going around saying that lupus was caused by Diet Coke consumption, which is untrue. At another point, there was one going around saying lupus was caused by a build up of toxins in the body due to processed foods, and can be cured by flushing those toxins out. This is also not true.

As a general rule of thumb, lupus related or not, it is best to fact-check something before clicking the 'Share' or 'Forward' button.

Now you know what NOT to say, check out our article on helpful things to say to and do for someone with lupus.