How to Navigate Dating With Lupus

by ANNA SCANLON

The Tricky Business of Dating With Lupus

Let’s face it, dating is difficult, with or without lupus. There’s the endless searching and strings of dates (many ending with a “thanks but no thanks” in your head). If you’ve gone online to search for The One, it means spending hours on profiles vetting out potential matches. Finding your next boyfriend or girlfriend can almost be like a second job — and if you’re using a service, it's a job you’re basically paying to do.

But when you have lupus, it can add an extra layer of trickiness to the mix that non-lupus patients don't have to think about.

When to Disclose?

When you’re dating with lupus, there is always the question of when to disclose the information to a potential partner. If you’re online dating, do you put it on your profile so people know right away? Do you hide it from people and tell them once you known them a little better? When I was searching for a partner, this was a huge dilemma.

My mother, who grew up in the 1950s and 60s in the south, when/where you didn’t want your business to become other people’s gossip, thought I should guard myself and keep the information from a new partner for as long as possible.

And although this may sound like a terrible idea to many lupus patients, I have met a few for whom this actually works. The type of people who are usually able to hide this information for a long period of time are typically not very ill or are not suffering symptoms at the moment. Most of them can hold a steady job and participate in hobbies, and in that respect, it may be acceptable to hold off on the big reveal until you fully trust the new person in your life.

I, and many others, are not so lucky. For me, lupus is an everyday thing. I suffer with extreme fatigue, lupus joint pain and fevers on a daily basis.

When I’ve dated, I’ve had two schools of thought. While doing online dating, I listed that I had lupus SLE outright on my page. Unsurprisingly, a lot of men don’t even read what you’ve written, so there was those awkward moments when I had to explain it anyway.

Other times, I went out on dates with men who had family members with lupus or similar diseases. This made things a lot easier, but it didn’t ensure a match made in heaven, unfortunately.

The second school of thought I employed was letting them get to know me and then springing it on them on date three or four. That way, they had already gotten to know me as a person outside of lupus — after all, we aren’t defined by our disease, which is something sometimes easily forgotten.

But if they decided to make a break for it, I wasn't super invested. Yeah, it might suck if I really liked the guy, but I'd get over it.

Trust Issues

I have found that as lupus patients we make our diagnosis out to be a much bigger deal in our heads than it is to other people. Yes, people have a right to not want to put up with your illness and to consider it a dealbreaker, just as you have a right to not want to date a Republican or a Democrat or a guy under 5'8.

One of the big issues with dating with lupus is that we often erroneously think lupus defines who we are as people. We may have had a bad experience here and there with a date or relationship in regards to lupus, and then expect the worst from people.

Before I was diagnosed and was experiencing my first symptoms, I was dumped because the guy wasn't too keen on how often I napped. When I told him I didn't feel well, he said he was looking for a girl who was more active and just didn't like "my lifestyle."

Obviously, neither of us knew at the time that I had SLE, but it took me a long time to trust that someone would actually want to be with me despite my illness. In the back of my head, I was positive the next guy was going to dump me because he was annoyed with my sleeping habits.

But despite my dire predictions, lupus has never been the cause for any of my breakups since — although sometimes the cause has been that I am so paranoid about being dumped that I am not able to be my full authentic self, leading to the relationship's ultimate demise.

Communication Is Key

When dating with lupus, it is totally up to you how you disclose. And you have to remember that in the beginning stages, it may be a turn off for people. But it may also be more of a turn off if you keep such a big part of you a secret and reveal just how much it affects you at a later date. If the potential new partner sees you hiding such a big part of yourself, he or she may ask what else it is you're hiding.

Dating with lupus, I find, takes a lot of communication, especially in the early stages. If you have to cancel a date because you don't feel well, you need to be clear that you actually have a reason to not feel well.

I also find that communication is extremely important in the early phase of a relationship because you may have to schedule dates well into the future because of doctors' visits, treatments, etc., and the other person can very easily assume this is because of a lack of interest.

But when you're open about your illness, especially if it affects you in day-to-day life, you'll be surprised at how accepting potential suitors can be. After putting up with hoards of dates and awkward goodbyes, I've finally found someone I am really suitable for, with or without lupus.

And that's the most important thing: to find someone who suits you for you as a person, not for you with lupus. Don't just date someone because they accept your lupus, date them because they accept you, and know that your lupus is just an add-on.