



<http://www.womenshealth.gov>

1-800-994-9662

TDD: 1-888-220-5446

# Lupus

**Q: What is lupus?**

**A:** Lupus (LOO-puhss) is a chronic, auto-immune (aw-toh-ih-MYOON) disease that can damage any part of the body (skin, joints, and/or organs inside the body). Chronic means that the signs and symptoms tend to last longer than six weeks and often for many years. In lupus, something goes wrong with your immune system, which is the part of the body that fights off viruses, bacteria, and other germs (“foreign invaders,” like the flu). Normally our immune system produces proteins called antibodies that protect the body from these invaders. Autoimmune means your immune system cannot tell the difference between these foreign invaders and your body’s healthy tissues (“auto” means “self”). In lupus, your immune system creates autoantibodies (AW-toh-AN-teye-bah-deez), which attack and destroy healthy tissue. These autoantibodies cause inflammation, pain, and damage in various parts of the body.

When people talk about “lupus,” they usually mean **systemic lupus erythematosus (ur-uh-thee-muh-TOH-suhss), or SLE**. This is the most common type of lupus. Studies suggest that more than 16,000 new cases are reported annually across the country.

Although lupus can affect almost any organ system, the disease, for most people, affects only a few parts of the body. For example, one person with lupus may have swollen knees and fever. Another person may be tired all the

time or have kidney trouble. Someone else may have rashes.

Normally, lupus develops slowly, with symptoms that come and go. Women who get lupus most often develop symptoms and are diagnosed between the ages of 15 and 45. But the disease also can develop in childhood or later in life.

For most people, lupus is a mild disease. But for others, it may cause serious problems. Even if your lupus symptoms are mild, it is a serious disease that needs treatment. It can harm your organs and put your life at risk if untreated.

Although the term “lupus” commonly refers to SLE, this is only one type of the disease. There are other, less common types of lupus:

- **Discoid (DISS-koid) lupus erythematosus**, also called DLE, mainly affects the skin. A red rash may appear. Or, the skin on the face, scalp, or elsewhere may become scaly or change color. Sometimes DLE causes sores in the mouth or nose. A doctor will remove a small piece of the rash or sore and look at it under a microscope to tell if someone has DLE. If you have DLE, there is a small chance that you will later get SLE. There is no way to know if someone with DLE will get SLE.
- **Drug-induced lupus** is a lupus-like disease caused by certain prescription drugs. The symptoms of drug-induced lupus are similar to those of systemic lupus, but only rarely will any major organs be affected. Symptoms can include: joint pain, muscle pain, and fever. Symptoms



<http://www.womenshealth.gov>

1-800-994-9662

TDD: 1-888-220-5446

are mild for most people. Most of the time, the disease goes away when the medicine is stopped. More men get this type of lupus because the drugs with the highest risk of causing it are used to treat heart conditions that are more common in men; however, not everyone who takes these drugs will develop drug-induced lupus. The drugs most commonly connected with drug-induced lupus are procainamide (Pronestyl®), Procanbid®) and hydralazine (Apresoline®; also, hydralazine is an ingredient in Apresazide® and Bidil®).

- **Neonatal lupus** is a rare condition that affects infants of women who have lupus and is caused by certain antibodies from the mother acting upon the infant in the womb. At birth, the infant may have a skin rash, liver problems, or low blood cell counts, but these symptoms disappear completely after several months with no lasting effects. Some infants with neonatal lupus can also have a serious heart defect. With proper testing, physicians can now identify most at-risk mothers, and the infant can be treated at or before birth. Most infants of mothers with lupus are entirely healthy.

**Q: Who gets lupus?**

**A:** Anyone can get lupus. But 9 out of 10 people who have lupus are women. African American women are three times more likely to get lupus than white women. Lupus is also more common in Hispanic/Latina, Asian, and Native American women.

African Americans and Hispanics/Latinos tend to get lupus at a younger

age and have more symptoms, including kidney problems. Lupus also tends to be more severe in these ethnic groups. For example, African Americans with lupus have more problems with seizures and strokes. Hispanic/Latino patients have more heart problems. Scientists believe that genes play a role in how lupus affects these ethnic groups.

It is estimated that between 161,000 and 322,000 adults in the U.S. have SLE. Nine out of 10 people who have lupus are women. African American, Latina, Asian, and Native American women are at greater risk of getting lupus than white women.

**Q: Why is lupus a concern for women?**

**A:** Nine out of 10 people who have lupus are women. And lupus is most common in women of childbearing years. Having lupus increases your risk of developing other health problems that are common in women. It can also cause these diseases to occur earlier in life:

- **Heart disease.** When you have lupus you are at increased risk for the main type of heart disease, called coronary artery disease (CAD). This is partly because people with lupus have more CAD risk factors, which may include: high blood pressure (hypertension), high cholesterol levels, type 2 diabetes, and an inactive lifestyle due to fatigue, joint problems, and/or muscle pain. Heart disease is the number one killer of all women. But, women with lupus are 50 times more likely to have chest pain or a heart attack than other women of the same age.



<http://www.womenshealth.gov>

1-800-994-9662

TDD: 1-888-220-5446

- **Osteoporosis (OSS-tee-oh-puh-ROH-suhss).** Women with lupus have more bone loss and breaks than other women. This is thought to happen because some medicines used to treat lupus cause bone loss. Bone loss also may occur as a direct result of the disease. Also, pain and fatigue can keep women with lupus from exercising. Keeping active is an important way to keep bones healthy and strong.

**Q: What causes lupus?**

**A:** The cause of lupus is not known. More than one factor is likely to play a role in getting lupus. Researchers are looking at these factors:

- Environment (Sunlight, stress, certain medications, and viruses might trigger symptoms in people who are prone to getting lupus.)
- Hormones (Lupus is more common in women during childbearing years.)
- Problems with the immune system

You can't catch lupus from another person, and it isn't related to AIDS.

**Q: What are the symptoms of lupus?**

**A:** The signs of lupus differ from person to person. Some people have just a few symptoms; others have more. Lupus symptoms also tend to come and go. Lupus is a disease of flares (the symptoms worsen and you feel ill) and remissions (the symptoms improve and you feel better).

Common signs of lupus are:

- joint pain and stiffness, with or without swelling
- muscle aches and pains
- fever with no known cause
- feeling very tired
- skin rashes
- anemia (uh-NEE-me-uh) (too few red blood cells)
- trouble thinking, memory problems, confusion
- kidney problems with no known cause
- chest pain when taking a deep breath
- butterfly-shaped rash across the nose and cheeks
- sun or light sensitivity
- hair loss

Less common symptoms include:

- blood clots
- purple or pale fingers or toes from cold or stress
- seizures
- sores in the mouth or nose (usually painless)
- severe headache
- dizzy spells
- "seeing things", not able to judge reality
- feeling sad
- strokes

**Q: What are flares?**

**A:** The times when your symptoms worsen and you feel ill are called flares. Flares tend to come and go. You may



<http://www.womenshealth.gov>

1-800-994-9662

TDD: 1-888-220-5446

have swelling and rashes one week and no symptoms at all the next. Even if you take medicine for lupus, you may find that some things trigger your symptoms to flare. You may find that your symptoms flare after you've been out in the sun or after a hard day at work. Common triggers include:

- overwork and not enough rest
- stress
- being out in the sun or close exposure to fluorescent or halogen light
- infection
- injury
- stopping your lupus medicines
- certain medications

See *What can I do to control my lupus symptoms and prevent flares?*

### **Q: How can a doctor tell if I have lupus?**

**A:** Lupus can be hard to diagnose. It's often mistaken for other diseases. Many people have lupus for awhile before they find out they have it. If you have symptoms, tell your doctor right away. No single test can tell if a person has lupus. But your doctor can find out if you have lupus in other ways, including:

1. Medical history. Telling your doctor about your symptoms and other problems you have had can help him or her understand your situation. Keep track of your symptoms by writing them down. See the symptom checklist.
2. Family history of lupus or other autoimmune diseases. Tell your doctor if lupus or other autoimmune diseases run in your family.

3. Complete physical exam. Your doctor will look for rashes and other signs that something is wrong.
4. Blood and urine tests. The anti-nuclear antibody (ANA) test can show if your immune system is more likely to produce the autoantibodies of lupus. Most people with lupus test positive for ANA. But, a positive ANA does not mean you have lupus. About 2 in 10 healthy people test positive for ANA. Positive tests also are seen in other conditions, such as thyroid disease, malaria, and other autoimmune diseases. That's why your doctor will use many tools—and maybe other tests—to tell if you have lupus.
5. Skin or kidney biopsy (BEYE-op-see). With a biopsy, doctors perform a minor surgery to remove a sample of tissue. The tissue is then looked at under a microscope. Skin and kidney tissue looked at in this way can show signs of an autoimmune disease.

Together, this information can provide clues to your disease. It also can help your doctor rule out other diseases that can be confused with lupus.

### **Q: How is lupus treated?**

**A:** There is no known cure for lupus, but there are treatments. Your treatment will depend on your symptoms and needs. The goals of treatment are to:

- prevent flares
- treat symptoms when they occur
- reduce organ damage and other problems

## FREQUENTLY ASKED QUESTIONS



<http://www.womenshealth.gov>

1-800-994-9662

TDD: 1-888-220-5446

Your treatment might include using medicines to:

- reduce swelling and pain
- prevent or reduce flares
- calm the immune system
- reduce or prevent damage to the joints
- reduce or prevent organ damage

Drugs play an important role in treating lupus. Most likely, the drugs prescribed

to you will change often during your treatment. Types of drugs commonly used to treat lupus include:

- **Nonsteroidal anti-inflammatory drugs (NSAIDs).** NSAIDs are used to reduce pain and swelling in joints and muscles. They can help with mild lupus—when pain isn't too bad and vital organs are not affected. Aspirin, ibuprofen, and naproxen are some over-the-counter NSAIDs. You need a prescription

### Symptom Checklist

Print out this table and use it to make notes to take to your doctor.  
Put a check mark beside the symptoms you have. Note when you have them.

Symptom	✓	Where?	When did you first notice?	How often?	Recent dates?
Example: rash	✓	face and chest	2 years ago	Once or twice a month	9/17, 10/8, 10/23, 11/15
Red rash or color change					
Painful or swollen joints					
Fever with no known cause					
Feeling very tired					
Trouble thinking, memory problems, confusion					
Chest pain with deep breathing					
Sensitivity to sun					
Unusual hair loss					
Pale or purple fingers or toes					
Sores in mouth or nose					
Other					

page 5

Adapted from National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS).



<http://www.womenshealth.gov>

1-800-994-9662

TDD: 1-888-220-5446

for stronger NSAIDs. NSAIDs can cause stomach upset, heartburn, drowsiness, headache, fluid retention, and other side effects. NSAIDs also can cause problems in your blood, liver, and kidneys if overused.

Never take vitamins or herbal supplements without talking to your doctor first. They might not mix well with medicines you use to treat lupus.

- **Corticosteroids.** Corticosteroids (KOR-tih-koh-STAIR-oyds) are hormones found in our bodies. Manmade versions are used to reduce swelling, tenderness, and pain in many parts of the body. In high doses, they can calm the immune system. Often, these drugs are called "steroids." They are different than steroids used by some people who play sports or lift weights. Corticosteroids come as pills or liquids, creams to apply to the skin, and as a shot. Prednisone (PRED-nuh-sohn) is one drug commonly used to treat lupus. Lupus symptoms tend to respond very quickly to these powerful drugs. Once this has happened, your doctor will want to lower your dose slowly until you no longer need it. The longer a person uses corticosteroids, the harder it becomes to lower the dose. But stopping this medicine right away can harm your body. Make sure to use your medicine exactly as your doctor tells you to.

Corticosteroids can have many side effects, so your doctor will give you the lowest dose possible.

Short-term side effects can include: a round or puffy face, acne, heartburn, increased appetite, weight gain, and mood swings. These side effects typically stop when the drug is stopped. Long-term side effects can include: easy bruising, thinning skin and hair, weakened or damaged bones, high blood pressure, damage to the arteries, high blood sugar, infections, muscle weakness, and cataracts. Your doctor can prescribe medicines to take with corticosteroids to prevent some side effects, such as osteoporosis.

- **Antimalarial drugs.** Medicines used to prevent or treat malaria are used to treat joint pain, skin rashes, and mouth sores. Two common antimalarials are hydroxychloroquine (heye-DROK-see-KLOR-uh-kween) (Plaquenil®) and chloroquine (KLOR-uh-kween) phosphate (Aralen® phosphate). Side effects of antimalarials can include stomach upset, nausea, vomiting, diarrhea, headache, dizziness, blurred vision, trouble sleeping, and itching.
- **Immunosuppressive agents/chemotherapy.** These agents are used in severe cases of lupus, when major organs are not working well and other treatments do not work. These drugs suppress the immune system to limit the damage to the organ. Examples are azathioprine (az-uh-THEYE-uh-preen) (Imuran®) and cyclophosphamide (seye-kluh-FOSS-fuh-myd) (Cytoxan®). These drugs can cause serious side effects including nausea, vomiting, hair loss, bladder problems, decreased fertility, and increased risk of cancer and infection.









