Having the Lupus Discussion

by BARBARA LEECH

Should I Keep Lupus a Secret?

Some things are better left unsaid. But is a lupus diagnosis one of those things?

I have struggled with this decision, particularly since most people don't know what lupus really is. Having the lupus discussion usually means providing an overview of the disease; how the disease affects me, what it means for my life and my ability to work, and as well as the inevitable question on whether or not it's contagious.

Honestly, it's usually more than I feel like discussing. Disclosing my disease makes me feel as though I've left my diary wide open for everyone to read.

I sometimes worry that people will treat me differently, avoid me or worse.

Many of us lupies worry the disease will hinder advancement at the office. Legally it should not, but too often, employees with lupus find themselves with greater workplace struggles than the general population. We should be able to tell our employers about lupus.

Health issue laws protect employment for people with lupus, but it has been known to cause problems on the job regarding promotions, expectations and sometimes reduced hours or termination.

Barbara's Experience

I worry about how people will perceive me if they know I have lupus. It could simply be my experience, but it feels as though us lupus warriors fight much of our battle in silence; it is simply easier than offering an explanation and the potential aftermath of sharing that information.

So when and who do I tell?

Family First

I have told my family members about my diagnosis. Most don't remember what lupus is, or what the disease does. I have to repeat and explain lupus all over again.

However, I can always be myself around my family — lupus and all.

Friends Old and New

I have told some old friends about my diagnosis, but the new people I meet must earn the right to know, in my opinion. It must be the right time, and the right level of trust.

They have to care about me. If they can’t handle my day-to-day issues, they won’t be able to handle my chronic disease disclosure with the care and dignity it deserves.

Employers

I am blessed to work for several excellent employers in jobs that I love — freelance writing and editing copy from my home. That said, I don’t discuss my health issues with everyone.

I use my instincts; if for example, there is friendly banter and they tell me things about their own health and family life, I may eventually tell them. I disclose my diagnosis on a need-to-know basis.

It’s different for everyone, and our first instincts are usually correct.

Knowing to whom and when to disclose my lupus diagnosis is a continual challenge. I feel that I am sometimes seen differently, but it has also brought about support I would otherwise not have received. Follow your heart but be prepared for possible repercussions.