

# The Importance of Learning About Lupus

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## Learning About Lupus

If you were to put 10 different people with lupus in a room together to talk about their condition, you would get 10 unique and individual stories. Lupus manifests itself in so many different ways that it looks different in each person it affects.

When active, new symptoms can pop up while others may completely disappear. Lupus seems to live in a state of evolution — changing the way it attacks those who have it.

Furthermore, if you have lupus, there is a chance another autoimmune condition could develop, such as Sjogren's syndrome, fibromyalgia, rheumatoid arthritis or scleroderma. Many of the symptoms associated with these additional chronic conditions are similar to those found in lupus patients.

It's important to learn all you can about your condition. Knowledge is power, and in knowing how lupus affects you, you are more likely to get a handle on controlling it.

## Surrounded in Mystery

If you are like me, you have probably been surprised by something new and mysterious presenting itself. I can recall countless times I have awoken to discover something unfamiliar: a strange new rash, odd lumps on my forehead, or swelling in my face and hands that didn't exist before. The list goes on.

Some of these new manifestations may be short-lived — a one-time-only sampling in the strange world of lupus. Others may become permanent features that stick around and show up every time you have a flare.

It can be alarming, and I often wonder if I did something that spawned the new symptom. There have been many studies regarding lupus, and despite the information medical professionals are learning, the condition mostly remains a mystery.

There doesn't seem to be a specific cause that can be pinned down. Depending on which body systems are involved, the precautions, treatments and restrictions may be different. There is simply not a "one-size-fits-all" treatment plan that will work for everyone plagued by lupus.

## **Lupus Affects Us Differently**

We know lupus can strike at any time. I may find myself dealing with massive water retention this week due to lupus kidney problems, or confusion and memory loss next week due to brain involvement. I have found it helpful to learn about all the ways lupus affects me so I can take the right precautions at the right time and get myself through the flare as quickly and as easily as possible.

I keep track of my symptoms and note the situation surrounding their onset. It's essential for me to know which body systems are involved so that I can be cognizant of the supplies I should have on hand if a flare should arise.

I'm diligent in my care and notify my doctor anytime something "new" rears its ugly head. In addition to standard lupus medications, I have many that I take to tackle specific issues. It would be irresponsible of me to incorporate every bit of advice for dealing with lupus that I find on the Internet.

Next page: learn how lupus can affect the different systems of your body — and what to do about it, and more learning about lupus.

## Lupus Affects Us Differently

What's good for one person isn't necessarily the best course of action for the next. For example, many will say that rigorous exercise is a great way to ease joint and muscle discomfort and tackle fatigue; however, because lupus affects my lungs, causing severe restriction, rigorous exercise is on my list of things to avoid.

Another example is "drink plenty of water." I have chronic kidney disease because of lupus, and there are times I actually have to restrict my fluid intake. Some of these well-intentioned words of wisdom and advice may be detrimental to my specific situation. I would say that this is the most important reason to learn all I can about my condition.

#### **A Few Specifics**

#### Musculoskeletal System

If lupus affects your musculoskeletal system, you may have complications related to your muscles, bones and joints. You may be prone to lupus and osteoporosis, muscle aches, inflammation, weakness, joint pain, joint stiffness, joint swelling, tendonitis, carpel tunnel syndrome, and fractures.

- Medical specialist: Rheumatologist
- Things to try: Soothing baths to ease aches and pains, yoga to build strength, calcium and vitamin D
- Things to avoid: Remaining sedentary

#### **Nervous System**

If lupus affects your nervous system, you may have complications related to your brain, spinal cord or nerves. You may be prone to headaches, memory loss, confusion, concentration difficulties, visual problems, ringing in the ears, dizziness, numbness, tingling, fatigue and mood swings.

- Medical specialist: Neurologist
- Things to try: Brain games for cognitive dysfunction (lupus fog) or ice packs for headaches
- Things to avoid: Cold environments if Raynaud's syndrome is an issue

## **Gastrointestinal System**

If lupus affects your gastrointestinal system, you may have complications related to your digestive system and surrounding organs, such as the liver, pancreas and gallbladder. You may be prone to swallowing difficulties, acid reflux, nausea, vomiting, diarrhea, constipation, abdominal pain and ulcers.

- Medical specialist: Gastroenterologist
- Things to try: The BRAT diet (bananas, rice, applesauce and toast) or probiotics
- Things to avoid: Fatty and overly acidic foods.

## Renal System

If lupus affects your renal system, you may have complications related to your kidneys and urinary tract. You may be prone to fluid retention, edema, elevated blood pressure, increased urination and frequent urinary tract infections.

• Medical specialist: Nephrologist

Things to try: Cranberry juice and compression stockings

• Things to avoid: Nonsteroidal anti-inflammatory drugs (NSAID), such as ibuprofen

Next page: how does lupus affect the other systems in your body?

## **A Few Specifics**

## Cardiovascular System

If lupus affects your cardiovascular system, you may have complications related to your heart, arteries, veins and capillaries. You may be prone to chest pain, heart palpitations, shortness of breath, lupus bruises, vasculitis, coronary artery disease and inflammation related to the heart such as pericarditis, myocarditis and endocarditis.

Medical specialist: CardiologistThings to try: Heart healthy foods

Things to avoid: Extended periods of strenuous activity or overexertion

#### **Pulmonary System**

If lupus affects your pulmonary system, you may have complications related to your lungs and diaphragm. You may be prone to chest pain, shortness of breath, dry cough, breathing difficulties, low oxygen levels, chronic lung disease, pulmonary embolism and inflammation related to the lungs such as pleuritis and pneumonitis.

• Medical specialist: Pulmonologist

- · Things to try: Breathing exercises and a pulse oximeter to monitor your oxygen level
- Things to avoid: Overexertion as well as lack of activity find a happy medium

#### The Skin

If lupus affects your skin, you may be prone to rashes, sores/lesions and hair loss.

- Medical specialist: Dermatologist
- Things to try: Sunscreen, sun-protective clothing, broad-brimmed hats and topical creams.
- Things to avoid: Sun exposure and extended hours under florescent lights

#### The Blood

If lupus affects your blood, you may have complications related to your red blood cells, white blood cells and platelets. You may be blood disorders such as anemia and thrombosis (blood clotting).

Medical specialist: HematologistThings to try: Iron supplements

• Things to avoid: Activities that could cause injury resulting in excessive bleeding

Think about how lupus affects you. Does it manifest as a skin condition, damage your heart, or cause you to have tummy troubles?

There is a wealth of information that can be found here on *NewLifeOutlook*, and many wonderful suggestions have been offered by those who walk your same path. However, wading through the information can become

daunting and overwhelming.

Which bits of advice do you incorporate? Which pieces of information are specific to your needs? For this reason, it's important to know all you can about your particular situation.

The material becomes more manageable when you know what you are looking for. Don't let lupus control and define you! Be proactive and seek the knowledge that will empower you to control your disease.