LIVING WITH LUPUS

Health Information Basics for You and Your Family

National Institute of
Arthritis and Musculoskeletal
and Skin Diseases

For Your Information

This publication contains information about medications used to treat the health condition discussed here. When this publication was printed, we included the most up-to-date (accurate) information available. Occasionally, new information on medication is released.

For updates and for any questions about any medications you are taking, please contact the U.S. Food and Drug Administration toll free at 888–INFO–FDA (888–463–6332) or visit its website at www.fda.gov. For additional information on specific medications, visit Drugs@FDA at www.accessdata.fda.gov/scripts/cder/drugsatfda. Drugs@FDA is a searchable catalog of FDA-approved drug products.

For updates and questions about statistics, please contact the Centers for Disease Control and Prevention's National Center for Health Statistics toll free at 800–232–4636 or visit its website at www.cdc.gov/nchs.

This publication is not copyrighted. You may make copies of it and give out as many as you want.

For more copies, contact:

National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) Information Clearinghouse
National Institutes of Health (NIH)
1 AMS Circle
Bethesda, MD 20892–3675

You can find this publication on the NIAMS website at **www.niams.nih.gov.**

LIVING WITH LUPUS

Health Information Basics for You and Your Family

National Institute of
Arthritis and Musculoskeletal
and Skin Diseases

Contents

Introduction 1

What Is Lupus? 2

What Are the Signs and Symptoms of Lupus? 4

What Is a Flare? 5

What Causes Lupus? 6

Who Gets Lupus? 7

What Will the Doctor Do? 9

Will I Get Medicine? 10

How Can I Cope With Lupus? 11

Hope Through Research 15

Where Can People Find More Information About Lupus? . . . 18

Information Boxes

Preventing a Flare 6

Diagnosis: How Do You Find Out If You Have Lupus? 8

Symptom Checklist 21

Introduction

If you have lupus, you probably have many questions. Lupus isn't a simple disease with an easy answer. You can't take a pill and make it go away. The people you live with and work with may have trouble understanding that you're sick. Lupus doesn't have a clear set of signs that people can see. You may know that something's wrong, even though it may take a while to be diagnosed.

Lupus has many shades. It can affect people of different races, ethnicities, and ages, both men and women. It can look like different diseases. It's different for every person who has it.

The good news is that you can get help and fight lupus. Learning about it is the first step. Ask questions. Talk to your doctor, family, and friends. People who look for answers are more likely to find them. This booklet can help you get started.

What Is Lupus?

Lupus is an autoimmune (AW-toe-ih-MYOON) disease. Your body's immune system is like an army with hundreds of soldiers. The immune system's job is to fight foreign substances in the body, like germs and viruses. But in autoimmune diseases, the immune system is out of control. It attacks healthy tissues, not germs.

You can't catch lupus from another person. It isn't cancer, and it isn't related to AIDS.

Lupus is a disease that can affect many parts of the body. Everyone reacts differently. One person with lupus may have swollen knees and fever. Another person may be tired all the time or have kidney trouble. Someone else may have rashes. Lupus can involve the joints, the skin, the kidneys, the lungs, the heart, and/or the brain. If you have lupus, it may affect two or three parts of your body. Usually, one person doesn't have all the possible symptoms.

There are three main types of lupus:

- **Systemic lupus erythematosus** (eh-RITH-eh-muh-TOE-sus) is the most common form. It's sometimes called SLE, or just lupus. The word "systemic" means that the disease can involve many parts of the body such as the heart, lungs, kidneys, and brain. SLE symptoms can be mild or serious.

- **Discoid lupus erythematosus** mainly affects the skin. A red rash may appear, or the skin on the face, scalp, or elsewhere may change color.
- **Drug-induced lupus** is triggered by a few medicines. It's like SLE, but symptoms are usually milder. Most of the time, the disease goes away when the medicine is stopped. More men develop drug-induced lupus because the drugs that cause it, hydralazine and procainamide, are used to treat heart conditions that are more common in men.

What Are the Signs and Symptoms of Lupus?

Lupus may be hard to diagnose. It's often mistaken for other diseases. For this reason, lupus has been called the "great imitator." The signs of lupus differ from person to person. Some people have just a few signs; others have more.

Common signs of lupus are:

- Red rash or color change on the face, often in the shape of a butterfly across the nose and cheeks
- Painful or swollen joints
- Unexplained fever
- Chest pain with deep breathing
- Swollen glands
- Extreme fatigue (feeling tired all the time)
- Unusual hair loss (mainly on the scalp)
- Pale or purple fingers or toes from cold or stress
- Sensitivity to the sun
- Low blood count
- Depression, trouble thinking, and/or memory problems.

Other signs are mouth sores, unexplained seizures (convulsions), "seeing things" (hallucinations), repeated miscarriages, and unexplained kidney problems.

What Is a Flare?

When symptoms appear, it's called 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 or after a hard day at work.

Even if you take medicine for lupus, you may find that there are times when the symptoms become worse. Learning to recognize that a flare is coming can help you take steps to cope with it. Many people feel very tired or have pain, a rash, a fever, stomach discomfort, headache, or dizziness just before a flare. Steps to prevent flares, such as limiting the time you spend in the sun (and artificial indoor light) and getting enough rest and quiet, can also be helpful.

Preventing a Flare

- Learn to recognize that a flare is coming.
- Talk with your doctor.
- Try to set realistic goals and priorities.
- Limit the time you spend in the sun and artificial indoor light.
- Maintain a healthy diet.
- Develop coping skills to help limit stress.
- Get enough rest and quiet.
- Exercise moderately when possible.
- Develop a support system by surrounding yourself with people you trust and feel comfortable with (family, friends, etc.).

What Causes Lupus?

We don't know what causes lupus. There is no cure, but in most cases lupus can be managed. Lupus sometimes seems to run in families, which suggests the disease may be hereditary. Having the genes isn't the whole story, though. The environment, sunlight, stress, and certain medicines may trigger symptoms in some people. Other people who have similar genetic backgrounds may not get signs or symptoms of the disease. Researchers are trying to find out why.

Who Gets Lupus?

Anyone can get lupus. But we know that many more women than men get lupus. African American women are three times more likely to get lupus than white women. It's also more common in Hispanic/Latino, Asian, and American Indian women.

Both African Americans and Hispanics/Latinos tend to develop lupus at a younger age and have more symptoms at diagnosis (including kidney problems).

They also tend to have more severe disease than whites. For example, African American patients have more seizures and strokes, while Hispanic/Latino patients have more heart problems. We don't understand why some people seem to have more problems with lupus than others.

Diagnosis: How Do You Find Out If You Have Lupus?

- **Medical history.** Telling a doctor about your symptoms and other problems you have had can help him or her understand your situation. Your history can provide clues to your disease. Use the checklist at the end of this booklet to keep track of your symptoms. Share this checklist with your doctor. Ask your family or friends to help you with the checklist or come up with questions for your doctor.

- **Complete physical exam.** The doctor will look for rashes and other signs that something is wrong.

- **Laboratory testing of blood and urine samples.** Blood and urine samples often show if your immune system is overactive.

- **Skin or kidney biopsy.** In a biopsy, tissue that is removed by a minor surgical procedure is examined under a microscope. Skin or kidney tissue examined in this way can show signs of an autoimmune disease.

Lupus is most common in women between the ages of 15 and 44. These are roughly the years when most women are able to have babies. Scientists think a woman's hormones may have something to do with getting lupus. But it's important to remember that men and older people can get it, too.

It's less common for children under age 15 to have lupus. One exception is babies born to women with lupus. These children may have heart, liver, or skin problems caused by lupus. With good care, most women with lupus can have a normal pregnancy and a healthy baby.

What Will the Doctor Do?

Go see a doctor. He or she will talk to you and take a history of your health problems. Many people have lupus for a long time before they find out they have it. It's important that you tell the doctor or nurse about your symptoms. This information, along with a physical examination and the results of laboratory tests, helps the doctor decide whether you have lupus or something else.

A rheumatologist (ROOM-uh-TALL-uh-jist) is a doctor who specializes in treating diseases that affect the joints and muscles, like lupus. You may want to ask your regular doctor for a referral to a rheumatologist.

In some cases, a dermatologist, a doctor who specializes in treating diseases that affect the skin, may be involved in diagnosis and treatment. **No single test can show that you have lupus. Your doctor may have to run several tests and study your medical history. It may take time for the doctor to diagnose lupus.**

Will I Get Medicine?

Remember that each person has different symptoms. Treatment depends on the symptoms. The doctor may give you aspirin or a similar medicine to treat swollen joints and fever. Creams may be prescribed for a rash. For more serious problems, stronger medicines such as antimalaria drugs, corticosteroids, chemotherapy drugs, and biologic drugs, including a BLyS-specific inhibitor, are used. Your doctor will choose a treatment based on your symptoms and needs.

Always tell your doctor if you have problems with your medicines. Let your doctor know if you take herbal or vitamin supplements. Your medicines may not mix well with these supplements. You and your doctor can work together to find the best way to treat all of your symptoms.

How Can I Cope With Lupus?

You need to find out what works best for you. You may find that a rheumatologist has the best treatment plan for you. Other health professionals who can help you deal with different aspects of lupus include psychologists, occupational therapists, dermatologists, and dietitians. You might find that doing exercises with a physical therapist makes you feel better. The important thing is to follow up with your health care team on a regular basis, even when your lupus is quiet and all seems well.

Dealing with a long-lasting disease like lupus can be hard on the emotions. You might think that your friends, family, and coworkers do not understand how you feel. Sadness and anger are common reactions.

People with lupus have limited energy and must manage it wisely. Ask your health care team about ways to cope with fatigue. Most people feel better if they manage their rest and work and take their medicine. If you're depressed, medicine and counseling can help.

Also,

- Pay attention to your body. Slow down or stop before you're too tired.
- Learn to pace yourself. Spread out your work and other activities.
- Don't blame yourself for your fatigue. It's part of the disease.

- Consider support groups and counseling. They can help you realize that you're not alone. Group members teach one another how to cope.
- Consider other support from your family as well as faith-based and other community groups.

It's true that staying healthy is harder when you have lupus. You need to pay close attention to your body, mind, and spirit. Having a chronic disease is stressful. People cope with stress differently. Some approaches that may help are:

- Staying involved in social activities.
- Practicing techniques such as meditation and yoga.
- Setting priorities for spending time and energy.

Exercising is another approach that can help you cope with lupus. Types of exercise that you can practice include the following:

- **Range-of-motion** (for example, stretching) exercise helps maintain normal joint movement and relieve stiffness. This type of exercise helps maintain or increase flexibility.
- **Strengthening** (for example, weight-lifting) exercises help keep or increase muscle strength. Strong muscles help support and protect joints affected by lupus.
- **Aerobic or endurance** (for example, brisk walking or jogging) exercises improve cardiovascular fitness, help control weight, and improve overall function.

People with chronic diseases like lupus should check with their health care professional before starting an exercise program.

Learning about lupus may also help. People who are well-informed and take part in planning their own care report less pain. They also may make fewer visits to the doctor, have more self-confidence, and remain more active.

Women who want to start a family should work closely with their health care team, for example, doctors, physical therapists, and nurses. Your obstetrician and your lupus doctor should work together to find the best treatment plan for you.

Hope Through Research

Scientists are working to find out what causes lupus and how it can best be treated. Here are some of the questions they are trying to answer:

- Who gets lupus and why?
- Why are women more likely to get lupus than men?
- Why are there more cases of lupus among certain racial and ethnic groups?
- What goes wrong in the immune system and why?
- How can we fix an immune system that isn't working well?
- What genes play a role in lupus?
- How can lupus symptoms best be treated?

The National Institutes of Health (NIH) supports research on health and disease. The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) supports research on the bones, connective tissue, joints, muscles, and skin. These are the parts of the body that can be affected by lupus. Research supported by the NIAMS is looking at these issues:

- Scientists have demonstrated that people with lupus who test positive for certain antibodies are more likely to have severe flares and that taking prednisone can prevent flares in many individuals.
- Researchers have found that the process of clearing out dead cells from the body may not work well in lupus. Finding out more about this process might lead to new treatments.
- Scientists are beginning to understand what roles different types of immune cells play in lupus. This knowledge might help them to find new ways to treat the disease.
- Proteins have been identified in the urine of lupus patients that can indicate the type and severity of kidney disease they have. A simple blood test based on this finding could help patients avoid painful and costly kidney biopsies.
- Certain genes make some people more likely to have serious complications, such as kidney disease. NIAMS researchers have found a gene linked to a higher risk of lupus kidney disease in African Americans. Changes in this gene keep the immune system from removing harmful germ-fighters from the body after they've done their job. Other genes have been identified that play a role in lupus.
- Lupus is more common in women than in men. Researchers are looking into the role of hormones and other male-female differences.

More information on research is available from the following websites:

- **National Institutes of Health (NIH) Clinical Research Trials and You** was designed to help people learn more about clinical trials, why they matter, and how to participate. Visitors to the website will find information about the basics of participating in a clinical trial, first-hand stories from actual clinical trial volunteers, explanations from researchers, and links to how to search for a trial or enroll in a research-matching program.
  Website: www.nih.gov/health/clinicaltrials
- **ClinicalTrials.gov** offers up-to-date information for locating federally and privately supported clinical trials for a wide range of diseases and conditions.
  Website: www.clinicaltrials.gov
- **NIH RePORTER** is an electronic tool that allows users to search a repository of both intramural and extramural NIH-funded research projects from the past 25 years and access publications (since 1985) and patents resulting from NIH funding.
  Website: www.projectreporter.nih.gov
- **PubMed** is a free service of the U.S. National Library of Medicine that lets you search millions of journal citations and abstracts in the fields of medicine, nursing, dentistry, veterinary medicine, the health care system, and preclinical sciences.
  Website: www.ncbi.nlm.nih.gov/pubmed

Where Can People Find More Information About Lupus?

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

National Institutes of Health
1 AMS Circle
Bethesda, MD 20892–3675
Phone: 301–495–4484
Toll free: 877–22–NIAMS (226–4267)
TTY: 301–565–2966
Fax: 301–718–6366
Email: NIAMSinfo@mail.nih.gov
Website: www.niams.nih.gov

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

American Academy of Dermatology

Website: www.aad.org

American Academy of Orthopaedic Surgeons

Website: www.aaos.org

American College of Rheumatology

Website: www.rheumatology.org

American Autoimmune-Related Diseases Association, Inc.

Website: www.aarda.org

Arthritis Foundation

Website: www.arthritis.org

Lupus Foundation of America

Website: www.lupus.org

SLE Foundation

Website: www.lupusny.org

In Appreciation

The NIAMS thanks the following people and organizations for their contribution to the original version of this booklet: Arthritis Foundation, Metropolitan Washington Chapter, Lupus Foundation of Greater Washington, Washington, DC; Lupus Foundation of America, Washington, DC; Barbara Mittleman, M.D., Clifton A. Poodry, Ph.D., Laura Robbins, D.S.W., Cheryl Contreras, M.P.I.A., Patricia Fraser, M.D., M.P.H., M.S., Lori Harrison Port, M.P.H., Bobbie Drake-Saucer, Juan Rivera, Ph.D., Jorge R. Toro, M.D., and Lourdes Villalba, M.D.

Special thanks go to our focus group participants and patients with lupus who reviewed this publication and provided valuable input.

Symptom Checklist

Use this page to make notes to take to your doctor. Put a check mark beside the symptoms you have. Note when you experienced them.

Symptom	√	Where?	When did you first notice?	How often?	Recent dates?
Example: Rash	√	*face and chest*	*2 years ago*	*Once or twice a month*	*9/17, 10/8, 10/23, 11/15*
Red rash or color change					
Painful or swollen joints					
Unexplained fever					
Chest pain with deep breathing					
Unusual hair loss					
Pale or purple fingers or toes					
Sensitivity to sun					
Other					

Do You Have Lupus or a Related Condition?

You may be able to help scientists learn more about these conditions.

For information about research projects across the country, call:

NIAMS
Toll free: 877–22–NIAMS (226–4267)
Email: NIAMSinfo@mail.nih.gov

You could make a difference!

Notes:

Notes:

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 **www.niams.nih.gov**.

National Institute of
Arthritis and Musculoskeletal
and Skin Diseases

NIH Publication No. 14–4958–E
July 2014