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# Lupus

**Q: What is lupus?**

**A:** Lupus (LOO-puhss) is a chronic, autoimmune (aw-toh-ih-MYOON) disease. It can harm any part of the body (skin, joints, and/or organs inside the body). Chronic means that the signs and symptoms 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 your immune system makes proteins called antibodies that protect the body from these invaders. Autoimmune means your immune system cannot tell the difference between these invaders and your body’s healthy tissues (“auto” means “self”). In lupus, your immune system creates autoantibodies (AW-toh-AN-teye-bah-deez), which sometimes attack and destroy healthy tissue. These autoantibodies add to inflammation, pain, and damage in 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. It is hard to guess how many people in the U.S. have lupus, because the symptoms are so different for every person. Sometimes it is not diagnosed. The Lupus Foundation of America thinks that about 16,000 new cases are reported across the country each year.

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. Over time, more symptoms can develop.

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

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

Although the term “lupus” commonly refers to SLE, there are several kinds of lupus:

- **Systemic lupus erythematosus, or SLE**, makes up about 70 percent of all cases of lupus. SLE can be mild or severe and can affect various parts of the body. Common symptoms include fatigue, hair loss, sensitivity to the sun (photosensitivity), painful and swollen joints, unexplained fever, skin rashes, and kidney problems. In general the diagnosis of lupus is based on both physical symptoms and lab results.
- **Cutaneous** (kyoo-TAY-nee-uhss) **lupus erythematosus** can be limited to the skin or seen in those with SLE. “Cutaneous” means “skin.” Symptoms may include rashes/lesions, hair loss, vasculitis (swelling of the blood vessels), ulcers, and photosensitivity. A doctor will remove a small piece of the rash or sore and look at it under a micro-



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scope to tell if someone has skin lupus and what form it is. There are two major kinds of cutaneous lupus:

- **Discoid (DISS-koid) lupus erythematosus**, also called DLE, mainly affects the skin. The discoid rash usually begins as a red raised rash that becomes scaly or changes color to a dark brown. These rashes often appear on the face and scalp, but other areas may also be affected. Many people with DLE have scarring. 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. Currently there is no way to know if someone with DLE will get SLE.
- **Subacute cutaneous lupus erythematosus**, makes up 10 percent of lupus cases. About 50 percent of the time, people with subacute cutaneous lupus also have SLE. Subacute cutaneous lupus causes skin lesions on parts of the body exposed to sun. These lesions do not cause scars.
- **Drug-induced lupus** is a form of lupus caused by certain medicines. The symptoms of drug-induced lupus are like those of systemic lupus, but only rarely affect major organs. Symptoms can include joint pain, muscle pain, and fever, and are mild for most people. Most of the time, the disease goes away when the medicine is stopped. However, not everyone who takes these drugs will get drug-induced lupus.

The drugs most commonly connected with drug-induced lupus are used to treat other chronic conditions, such as seizures, high blood pressure, or rheumatoid arthritis. Examples include procainamide (Pronestyl®; Procanbid®); hydralazine (Apresoline®; also, hydralazine is an ingredient in Apresazide® and BiDil®); phenytoin (Dilantin®); etanercept (Enbrel®); and adalimumab (Humira®).

- **Neonatal lupus** is a rare disease in infants that is caused by certain antibodies from the mother. These antibodies can be found in mothers who have lupus. But it is also possible for an infant to have neonatal lupus even though the mother is healthy. However, in these cases the mother will often develop symptoms of lupus later in life. At birth, an infant with neonatal lupus may have a skin rash, liver problems, or low blood cell counts, but these symptoms disappear completely after several months and have no lasting effects. Infants with neonatal lupus can also have a rare but 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 healthy.

### Q: Who gets lupus?

**A:** Anyone can get lupus. About 9 out of 10 adults with lupus are women ages 15 to 45. African-American women are three times more likely to get lupus than white women. Lupus is also more common in Latina, Asian, and Native American women. Men are at a higher risk before puberty and after age 50.



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Despite an increase in lupus in men in these age groups, two-thirds of the people who have lupus before puberty and after age 50 are women.

### Lupus affects young women most

More than 90 percent of people with lupus are women between the ages of 15 and 45. African-American, Latina, Asian, and Native American women are at greater risk of getting lupus than white women.

African-Americans and Latinos tend to get lupus at a younger age and have more severe symptoms, including kidney problems. African-Americans with lupus also have more problems with seizures, strokes, and dangerous swelling of the heart muscle. Latina patients have heart problems as well. Scientists believe that genes play a role in how lupus affects these ethnic groups.

Apart from genetic factors, lupus can be more severe for people who aren't getting the care they need. Studies have shown that people with lupus who have a lower household income, lower level of education, or less of a support system tend to do worse with the disease. For some people with lupus, severe symptoms of the disease leave them unable to work, which may result in low income and lack of health insurance. These factors make it hard for a person with lupus to get the right treatment — or sometimes even diagnosis — that they need.

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

**A:** Lupus is most common in women, especially women in their childbearing years. Having lupus increases your risk

of other health problems that are also common in women. It can cause these diseases to occur earlier in life:

- **Heart disease.** When you have lupus you are at bigger risk of 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, high cholesterol, and type 2 diabetes. The inflammation that accompanies lupus also increases the risk of developing CAD. Women with lupus are often less active because of fatigue, joint problems, and/or muscle pain, and this also puts them at risk. 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.
- **Osteoporosis (OSS-tee-oh-puh-ROH-suhss).** Women with lupus have more bone loss and broken bones than other women. This might be because some medicines used to treat lupus cause bone loss. The disease itself can also cause bone loss. Also, pain and fatigue can keep women with lupus from exercising. Staying active is important for keeping bones healthy and strong.
- **Kidney disease.** Many symptoms of lupus come from the swelling of organs in the body. Almost half of all people with lupus develop kidney problems, called lupus nephritis. Kidney problems often begin within the first five years after lupus symptoms start to appear. This is one of the more serious complications of lupus, but there are treatments if



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problems are caught early. However, it is important to know that kidney inflammation is not painful and you can't feel it. That is why it's important for people with lupus to keep up-to-date with the screenings their doctors recommend. These will include urine and blood tests.

### Q: What causes lupus?

**A:** The cause of lupus is not known. It's not a disease you can catch from another person. Researchers are looking at these factors:

- Environment (sunlight, stress, smoking, certain medications, and viruses might trigger symptoms in people who are prone to getting lupus)
- Hormones such as estrogen (lupus is more common in women during childbearing years)
- Problems with the immune system
- Genes play an important role, but are not the only reason a person will get lupus. Even someone who has one or more of the genes associated with lupus has a small chance of actually getting the disease. And only 10 percent of people with lupus have a parent or sibling who also has it.

### 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, pains, or weakness
- Fever with no known cause
- Feeling very tired
- Butterfly-shaped rash across the nose and cheeks
- Other skin rashes
- Unusual weight loss or weight gain
- 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
- Sun or light sensitivity
- Hair loss
- Purple or pale fingers or toes from cold or stress

Less common symptoms include:

- Blood clots
- Seizures
- Sores in the mouth or nose (usually painless)
- Severe headache
- Dizzy spells
- "Seeing things," not able to judge reality
- Feeling sad



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- Strokes
- Dry or irritated eyes

### Q: What are flares?

**A:** The times when your symptoms worsen and you feel ill are called flares, and they come and go. You may have swelling and rashes one week and no symptoms the next. Sometimes flares occur without clear symptoms and are only seen with laboratory tests. Even if you take medicine for lupus, you may find that some things trigger a flare. For instance, your symptoms may 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: Is lupus fatal?

**A:** Many men and women live long, productive lives with lupus. However, it can be fatal for some people. It depends on the severity of illness, how the body responds to treatments, and other factors. Infections are the leading cause of death in people with lupus. Studies show that people with lupus are living longer lives compared to decades past.

### Q: How can my 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 a while before they find out they have it. If you have symptoms, tell your doctor right away. No one 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 can help her understand your situation. Keep track of your symptoms by writing them down. See the symptom checklist below.
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 make the autoantibodies of lupus. Most people with lupus test positive for ANA. But, a positive ANA does not mean you have lupus. About 5 to 10 percent of healthy women test positive for ANA.
5. **Skin or kidney biopsy (BEYE-op-see).** With a biopsy, a doctor removes a sample of tissue. The tissue is then viewed under a microscope. Skin and kidney tissue 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.

## FREQUENTLY ASKED QUESTIONS



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**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

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

<b>Symptom Checklist</b>					
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					



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### Be careful with supplements

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

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 for stronger ones. NSAIDs can cause stomach upset, heartburn, drowsiness, headache, fluid retention, and other side effects. If overused, NSAIDs also can cause problems in your gastrointestinal tract (which includes the stomach), blood, liver, and kidneys. In pregnant women, NSAIDs should be avoided after the first trimester. They should be used with caution in women who breastfeed.
- **Corticosteroids.** Corticosteroids (KOR-tih-koh-STEER-oyds) are hormones found in our bodies. Manmade versions, often called "steroids," are used to reduce swelling, tenderness, and pain in many parts of the body. In high doses, they can calm the immune system. These drugs 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 shots. Prednisone is one

that is 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 these drugs, 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. However, the weight gain will not reverse on its own, so be careful not to overeat while on steroids. 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. Some people may have ulcers, depression, or even congestive heart failure. Your doctor can prescribe medicines to take with corticosteroids to prevent some side effects. Corticosteroids can be used during pregnancy with your doctor's supervision.

- **Antimalarial drugs.** Medicines used to prevent or treat malaria are used to treat joint pain, skin rashes, fatigue, and inflammation of the lungs. Two common antimalarials are hydroxychloroquine sulfate (Plaquenil®) and chloroquine phosphate (Aralen® phosphate). Side















