

What is lupus?

Lupus (also called systemic lupus erythematosus or SLE) 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 is a chronic (long-term) disease. Your child needs regular checkups and treatment over time.

What is a flare?

Our goal is for your child's lupus to be in **remission**. Remission means the disease is under good control and your child feels well.

A **flare** is when lupus symptoms come back or get worse after they have been better.

Think of lupus like a fire:

- At first, the fire is big and can be hard to get under control. Your child may be very sick and need to start several new medicines, including possibly I.V. medicines. Like the fire hose that fire fighters use to help put out a fire quickly, these early treatments help to get the inflammation under control quickly to prevent damage. You do not just throw buckets of water when your house is on fire!
- As your child gets better, they may need fewer medicines to keep the fire out. The doctor may be able to gradually decrease medicines to find the right combination for your child.
- A flare is when the fire comes back all of a sudden. It can damage things if not treated. We want to catch a mild flare before it needs the fire hose (much stronger medicines) again.

How can I help prevent a flare?

The best ways to help prevent a flare are:

- Make sure your child takes their medicines as prescribed.
- Keep their clinic visits and make sure you understand the plan at each visit.

What should I do if a flare starts?

Call your rheumatology care team at 404-785-8330 if your child has symptoms that worry you. Flares can happen even when you are careful.

Do **not** wait for things to get really bad. Lupus can harm organs (like kidneys) even when your child does not feel very sick. Catching a flare early often means:

- Less damage.
- Less medicine.
- Faster recovery.

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

Lupus flare, continued

If you are unsure, it is safer to call or send a MyChart message to ask: “Is this something I can watch at home or do I need to do something about it now?”

Your child may not need an urgent visit for mild changes, such as:

- Mild aches your child has had before that come and go.
- Slightly more tired days that get better with rest. Your child can keep their daily routine.
- Small, known rashes your child has had before and the doctor already knows about.

Even for mild changes, it helps to:

- Write down their symptoms in a symptom diary (what kind, when and what you tried).
- Tell your child’s doctor or nurse at their next visit or send a MyChart message if you need an answer sooner.

When should I call the doctor?

Call your child’s doctor **the same day or the next day** if your child has any of these:

- New or much worse joint pain or swelling
- New rash, especially after sun, that spreads or hurts
- Fever of 100.4°F or higher without cold, flu or stomach virus symptoms
- So tired they can barely do normal things, such as school, work or chores
- Severe (very bad) headache that does not improve with medicine
- Urine that looks foamy or reddish
- Urinating (peeing) much less than normal
- Belly pain that is strong or keeps coming back
- Vomiting (throws up) and cannot take or keep down their medicines
- Other symptoms that worry you

When should I call 911?

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

- Trouble breathing
- Chest pain or very fast heartbeat
- Sudden weakness or cannot move parts of their body
- Cannot speak clearly or their face droops
- Seizures
- Confusion or not acting like themselves
- Very strong, sudden pain that does not improve with any treatment at home

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.

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