Explaining Lupus to Just About Anyone

by BRANDY OSTLER

Explaining Lupus to Family, Friends, Colleagues, Children and Acquaintances

I know we've all heard it — those five little words of no more than three or four letters each: "But you don't look sick."

Lupus is one of those "invisible" illnesses. Most of the damage caused by this mysterious, chronic illness is internal.

Certainly, there are external signs at times — lupus hair loss, instability, skin rashes, and in my case, the constant companion of an oxygen tank. However, this external damage is only a fraction of what is really going on inside.

As a result, explaining lupus is not an easy task. I know that if I share all of the symptoms and complications I have, many people will think I'm exaggerating — especially if it is thrown out there haphazardly or in a disorganized fashion.

I have felt judged on more than one occasion because so many of my problems cannot be seen from the outside. I'm sure we have all experienced that at one time or another — but it doesn't change the reality of what lupus *is* and what lupus *does*.

The support of others — and their acceptance — is something we all need.

I can recall several instances when I have matter-of-factly told people of my condition only to discover that they have never heard of lupus. And those that have heard of it often do not understand it.

Lupus is not easy to define. There is no clear-cut description of what it is or what it does because it can attack so many different body systems that no two people have the exact same lupus.

It has many different faces and presents itself in many different ways. It continues to evolve and change. It seems that once I get a handle on it, something new pops up.

Honestly, one of my biggest fears is that people will think I'm shopping for sympathy or pity-seeking. This is simply not the case. But, I do want people to understand because it affects what I am able to do.

My abilities can change on a daily basis — good days, bad days, really bad days, times when I'm flaring on maximum overdrive and times when I almost seem 'normal' (if there is such a thing).

I have found myself needing to explain lupus in a variety of settings: with family and friends, to my third grade students, and even in social or professional situations. Each explanation may look different depending on who the audience is, what they need to know, and why they need to know it.

I would like to share what it might look like in each of these scenarios. It's never easy, but with a plan of action

tailored to fit a variety of circumstances we can be prepared to explain our individual lupus accurately, concisely, and authentically.

First, Know Your Lupus

For me, one of the most important factors is knowing MY lupus personally. Just as if I were getting to know a new friend, I want to be aware and understand the many character traits that my lupus has.

I keep information, lists, and records regarding dates, symptoms, complications, damage, treatments, medications, side effects, doctors, specialists, hospitalizations, procedures, limitations, improvements, and victories. I also take photographs of visual symptoms just in case I need them.

There is a variety of apps that can help organize these concepts. Apps for lupus include The Lupus Companion and My Lupus Log, but there are also countless apps to help with lists and organization that may be useful.

Alternatively, an expanding file or a binder sectioned and labeled, a day-planner, a journal or notebook, and a hand-held recorder are also good to have on hand.

I also have a 'lupus folder' on my computer as well as in my internet browser's bookmark list so I can save websites or documents that help me know my lupus personally. I listen to my doctors, but I do my own research because I know I cannot truly explain it if I do not understand it myself.

So for me, this is the very first step. Granted, the contents will change over time, but having this knowledge is absolutely essential if my intention is to share the truth of what I have and what it looks like for me personally.

Certainly, I know the basic description of lupus, and although that will suffice some of the time, it is not always good enough. Telling people all it *can* do is much different than telling people all it *is* doing. Accuracy and honesty is always a best practice!

Next page: more on knowing your lupus, and explaining lupus to family.

First, Know Your Lupus

When I was first diagnosed, my immediate family experienced the discovery with me. As I learned new things, I would pass it on. Because of this, my need to truly explain it to those closest to me was not really a necessity.

However, as time went on and more symptoms and complications presented themselves, I found that I needed to expand the awareness to those beyond my immediate family.

I was a school teacher at the time and because I found myself under the weather more frequently, it became necessary to share what was going on with my colleagues, administration, and students.

I also became aware of the fact that very few of my extended family knew what I was going through, and it became serious enough that I felt the need to also reveal my condition to those who cared about me, but were not present in my everyday life.

Explaining Lupus to Family

The first thing I did was write a family letter. I went back to the beginning and shared my timeline of discovery as concisely as I could.

It was a bit overwhelming, but I was able to mold my illness in this form so that it was clearly explained with the most important details, without just spitting it out.

By the time I shared the letter, it was well written and easy to follow. I wrote it much like a story and included humor where I could so that the information wasn't too heavy or doom and gloom.

I shared a link to The Lupus Foundation of America as their website is full of information, details, and descriptions. By directing them to an official site, much of the explanation was done for me.

Certainly, I shared which organs were involved in my particular case so that they could explore those areas without having to pick through the information to determine what was relevant to me. This was a huge help!

I was open and honest and suggested they ask me any questions they had. I did not want them to feel uncomfortable or see me as a fragile sick person.

My family was receptive and since sharing the initial information, I continue to offer updates through e-mail. I also started a blog, which allows my family — as well as others — to follow along with my journey without me needing to constantly update them with details.

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Explaining Lupus to Friends

Similar to my immediate family, my closest friends were in the loop with my initial discovery. So many of them have been an important support system throughout this journey.

Because they were my closest friends, I did not worry about them seeing me as someone seeking pity. In fact, it was many of my friends who noticed so much of what was going on that they were the ones who initially encouraged me to go to the doctor to get it figured out! However, I have a wide network of friends and eventually I realized I needed to fill them in.

During the earlier stages, I was extremely hesitant to post anything on social media sites such as Facebook; however, I later discovered that this was an excellent format to share what I was going through. Facebook allows you to customize who sees your posts, which is something I utilize.

Furthermore, by joining various groups that have been established on Facebook and others areas of the internet (such as NewLifeOutlook!), I have access to a variety of people and a bank of resources that can offers tips for sharing information.

I invited friends to follow my blog and now embrace all of the social media sites for providing information without intruding on individual lives.

I didn't want to make it all about me, so I shared it as 'awareness' and I left it them to choose to read if they were interested in learning more. By doing this, they have access to the information without me throwing it in their faces!

Have some avoided it? Certainly. But that is okay, as their knowledge and understanding is not essential to my well-being.

The most important factor is that I'm not hiding any information or being vague, secret, or cryptic in my posts, which really just annoys people!

Explaining Lupus to Colleagues

This one was a great worry for me, but I actually found it to be one of the easiest! In the earlier stages, I was worried about losing my job because I would often deplete my allocated sick days.

My doctors have provided me with valuable resources for knowing my rights. Lupus is protected under the Americans with Disabilities Act, depending on specific limitations. Additionally, I strongly encourage anyone with lupus to review the rules and regulations of the Family and Medical Leave Act (FMLA).

At the beginning of every school year, my primary lupus doctor would complete the necessary forms for intermittent leave under FMLA. By doing this, job protection and health insurance would remain intact, even if I should miss too many days as determined by my contract.

Develop an open line of communication with your immediate supervisor, administrator, or HR department. Remember, they are human and for the most part, they are accommodating and understanding (based on my personal experience).

Additionally, if you happen to be in school (I am currently pursuing my second master's degree) and lupus is a disability for you, be sure to register with your school's office of disability services. This will ensure that you receive necessary accommodations — such as extended time — to meet you deadlines without penalty. Virtually every campus, whether online or brick and mortar has this available.

Next page: explaining lupus to children.

Explaining Lupus to Children

My son was a teenager when I was diagnosed, so explaining my condition to him was not so difficult. He discovered it as I did, and although he initially worried about my mortality, he was able to grasp the conditions and limitations of my illness.

However, because I was also an elementary school teacher at the time, I found myself needing to explain lupus in simplistic terms to young children.

I wanted to ensure that they could understand, particularly because I would often miss days or require a germ protection mask during common illness seasons. I started with a variety of health lessons so that the children could understand the basics of illness, germs, protection, and how our body's immune system is designed to work.

I have found that children are quite accepting of chronic illness — especially if they feel informed!

I generally explain it like this: "Inside our bodies, we have a bunch of tiny superheroes; these superheroes are our immune system! When we get sick, our superheroes fight off the enemies, which are bad germs. When we take medicine, our superheroes get a boost of power and energy and they fight even harder!

"But because I have lupus, sometimes my superheroes get confused and they start fighting each other. This causes me to get sick and I have to spend time in bed or at the doctor. I take different kinds of medicine to help my superheroes get back on track. When my superheroes aren't confused anymore, I feel better!

"Sometimes I wear a mask to help keep the bad germs away so that my superheroes won't start fighting each other. This helps keep me healthy!"

The children are usually satisfied with this description and they seem to understand it. Certainly it can be tailored to fit your individual needs, but I have found that keeping it simple is best. There are also several books available that are designed specifically for explaining lupus to children.

Explaining Lupus in Social Situations

For the most part, I tend to avoid most social settings, as a large number of people can trigger an attack. Certainly, I participate in family and friend social gatherings, but I say no situations that include a large gathering

of strangers that could potentially have a variety of ailments that I could be exposed to.

However, there are times that this cannot be avoided. Typically, I do not worry about it — but I have felt self-conscious because I use a disabled parking placard, carry oxygen wherever I go, have been confined to a wheelchair from time to time, and wear a mask when I have a high risk of infection.

I have found that the best way to deal with the stares and curiosity of strangers is to simply let it go! What they think is really of no concern to me.

I know that the people who matter in my life know what is going on. Yes, it can be difficult to ignore the possible criticism of strangers, but I am a firm believer in choosing your battles, and this is one I choose not to engage in.

This may not work for everyone, but it works for me! If I’m really uncomfortable, I will wear a "Lupus Warrior” t-shirt, purple awareness ribbon, or something similar to give an outward explanation without having to explain myself.

Explaining lupus can be a challenging situation; however, it can be managed. Equip yourself with knowledge and a process to explain your condition in any situation. Furthermore, don’t let judgment get you down! The next time you hear, "But you don't look sick," simply smile and say, “Thank you!”