Who Should You Tell If You're in a Flare?

by BARBARA LEECH

Disclosing a Lupus Flare

With lupus, you never know when something major will occur and gravely affect your health. You are always on guard. That pain in your chest could just be that you ate too much, or it could be the first sign of something major happening to one of your organs. It is hard to ever be fully at peace.

The question is, when that pain or those weird symptoms turn out to be something major, like swelling in your heart or your kidneys not functioning well, who do you let in on your secret?

Friends?

It is hard to know how your friends will react unless you have gone through this before.

Sometimes you get to see who your true friends are because they are the ones who stick around through a major lupus flare. For others, it can be too much to take in. They don't mean for it to hurt you, but they don't know how to cope with the knowledge of what is happening inside your body because of lupus.

Coworkers?

Deciding whether to let your coworkers know is a tricky decision as well. If they know, your boss will most likely find out and sometimes, whether it is legal or not, it can affect your standing on the job.

People begin to look at you like you could be out of work sick at any moment and that impacts their bottom line. If you have to take time off it can be seen as a foreshadowing of how you will be as an employee in the future; out sick and in need of lots of TLC. Naturally, employers are not impressed by that image.

So coming out with the fact that you are in a serious flare and it is affecting your health in a major way can really change how people view you. I have found that once you do, there is no going back. You are seen as different.

I used to worry about writing for this site because my other freelance writing employers do not know I have lupus. I feared if they knew they would slowly pull back on my assignments.

"Maybe she will miss deadline!" It is a real issue us lupies must face. Once people know the depth of what lupus can do, you might be looked at as less of a "superstar" at work and more like a liability.

Family?

Family is tricky too. Sometimes it seems they have a limit to how many things they can hear about and still care. If you have had several flares or an ongoing one for several months, the level of concern seemingly drops and some people even seem to forget there is a major health battle going on in your life.

Sympathy and concern seem to have an expiration date.

Disclosing a Lupus Flare: So Who Can You Tell?

- **I only tell certain people about the big threats to my health.** I think about the possible repercussions of each and every disclosure. I weigh the character of the person I am about to tell.
- **I limit the details if I do disclose a major health issue.** A brief synopsis is all most people can take in.
- **I do not tell my employers except the few (since I freelance I have several) who know I have lupu**s.
- **I do not give too much information to my children.** They are on a need-to-know basis. They may be told I am in a flare and I need to go to the doctor, but I gloss over anything that I feel is too much worry for a child to deal with.

What are some of your experiences disclosing a major flare to people?