

Systemic lupus erythematosus (SLE or lupus)



What is lupus?

Systemic lupus erythematosus (also called SLE or lupus) is an autoimmune disease that can affect many different parts of the body.

- The immune system normally fights off germs and diseases in the body. An **autoimmune disease** happens when the body's immune system attacks a person's own body.
- Lupus can affect different parts of the body in different people. This may include the skin, joints, kidneys, liver, lungs, heart and/or brain.
- Lupus is a **chronic disease**. This means your child will need continued monitoring and treatment over time.

What are the possible symptoms?

Your child may have 1 or more symptoms at different times. Some possible symptoms include:

- Fever (temperature of 100.4°F or higher)
- Fatigue or tiredness
- Weight loss
- Hair thinning
- Mouth sores
- Joint pain and swelling
- Chest pain with deep breathing due to inflammation (swelling) around the heart or lungs
- Rashes on areas exposed to the sun, especially the face
- Raynaud's phenomenon (fingers or toes turn white, blue, and then red when exposed to cold)
- Swelling in the legs or around the eyes
- Headaches

What tests could my child have?

Your child's doctor will look at different test results to diagnose and monitor lupus. Your child may have 1 or more of these tests:

- **Blood tests (labs)** to check for inflammation and to check how the organs are working.
- **Urine tests** to check for kidney disease.
- **Echocardiogram (echo)** to look at the structure of the heart and how it is working.

Your child may need:

- Some tests only 1 time.
- Repeat tests at different times to monitor the disease and how well treatment is helping.

In case of an urgent concern or emergency, call 911 or go to the nearest emergency department right away.

Systemic lupus erythematosus, continued

Who makes up my child's care team?

- A rheumatologist will guide your child's treatment.
- The rheumatologist may work with other specialists to choose the best care plan for your child. This may include:
 - Nephrologists (kidney doctors)
 - Dermatologists (skin doctors)
 - Cardiologists (heart doctors)
 - Other specialists as needed
- Your child's pediatrician (primary care doctor) is also a very important part of your child's care team.

What is the treatment?

Your child may need:

- Medicines to improve or stop their symptoms.
- Medicines to stop the disease from damaging the body.
- Delayed vaccines depending on their treatment.
- Extra vaccines to help protect them from infection.

What medicines could my child need?

Talk with the care team about specific medicines for your child. They may need a combination of medicines when first diagnosed. Some of these medicines work quickly, while others take time.

- **Steroids** work quickly to calm down the immune system and stop it from attacking the body.
- **Immunomodulatory medicines** modify the immune system, helping it work at its best over time.
- **Immunosuppressant medicines** weaken certain parts of the immune system that are involved in causing inflammation and organ damage in lupus.

When should I call the doctor?

Call the doctor **right away** if your child has any of these:

- Fever (temperature of 100.4°F or higher)
- Headache that does not improve with pain medicine, such as ibuprofen (Motrin, Advil or less costly brand) or acetaminophen (Tylenol or less costly brand)
- Confusion, weakness, numbness or tingling, slurred speech, or changes in vision
- Changes in mood
- Blood in the urine

In case of an urgent concern or emergency, call 911 or go to the nearest emergency department right away.

Systemic lupus erythematosus, continued

Also call the doctor if:

- Your child's typical lupus symptoms worsen.
- Your child is not tolerating their lupus medicines.

When should I call 911?

Call 911 **right away** if your child has any of these:

- Very bad abdominal (belly) pain
- Chest pain
- Trouble breathing
- Seizures
- Trouble waking up

Where can I learn more?

Visit the Lupus Foundation of America website at lupus.org to learn more. You can also scan the QR codes below for more information.

Lupus and Children



Lupus and Teenagers



Children's Healthcare of Atlanta has not reviewed all of the sites listed as resources and does not make any representations regarding their content or accuracy. Children's Healthcare of Atlanta does not recommend or endorse any particular products, services or the content or use of any third party websites, or make any determination that such products, services or websites are necessary or appropriate for you or for the use in rendering care to patients. Children's Healthcare of Atlanta is not responsible for the content of any of the above-referenced sites or any sites linked to these Sites. Use of the links provided on this or other sites is at your sole risk.

This teaching sheet contains general information only. Talk with your child's doctor or a member of your child's healthcare team about specific care of your child.

In case of an urgent concern or emergency, call 911 or go to the nearest emergency department right away.