Why You Should Demand Better Lupus Care

by BARBARA LEECH

How to Get the Lupus Care You Deserve

If you are like many lupus warriors, getting yourself a doctor that listens to you, takes your concerns seriously, and responds to your questions is something you may search forever to find.

Part of this, I believe, is because lupus is so hard to diagnose in the first place. My doctor believes I have had it since I was 17, but I was not taken seriously or diagnosed until I was in my 40s.

Granted, I had periods of lupus remission in those years; times where I wondered why all the horrible pain and weird medical issues (like sudden pleurisy or pancreatitis for no known reason) suddenly stopped occurring. My condition was a mystery. But, there were enough flares you would think someone would have made a diagnosis sooner.

Instead, I received odd questions, like “are you depressed?” and I was offered prescriptions to treat mental health issues rather than someone taking the time to consider if autoimmune disease was at the root of my symptoms. Essentially, many doctors made me feel like I was imagining pain, seeking attention, and simply just getting old.

Doctors Are Rushed

Sometimes it feels like you are on a timeclock and the doctor simply wants to see your face, take a few vitals, hand you a slip, and send you on your way. Mention a new concern and you throw the whole schedule out of whack. You are a troublemaker.

Doctors are busier today than ever before, particularly specialists, because the Affordable Care Act now has many more people insured and seeking an appointment. So, the result is your appointment time is limited and your doctor has one eye on you, but the other eye is on the door to see their next patient.

So, how do you garner your doctor’s attention? How do you leave your appointment feeling your issues and questions have been addressed properly and with great care? How do you keep it short, but also accomplish everything you went to the doctors to do?

Make a List of Your Questions in Advance

With our lupus memory issues, it may be hard to think of everything you want to say and articulate it well if you feel rushed. Stumbling with questions or wandering off-point can make your doctor cut you off before you get to everything you came there to discuss. Make a list and use it.

Don't Be Afraid to Speak Your Mind

I know you probably feel your doctor is judging your complaints or symptoms. Maybe you feel dismissed. Don’t allow it.

One study found doctors would only let a patient speak for 24 seconds before redirecting them. Don’t allow that to happen — bring the conversation right back to your question. If you want to know other treatment options, your doctor should be able to tell you other choices you may have and not limit your treatment by simply rewriting the same old prescription.

Don't Dress up or Look Overly Presentable

This sounds silly, but doctors actually take stock of your appearance in their appointment notes. If you can work magic and hide how you feel by applying makeup and dressing up in nice clothing, this is not the time to do so and risk masking how badly you have been feeling.

Dress comfortably. Don’t primp. Let the doctor see how you have been living.

Don’t Be Afraid

If you are afraid of your doctor and their thoughts on your condition, it may be time to find one who listens and you feel comfortable with. You should be able to disagree, ask questions and request second opinions.

Fear is the enemy for you advocating for yourself properly. You deserve to be heard and if you do not agree with your doctor, you should be able to speak your mind without fear.

Next page: don't allow yourself to be dismissed, and other tips for demanding better lupus care.

Don't Allow Yourself to Be Dismissed

If you feel your doctor dismisses your concerns at every appointment, it is defiantly time to seek another physician. This is a relationship you should be able to count on.

If a new symptom arises and you tell your doctor, it should be addressed or they should be able to explain why it isn’t something that can be managed. You should be given options and answers, or at the very least a reason why your symptom is being pushed aside.

Take hair loss, for example; most doctors are not concerned with it and cannot do much about it. However, when you ask about it they should know that lupus can cause this, and even the medication some of us are prescribed for lupus can contribute to it. Essentially, the issue should be acknowledged even if the doctor cannot treat it or prevent it.

Not All Doctors Know Enough About Lupus to Treat You

It is my feeling that most doctors, unless they have encountered lupus many, many times, do not know all of its little nuances and the things it can do. They seem to rely on the textbook explanation and a checklist you must have and conform to.

Perhaps I am wrong, but that has been my experience. Seek a doctor that has experience with lupus, meaning a rheumatologist who specializes in lupus or the bulk of his patients battle it.

This way you have someone who sees the myriad of issues this disease can cause, not all of which are in the textbooks. You want someone who realizes lupus can be much bigger than a checklist.

Finally, set the bar high and require answers to your questions. Some doctors are not afraid to say they do not

have all the answers.

One of the best things you can do for yourself is be your own advocate. Ask yourself if your doctor hears your concerns, answers your questions and/or offered explanations, considered further testing, or suggested other treatment options. Don’t settle for treatment that just gets you in and out of the office as quickly as possible and ignores your questions and concerns.

Searching for the Right Rheumatologist

Finding the right doctor is an amazing blessing. Here are a few things I have found important when searching:

- **Experience with lupus**: A rheumatologist who specializes in lupus or the bulk of whose patients battle lupus can see the myriad of issues this disease can cause, not all of which are in the text books. You want someone who realizes lupus can be much bigger than a checklist.
- **Possesses empathy**: Not a classic trait of many busy doctors these days, but you want someone who feels some compassion for the pain that lupus causes and will work with you to find ways to manage it.
- **Will take the time to listen**: Having a doctor that takes the time to hear you, asks questions and waits to get the full answer and considers what you say and feel as an important piece to the puzzle is vital.
- **Seeks answers**: Some doctors are not afraid to say they do not have all the answers. I have had one who was not bashful about saying that he needed to speak with some colleagues for advice and hopefully come up with some answers and possible solutions. I respect this more than anyone who thinks they know it all.

If you do not feel your doctor is giving you the kind of lupus care you need or deserve, it may be time to continue your search. Asking for referrals from others with lupus is often a great place to start.