

# What Is Lupus?

*Fast Facts: An Easy-to-Read Series of Publications for the Public*

## What Is Lupus?

The immune system is designed to attack foreign substances in the body. If you have lupus, something goes wrong with your immune system and it attacks healthy cells and tissues. This can damage many parts of the body such as the:

- Joints
- Skin
- Kidneys
- Heart
- Lungs
- Blood vessels
- Brain.

There are many kinds of lupus. The most common type, systemic lupus erythematosus, affects many parts of the body. Other types of lupus are:

- Discoid lupus erythematosus—causes a skin rash that doesn't go away
- Subacute cutaneous lupus erythematosus—causes skin sores on parts of the body exposed to sun
- Drug-induced lupus—can be caused by medications
- Neonatal lupus—a rare type of lupus that affects newborns.

## Who Gets Lupus?

Anyone can get lupus, but it most often affects women. Lupus is also more common in women of African American, Hispanic, Asian, and Native American descent than in Caucasian women.

## What Causes Lupus?

The cause of lupus is not known. Research suggests that genes play an important role, but genes alone do not determine who gets lupus. It is likely that many factors trigger the disease.

## What Are the Symptoms of Lupus?

Symptoms of lupus vary, but some of the most common symptoms of lupus are:

- Pain or swelling in joints
- Muscle pain



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- Fever with no known cause
- Red rashes, most often on the face
- Chest pain when taking a deep breath
- Hair loss
- Pale or purple fingers or toes
- Sensitivity to the sun
- Swelling in legs or around eyes
- Mouth ulcers
- Swollen glands
- Feeling very tired.

Less common symptoms include:

- Anemia (a decrease in red blood cells)
- Headaches
- Dizzy spells
- Feeling sad
- Confusion
- Seizures.

Symptoms may come and go. The times when a person is having symptoms are called flares, which can range from mild to severe. New symptoms may appear at any time.

### **How Is Lupus Diagnosed?**

There is no single test to diagnose lupus. It may take months or years for a doctor to diagnose lupus. Your doctor may use many tools to make a diagnosis:

- Medical history
- Complete exam
- Blood tests
- Skin biopsy (looking at skin samples under a microscope)
- Kidney biopsy (looking at tissue from your kidney under a microscope).

### **How Is Lupus Treated?**

You may need special kinds of doctors to treat the many symptoms of lupus. Your health care team may include:

- A family doctor
- Rheumatologists—doctors who treat arthritis and other diseases that cause swelling in the joints
- Clinical immunologists—doctors who treat immune system disorders
- Nephrologists—doctors who treat kidney disease

- Hematologists—doctors who treat blood disorders
- Dermatologists—doctors who treat skin diseases
- Neurologists—doctors who treat problems with the nervous system
- Cardiologists—doctors who treat heart and blood vessel problems
- Endocrinologists—doctors who treat problems related to the glands and hormones
- Nurses
- Psychologists
- Social workers.

Your doctor will develop a treatment plan to fit your needs. You and your doctor should review the plan often to be sure it is working. You should report new symptoms to your doctor right away so that treatment can be changed if needed.

The goals of the treatment plan are to:

- Prevent flares
- Treat flares when they occur
- Reduce organ damage and other problems.

Treatments may include drugs to:

- Reduce swelling and pain
- Prevent or reduce flares
- Help the immune system
- Reduce or prevent damage to joints
- Balance the hormones.

In addition to medications for lupus itself, sometimes other medications are needed for problems related to lupus such as high cholesterol, high blood pressure, or infection. Alternative treatments are those that are not part of standard treatment. No research shows that this kind of treatment works for people with lupus. You should talk to your doctor about alternative treatments.

### **What Can I Do?**

It is vital that you take an active role in your treatment. One key to living with lupus is to know about the disease and its impact. Being able to spot the warning signs of a flare can help you prevent the flare or make the symptoms less severe. Many people with lupus have certain symptoms just before a flare, such as:

- Feeling more tired
- Pain
- Rash
- Fever
- Stomach ache
- Headache
- Dizziness.

You should see your doctor often, even when symptoms are not severe. These visits will help you and your doctor to:

- Look for changes in symptoms
- Predict and prevent flares
- Change the treatment plan as needed
- Detect side effects of treatment.

It is also important to find ways to cope with the stress of having lupus. Exercising and finding ways to relax may make it easier for you to cope. A good support system can also help. A support system may include family, friends, community groups, or doctors. Many people with lupus have found support groups to be very useful. Besides providing support, taking part in a support group can make you feel better about yourself and help you to keep a good outlook.

Learning more about lupus is very important. Studies have shown that patients who are informed and involved in their own care:

- Have less pain
- Make fewer visits to the doctor
- Feel better about themselves
- Remain more active.

### **Pregnancy and Contraception for Women With Lupus**

Women with lupus can and do have healthy babies. There are a few things to keep in mind if you are pregnant or thinking about becoming pregnant:

- Pregnancy in women with lupus is considered high risk, but most women with lupus carry their babies safely.
- Pregnant women with lupus should see their doctors often.
- Lupus can flare during pregnancy.
- Pregnancy counseling and planning before pregnancy are important.

Women with lupus who do not wish to become pregnant or who are taking medicine that could be harmful to an unborn baby may want reliable birth control. Recent studies have shown that oral contraceptives (birth control pills) are safe for women with lupus.

### **What Are Researchers Trying to Learn About Lupus?**

Current lupus research projects include:

- A Specialized Center of Research in Lupus at the University of Virginia School of Medicine
- A Lupus Registry and Repository that researchers across the country can utilize to help identify genes that determine susceptibility to the disease
- A Neonatal Lupus Registry that researchers across the country can utilize to research data and genetic information on neonatal lupus
- Funding for The Lupus Federal Working Group—to focus on lupus research progress

- Research studies to better understand:
  - Genetics—genes that are associated with susceptibility to lupus or play a role in the development of lupus
  - Biomarkers—something that can be found in cells or tissues that predicts lupus flares or lupus disease process
  - The lupus disease process—how it affects different organs, how it behaves in its earliest clinical manifestations
  - Treatments, such as the medication rituximab, which lowers the number of white blood cells that produce antibodies
  - Overcoming barriers that tend to keep some populations from complying with prescribed treatment.

**For More Information on Lupus and Other Related Conditions:**

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The information in this fact sheet was summarized in easy-to-read format from information in a more detailed NIAMS publication. To order the Systemic Lupus Erythematosus Handout on Health full-text version, please contact the NIAMS using the contact information above. To view the complete text or to order online, visit [www.niams.nih.gov](http://www.niams.nih.gov).

**For Your Information**

This publication may contain information about medications used to treat the health condition discussed here. When this publication was printed, we included the most up-to-date (accurate) information available. Occasionally, new information on medication is released.

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