



Lupus and Teenagers

As a teenager, there's a lot you can do to stay on top of your health with lupus. Learning as much as you can about the disease is an important first step.

| What is lupus?

Lupus is a chronic (long-term) disease that can cause inflammation (swelling) and pain in any part of your body. It's an autoimmune disease, meaning that your immune system attacks healthy tissue (tissue is what our organs are made of) and can cause organ damage. The immune system is the part of the body that fights off germs to help you stay healthy.

| Who is at risk of developing lupus?

People of all ages, genders, and racial and ethnic groups can develop lupus. But certain groups are at higher risk than others, including:

- Women ages 15 to 44
- People who are African American, Asian American, Hispanic/Latino, Native American, or Pacific Islander
- People who have a family member with lupus or another autoimmune disease

In the United States, at least 1.5 million people have lupus — and about 16,000 new cases of lupus are reported each year.

| How will lupus affect my body?

Lupus can affect different people in different ways. For some, it can be mild — for others, it can be life-threatening.

**1 in 5 people who
have lupus develop
it in childhood.**

Help Us Solve
The Cruel Mystery
LUPUS[™]
FOUNDATION OF AMERICA



**Lupus isn't contagious —
you can't catch lupus or
give it to someone.**

| What causes lupus?

No one knows what causes lupus, but experts think it develops in response to a combination of factors, including hormones, genetics and environmental triggers. An environmental trigger is something outside of the body that can bring on lupus symptoms — or make them worse.



Some common triggers of lupus symptoms include:

- ✓ Ultraviolet (UV) rays from the sun or fluorescent lights
- ✓ Infections
- ✓ Exhaustion (feeling very tired)
- ✓ Physical and emotional stress
- ✓ Low vitamin D
- ✓ Cigarette smoke, including second-hand smoke

Lupus most commonly affects the skin, joints, and major internal organs — like the kidneys, liver, brain, heart or lungs. Lupus tends to be more aggressive and severe in children and adolescents than in adults. People diagnosed in childhood also are more likely to have higher rates of organ damage than people diagnosed as adults.

| What are the symptoms of lupus?

Because lupus can affect many parts of your body, it can cause a lot of different symptoms.

Symptoms of lupus may include:

- Fatigue (feeling tired often)
- Painful or swollen joints
- Swelling in the hands, feet, or around the eyes
- Headaches
- Low-grade fevers
- Sensitivity to sunlight or fluorescent light
- Chest pain when breathing deeply

People with lupus may also have problems with the skin and hair, including:

- A butterfly-shaped rash on the cheeks and nose
- Hair loss
- Sores in the mouth or nose

Lupus may also cause problems with the blood and blood vessels, like:

- Blood clots
- Low numbers of red blood cells (anemia)
- Fingers and toes turning white or blue and feeling numb when a person is cold or stressed (Raynaud's phenomenon)



What kinds of doctors treat lupus in teenagers?

Most teenagers who have lupus will see a **pediatric rheumatologist**. Pediatric rheumatologists specialize in diagnosing and treating children and teens with autoimmune diseases, like lupus, and diseases in the joints, muscles, bones, and tendons. But because lupus can cause problems anywhere in the body, you'll likely have other kinds of doctors and health care professionals on your treatment team too.

What medicines treat lupus?

Because lupus can cause a lot of different symptoms, there are many different kinds of medicines that can treat it. A doctor will need to prescribe some of these medicines — others are available over the counter. Some medicines are pills you can take by mouth. Others are fluids that a health care professional puts directly into your bloodstream using a needle or catheter (tube).

The most common medicines used to treat lupus include:

- **Anti-inflammatories** to help with inflammation and pain
- **Antimalarials** to protect skin from rashes and UV light
- **Biologics** to help the immune system work correctly
- **Anticoagulants** to help prevent blood clots
- **Immunosuppressives** to help keep your immune system from attacking your body
- **Steroids** to help with inflammation

How is lupus treated?

While there's no cure for lupus right now, having the right treatment plan can help:



- ✓ Control symptoms — like joint pain and inflammation
- ✓ Keep the immune system from attacking healthy tissue
- ✓ Protect the organs from damage

A pediatric rheumatologist is the type of doctor who treats teens with lupus.

| What can I do to take charge of my health?

There's a lot you can do to learn how to manage lupus and take charge of your own health care.



Start with these steps:

- ✓ Work together with your doctors to develop a plan for managing your symptoms
- ✓ Talk to your doctors and ask them any questions you have about your health
- ✓ Use a journal to keep track of your medicines and any side effects you notice
- ✓ Pay attention to how you feel, and share what you notice with your doctors
- ✓ Share any concerns you have about your treatment with your doctors
- ✓ Keep a calendar to record appointments and reminders
- ✓ Stay connected with friends and family, and build a support system



You may need to make some changes in your life because of lupus. But with the help of your family and treatment team, you can learn to live with your symptoms — and keep doing many of the things you want to do.

One of the most important tools you have to manage lupus is yourself — your effort, your attention, and your awareness of your body.

Keep in mind that any medicine you take for lupus can have side effects, and some medicines could put you at risk for life-threatening infections. Talk with your doctor about what changes to watch for with the medicines you're taking. And tell your parents and treatment team right away if you have any side effects.

| What can I do to manage (control) my symptoms?

It's important to avoid factors that trigger your lupus symptoms — or make them worse.

Remember to:

- Use sunscreen with SPF 30 or higher, and wear sun-protective clothing, like wide-brimmed hats, long sleeves, and pants
- Wash your hands often, and avoid people with colds or other contagious illnesses
- Ask for help when you need it
- Take a break when you're feeling tired or stressed
- Tell an adult when you're not feeling well

| How can I develop healthy habits?

You may need to make some changes to your daily routine to manage your symptoms.

Start by developing these healthy habits:

- Always take your medicines as prescribed
- Always attend your health care appointments and follow instructions from your doctors
- Eat a healthy diet and be physically active
- Get enough sleep — aim for at least 9 hours each night
- Take breaks during the day to rest and recover
- Stay away from alcohol, drugs, and tobacco
- Plan outdoor activities for early in the morning or later in the evening

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For more information about lupus and teenagers,
please visit the **National Resource Center on Lupus** at:
Resources.Lupus.org