Lupus Aggravations We All Know Too Well

by BARBARA LEECH

Five Things That Bother People With Lupus

Having a positive attitude can be a beautiful thing. But when you suffer with a chronic, often debilitating, disease that few people understand (or even know what it is) the odds are stacked against you when it comes to maintaining positivity.

The effects lupus has on the body can be anything from mild to devastating — a nuisance you must endure to a life-threatening attack. Having lupus can feel like a rollercoaster ride where you just don't know how fast and extreme that next drop will be. When you survive the big drop you feel victorious, but when you are climbing slowly towards a freefall, well, that confidence is gone.

That fear and frustration can lead to changes in your mood, how much you can tolerate (without losing your cool) and in general how you perceive things in your life. Challenges, work, weather, and the behavior of others can get the better of you when you are in constant pain, horribly fatigued, and battling to survive another day.

There are several things that seem to bother me more when I am in the midst of a flare. Everything from people's lack of understanding to everyday challenges. I am a part of several lupus support groups and I have learned it is fairly common for someone with lupus to feel like their life, and everyone in it, is slowly pushing them to the limits.

1. Weather Extremes When We Have to Be Outside

I am a mom of four and as hard as I try to avoid extreme cold or hot temperatures, as well as excessive direct sunlight, there are times I have to endure it.

My boys play soccer in fall and baseball in the spring. Though I feel that I must be there to support them, it is usually something I feel I go into "survival mode" be able to endure.

Typically, I force myself to go and then feel irritated that everyone else at the field is only mildly annoyed by the weather, while it is almost unbearable for me. As I hide under trees from the sun or sit hugging myself and going numb from the painful cold, I see other parents laughing and enjoying the moment.

I am jealous. I admit it and it is not the right way to feel, but it happens.

2. When Others Compare Their Life to Ours

I have a friend who constantly boasts about how hard she is working out, how driven she is to have a beach body, and how hard she works at her job — though she has a less than average work week compared to most. Her Facebook statuses are always about how amazing life always is for her.

I get it. Your life is awesome, your health is amazing, and you have never struggled financially, but instead have

traveled the world. Honestly, the way she talks it would appear that she never has a bad day and is convinced she will be rich and continue to travel, healthy and happy forever.

In the midst of a flare, this is a big button pusher for me. She has said her life is perfect because she is always happy (she has gone as far as to say there is no reason ever to be unhappy) and mine life is filled with challenges and lupus because we each get what we deserve.

It has not occurred to her that she is happy *because* she has not yet been really challenged. The comparison makes me resentful and yes, angry. Walk a mile in my shoes and see how happy you always feel.

Next page: horrible health advice and more lupus aggravations.

3. Horrible Health Advice

While I am struggling to get through a flare, the last thing I want to hear is how I should be taking a supplement someone has tried that boosts the immune system.

The only way this is more irritating is when I know for a fact we have had this conversation before, and I have already explained that people with lupus must calm their immune system, not boost it. I think this pushes my buttons because it reminds me that this person has no clue what lupus is and the battle I face.

4. An Over-Packed Schedule

If I am pushed to the limits with a schedule of things to do on a day when lupus has the better of me, I stand a 50/50 chance of getting very moody with a strong possibility of tears before crawling into bed that night.

Not only are endless activities or demands exhausting and more than I can bear during a flare, but the fact that I am expected to keep up with a crazy schedule makes me feel invisible. It is like nobody remembers I might be struggling to keep going.

If it is family that expects this of me, it hurts all the more. I look out for them, so why wouldn't they look out for me and my health?

This happens a lot around the holidays and frankly, I can count on being aggravated every Christmas by a daily demand to be somewhere and be actively social. Lupus and social do not always mix, and my ideal schedule reflects that fact.

5. A New Pain or Sudden Flare

I cannot even begin to describe the frustration when I am trudging through the week and suddenly am stricken with a whole new set of symptoms and pain. I can be fine one day and wake up with pleurisy (swelling in my lungs) and incredible pain caused simply by breathing.

I can wake with my feet and hands painfully swollen or horrible sores in my nose. Each day has some level of pain, so when some new one joins the party it is enough to make me feel very overwhelmed and angry.

I suffer from the "why me?" or "what did I do to cause this one?" attitude during these times. It shakes my inner strength to the core when it feels like each day is nothing but an opportunity for me to endure even more pain.

A lot of the time, I did nothing to aggravate my symptoms and have no logical reason for the attack. It simply is a daily possibility that my battle might increase and when it does I feel angry and caught up in the inner turmoil of how unfair it all is.

Find Comfort

I think one of the hardest parts about having lupus is the emotional toll it takes to face each day and to endure the pain and threats to your survival, while the people around you seem to be blissfully unaware of the war you are fighting.

My greatest source of comfort can be found in the few who do understand and support me through my daily fight with this disease, and the realization that these emotions are natural and to be expected given the battle I am in. I may still get aggravated, but there is peace in realizing that it is normal to feel this way.