# What Is Lupus and What Is Not Lupus?

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## What Is Lupus?

Lupus has been difficult to comprehend since it was first classified and named in the 12th century. Referred to as “the great imitator,” it is easily mistaken for other diseases.

Even the origin of the name can be debated. Lupus may have been used because it’s the Latin word for wolf – as the common facial rash has been visually compared to a wolf bite or possibly the fur on a wolf’s face – or it could have come from a French mask called a “loup” that women wore to hide their rashes.

At its core, lupus is a mismanaged immune system response that causes the body to attack itself and inflict damage. But the way that lupus appears and the parts of the body that it focuses on can vary widely in each person.

There is much about lupus that has not yet been revealed or understood, and so this article will focus on what is known about the diverse aspects of lupus.

### Types of Lupus

There are several types of lupus; the two primary forms are systemic lupus erythematosus (SLE) and cutaneous lupus erythematosus (CLE). SLE can potentially affect the entire body while cutaneous lupus is limited to skin involvement.

#### Systemic Lupus

Systemic lupus is the most common and variable form of lupus. It can range from mild to severe in disease activity and affect nearly any part of the body, although the heart, lungs, kidneys, skin, joints, and/or nervous system are popular targets.

#### Discoid Lupus

The most common type of CLE is discoid lupus, which is characterized by round or disk-shaped skin rashes. Discoid lupus can also cause sores, lesions, or thick, red, scaly patches of skin above the neckline.

#### Is It Possible to Have SLE and CLE?

It is possible, though unusual, to have both SLE and CLE. In fact, it has been suggested that lupus may operate on a sliding scale with CLE on one end and SLE on the other.

This is why it’s recommended that those with SLE be evaluated for skin involvement and those with CLE be monitored for systemic activity.

**Drug-Induced Lupus**

Another type of lupus is drug-induced lupus. This is an onset of lupus symptoms as a side effect of medication that typically stops when the medication is discontinued.

There are dozens of medications that can cause drug-induced lupus, including procainamide, isoniazid, hydralazine, quinidine, and phenytoin.

**Neonatal Lupus**

One of the rarer forms of lupus is neonatal lupus. This occurs when a pregnant woman passes autoantibodies to her baby in-utero.

It is a temporary but potentially damaging condition that can result in skin issues at birth or possibly more serious problems such as a congenital heart block.

## The Potential Causes of Lupus

There is no known cause for lupus, but research is starting to reveal some potential roots.

There is a suspected genetic link as lupus tends to run in families. Two lupus studies from *BMJ Journals* and *Science Immunology* have further validated the idea that genetic material is part of the reason why women develop lupus more than men do.

Someone may be more susceptible to lupus because of their genes and then develop it after encountering lupus triggers.

Known triggers are:

- A particularly bad infection
- An increase in female sex hormones (such as during pregnancy)
- Exposure to sunlight
- Certain medications
- A vitamin D deficiency
- Smoking.

It’s common to hear from people with lupus that their symptoms first surfaced after an intense sunburn or during their first pregnancy.

## Who Gets Lupus?

The highest rates of lupus are found in the USA and France, with the global SLE rate ranging from 20-70 per 100,000 people (or less than 0.1 percent). Sun exposure could possibly play a factor in the varying geographic rates of lupus.

Even though the rate of lupus seems relatively low, it is not considered a rare disease (at least not in the United States). People who are most likely to develop lupus include:

- Women – nine out of 10 people with lupus are women.
- African Americans – black women are two to three times more likely to get lupus compared to white women.
- Hispanics, Asians, and Native Americans.
- Those between the ages of 15 and 45.

*Next Page: Common questions about lupus, the symptoms of lupus, and how lupus is diagnosed.*

## Is Lupus Contagious?

Lupus is not contagious in any form. As an autoimmune disease, it is intrinsic to a person's immune system and cannot be spread through physical contact.

People with lupus are often unable to donate blood due to their medications, but even if someone were to receive blood with lupus-related autoantibodies theoretically, they would likely only have a mild, temporary reaction as their body neutralized them.

## Is Lupus Fatal?

Lupus is capable of killing, but it is not necessarily fatal. In the 1950s, before many modern medical treatments for lupus, people suffering from SLE were expected to live less than five years after their diagnosis.

Today, up to 90 percent of people with lupus will have a normal lifespan if they are diligent about their medical care and treatment. Many lupus related fatalities stem from people who were unable to accept or cope with their diagnosis and therefore avoided treatment for an extended period of time.

While odds have improved significantly, there is still an overall lower life expectancy for people with SLE. Men, children, and people of color are more likely to suffer serious, potentially fatal lupus complications.

## Is There a Cure for Lupus?

There is no cure for lupus, but medical research continues to uncover new and promising treatments. Determining the cause of lupus would likely be one of the first steps towards finding a cure.

Options are expanding for lupus patients, and many treatments are tailored to specific lupus manifestations. People who make the most of medical treatments and lifestyle changes may be able to achieve remission and live with very few symptoms.

## Understanding Lupus Symptoms

The symptoms of lupus are wide-ranging and often mimic other diseases, making diagnosis difficult in many cases. Furthermore, the symptoms will vary according to how lupus is affecting the body.

These are some of the many symptoms of lupus:

- Malar rash (a red, butterfly-shaped rash across the face)
- Fatigue
- Fever
- Shortness of breath
- Cognitive impairments (headaches, confusion, memory loss)
- Photosensitivity (skin rashes or lesions after sun exposure)
- Chest pain (pleurisy)
- Pain, stiffness, and swelling in joints
- Muscle pain
- White or blue extremities when cold (Raynaud's phenomenon)
- Hair loss
- Dry eyes
- Ulcers in the mouth or nose
- Appetite loss
- Nausea

## How Is Lupus Diagnosed?

Receiving a lupus diagnosis is often a long, difficult process. In my case, it took three years of experiencing symptoms and visits to three different doctors before I was diagnosed with lupus, but it's common for people to wait up to five years or even longer.

The diagnosis process will begin with a full medical history, a physical exam, various laboratory tests, specialist visits, and skin or kidney biopsies.

Usually, blood is drawn and analyzed for the levels of white and red blood and platelets, hemoglobin (a protein in red blood cells), inflammation markers, and antinuclear antibodies in the blood, as these may have abnormal results in people with lupus. Blood tests can also reveal problems within the kidneys or liver.

Urine samples are collected to look for protein or red blood cells in the urine, which could indicate kidney involvement.

Imaging tests such as x-rays or echocardiogram are used if inflammation is suspected in the heart or lungs.

Skin and kidney biopsies are taken on an as-needed basis after a physical exam or lab results that indicate potential issues.

*Next page: how is lupus diagnosed? contd. And how does lupus affect the body?*

## How Is Lupus Diagnosed?

Many rheumatologists use the 11 criteria from the American College of Rheumatology (ACR), established in 1982, in order to diagnose systemic lupus. These criteria are:

1. Having a malar rash.
2. Having a discoid (skin) rash.
3. Photosensitivity.
4. Ulcers in the mouth or nose.
5. Lupus arthritis (nonerosive arthritis in two or more joints).
6. Signs of cardio-pulmonary involvement (such as pericarditis or pleurisy).
7. Signs of neurological issues (such as seizures or psychosis).
8. Kidney involvement.
9. Blood disorder (such as low white blood cell count or low platelet count).
10. Immune issues (such as antibodies to double-stranded DNA, Sm, or cardiolipin)
11. Antinuclear antibodies (in the absence of drugs known to induce them).

Most rheumatologists will use the four criteria rule to diagnose lupus – meaning you must have at least four of the above criteria in order to be diagnosed.

When I first visited my rheumatologist, I only exhibited three of the criteria, and so he initially diagnosed me with early lupus or, less specifically, undifferentiated mixed connective tissue disease.

However, within two additional months, I had symptoms that matched five of the criteria and received a full lupus diagnosis.

If lupus is suspected, it can be helpful to go back for more tests or frequent monitoring to possibly find additional diagnostic evidence, as some symptoms may only be evident for a short period of time or during flares.

## How Lupus Affects the Body

The variety of ways that lupus can affect the body would be impressive if it weren't such a sorrowful topic. There are very few body parts that are truly off limits.

**Lupus and Your Kidneys**

When lupus attacks the kidneys, it is called lupus nephritis. Nephritis occurs when the parts of the kidneys that filter blood become inflamed and can no longer function properly.

Signs of kidney inflammation include high blood pressure, sudden and intense swelling, increased urination, and foamy urine.

Lupus nephritis affects up to 50 percent of people with lupus, and up to 30 percent of people will progress to kidney failure.

While kidney disease is often caught early and managed well, it is ultimately one of the leading causes of death for people with lupus (particularly for African Americans). In fact, it was the number one cause of lupus fatalities before modern treatments such as dialysis and kidney transplantation.

**Lupus and the Cardiovascular System**

Lupus tends to cause inflammation in the outer membrane of the heart (called pericarditis), which can lead to sharp chest pain or shortness of breath. It can also inflame the heart muscle (myocarditis), its inner membrane (endocarditis), or the arteries. Over time, inflammation can scar the heart tissue and restrict its function.

People with lupus have a high risk of cardiovascular disease, artery disease, circulatory issues, and heart attacks. Cardiovascular issues are currently the leading cause of death for people with lupus.

**Lupus and the Lungs**

There are several lupus-related lung issues, including pleurisy, pneumonitis, pulmonary hypertension, and reduced lung volume.

Pleurisy occurs when the membrane around the lungs becomes inflamed – a painful condition that tends to happen during lupus flares.

About 50 percent of people with lupus will experience lung involvement of some kind. Many of those affected will suffer from breathlessness, lung disease, or possibly lung failure.

**Lupus and Your Skin**

Approximately two-thirds of people with lupus experience skin problems. The inflamed skin may have lesions, red, scaly patches, or a rash that looks and feels like a sunburn.

People with discoid lupus may have scarring, skin discoloration, or hair loss due to skin lesions.

**The Brain and Nervous System, and Lupus**

There are several ways that lupus can affect the brain and nervous system beyond the typical cognitive dysfunctions.

Some people may experience lupus headaches, brain inflammation, seizures, strokes, vision problems, or mood disorders.

The ACR has defined 19 different lupus related neuropsychiatric syndromes, and there may be more than have not yet been recognized.

**Lupus and Your Blood and Blood Vessels**

Blood vessels can become inflamed (a condition called vasculitis) due to lupus.

Other blood problems include anemia and increased risk of bleeding or blood clotting – especially if lupus coincides with antiphospholipid syndrome (APS). Around 20 percent of people with SLE will have APS as well.

*Next Page: How lupus affects the body? contd. And treatment for lupus information, and self-care tips for living with lupus.*

## How Does Lupus Affect the Body?

**The Bones and Joints, and Lupus**

Tissue death can occur in bones if the blood supply is decreased, leading to weak bones, bone fractures, or bone erosion.

Joint pain is one of the most frequent lupus-related complaints since lupus arthritis can cause stiff, swollen, and painful joints.

Less than 10 percent of the time lupus arthritis can also cause joint-related deformities.

**Lupus and the Muscles**

Muscle pain is present in up to 50 percent of people with lupus and happens when the muscles become inflamed or swollen.

Muscle inflammation can become very problematic if it leads to muscle weakness and loss of strength.

**Lupus and Pregnancy**

Miscarriage, preeclampsia, preterm birth, and fetal death are all serious concerns for women with lupus who become pregnant.

Around 70 percent of lupus pregnancies result in a live birth, and negative outcomes seem to be connected to disease flare-ups during pregnancy.

## Lupus Treatment: What's Available?

Treatment for lupus will vary according to how it is affecting the body; someone with mild lupus will have a vastly different treatment plan compared to someone with lupus nephritis.

All symptoms need to be taken into account when devising a lupus treatment plan. The focus of any plan will be to prevent and limit flares and organ damage.

Managing lupus will likely include a combination of medications, preventative measures, lifestyle changes, diet,

and exercise.

Here is an overview of some common lupus medications:

- **Nonsteroidal anti-inflammatory drugs (NSAIDs)** are used to reduce pain, swelling, fever, and inflammation. However, they can cause stomach bleeding, kidney issues, and heart problems.
- **Antimalarial drugs**, such as hydroxychloroquine, decrease lupus symptoms and flare frequency by interfering with the immune system. Side effects tend to be few, but include stomach and –rarely – eye damage.
- **Corticosteroids** are used to treat a variety of lupus issues, and high doses are utilized when disease activity becomes serious. Side effects can be intense and range from weight gain, high blood pressure, bone thinning, diabetes, insomnia, cataracts easy bruising, and higher risk for infection.
- **Immunosuppressants** are powerful drugs for lowering disease activity with lupus. There are several different immunosuppressant options; azathioprine and methotrexate are common choices, but someone with lupus nephritis might take mycophenolate mofetil (CellCept) or cyclophosphamide instead. These drugs can increase the risk of cancer, infertility, liver damage, and infection.
- **Biologics**, such as Benlysta, reduce lupus symptoms by targeting specific parts of the immune system. Side effects vary but may include depression, intestinal issues, nausea, and infections.

Medications to treat pain and other lupus-related issues, such as high blood pressure or high cholesterol, are often part of a lupus treatment plan. Topical creams, ointment, corticosteroid injections are used for skin involvement.

Lifestyle changes and preventative measures can be very effective components of a comprehensive lupus treatment plan. This will vary for each person but may include careful sun protection, resting often, avoiding known flare triggers, a healthy diet, and a regular exercise regimen.

**Tips for Living With Lupus**

Lupus can easily seem overwhelming, but many people learn to cope it with well – especially after the first few years. Essential tips for living well with lupus are frequently learned through trial and error.

**Find Excellent Doctors and See Them Regularly**

You may need to see your primary doctor, rheumatologist, dermatologist, and other doctors on a periodic basis. Review your doctors' notes and lab tests after each appointment, and keep an ongoing list of questions to prepare for your next one.

**Educate Yourself About Lupus as Much as Possible**

Reading *The Lupus Encyclopedia: A Comprehensive Guide for Patients and Families* is a great place to start.

There are plenty of online resources to help you stay up to date such as The Lupus Foundation, Kaleidoscope Fighting Lupus, and Lupus News Today.

**Establish a Self-Care Routine**

This will help to combat fatigue and lower stress levels. Turning self-care into a routine ensures that you make time to rest regularly and prevents over-activity that can lead to flares.

**Make Lifestyle Changes Where Necessary**

Stop smoking, add healthier foods to your diet, prioritize sleep, and find an exercise routine that works for you. Be sure to ask your doctor what lifestyle changes they recommend in addition to possible medications.

**Learn to Communicate Effectively About Lupus**

Others may not be able to tell how lupus is making you feel. Learning to communicate about what you are going through will enable others to understand and be better equipped to help you.

**Avoid the Sun as Well as Indoor Uv Lighting as Much as Possible.**

When you can’t avoid either, wear sunscreen and sun protective clothing – always put on more than you expect you might need.

**Connect with Others Who Have Lupus**

A lupus support group can be surprisingly helpful; talking to other lupus warriors can be cathartic and a valuable way to find resources.