How Lupus Patients Cope With Doctor Frustrations

by BRANDY OSTLER

Minimizing Healthcare and Doctor Frustrations

Have you ever walked out of the doctor’s office feeling less than satisfied? Perhaps you have left feeling confused, frustrated, or maybe even angry.

As individuals dealing with the effects of lupus, we absolutely depend on the expert knowledge and advice of medical professionals. However, when medical care is a regular occurrence in your life, doctor frustrations are inevitable. I know that I have certainly had my fair share!

The old adage, “You can’t live with them, you can’t live without them,” seems to describe the relationship we share with our doctors, and having multiple issues that require numerous doctors only adds to the potential problem.

Over the years, I have learned a few things from my dealings with health care professionals. Perhaps most importantly, I now know that taking an active role (rather than remaining passive) in my treatment is essential to my wellbeing.

I’d like to share a few of the frustrations I have personally experienced as well as the steps I have taken to alleviate the frequency of feeling less than satisfied.

Personal Frustrations

Consider the following situations. I imagine that there are a few you can probably relate to!

When I was first sick, I saw a rheumatologist who just didn’t take my condition seriously. He NEVER saw me in a “flared” state because he was impossible to see with short notice.

At the time, I was working full-time as a teacher and the last appointment he would schedule for the day was 2:00 p.m. To see him, I had no choice but to take a half-day off work; yet, he refused to fill out any paperwork that granted job protection (namely FMLA intermittent leave).

In fact, he was so opposed to it that he had a sign hanging by the check-in counter stating that his office would not (under any circumstances) fill out paperwork for family medical leave or disability. Furthermore, he discounted any contributions made about my condition by other doctors.

At the same time, I was seeing a pulmonologist (who I highly respected) due to the significant breathing problems that accompanied my condition. He was great, filled out my paperwork, took scans and X-rays all the time — but missed many significant clues.

He and my rheumatologist never communicated and completely disagreed about what my condition actually was.

I always felt so confused because this constant disagreement left me wondering who I could trust to provide the proper treatment and — more importantly — what condition actually plagued me.

My family doctor was another story entirely. Although she considered the findings of the other doctors, she was not an expert in the field of autoimmune diseases (which was the only thing they could all agree upon).

It seemed that any situation or symptom that presented itself just went into the bucket of “related complications” with no treatment plan in place because that wasn’t within her realm of expertise, and I would simply be referred back to the other doctors.

Next page: creating an effective team and reducing doctor frustrations.

An Ongoing Problem

This sort of thing went on for years! At one point or another I was told I had lupus, sarcoidosis, scleroderma, Sjogren’s syndrome, lymphoma, mixed connective tissue disease, etc. Granted, I know that a diagnosis is difficult to come by, but when each doctor “diagnoses” you with something different and discounts the diagnosis given by the others, well, it gets frustrating!

Furthermore, more than once I had one doctor prescribe a particular medication only to have another doctor discontinue it and prescribe something else. I’m sure you can guess what happened when I went back to the doctor who prescribed the previous medication!

Honestly, I could fill pages with these types of experiences, but I’m sure you get the idea and have probably experienced similar situations at some point during the daunting process of discovery, diagnosis and treatment. I quickly learned that the only way to deal with the situation was to streamline my care and have a team of doctors who could work together.

Granted, it's pretty much guaranteed that frustrations will still exist, but hopefully they will be less frequent and less severe once all of your medical professionals are on the same page!

Creating a Team

So how does one go about creating a team of doctors? Well, for me, it all started with one doctor.

Remember that the doctor(s) you see essentially work for you! If they make you feel rushed, unimportant, or seem disinterested in what’s going on, stop seeing them and find another doctor! That is what I did.

I found a new rheumatologist. She was inspired and passionate about her work and truly wanted to find the underlying cause of what was going on. I knew she was the doctor for me from the very first appointment. She wasn’t just interested in treating my symptoms — she wanted to make me well. Wow! What a concept!

Although I went in equipped with a prepared list of all the symptoms, complications, preliminary diagnoses, medications, etc. that I had experienced over the years, I chose not to babble it all off at once. I have found that some doctors will piggy-back off the findings of other doctors and I wasn’t interested in the same old thing.

I waited for her to ask questions and provided the answers as efficiently as I could. This allowed her the room to truly take in my answers, consider them, and ask the follow-up questions. I wanted her to start from scratch — and she wanted that as well.

She conducted a battery of tests — far more complete than any I had experienced before. Based on the findings, she personally selected and referred me to doctors with specialties in the areas that pertained to my condition, such as a nephrologist, a neurologist, a hematologist, a pulmonologist, etc.

Although a specialist herself, she essentially became my primary care physician and oversaw and coordinated ALL of my care with each additional specialist reporting back to her. This made all the difference in the world.

Next page: finding the right doctor.

Finding the Right Doctor

My diagnosis was quickly confirmed and appropriate treatment was implemented. Furthermore (and most importantly), she made herself available to me at any time. If I flared up, I called and saw her that day.

She was aggressive, thorough and extremely efficient. She kept detailed records and provided me with copies of everything.

When she decided to retire me from my job, she completed all necessary paperwork and provided all requested documentation to those that needed it.

As a result, I was able to build a trusting relationship with a top-notch medical professional who I knew had my best interests in mind. I will always be grateful for what she has done for me.

I realize that doctors like this may be few and far between, but they do exist. Do your research, read and explore the many lupus resources available (including patient satisfaction entries online), stay informed, follow your instinct and become your biggest advocate.

Find one great doctor who you trust, respect, and can form a personal relationship with who can coordinate all of your care — including your referrals to other specialists. By doing this, your primary doctor will be able to keep all the others in the loop and relieve you of that challenging burden.

Keep the lines of communication open and ask as many questions you feel are necessary. A caring doctor will take the time to provide you with all the answers and time you need.

Trust your instinct and remember that you aren’t just a number, you aren’t a just case or a random patient, and you certainly aren’t a guinea pig when it comes to your care!

Did I still experience frustration from time to time? Of course, it’s inevitable — but it’s of a different nature. Mostly, I found myself needing to keep a day planner to keep track of all my scheduled and ongoing appointments with each doctor on my team.

At times it felt like a full-time job, but the benefits were well worth it! I knew that I was getting the care I needed and, more importantly, the care I deserved.

With determination, you can find this as well!