

Lupus

Lupus is a chronic autoimmune disease. It causes inflammation in the body and blood. Lupus can affect the lining of the heart, lungs, skin, joints and many other organs.

When you are healthy, your immune system protects your body from bacteria, viruses, chemicals and toxic substances. When you have lupus, your immune system thinks your own tissue is foreign and attacks it. This causes inflammation.

How is lupus diagnosed?

We diagnose lupus through a series of visits and tests. You will likely need:

- Visits with a rheumatologist who specializes in lupus
- Blood tests
- Urine test
- Skin or tissue biopsy

Causes

Though the cause of lupus is not known, it may be caused by:

- genetics
- environment
- the makeup of your tissues

Who is at-risk to develop lupus?

Anyone can get lupus, but it is more common among certain groups of people. Lupus is more common in women between the ages of 15-44. The highest rates are among women who are:

- African American
- Hispanic
- Asian
- American Indian

Symptoms

- Extreme tiredness (fatigue)
- Pain
- Swelling or stiffness in joints
- Hair loss
- Low-grade fevers
- Mouth sores
- Skin rashes (this includes a butterfly rash from sun exposure)
- Chest pain with deep breaths
- Foamy urine
- Numbness or weakness in your arms and/or legs

Flares

A flare is an increase in your lupus activity with signs and symptoms that can be measured. Your doctor will tell you if your flare means you need to change your treatment. Track your symptoms and triggers and share any changes with your doctor. Lupus can flare after times when the disease has been quiet. When flares are severe, seek medical help.

Triggers

- Sun, sun lamps or tanning beds
- Sulfa drugs
- Medicines that make you more sensitive to the sun
- Stressors like infection, viral illness, stress and pregnancy

Avoiding Triggers

- Always use sunscreen and wear clothes that block UV rays
- Avoid tanning beds and sunlamps
- Plan pregnancies
- Avoid stress
- Talk to your doctor if you take sulfa medicine

Fatigue

Fatigue is very common. It is important to know the difference between fatigue and flares. You can manage fatigue with proper exercise, sleep and a healthy diet.

- Listen to your body and know your limits.
- Do daily aerobic exercises.
- Allow for short periods of rest throughout the day.
- Plan ahead. Focus on the most important activities.
- Save energy by shopping online.
- Cook meals in advance.
- Accept fatigue and don't blame yourself.
- Ask family and friends for help when you need it.
- Join a support group to learn more tips for fighting fatigue.
- Try to have good sleep habits and eat a healthy diet.

Lupus Treatments

Most people with lupus can lead normal lives with treatments. Some common treatment options are:

- Acetaminophen (Tylenol®)
- Anti-inflammatory medicines such as ibuprofen, naproxen, meloxicam and celecoxib
- Immunosuppressive medicines such as hydroxychloroquine, corticosteroids, mycophenolate and azathioprine
- Infusion treatments such as cyclophosphamide and belimumab

Medicine

Hydroxychloroquine:

- Do not crush, break, or chew
- Take with food or milk to avoid stomach upset
- Have an eye exam every year
- Safe for pregnancy and breastfeeding

Tracking Symptoms

Track your symptoms. Call your doctor if you have any new symptoms or if your symptoms get worse. Call if you have:

- A butterfly-shaped rash over the cheeks or a red rash with raised round or oval patches
- A rash that lasts for 2-3 days on skin that was exposed to the sun
- Alopecia/bald spots
- A cough that lasts over 24 hours or shortness of breath
- Frequent sores in the mouth or nose that last a few days
- Joint stiffness or swelling in two or more joints that lasts for a few weeks
- Constant chest pain that gets worse with deep breaths
- Urine that is bloody and/or foamy
- Swelling in your ankles or around your eyes (especially in the morning)
- New seizures
- New weakness or numbness in your arms and legs that does not go away

Health Screenings

Lupus can lead to other health problems. It can cause clogging of the arteries and heart attacks, heart failure or strokes. Lupus patients should be screened for:

- High blood pressure
- High cholesterol
- Symptoms of concern for heart attacks
- Bone health
- Retinal (eye) exam

Manage Your Diet

- Use myplate.gov to plan meals, find diet tips and learn more about healthy types of foods.
- Eat more berries and citrus fruits (Ask your pharmacist before drinking grapefruit juice), fruits and

vegetables in a variety of colors, nuts/seeds, olive oil, whole grains.

- Eat foods that are sautéed, steamed or roasted. Raw vegetables can increase bloating or diarrhea.

Preventing Infections

- Get a pneumonia vaccine.
- Get your flu vaccine during flu season (October to February).
- If you are on immunosuppressive medicines or high doses of steroids **do not get live vaccines** (mumps, rubella, measles, chickenpox, oral typhoid vaccine, yellow fever, nasal flu vaccine and live zoster vaccines).
- **Wash your hands often.** Wash your hands after you use the bathroom, blow your nose or touch areas in public spaces and before you eat or touch your face.

Pregnancy Planning

- Meet with a rheumatologist and a high-risk obstetrician before trying to get pregnant.
- Wait until your disease has been stable for at least six months to get pregnant. Pregnant patients with active lupus are at higher risk of high blood pressure, miscarriages, preterm delivery, excessive bleeding after delivery and/or blood clots in the leg or lung.
- Pregnancy can cause a lupus flare.
- Ask your pharmacist about the risks and benefits of taking your medicines during pregnancy. **Do not** get pregnant while taking certain medicines like Mycophenolate, Methotrexate, or while on infusions.

Quit Smoking

Smoking is a known lupus trigger. Talk to your doctor if you need help quitting.

Managing Lupus Symptoms

There are ways to manage your lupus symptoms. We have some tips for treating common lupus symptoms.

Mouth Sores

Try the options below to manage your sores. If your sores **do not** improve, talk with your doctor about other treatment options.

- **Alum powder** - Apply for 60 seconds and spit. (**Do not swallow**). **Do not** rinse with water for 24 hours. Avoid frequent use.
- **Oral hygiene** - Brush your teeth twice a day with fluoride toothpaste and floss daily.
- **Quit smoking** - Smoking increases your risk for gum disease and mouth sores.
- **Magic Mouthwash®** - Apply for 60 seconds and spit (do not swallow). Use up to three times daily.
- **Benzocaine®** - Apply to sores up to four times daily and **do not** swallow. Avoid frequent use.

Thinning Hair

- **Vitamin B complex/biotin supplements** - Daily use helps strengthen the nervous system and the body's skin and hair.
- **Thyroid check** - If you have hair loss, feel fatigued and/or have cold sensitivity or hot flashes, talk to your doctor about getting your thyroid hormone levels checked.
- **Multivitamin and minerals** - Take a multivitamin daily to make sure your body gets the vitamins and minerals it needs.

Joint Pain

- **Omega-3 supplements** - This fatty acid is found in soybean, canola oil, flaxseed and fish oil. Omega 3 supplements have anti-inflammatory

benefits which can help with joint pain, stiffness and swelling.

- **Turmeric**® - Turmeric is an ancient herb used in cooking which may help reduce swelling in joints. Turmeric is safe but high doses or long-term use may cause stomach upset and thinning of the blood. If you are pregnant or on blood thinners, talk to your doctor before you start this herb.
- **Glucosamine Sulfate**® - This may work to relieve joint pain. Talk to your doctor before starting this supplement if you are pregnant or on a blood thinner.

Sun Sensitivity

- **Sunscreen** - Carry 70 SPF sunscreen or higher and be sure that it blocks UV-A and UV-B rays. Both are harmful to people with lupus. Apply sunscreen to all areas of the body, even those covered by clothes. Reapply sunscreen every three hours, especially if you are in the water.
- **Protective clothes** - Wear long sleeves, hats, pants, and scarves when you go outdoors on a sunny day. Wear clothing that includes UV ray blocking protection.
- **No tanning** - **Do not** use tanning beds and sun lamps.

Trouble Sleeping

- **Get enough sleep** - Maintain a regular sleep routine. Go to bed and wake up at the same time each day. Limit daytime naps to 30 minutes.
- **Avoid caffeine and nicotine** - Stop eating and avoid caffeine and nicotine for at least two hours before you go to sleep.
- **Exercise** - Regular exercise can help the quality of your sleep.

- **Drink milk** - Milk at bedtime may help you sleep.
- **Talk to your doctor** - If you snore at night or are often tired in morning, talk to your doctor.
- **Keep a sleep diary** - Keep track of any triggers you find that keep you awake and tips that help you sleep.
- **Melatonin** - Ask your doctor if you should use melatonin as a sleep aid.

Exercise

Exercise helps with joint pain by keeping joints flexible. It also helps you relax and sleep better. Exercises like yoga, walking, water aerobics and swimming are good for patients with lupus.

Yoga

Yoga helps the body relax. Restorative and chair yoga are helpful for all forms of arthritis. Some forms of yoga should not be done without instruction or supervision.

Find UW Health yoga resources. You can use the Arthritis Foundation resource at arthritis.org to find a yoga studio near you. You can also choose a yoga DVD that includes modified poses and step-by-step instructions.

Water Aerobics

Walking in water is good for joint pain and damage. Water supports the body's weight, which lowers stress on the joints and helps with pain. Walking in water also strengthens and builds muscle. Heated pools—about 82 to 88 degrees—can help soothe pain. Cooler water might not feel as good, but you'll still get the benefits. To find out more about warm water pools visit:

<https://www.uwhealth.org/conditions/lupus>.

You can use the Arthritis Foundation resource to find pools near you at arthritis.org.

Walking

Track your steps and try to walk non-stop for 20-30 minutes. Track your activity levels and set goals for each week to help you increase your endurance.

Muscle Strengthening

Knees - Strengthen muscles to support your knees. Do a ball squeeze between your knees. Do 5 second squeezes, for 60 total seconds or do seated straight leg raises for 30 seconds on each leg.

Hips and thighs - Strengthen hip and thigh muscles. March in place for 30 to 60 seconds or walk forward and backward, 10 steps each way.

Upper body - Strengthen and improve your upper body range of motion. Do arm circles backward for 30 seconds. Work arms and back by moving your arms on a tabletop as if you're doing the breaststroke. Continue for 60 seconds. Do wrist circles, wrist bends (up and down), and open and closed fingers for 10 seconds each.

Your health care team may have given you this information as part of your care. If so, please use it and call if you have any questions. If this information was not given to you as part of your care, please check with your doctor. This is not medical advice. This is not to be used for diagnosis or treatment of any medical condition. Because each person's health needs are different, you should talk with your doctor or others on your health care team when using this information. If you have an emergency, please call 911. Copyright © 9/2021 University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing HF#8214.