Why You Need to Advocate for Yourself

by BARBARA LEECH

Being Your Own Advocate With Lupus

When it comes to your physician and the team of doctors that manage your treatment plan for lupus, it can sometimes feel like you are the only one who truly understands this chronic disease.

Short of finding yourself a doctor who also has lupus, there are some ways you can advocate for the best possible care, no matter what lupus is doing to your body right now. Being your own health advocate is a tough job, but it is vital for us lupies.

Sadly, I believe many doctors do not know all they could and should about this complicated and multi-faceted disease, and that means some of the burden of proof and explanation falls upon us, the patients.

Why It Is Hard to Advocate for Yourself

You may feel that having to argue or stand up for better care is not in your nature and should not be required; I totally sympathize. I tend to avoid conflict more than I should and I really take it personally if I feel a doctor is dismissing a symptom I feel is important.

I even once had a primary care doctor who said my hair loss, rash and fatigue were caused by stress and getting older. His response to most of my concerns, including a bout of sudden and severe chest pain was: “Lupus does not do that. It is stress or depression — are you depressed?”

Meanwhile, I was thinking, “Um, no, only angry about your lack of concern and dismissive attitude over this crushing pain every time I inhale.”

Once I felt humiliated and dismissed enough that I got angry, I took action. Sometimes it takes outrage to stir me into proper action.

So I switched doctors, twice, until I found someone who listened, showed genuine concern and took what I said and searched for answers if she did not have them off the top of her head. She was the real deal — my medical detective and I believe the needle in a haystack of doctors who only know the basics about lupus.

My new doctor confirmed I had pleurisy (swelling of the lining of my lung due to lupus) and also sent me to a rheumatologist who she trusted and recommended. He re-confirmed my lupus diagnosis, began a treatment plan of medication (Plaquenil), pain relief options and diet modifications (no processed foods) to avoid flares.

He listened and explained things and addressed my previously dismissed concerns with, “Yes, lupus hair loss is quite common in lupus patients.” Finally.

We Are Not Crying Wolf

So, this brings me to my mission: to get you to advocate for your own better care and acknowledgement from the doctors that are supposed to be watching out for you. You may have a team you trust and who are amazing, but the odds are you may not.

When a new lupus flare arrives at your door you need doctors who do not assume you are crying wolf. The lupus wolf is real and dangerous and the last thing someone battling this disease needs is to be dismissed by a doctor because of their lack of knowledge.

If this is happening to you, you need to advocate for better treatment, more tests, different medications — whatever it might take to ease your pain and perhaps even save your life. You may need to switch doctors, and keep switching until you find one that is well educated about lupus and right for you.

Next page: how to be your own advocate.

How to Be Your Own Advocate

The first step in advocacy is knowledge. Knowledge is power. Knowledge gives you confidence.

Research as much as you can and educate yourself on lupus. The Lupus Foundation of America has a wealth of information on its website (there are many other organizations as well) where you can learn about the many health issues lupus can cause, the symptoms and treatments for lupus. This will give you the power to argue with facts rather than blindly trusting your doctor when they brush off a major symptom.

The second step is to ask questions. Yes, we all ask the obvious questions, but what about when what your doctor says does not add up in your mind?

He works for you and should be doing so with kindness and respect for your concerns. If your doctor says something that does not make sense, ask him to clarify what he means.

If he says something that seems to be misinformation, mention your research and ask for more details on the “facts” that he knows. A good doctor may look into the latest information and admit he might not know all there is to know.

The next step is to get your medical history with lupus onto paper. Create a complete list of your conditions, medications, all of the doctors you see, past treatments and their outcomes and include general dates. This will help if you start with a new physician or if you go to the hospital for an issue.

Next in advocating for yourself is a tough one — something we all dread doing. If a current doctor does not seem to take your symptoms seriously or does not seem to understand lupus or offer much in the way of treatment, find another doctor.

Do not feel guilty or ashamed. This is your health and your life. You deserve to be taken seriously and be provided with the best in care.

Find a new doctor and seek different or additional treatment options, which were not discussed by the previous physician. Plan out your questions for the new doctor before your first visit and have it written down so you will not forget these questions and concerns. Be organized, detailed and to the point. Expect the same in return from your new doctor.

When asked, “What brings you here?” don’t bash the previous doctors you have had. This tends to make other doctors nervous that maybe you just cannot be satisfied. You want to be taken seriously.

Keep your comments factual, without emotion, as to why you are seeking a new doctor. Simply explain: “I had concerns that there were possible avenues of treatment and aspects of the disease, because of its complexity,

that were not being explored by my previous physician. I am here because I am seeking the best possible care I can find."

This is a credible and reasonable concern for anyone battling a chronic illness. No doctor can blame you for seeking the best care.

Finally, be sure to ask for and collect your medical records from your previous doctor and have them sent to the new one at least two weeks before your appointment. Many doctors will review the new patient records and be better prepared for your first appointment.

Becoming your own advocate is a vital step to take when battling lupus. You cannot always trust that you are getting the best treatment or the proper level of concern regarding your symptoms. Follow your gut instinct. If you feel there is a lack of action from your doctor, be willing to express your concerns and advocate for yourself. Facing the wolf requires bravery and sometimes facing your doctor requires it as well.