Understanding and Managing Lupus Headaches

by BARBARA LEECH

Lupus Headaches and What Can Be Done About Them

I have read that as many as half of us with lupus experience lupus fog, where our memory can be fuzzy or near non-existent. I have actually forgotten how to turn on my headlights in the car or even where I was as I was driving — so scary! Along with lupus fog and the related difficulty expressing our thoughts and remembering names or appointments, people with lupus may be twice as likely to experience lupus headaches. Lupus headaches are migraine-like in their intensity and can last for days.

I am one of the unlucky ones who experiences both, sometimes together, and they are brought on by a flare, fatigue or even just a day of poor diet choices. The headache is the worst of the two issues, causing such intense pain that I seriously wonder how this issue is not fatal.

These headaches are often classified as migraines because of their intensity, where they affect us (often one side of the head) and their length (often lasting several days), but it doctors cannot always determine if we are actually experiencing a migraine or if it is something else.

As with many autoimmune disorders, there can be a high rate of other conditions that accompany it like lupus and seizures. Because of this, doctors are unclear if there is such a thing as a lupus headache and will often suggest having lupus may open you up to having conditions like migraine headaches.

What We Know About Lupus Headaches

A headache specific to lupus sufferers is still debated by some in the medical profession and even within the rheumatology community. There has not been a lot of study on migraines and lupus, so more information is certainly needed to draw any real conclusions.

In my opinion, I believe the blood flow issues within my body are caused by lupus and play a major part in my headaches. All of my doctors agree I have an issue with blood flow; I have severe Raynaud’s syndrome and when I sit both my legs turn purple from the knee down.

I lose feeling in both my hands during the night and sometimes my face will become slightly numb, horribly pale, or have a blueish tone to it. My blood pressure is so low it sets off alarms whenever I am in the hospital.

Simply put, I believe blood is not flowing as it always should and I believe lupus is the root cause. My doctors have not disagreed; they simply say they really do know for sure if lupus is behind it.

I also have white lesions on my brain caused by lupus. Similar to those seen in multiple sclerosis (MS), though not located in the typical areas that MS lesions appear, lupus lesions on the brain have caused me problems with balance and even the ability to speak at times.

Through the years, brain scans have shown that I have old lesions as well as the formation of new ones. MS has been ruled out and my neurologist determined lupus is the cause. This makes me wonder if headaches are more likely to occur when these lesions are forming.

What Can You Do?

First, I recommend keeping a log so you can avoid things that trigger your headaches. You may notice a pattern that relates to certain activities in your daily life that seem to be the trigger of headache pain and migraines.

Staying active and eating a healthy diet are very important to keep headaches at bay. I have found there is a list of things I must avoid and things I must do:

- **Stress is a huge factor in triggering a headache for me.** I try and listen to relaxation music to let stress go. I pray for peace within myself and think about all the good things in my life.
- **Drinking excessive caffeine or alcohol and can trigger a major lupus headache.** I try and drink a lot of water every day instead.
- **I avoid processed foods, which can be a huge factor in triggering days of major brain pain for me.** I read labels and eat lots of veggies — locally grown if possible.

- **I take pain relievers (the anti-inflammatory ones) at the first sign of a headache.** Once my headaches get going, there seems to be no quelling the pain. But, if I catch it early and take something for it, I have a chance to fend it off before it takes over my life for three days.
- **I use ice packs on my neck and head.** For some reason icing the area of pain seems to help.
- **I wear sunglasses everywhere, even on cloudy days.** The sun is my enemy in more ways than one. I avoid sun exposure and I shade myself whenever possible.
- **Lack of adequate sleep and/or overextending myself triggers headaches.** I know if I overdo it or get a few nights of really poor sleep, I am going to trigger a reaction.
- **Gentle exercise and stretching seems to do wonders for loosening tight muscles and slow blood flow, which seem to fuel my headaches.** I try and do yoga or take a short walk once per day to keep my body moving and free of muscle tension.

Though some doctors may still debate whether migraines are often a comorbid condition of lupus, this type of headache seems to me to be clearly connected to my flares and the disease I battle each day.

I think blood flow issues are very common with lupus patients and that is a factor in developing chronic migraines. If you have severe lupus headaches, what seems to trigger them?