



# Systemic Lupus Erythematosus (Lupus)

IN-DEPTH

## Overview of Systemic Lupus Erythematosus (Lupus)

Systemic lupus erythematosus (lupus) is a chronic (long-lasting) autoimmune disease that can affect many parts of the body. Lupus occurs when the immune system, which normally helps protect the body from infection and disease, attacks its own tissues. This attack causes inflammation, and in some cases permanent tissue damage, which can be widespread – affecting the skin, joints, heart, lung, kidneys, circulating blood cells, and brain.

If you have lupus, you may experience periods of illness (flares) and periods of wellness (remission). Lupus flares can be mild to serious, and they are unpredictable. However, with treatment, many people with lupus can manage the disease.

## Who Gets Systemic Lupus Erythematosus (Lupus)?

Anyone can get lupus; however, women get the disease about nine times more often than men. Most often it happens in people between ages 15 and 45 years, but lupus can occur in childhood or later in life as well.

Lupus is more common in African Americans than in white people and is also more common in people of American Indian and Asian descent. Men, African Americans, and Chinese and Hispanic people are also more likely to have serious organ system involvement. If you have a family member with lupus or another [autoimmune disease](#), you may be more likely to develop lupus.

## Symptoms of Systemic Lupus Erythematosus (Lupus)

The symptoms of lupus vary from person to person and can range from mild to severe. You may have just a few symptoms affecting just one area of your body, or you could have many symptoms throughout your body. Symptoms may come and go, and you may develop new symptoms over time. Some symptoms happen when the disease causes inflammation in organs, such as the joints, skin, kidneys, lining of the heart and lungs, brain, and blood cells. Symptoms of lupus can include:

- [Arthritis](#), causing painful and swollen joints and morning stiffness.
- Fevers.
- Fatigue or feeling tired often.
- Malar or “butterfly” rash that appears on the face across the nose and cheeks.
- Discoid, round scaly rashes that can appear anywhere on the body.
- Sensitivity to the sun that may cause a rash.
- Hair loss.
- Sores, which are usually painless, in the nose and mouth (most often on the roof of the mouth).
- Change of color in the fingers and toes – blue-purple, white, or red – from cold and stress ([Raynaud’s phenomenon](#)).
- Swollen glands.
- Swelling in the legs or around the eyes.
- Pain when breathing deeply or lying down, from inflammation of the lining around the lungs or heart.
- Headaches, dizziness, depression, confusion, or seizures.
- Abdominal pain.

Lupus causes inflammation throughout the body, which can affect other areas of the body and lead to other problems, including:

- Lupus nephritis, which causes kidney damage that can lead to changes in kidney function, including kidney failure.
- Seizures and memory problems due to changes in the brain and central nervous system.
- Heart problems:
  - Heart valve damage due to inflammation that leads to scarring.
  - Pericarditis, inflammation of the lining around the heart muscle.
  - Myocarditis, inflammation of the heart muscle itself.
- Vasculitis due to the inflammation of blood vessels.
- Blood clots due to high levels of certain autoantibodies referred to as antiphospholipid antibodies.

- Low blood cell counts, including red blood cells, white blood cells, and platelets.
- Infection from low blood cell counts and some of the medications used to treat lupus.
- Pleurisy from inflammation of the tissue that surrounds the lungs, making it painful to breathe.
- Bones that become weak due to the use of glucocorticoids.

Some people with lupus may be more likely to develop other conditions, such as cardiovascular disease due to inflammation of the heart and blood vessel tissues caused by lupus, which can lead to:

- Atherosclerosis in blood vessels throughout the body, which happens when fat and other materials attach to the blood vessel wall and form plaque. This can happen in blood vessels throughout the body.
- Coronary artery disease, which happens when plaque builds up in the arteries that supply blood to the heart. This can interrupt blood flow when a blood clot forms or a piece of plaque breaks off, causing a heart attack.

## Causes of Systemic Lupus Erythematosus (Lupus)

The cause of lupus is unknown, and researchers are still trying to learn what may trigger or lead to the disease. Doctors know that it is a complex autoimmune disease in which the body's immune system attacks the person's tissues and organs. Studies show that certain factors may trigger your immune system, causing the disease. These factors include:

- **Genes.** Research shows that certain genes play a role in the development of lupus. The different forms of these genes carry instructions for proteins that may affect the immune system. Researchers are studying how high levels or low levels of these proteins may be important in the development of the disease.
- **Environment.** Exposure to certain factors in the environment – such as viral infections, sunlight, certain medications, and smoking – may trigger lupus.
- **Immune and Inflammatory Influences.** Researchers think that if the body does not remove damaged or dead cells normally, this could trick the immune system into constantly fighting against itself. This process could cause an autoimmune response, which could lead to lupus. In addition, researchers are studying different cell types and how changes could lead to lupus.

## Diagnosis of Systemic Lupus Erythematosus (Lupus)

Lupus can be difficult to diagnose because it has many symptoms that come and go, and also can mimic symptoms of other disorders or diseases. When speaking to your doctor about your symptoms, be sure to include symptoms that may no longer be present. Your doctor may need to rule out other causes before diagnosing lupus. At this time, no single test diagnoses lupus. Doctors can diagnose the condition by:

- Asking about your medical history and symptoms, and, if necessary, reading your previous medical records.
- Asking if anyone in your family has lupus or other autoimmune diseases.
- Performing a complete physical exam.
- Taking samples of blood for laboratory tests, such as:
  - Antinuclear antibodies (ANA), a sensitive test for lupus. Almost all people with lupus with have a positive ANA. However, having a positive ANA does not mean you have lupus since totally healthy people can have a positive ANA.
  - Antiphospholipid antibodies, anti-smith, and anti-double-strand DNA antibodies, which doctors order when you have a positive ANA and can help determine if you have lupus.
  - Complete blood counts, to check for low platelet counts, low red blood cell counts, and low white blood cell levels, which can happen if you have lupus.
  - Metabolic panel to look for changes in kidney function.
- Taking urine samples to check for abnormal levels of protein in the urine .
- Performing a biopsy of the skin or kidney (when labs indicate there may be a problem with the kidney) by taking a small sample of tissue to examine under a microscope.

## Treatment of Systemic Lupus Erythematosus (Lupus)

Doctors treat lupus based on your symptoms. The goal of treatment is to:

- Manage symptoms.
- Prevent, limit, and stop flares.
- Maintain the lowest level of disease activity, and, if possible, achieve complete remission.
- Prevent or slow organ damage.
- Improve your quality of life.

Lupus is a chronic (long-lasting) disease, and there is no cure at the present time. However, treatments have improved dramatically, giving doctors more choices to manage the disease. Because symptoms can change, and treatments can have side effects, your doctor may recommend a combination of treatments to manage lupus.

Treatments for lupus may include the following.

## Medications

- Anti-inflammatory drugs help treat pain or fever.
- Antimalarials, which are used to prevent and treat malaria, have been found to be useful for treating fatigue, joint pain, skin rashes, and inflammation of the lungs caused by lupus. These drugs may also prevent flares from recurring.
- Corticosteroids help to lower inflammation in the body. Doctors prescribe these medicines in the following forms:
  - Liquid or pills that you swallow.
  - Cream that you apply to the skin.
  - Injection.
  - Intravenous (IV) infusion that doctors give to you through a tube in your vein.

Because they are potent drugs, your doctor will prescribe the lowest dose possible to achieve the desired benefit.

- Immunosuppressants help suppress or curb the overactive immune system, and they may be given by mouth or by IV infusion. The risk for side effects increases with the length of treatment.
- B-lymphocyte stimulator (BlyS) protein inhibitor, a type of biologic medication, can help reduce the activation and life span of abnormal B-cells in the body, which may help control lupus.

You may need to take medicines to treat or prevent complications related to lupus or side effects from the medicines that treat the disease, such as heart disease, high blood pressure, osteoporosis, or infection.

In addition, your doctor may prescribe medications that are typically used to treat other diseases that have symptoms similar to those of lupus. For example, medications that doctors prescribe for [rheumatoid arthritis](#) may help improve some of the symptoms of lupus.

## Alternative and Complementary Therapies

Some people may try alternative and complementary therapies to improve symptoms. However, research has not shown whether they help treat lupus. Examples include:

- Special diets.
- Nutritional supplements.

- Fish oils.
- Ointments and creams.
- Acupuncture.
- Chiropractic treatment.
- Homeopathy.

Some over-the-counter medicines, herbs, and supplements can interfere with other medicines you are taking. Before beginning any new therapy, speak with your doctor.

No matter what treatment you receive, it is important that you have regular visits with your doctor to monitor your disease and potential side effects of prescribed therapies. Never stop your medicines or treatments without speaking to your doctor.

## Who Treats Systemic Lupus Erythematosus (Lupus)?

Most people will see a rheumatologist for their lupus treatment. A rheumatologist is a doctor who specializes in rheumatic diseases, such as [arthritis](#) and other inflammatory or [autoimmune disorders](#). Clinical immunologists, doctors who specialize in immune system disorders, may also treat people with lupus. Other health care providers may provide treatment, including:

- Primary care providers, such as a family physician or internal medicine specialist.
- Mental health professionals, who provide counseling and treat mental health disorders such as depression and anxiety.
- Nephrologists, who treat kidney disease.
- Cardiologists, who specialize in treating diseases of the heart and blood vessels.
- Hematologists, who specialize in blood disorders.
- Endocrinologists, who treat problems related to the glands and hormones.
- Dermatologists, who specialize in conditions of the skin, hair, and nails.
- Pulmonologists, who treat lung problems.
- Neurologists, who treat disorders and diseases of the spine, brain, and nerves.

## Living With Systemic Lupus Erythematosus (Lupus)

Living with lupus can be physically and emotionally hard. At times, you may think that your friends, family, and coworkers do not understand how you feel. You may experience sadness and anger. A good place to start managing the disease is working with your doctor to determine the best treatment plan and taking your medications as prescribed. But keep in mind, many people with lupus live wonderfully happy lives, and therefore a positive outlook is very important.

You can do several things to help you live with lupus:

- Learn to recognize the warning signs of a flare so that you and your doctor might reduce or prevent them. Warning signs include:
  - Increased tiredness.
  - Joint swelling.
  - Pain.
  - Rash.
  - Fever.
  - Abdominal pain.
  - Headache.
- Eat a healthy well-balanced diet rich in fruits, vegetables, and whole grains.
- Exercise to help keep your body strong; however, talk to your doctor before starting an exercise program.
- If you smoke, quit. This will help lower your risk for heart disease that can be a complication of lupus.
- Protect yourself from the sun – sometimes, exposure to the sun can cause a flare. Wear protective clothing, such as a hat or long-sleeved shirts, and use sunscreen any time you go outside.
- Reach out to online and community support groups.
- Keep the lines of communication open. Talk to your family and friends about your lupus to help them understand the disease.
- Ask for help when you need it.
- Take a break from focusing on the disease, and spend some time doing activities you enjoy.
- Lower your stress – try meditating, reading, or deep breathing. Remember, stress can trigger a flare.
- Make changes if you need to in your work environment so you can try to continue to work, such as:
  - Creating a flexible schedule – for example, work from home or start the workday later.
  - Working part time.
  - Adjusting your work area so that you are more comfortable.

Most people with mild disease or who are in remission can usually participate in the same life activities they did before they were diagnosed.

Pregnancy and Contraception for Women With Lupus

Most women with lupus can have healthy pregnancies if the disease is under control. If you start to plan a pregnancy, talk to your doctor so you can be as healthy as possible before becoming pregnant. Close monitoring during pregnancy is essential, especially if you have low platelets, antiphospholipid antibodies, anti-SSA/Ro antibodies, high blood pressure, lung or heart problems, or kidney disease. It is important to find an obstetrician who manages high-risk pregnancies and has experience working with women who have lupus.

Research shows that birth control pills do not increase the risk for severe flares among women with lupus, but estrogen-containing pills are not recommended for women with antiphospholipid antibodies. Talk with your doctor about your antibody test results before starting oral contraceptives.

## Research Progress Related to Systemic Lupus Erythematosus (Lupus)

The NIAMS [Lupus Clinical Research Program](#) conducts translational and clinical research into the causes, treatment, and prevention of lupus. In addition, the NIAMS funds and supports many researchers at universities and other organizations throughout the country who are studying lupus to better understand the cause, in hopes to prevent and cure the disease. Topics include:

- **Genetics.** Several genes associated with lupus risk and severity have been discovered.
- **Sex differences.** Researchers are trying to understand the biological bases for sex differences in immune and inflammatory systems to better understand why women are more likely than men to have the disease.
- **Biomarkers.** Certain proteins or genes could help doctors predict flares in lupus and, in the future, response to specific treatments.
- **Disease processes.** Researchers are exploring possible triggers for lupus.
- **Treatment.** Scientists are exploring how lupus develops and how therapies affect the course of the disease. They are also exploring drugs to prevent or delay kidney failure, one of the most serious and life-threatening complications of lupus.

Experts are also collaborating to develop registries and working groups, such as:

- The Lupus Family Registry and Repository, which gathers medical information as well as blood and tissue samples from patients and their relatives. This will help identify genes that make someone more at risk for the disease.
- Lupus Federal Working Group, which gathers experts across various public health agencies, pharmaceutical companies, and professional organizations.

- National Institutes of Health (NIH) Accelerating Medicines Partnership, which aims to reduce the time and cost of developing new diagnostics and therapies for diseases, including lupus.

## For More Info

### **U.S. Food and Drug Administration**

Toll free: 888-INFO-FDA (888-463-6332)

Website: <https://www.fda.gov>

Drugs@FDA at <https://www.accessdata.fda.gov/scripts/cder/daf> Drugs@FDA is a searchable catalog of FDA-approved drug products.

### **Centers for Disease Control and Prevention, National Center for Health Statistics**

Website: <https://www.cdc.gov/nchs>

### **American College of Rheumatology**

Website: <https://www.rheumatology.org>

### **American Autoimmune Related Diseases Association, Inc.**

Website: <https://www.aarda.org>

### **Arthritis Foundation**

Website: <https://www.arthritis.org>

### **Lupus Clinical Trials Consortium**

Website: <https://www.lupusclinicaltrials.org>

### **Lupus Foundation of America**

Website: <https://www.lupus.org>

### **Lupus Research Alliance**

Website: <http://www.lupusresearch.org>

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If you need more information about available resources in your language or other languages, please visit our webpages below or contact the NIAMS Information Clearinghouse at [NIAMSInfo@mail.nih.gov](mailto:NIAMSInfo@mail.nih.gov).

- [Asian Language Health Information](#)

- [Spanish Language Health Information](#)