Maintaining Relationships With Lupus

by BARBARA LEECH

Juggling Lupus and Relationships Takes Work

I find it very difficult at times to pretend all is well and work on relationships when the wolf is at my door, huffing, puffing and threatening to blow my house down. How can I make small talk when I am not certain if my kidneys are going to fail? How can I be the loving spouse I want to be — sexy, fun and exciting — when it is an effort just to take a shower and get through my day?

Lupus affects relationships — this is a fact.

I would like to say it is in your control how much you "let" it affect your relationships, but often it is not. And this is not your fault. Not one of us with lupus asked for this to happen, or did anything to cause the wolf to appear.

This is life. Everyone has their own set of challenges, and for some reason this is ours. The trick is making the most of the good days with lupus, letting those you love know how awesome you think they are, surrounding yourself with people who understand your struggles and flares, and love you anyway.

This may take time, faith and burning some bridges, but it is worth it.

My first marriage was not one of love and support. I had lupus throughout the nearly 20 years I spent trying to be everything he wanted. In the end, it was his temper, impatience and my own personal strength to finally leave that ended it — not the lupus.

But I have to admit that his lack of any concern, empathy or care during flares over those years played a role in my losing that loving feeling toward him. People who say they love you but do not care if you are in unbearable pain, or if your organs are threatening to shut down, don't really love you. Not the way you need them to.

It is hard to hear that, especially if that person is your spouse, but that is rule number one.

Other Rules I Believe In

- **There is life after divorce/breaking up –** There are amazing, kind, supportive people out there and eventually, when you least expect it, this kind of love will find you. I call my husband of the last eight years my miracle.
- **Friends and family may not all support you through your flares –** Forgive them and move on. This may mean focusing your attention on those few who do support and love you through the bad times. It may mean releasing resentment or sadness that they are not what you wish them to be.

- **Ask for help –** When you are in a flare it is ok to ask for help or turn down social obligations. Relationships should be based on each person caring for the other's well being.
- **Join a support group –** There are local support groups in most communities for chronic illness/pain and

perhaps even lupus specifically. Contact your local hospital or ask your doctor for information. Join online groups, like New Life Outlook, for lupus and share your feelings.

- **Get help if you are feeling depressed and alone –** If you are feeling isolated and alone, or severely depressed, reach out for help. Between 15 and 60 percent of people with a chronic illness will experience clinical depression and this strains relationships. Contact your doctor, local hospital or the Lupus Foundation of America and ask for help.

With lupus, there are periods of time where it feels like you are not actively working on supporting your relationships. I am here to say that it is precisely at those times that your relationships should be actively working to support you.