

# Lupus: Care Instructions

## Overview

Lupus (systemic lupus erythematosus) is a long-term disease that can cause inflammation, pain, and tissue damage in your body. It is an autoimmune disease. This means the immune system attacks its own tissues. Lupus may cause problems with your skin, kidneys, heart, lungs, nerves, or blood cells. There are other types of lupus, but systemic lupus erythematosus is the most common and most serious type.

When you have lupus symptoms, you are having flares or relapses. When your symptoms get better, you are in remission. Lupus may get worse very quickly. There is no way to tell when a flare will happen or how bad it will be. When you have a lupus flare, you may have new symptoms as well as symptoms you have had in the past.

Learn your body's signs of a flare, such as joint pain, a rash, a fever, or being more tired. When you see any of these signs, take steps to control your symptoms.

**Follow-up care is a key part of your treatment and safety.** Be sure to make and go to all appointments, and call your doctor if you are having problems. It's also a good idea to know your test results and keep a list of the medicines you take.

## How can you care for yourself at home?

### Reduce stress and tiredness

- Keep your daily schedule as simple as possible.
- Keep your list of things to do as short as you can.
- Exercise regularly. A daily walk or swim, for example, can lower stress, clear your head, improve your mood, and help fight tiredness.
- Use meditation, yoga, or guided imagery to relax.
- Get plenty of rest. Some people with lupus need up to 12 hours of sleep every night.
- Pace yourself. Do not do too many activities.
- Ask others for help. Do not try to do everything yourself.
- Take short breaks from your usual activities. Think about cutting down on work hours when your symptoms are severe.
- If you think that depression or anxiety is making you feel more tired, talk to your doctor, a mental health professional, or both.

### Take care of your skin

- Ask your doctor about the use of corticosteroid creams for skin symptoms.
- If you are bothered by the way a lupus rash looks on your face or if you have scars from lupus, you can try makeup, such as Covermark, to cover the rash or scars.
- Stay out of the sun, especially when the sun's rays are the strongest, usually between 10 a.m. and 4 p.m. If you must be in the sun, cover your arms and legs, and wear a hat. Make sure to use a broad-spectrum sunscreen that has a sun protection factor (SPF) of 50 or higher. Put more sunscreen on after swimming, sweating, or toweling off.

### Practice good self-care

- Learn more about lupus and how to take care of yourself.
- Take your medicines exactly as prescribed. Call your doctor if you have any problems with your medicine.
- Do not smoke. If you need help quitting, talk to your doctor about stop-smoking programs and medicines. These can increase your chances of quitting for good.
- Eat a healthy, balanced diet. A balanced diet includes whole grains, dairy, fruits and vegetables, and protein. Eat a variety of foods from each of those groups so you get all the nutrients you need.
- Avoid other people who are sick with colds or the flu. These illnesses can cause lupus flares. Talk with your doctor about any vaccines you may need, including flu shots and pneumococcal vaccines. If you do get sick or think you are getting an infection, talk with your doctor so you can treat your symptoms right away.
- Brush and floss your teeth each day. See your dentist two times a year.
- Get regular eye exams.
- Build a support system of family, friends, and health professionals.

### When should you call for help?

**Call** anytime you think you may need emergency care. For example, call if:

- You have symptoms of a heart attack. These may include:
  - Chest pain or pressure, or a strange feeling in the chest.
  - Sweating.
  - Shortness of breath.

- Nausea or vomiting.
- Pain, pressure, or a strange feeling in the back, neck, jaw, or upper belly or in one or both shoulders or arms.
- Lightheadedness or sudden weakness.
- A fast or irregular heartbeat.

After you call , the operator may tell you to chew 1 adult-strength or 2 to 4 low-dose aspirin. Wait for an ambulance. Do not try to drive yourself.

**Call your doctor now** or seek immediate medical care if:

- You are short of breath.
- You have blood in your urine or are urinating less often and in smaller amounts than usual.
- You have a fever.
- You feel depressed or notice any changes in your behavior or thinking.
- You are dizzy or have muscle weakness.
- You have swelling of the lower legs or feet.

Watch closely for changes in your health, and be sure to contact your doctor if:

- Your symptoms get worse or you develop any new symptoms. These may include aching or swollen joints, increased fatigue, loss of appetite, hair loss, skin rashes, or new sores in your mouth or nose.

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