What Not to Do When Living With Someone With Lupus

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No Room for Judgement When Living With Someone With Lupus

My loved ones do not have lupus, so it can be very hard for them to understand what I go through each and every day of my life. Things like the fear I live with and the pain I endure are not ever-present in their minds.

I am actually very lucky because, for the most part, my husband is very supportive; he is what keeps me going during really horrible flares. He has been by my side through emergency room visits, appointments with many specialists, and even some unpleasant treatments. He is my rock.

He is also my second marriage. My first was the polar opposite of the relationship I now have — I did not have love or support back then, so my lupus and my life was hell.

The fact is that without the right support from loved ones who live with us lupus warriors, life can often feel like it is more than any of us can withstand. This endless battle takes a lot out of those who fight it.

It changes us, steals precious moments, and alters our physical appearance at times. Pain is a terrible thing to live with on a daily basis, so is the fear that accompanies lupus — always worried what next life-threatening health challenge may be.

So, if you are living with someone with lupus, you should realize it requires endless patience, support, love and understanding. It requires that you do not judge situations you are not physically experiencing for yourself.

It requires you to be an advocate for your loved one, not another obstacle they must overcome or manage. It probably requires way too much of you. But, your support is needed.

What Not to Do

If you live with a lupus warrior, there are things you should do, and things you should decidedly not do, to make their lives and their battle easier for them. You may think what you do and say has very little control over the intensity of their flare or the ease of their day, but it does.

As I said, I have been on the flip-side of where I am now. I have been judged, condemned, and left without any support during times when my life was threatened by lupus. I have a pretty complete list of what you should not do if your love done has lupus.

Do Not Judge or Compare

In my first marriage, I used to be compared to others and how they looked and handled illness on a regular basis. My ex would remind me that he could keep working even when sick (from a head cold), or keep going with only a few hours of sleep.

He would compare me to women who were thinner than I was (they were also not on steroids) and if I gained two pounds he would notice and would comment on it. It was like even though I had extreme health issues, I was expected to make it appear that I was not sick.

My mission was to express no feelings of pain, fatigue, or ever gain any weight. I should also say, I never got above 140 pounds except when pregnant, so the weight thing was an excessive lack of support on his part.

If your loved one gains some weight during a flare, or cannot keep up with normal activities, do not compare or judge them as weak or lazy. This hurts a lupus warrior at a very deep level.

Do Not Blame Them for Medical Costs

Nobody likes to see that hospital bill arrive with several zeros on the end of the balance due. But, you would not blame someone for having cancer, right?

Next page: more on what not to do when living with someone with lupus.

Do Not Blame Them for Medical Costs

Lupus is not a choice and its impact to the household finances is not something someone should be blamed or feel guilty about. I was told constantly what I “cost” the family — how well off he would be if he was not with me.

Lupus guilt is already a natural thing that occurs for those of us who fight the battle, so we do not need to be brought further down by attaching a dollar figure to how guilty we feel.

Do Not Complain That You Are Tired of Their Pain

This was the worst for me. I went through a period of time where I had painful attacks that were later discovered to be pancreatitis. Lupus would make my pancreas swell and the attack felt as if something inside was exploding.

The pain was much worse than all four of my labor/deliveries of my children — and I made it through all of them without any drugs or epidurals. I am not weak.

This was so much worse. During one of the attacks my ex was driving me to the ER and a wave of the pain hit me. I could hardly breathe and I honestly feared I was going to die.

I made the mistake of saying as much. His response was that he was sick of the pain I had and he wished I would just go ahead and die.

I get that it is very hard to see someone in such pain. Maybe you feel helpless and have no idea what to say to support someone in these moments. But do not let fear or helplessness evoke a horrible response to come from you in these moments.

Show compassion and if you can’t, then simply say you are sorry for their pain and suffering and leave it at that.

Do Not Expect a Cure

So, while it is true we all would like a cure for lupus to be found, the fact is there isn’t one. There are no health shakes or supplements or miracle medicines that make lupus vanish permanently.

Even for those who enter remission, another flare or resurgence of the disease is a constant threat. So, when your loved one has been feeling better, than suddenly is stricken by a lupus attack, do not express that you thought it was gone or cured.

This makes a lupus warrior feel as though they somehow disappointed you — even though you should have known it can always come back, and probably will at some point.

Do Not Over-Book Activities and Obligations

This is one I still battle with at times. It is easy to say we will take it easy, but then schedule something to do every day. With lupus, even when you are doing well, overdoing it can cause serious flares or exhaustion.

Do not expect your loved one's abilities and schedule to be business as usual. Let them take the lead as to how much they can take on each day at home, at work, and even while on vacation.

Do not expect them to be able to be out late, drinking and socializing if they express that they do not feel up to it. Do not schedule activities without discussing it with them and checking in on how they feel.

Those who love and live with someone who has lupus do not have it easy. But, it is important to remember that no matter how difficult it feels for you, it is much harder and more painful for those who battle this terrible disease.

Think before you speak and don't let your frustrations with the illness spill out onto your loved one. Your words and actions matter and can make a lupus warrior's life easier or more of a challenge. You get to decide.