

# LUPUS

## Overview

Systemic Lupus Erythematosus, sometimes called SLE or Lupus for short, is a complicated disease that can look different in any given person. This is why it is often called the disease of 1000 faces. While sometimes difficult to recognize, a rheumatologist can help to diagnose and manage lupus. Read below for further information on this often misunderstood condition.

## Frequently Asked Questions

### What is Systemic Lupus Erythematosus?

- Systemic lupus erythematosus (SLE, or lupus) is an autoimmune disease, meaning the immune system can attack and cause problems to different parts of the body including the joints, the kidneys, the lungs, the skin, the blood cells, the brain or even the gastrointestinal tract.
- Different people can have different types of symptoms and signs, which is why SLE is also known as the “disease of 1000 faces”.

### How common is SLE?

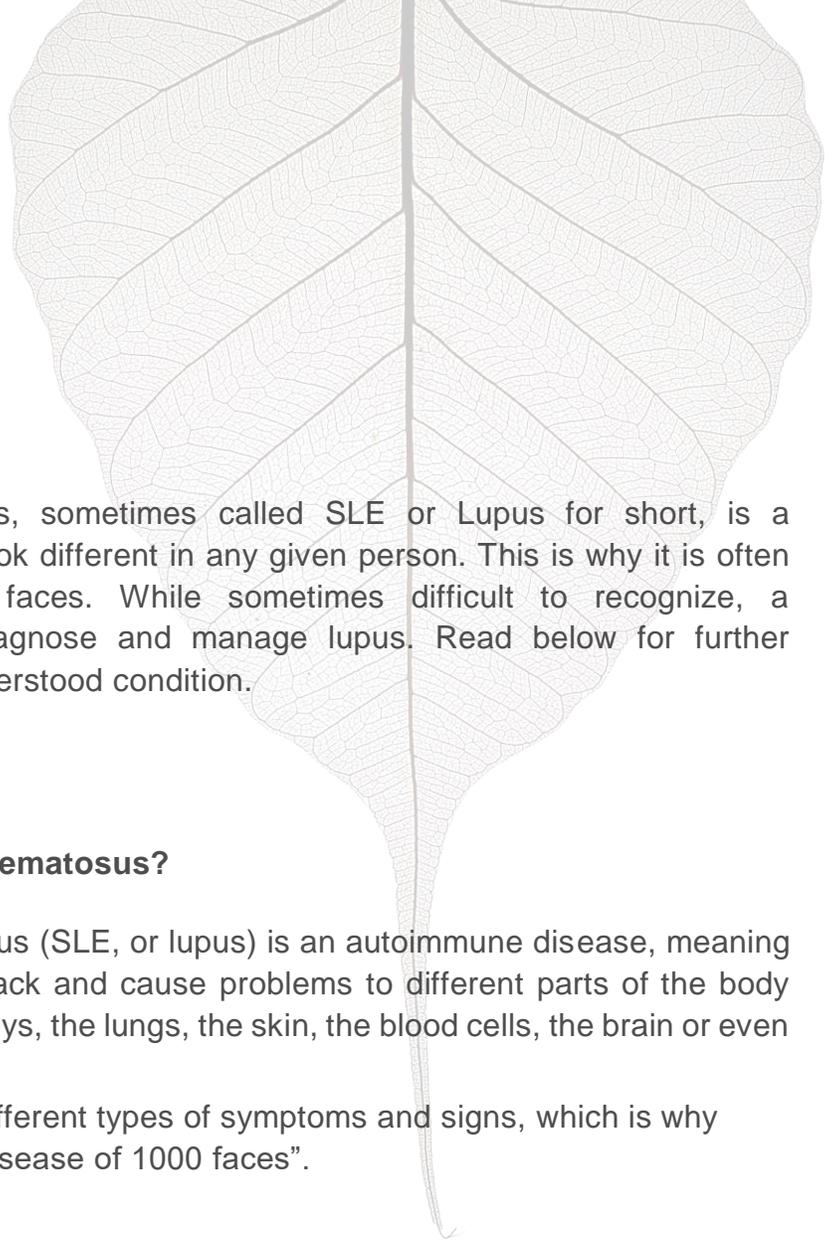
- Lupus is not a common disease, occurring in less than 0.1% of the population.
- It is more common in women than men and is often diagnosed in one’s 20-30’s, although it can also occur in children and seniors.

### What causes SLE?

- It remains unclear. SLE is felt to be a result of both genetic and environmental factors resulting in abnormalities in the immune system.

### What are typical symptoms of SLE?

- The disease severity can range from very mild to severe. Examples of signs and symptoms of lupus include:
  - Fatigue, lack of appetite, weight loss
  - Joint pain and stiffness (especially the small joints of the hands and feet)
  - Sores in the mouth and nose



- Hair loss
- Sensitivity to sun
- Skin rashes including the malar (butterfly) rash on the face
- Painful finger or toes in the cold associated with colour changes
- Difficulties breathing
- Chest pain
- Seizures
- Difficulties concentrating
- Leg swelling
- Blood clots or a history of miscarriages

**I have some of the symptoms listed above. Does that mean I could have lupus?**

- While it is possible, there are many other conditions which are more common that are associated with one or more of the symptoms or signs listed above.

**How is SLE diagnosed then?**

- SLE is diagnosed by a rheumatologist after he/she performs a history and physical examination, and reviews various blood work and imaging studies. It is the right combination of findings from your history, exam and tests which determine if in fact you may have lupus.

**Is there a blood test that can diagnosis lupus? My doctor told me I have a positive blood test for lupus called ANA. Do I have Lupus?**

- Probably not. Nearly all patients who have lupus are positive for ANA, or an antinuclear antibody test. However, an ANA is found to be falsely positive in up to 10% of the population. In fact, only 1 in 200 people who are ANA positive actually will have lupus. While a negative ANA test effectively rules out a diagnosis of lupus, a positive test is far from conclusive.

**I have been diagnosed with lupus? How is it treated?**

- Many SLE patients are put on various medications to help reduce disease activity with a goal of remission. Currently, no cure exists for SLE; however, a growing number of medications exist which if taken regularly, can keep the disease in control and possibly remission. Examples of commonly used medications include:

antimalarial (eg. hydroxychloroquine (Plaquenil), chloroquine (Aralen), azathioprine (Imuran), mycophenolate mofetil (Cellcept), and cyclophosphamide .

- If someone has aggressive disease or the threat that a particular organ may be failing, glucocorticoids (steroids) are used because they have the fastest onset of action and can be life-saving. In the long-term however, steroids can have significant side effects which is why steroid-sparing immunosuppressants such as antimalarials, azathioprine, cyclophosphamide are needed for long-term control of the disease.
- Anti-inflammatories (NSAIDs) can be used for joint pain however should be avoided if there is kidney involvement, high blood pressure or a history of heart attacks or stroke.
- Agents to prevent bone loss such as the bisphosphonates (etidronate, alendronate, risedronate, zoledronate) may be used, especially if you are on steroids at higher dosage for longer periods of time.
- Antimalarial drugs are one of the mainstays of treatment for SLE as multiple studies have shown they can delay onset of SLE, reduce the symptoms, and prevent flares. They are also safe in pregnancy and breastfeeding.
- If an SLE patient has a history of blood clots, miscarriages or strokes and is found to be positive for antiphospholipid antibodies, they may be put on blood thinners including warfarin (Coumadin), heparin and/or aspirin.

### **Is it safe to become pregnant if you have lupus?**

- Many SLE patients are in their childbearing years and have or are considering families. Overall, there are not significant changes in fertility or conception rates for SLE patients.
- Rheumatologists recommend that any female with SLE should avoid unplanned pregnancies and ensure SLE disease activity is at a minimum for at least 6 months prior to conception attempts.
- While SLE activity is unpredictable in pregnancy, the longer the disease is quiet before pregnancy, the more likely it should remain that way during pregnancy.
- Some pregnancies require the use of aspirin or blood thinners (heparin) if a patient has antiphospholipid antibodies.
- All medications require review before attempting conception, as some are safe and others are not during pregnancy.
- For more information, [click here to read more](#) and to see our video.

### **What is the prognosis for SLE?**

- The answer depends on the severity of your disease and which organs are affected. Survival rates have improved dramatically over the last few decades, from under 50% to better than 90% today. However, there is still risk of complications due to the disease and/or its management. For some patients, there are those who are able to remain in remission for some time without any medications.

### **What is in the future for SLE treatment?**

- Many new medications targeting different parts of the immune system are in various phases of trials. Various organizations in Alberta and Canada exist to provide further information including: Lupus Canada, the Lupus Society of Alberta, and CaNIOS (the Canadian Network of Improved Outcomes in SLE). All rheumatologists in Edmonton diagnose and follow SLE patients. The Lupus Clinic at the University of Alberta also diagnoses and follows SLE patients as well as collects data for research and conducts clinical trials. If interested, please speak to your rheumatologist to determine if you are eligible for a clinical trial.