

# LIVING WITH LUPUS

## *Health Information Basics for You and Your Family*

Focused on systemic lupus erythematosus (SLE), the most common form of lupus



National Institute of  
Arthritis and Musculoskeletal  
and Skin Diseases

## For Your Information

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**<https://www.niams.nih.gov>**

# Contents

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What Is Lupus?.....	1
What Are the Symptoms of SLE? .....	2
How Do Doctors Recognize SLE? .....	3
How Do Doctors Treat SLE?.....	4
How to Help Manage SLE .....	5
Research Supported by NIH/NIAMS.....	9
Clinical Trials: You Could Make a Difference! .....	10
Where Can I Find More Information About SLE?.....	11

## Tear-out Tools

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Lupus Symptom Tracker .....	15
Daily Activity Tracker .....	16
What Questions Should I Ask My Doctor About Lupus?.....	17
Medication Tracker .....	18



# What Is Lupus?

Lupus is a chronic (long-lasting) autoimmune disease. This booklet focuses on systemic lupus erythematosus (SLE), the most common form of lupus.

Lupus is different for each person and can affect different areas of the body, including:

- Skin.
- Joints.
- Heart.
- Lungs.
- Kidneys.
- Brain.

If you have lupus, you may have times of more symptoms (flares) and times of feeling better (remission). Lupus flares can be mild to serious, and they do not follow a pattern. However, with treatment, many people with lupus can manage the disease.

Anyone can get lupus, but women are more likely to get the disease than men are. Doctors and researchers are not sure what causes lupus, but they are working to learn more about what triggers the problems with the immune system.

An autoimmune disease is a condition where your immune system—which is supposed to fight off viruses, bacteria, and infection—attacks its own tissues instead.



# What Are the Symptoms of SLE?

The symptoms of SLE can be different for everyone. They may include:

- Arthritis, causing painful and swollen joints and morning stiffness.
- Change of color in the fingers and toes—blue-purple, white, or red—from cold and stress.
- Fevers.
- Swollen glands.
- Feeling tired often.
- Swelling in the legs or around the eyes.
- Rashes.
- Pain when breathing deeply or lying down.
- Hair loss.
- Headaches, dizziness, depression, confusion, or seizures.
- Sores, which are usually painless, in the nose and mouth.
- Stomach pain.

Your symptoms may be mild or severe; they may come and go; and they may affect one or several parts of your body. Some people with lupus start to have other problems with the kidneys, heart, or lungs.

See page 15 for a symptom tracker that you can tear out and use to keep track of your symptoms and how they affect your daily life.

# How Do Doctors Recognize SLE?

Many people can have lupus for a long time before they find out they have it. This happens because many of the symptoms of lupus are also the same symptoms that happen with other disorders or diseases. That's why it's important to tell your doctor about your symptoms.

There isn't just one test to diagnose lupus. Your doctor uses the information you tell them during your visit, along with a physical exam and the results of laboratory tests, to help diagnose lupus or decide if you have something else.

You may want to ask your primary care doctor for a referral to a rheumatologist. You may also see other types of doctors, depending on how lupus affects you.

A rheumatologist is a doctor who specializes in treating diseases that affect the joints and muscles, like lupus.



# How Do Doctors Treat SLE?

Although there is no cure for lupus right now, doctors have many ways to manage the disease. Treatment depends on the symptoms you have. You may receive medications to help:

- Control pain.
- Lower a fever.
- Stop your immune system from being overactive.

No matter what treatment you receive, it is important that you have regular visits with your doctor to keep track of your symptoms and potential side effects of treatment. Never stop your medicines or treatments without speaking to your doctor.

Use the tear-out medication tracker on page 18 to help you keep track of medications and supplements you currently take. Bring the list to every doctor you visit.





# How to Help Manage SLE

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Living with lupus can be hard, but a positive outlook is important. You can do several things to help you live with lupus. A good place to start managing your lupus is to work with your doctor and take your medications as directed. At times, you may feel sadness and anger. But keep in mind, many people with lupus live satisfying and productive lives. Most people with mild disease or who are in remission can usually participate in the same life activities they did before they were diagnosed.

Here are some tips to help you and your family manage lupus.

## Learn About the Signs of a Flare

These signs may come and go. You may have swelling and rashes one week and no symptoms at all the next. You may find that your symptoms flare after you've been out in the sun, after a hard day at work, or at times when you are stressed.

Learning to recognize that a flare is coming can help you take steps to cope with it. Just before a flare, many people feel very tired or have pain, a rash, a fever, stomach discomfort, a headache, or joint swelling.

## Steps to Help With Flares

Taking steps to prevent flares can be helpful. You can:

- Talk with your doctor.
- Set realistic goals and priorities.
- Limit the time you spend in the sun.
- Eat a diet rich in fruits, vegetables, and whole grains.
- Manage your stress (see the “Cope With Stress” section on page 7).
- Get enough rest and quiet time.
- Exercise moderately when possible.
- Ask for help from family and friends when you need it.



## Cope With Stress

Dealing with a long-lasting disease like lupus can be hard on your emotions. You might think that your friends, family, and coworkers do not understand how you feel. If you feel sad, depressed, or alone, consider:

- Seeking counseling from a mental health professional.
- Joining online and community support groups, and connecting with others on social media.
- Learning as much as you can about lupus and what you can do to feel better. **See the list of additional resources on page 12.**
- Talking to your friends and family to help them understand what is happening to your body.
- Taking a break from focusing on the disease, and spending some time doing activities you enjoy.
- Meditating, reading, or deep breathing.

Exercising is another approach that can help you cope with stress and with lupus. Exercise can improve the strength and flexibility of your muscles, maintain the health of your joints, and increase your overall endurance. Be sure to talk with your doctor before starting any type of exercise program.



## Pregnancy With Lupus

Most women with lupus can have healthy pregnancies if the disease is under control. If you are planning to become pregnant, talk to your doctor so you can be as healthy as possible before becoming pregnant. Find an obstetrician who has experience working with women who have lupus.

# Research Supported by NIH/NIAMS

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Thanks to medical research, people with lupus are living longer and more active lives. Scientists supported by the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), part of the National Institutes of Health (NIH), continue to study the causes of lupus and how it can best be treated.

Researchers are:

- Looking at several genes that are associated with lupus risk and severity.
- Trying to understand why women are more likely than men to have the disease.
- Seeking new ways to measure what is happening inside the body, which could help doctors predict flares in lupus and response to specific treatments.
- Searching for possible triggers for lupus.
- Exploring how lupus develops and how therapies affect the course of the disease. They are also looking into drugs to prevent or delay kidney failure, one of the most serious and life-threatening complications of lupus.

## Clinical Trials: You Could Make a Difference!

A clinical trial is a type of research study that involves people who volunteer to take part. Most clinical trials test a new treatment for a health problem, such as a new drug or diet. Clinical trials help doctors learn if a new treatment is better, the same, or worse than standard care. Other clinical trials test ways to prevent a disease or find it early.

Talk to your doctor about whether a clinical trial would be right for you. When you volunteer to take part in clinical research, you help doctors and researchers learn more about SLE.

Also, when you participate in a study, you may have the chance to receive the newest treatment and have additional care from the clinical trial staff.

To learn more about the basics of participating in a clinical trial, visit the website NIH Clinical Research Trials and You at <https://www.nih.gov/health-information/nih-clinical-research-trials-you>.

At that website you will find:

- Information on risks and potential benefits.
- Firsthand stories from clinical trial volunteers.
- Explanations from researchers.
- Instructions for finding a clinical trial at the NIH or somewhere else in the country.

To hear from people who have taken part in clinical studies led by NIAMS researchers, watch the videos at <https://www.niams.nih.gov/community-outreach-initiative/clinical-research>.

# Where Can I Find More Information About SLE?

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## **National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) Information Clearinghouse**

National Institutes of Health

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Website: **<https://www.niams.nih.gov>**

For more information about systemic lupus erythematosus, visit the NIAMS online Health Topic at **<https://www.niams.nih.gov/health-topics/lupus>**.

If you need more information about available resources in your language or another language, please visit our website or contact the NIAMS Information Clearinghouse.

# Other Resources

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## **U.S. Food and Drug Administration**

Toll free: 888-INFO-FDA (888-463-6332)

Website: <https://www.fda.gov>

## **American College of Rheumatology**

Website: <https://www.rheumatology.org>

## **American Autoimmune Related Diseases Association, Inc.**

Website: <http://www.aarda.org>

## **Arthritis Foundation**

Website: <https://www.arthritis.org>

## **Lupus Clinical Trials Consortium**

Website: <https://www.lupusclinicaltrials.org>

## **Lupus Foundation of America**

Website: <https://www.lupus.org>

## **Lupus Research Alliance**

Website: <https://www.lupusresearch.org>



The mission of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), a part of the U.S. Department of Health and Human Services' National Institutes of Health (NIH), is to support research into the causes, treatment, and prevention of arthritis and musculoskeletal and skin diseases; the training of basic and clinical scientists to carry out this research; and the dissemination of information on research progress in these diseases. The NIAMS Information Clearinghouse is a public service sponsored by the NIAMS that provides health information and information sources. Additional information can be found on the NIAMS website at <https://www.niams.nih.gov>.



# Lupus Symptom Tracker

The symptoms of lupus vary from person to person and can range from mild to severe. This lupus symptom tracker can help you and your doctor understand more about your condition and health.

Write down how you feel and any changes in your health in the tracker. Share this information with your doctor at each appointment.

## Symptom Rating Scale

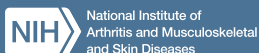
1	2	3	4	5	6	7	8	9	10
<b>Very poor</b> Unable to get out of bed	<b>Poor</b> Able to get up but unable to do everyday tasks	<b>Okay</b> Able to get up and able to do everyday tasks	<b>Better</b> Do most everyday tasks, able to go to work or school some of the time	<b>Good</b> Able to do everyday tasks, go to work or school without any difficulty					

### Common lupus symptoms:

- Joint pain and stiffness.
- Fevers.
- Color change in fingers and toes.
- Depression.
- Swelling of legs, glands, or around eyes.
- Rashes.
- Hair loss.
- Headaches.
- Confusion.
- Sores in the nose and mouth.
- Seizures.
- Stomach pain.
- Feeling tired often.
- Dizziness.

Symptom (describe what it is and where)	When did the symptom start?	Did the symptom go away? If so when?	Rate the symptoms using the scale above	Describe how the symptom affects your life	What helps you feel better?
Pain or stiffness in joints	10/30	No, stays all the time	2	Stayed home, couldn't get myself dressed	Rest and taking my medicines

Notes or Concerns:



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# Daily Activity Tracker

To help you manage your condition, it's important for you to tell your doctor about your ability to do day-to-day tasks. Use this tool to monitor your daily activities. Share this information with your doctor at every appointment.

Below you will find a few examples. Fill in blank rows with similar activities that you do every day.

Activity	Easy to Do	Some Effort	Extra Effort	Difficult	Unable
Attend social events	November 1		November 22, 23		December 1
Bathe or shower					
Concentrate or focus					
Do chores around the house such as cleaning					
Get dressed					
Keep appointments					
Exercise					
Walk					
Run					



# What Questions Should I Ask My Doctor About Lupus?

Use this worksheet as a guide to start a conversation about lupus with your doctor. By talking with your doctor, you can work together to help manage your symptoms and improve your quality of life. Ask some of the questions below, and use the blank spaces to fill in your own questions.

Common Questions	Answers/Notes
How long before I know if my medications are working?	
How long will I need to take my medications?	
Do any of my medications cause side effects?	
Are there any new treatments that may help my symptoms?	
Should I see other types of health care providers to help manage my lupus?	
Under what circumstances should I contact you?	
How often do I need to come to the doctor's office for regular checkups?	
Do I need to have any routine tests or blood work?	
Can you refer me to services in the community that support people with lupus?	
Do you know of research studies about lupus that I might be able to participate in or learn more about?	
Is there anything else I can do to help make my symptoms better?	



# Medication Tracker

Keeping track of your medications helps you and your doctor keep you healthy.

Use this page to keep track of all your medications, including any over-the-counter medications or supplements. Take it with you to all of your doctor appointments.

Name of Medication	What's It For?	Doctor	Dose	When to Take It	How Often	Notes or Concerns About Medications







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