

Lupus (Systemic Lupus Erythematosus)

What is lupus?

Lupus is a disease in which the immune system does not work properly.

What is the immune system?

The job of the immune system is to protect the body from infections. Two parts of the immune system are white blood cells and proteins called antibodies. Both of them attack germs that enter to body.

What does the immune system do in lupus?

In lupus, instead of the immune system attacking germs, it starts to attack different parts of your own body. We don't know what causes lupus. Women and girls have it more often than men and boys, but they can get it too.

Lupus is mainly a disease of the blood vessels. The white blood cells attack the blood vessels and injure them. Every part of the body depends on blood vessels to supply blood to them, so lupus can affect any part of the body.

Some of the common signs (symptoms) people have are:

- Joint pain
- Fevers
- Rash
- Tiredness
- Low blood counts
- Swelling (called "edema")
- Blood in the urine
- Protein in the urine
- Abdominal (belly) pain
- Hair loss
- Nausea (feeling sick to your stomach)
- Diarrhea
- Problems with concentration or memory
- Blood clots
- Pain and inflammation in the eyes, vision changes

Lupus is a chronic disease. That means it never goes away. There is no cure. But with treatment, it can go into **remission**. Remission means the disease is quiet, not active, and is not making you sick. Medicines taken every day help keep lupus in remission.

How is lupus treated?

Since the cause of lupus is immune cells that do not work properly, the treatment involves medicines that reduce the strength the immune system. Treatment helps to calm down the overactive immune system. Some of these medicines are taken by mouth; others go directly into a vein. Usually you have to take a lot of medicine at first, when the disease is most active. The medicines help make the disease inactive (or put it in **remission**). Then less medicine is needed to keep it inactive. **It is very important to keep taking medicines and seeing your doctors even when you feel well.** This helps keep lupus from becoming active again. If lupus becomes active again, we call this a "**flare**". If you have a flare, your doctor will increase your medicine doses to help put the disease back into remission.

Medicines

There are many medicines to treat lupus. Some of the common ones are listed below.

Medicines for Lupus

Prednisone (Deltasone™, Orapred™, Prelone™)

Cyclophosphamide (Cytoxan™)

Anti-immune medicines

These medicines reduce the function of the immune system.

Azathioprine (Imuran™)

Cyclosporine (Neoral™, GenGraf™)

Mycophenylate mofetil (Cellcept™)

Aspirin

Anti-inflammatory medicines

These medicines relieve pain and inflammation.

Ibuprofen (Motrin™, Advil™)

Naproxen (Naprosyn™, Aleve™)

Anti-malarial medicines

This medicine is used to treat or prevent malaria, but also fights lupus (we don't understand how it works).

Hydroxychloroquine (Plaquenil™)

Your doctor may prescribe other medicines, depending on what kind of symptoms you have. For example, you may need medicines to lower your blood pressure. You may need iron and vitamin D supplement, too.

Other Treatments

Sun protection is very important. Sunlight can make lupus worse. Lupus also makes your skin very sensitive to the sun, so it's easy to get a sunburn. **Always wear sunscreen** when you go outdoors (minimum SPF 50, waterproof sunscreen is best), **even on cloudy days**, and even in the winter--every day of the year. It's important to apply sunscreen at least 30 minutes before your sun exposure and reapply often while outside. Wear clothes that cover your skin, a hat if possible, and try to stay out of the sun, especially between 10 a.m. and 2 p.m. That's when the sunlight is the most intense. For your overall safety it's best to apply sunscreen everyday.

Your Care Team

Lupus is a complicated disease. Treatment usually involves seeing several doctors and other health professionals to help keep you healthy. Some of the people you may visit are listed below.

Your **primary care physician** is usually a **pediatrician** or a **family physician**. This doctor helps organize all your other doctor visits, and gives you your regular checkups and vaccines.

A **rheumatologist** is a doctor who specializes in diseases where the immune system is not working right, including lupus, and will help design your overall treatment plan.

Some of your doctors may have a **nurse** or **nurse practitioner**. This person works closely with the doctor and can answer most of your questions.

A **nephrologist** is a kidney doctor, who can help with the kidney problems from lupus.

An **ophthalmologist** is an eye doctor, who can check your eyes to see if lupus is affecting them.

A **pharmacist** can teach you about your medicines, how they work, and how to take them.

A **dietician** or **nutritionist** can teach you about foods. He or she will help you pick the right foods to give you good nutrition and help avoid gaining weight or getting swollen.

A **psychologist** can help you with some of the emotional aspects of having lupus. Lupus can cause many changes in your life which can bring up a lot of emotions.

Every lupus patient is different, and your doctor will create a treatment plan just for you. You may not see all of the people on this list, or you may see everyone on the list and other people who are not listed here. You may use some of the medicines listed above, or others that are not listed.

What is the prognosis?

With **good care and taking medicines every day**, most patients with lupus do very well and have a pretty normal life. There are many treatments available to put lupus into remission and keep it there. Most patients with kidney disease from lupus do not develop kidney failure. **It's very important to keep taking your medicines and go to your doctor visits, even when you feel well. This helps to keep you healthy and prevent flares.** There are many research studies taking place right now. We may have even better treatments in the future.

Where can I get more information?

Your doctors and nurses can provide you with a lot of helpful information. **If you have any questions, be sure to ask them.** Some people like to write down all their questions and bring the list when they visit the doctor, so they don't forget anything.

But you don't have to wait until your next visit to ask questions. **It's okay to call your doctor's office when you have questions.** They want to be sure you understand your disease and your treatment plan.

Your doctor may be able to tell you if there are support groups in your area. The Lupus Foundation of America can also give you more information.

