

- Glucosamine Sulfate®. Most studies show it to be likely effective for joint tenderness in arthritis. Talk to your doctor before starting this supplement if you are pregnant or on a blood thinner.

Sun Sensitivity

- Sunscreen. Carry sunscreen with an SPF of at least 70 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. Try to wear long sleeves, hats, pants, and scarves when you go outdoors on a sunny day. Wear clothing that includes UV ray blocking protection.
- Do not use tanning beds and sun lamps.

Better Sleep

- 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 in the evening and stop eating at least two hours before you go to sleep.
- Regular exercise can help the quality of your sleep.
- Drink milk at bed time.
- Talk to your doctor if you snore at night time, feel unrefreshed or fatigued in morning.
- Keep a sleep diary. Keep track of any triggers you find and/or strategies that help you sleep.
- Melatonin. Talk to your doctor if you use melatonin as a sleep aid.

Exercise

Exercise helps with joint pain by keeping joints flexible. It also helps people 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, Iyengar and chair yoga are recommended for all forms of arthritis. Some forms of yoga should not to be done without instruction or supervision. Find UW Health yoga resources at uwhealth.org/46914. You can use the Arthritis Foundation resource to locate a yoga

facility near you. Go to arthritis.org or choose a yoga DVD that includes modified poses and step-by-step instructions

- Water Aerobics. Walking in water is good for people with joint pain and damage. The water's buoyancy supports the body's weight, which lowers stress on the joints and helps with pain. In fact, water provides 12 times more resistance than air, so walking strengthens and builds muscle. It is most ideal to do in heated pools — about 82 to 88 degrees — which can help soothe pain. Cooler temps might not feel as good, but you'll still reap the benefits. Find UW Health warm water pool resources at uwhealth.org/47274. 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.
- 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.
- Strengthen hip and thigh muscles. March in place for 30 to 60 seconds or walk forward and backward, 10 steps each way.
- 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 table top as if you're doing the breast stroke. Continue for 60 seconds. Do wrist circles, wrist bends (up and down), and open and closed fingers for 10 seconds each.

UW HEALTH LUPUS CLINIC

WHAT IS LUPUS?

Lupus is a chronic autoimmune disease that causes inflammation in the body and blood. Lupus can affect the lining of the heart and lungs, skin, joints and many other organs. When a person is healthy, their immune system protects their body from bacteria, viruses, chemicals and toxic substances. When people have lupus, their immune system thinks its own tissue is foreign and attacks it. This causes inflammation.

Diagnosing Lupus

Our specialists diagnose lupus through a series of visits and tests. This includes but is not limited to:

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

About Lupus

The Cause

While the cause of lupus is not known, a person may get lupus because of genetics, the environment, the makeup of their tissues and certain triggers.

The Patient

Anyone can get lupus; but, it is most common in women between the ages of 15-44. African American women are three times more likely to get lupus than Caucasian women. It is more common in Hispanic, Asian and American Indian women, all of whom tend to develop lupus at a younger age and have more symptoms.

Symptoms

General symptoms include extreme tiredness (fatigue), pain, swelling or stiffness in joints, hair loss and low-grade fevers. Symptoms that involve

organs are mouth ulcers, skin rashes (this includes a butterfly rash from sun exposure), joint stiffness or swelling, chest pain with deep breaths, foamy urine and/or numbness or weakness in your arms and/or legs.

Flares

A flare is an increase in disease activity in one or more organ systems with signs and symptoms that can be measured. Your doctor will tell you if the increase is enough to consider changing your treatment. It is important to 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. Common triggers of flares include sunlight, viral infections, sulfur medicines and stress.

Triggers

- Ultraviolet (UV) rays from the sun or from fluorescent light bulbs like sun lamps or tanning beds
- Sulfa drugs such as: Bactrim and Trimethoprim-Sulfamethoxazole (Septra®), Tolbutamide (Orinase®), Sulfasalazine (Azulfidine®)
- Medicines that make you more sensitive to the sun such as tetracycline and minocycline (Minocin®)
- Stressors like infection, viral illness, stress and pregnancy

To avoid triggers:

- Always use sunscreen and wear clothes that block UV rays
- Avoid tanning beds/sunlamps
- Plan pregnancies
- Avoid stress
- If you take medicine that includes sulfur, ask if it is safe for people with lupus

Fatigue

More than 80 percent of lupus patients have fatigue. It is important to know the difference between fatigue and flares. Fatigue can be managed with proper exercise, sleep and a healthy diet. A doctor can suggest ways to manage fatigue, including:

- Listen to your body and know your limits
- Daily aerobic exercise helps to lessen lupus fatigue
- Allow for short periods of rest between daily activities
- Plan ahead, and focus on the most important activities
- Shop online and have items shipped directly to you
- Cook meals in advance
- Accept fatigue and never self-blame
- Ask for help
- Build a strong family and friend network to support you during times of extreme fatigue/flare
- Join a support group to learn more fatigue-fighting tips
- Establish good sleep patterns and eat a healthy diet

Lupus Treatments

With new and better treatments to help keep lupus quiet, most people with lupus can lead normal lives. Some common treatment options are

- Acetaminophen (Tylenol®)
- Nonsteroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen, naproxen, meloxicam and celecoxib
- Immunosuppressive medicines such as hydroxychloroquine, corticosteroids, mycophenolate and azathioprine
- Infusion therapies such as cyclophosphamide and belimumab

It is important to fully understand your medicines.

- Hydroxychloroquine. Do not crush, break, or chew it as it is a coated medicine. Take with food or milk to avoid abdominal pain. Have an eye exam every year. This medicine is safe during pregnancy and breastfeeding.
- Mycophenolate. Swallow the capsule or tablet whole. Do not crush, break or chew. Take with food if needed to prevent nausea or stomach pain. Use contraception while on this medicine and talk with your doctors if you plan to become pregnant. This medicine is safe to take while breastfeeding.

- Azathioprine. Take this with food, or in divided doses, to decrease gastrointestinal intolerance. This medicine can make skin more sensitive to sunlight so always wear sunscreen and do not use sunlamps or tanning beds. This medicine is safe to take while breastfeeding.

Lupus Self-Management Tools

Track your symptoms and call your doctor if you have any new or worsening symptoms such as:

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

Get Screened

Lupus can lead to accelerated atherosclerosis (clogging of the arteries) and heart attacks, heart failure or strokes. Lupus patients should be screened/watched for:

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

Manage Your Diet

- Use choosemyplate.gov to plan meals, discover ways to improve your diet and learn more about the types of foods that are healthy.
- Eat more berries/citrus fruits (Talk with your pharmacist before drinking grapefruit juice with certain medicines), fruits and vegetables in a variety of colors, nuts/seeds, olive oil, whole grains.

- Try to eat foods that are sautéed, steamed or roasted. Raw vegetables can increase bloating or diarrhea.
- Avoid nightshades and garlic for two weeks. If symptoms stay the same, you can try to add them back into your diet.

Focus on Infection Prevention

- Get a pneumonia vaccine. Lupus patients are more likely to get pneumonia and blood stream infections. Pneumonia vaccines are killed vaccines and can help prevent lung/ blood stream infections. Ask your doctor about getting your 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 like mumps, rubella, measles, chickenpox, oral typhoid vaccine, yellow fever, nasal flu vaccine and live zoster vaccines.
- Practice good hand hygiene. 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.

Pre-plan and Discuss Your Pregnancies

- Meet with a rheumatologist and a high-risk obstetrician before you try to get pregnant and try to delay pregnancy until your disease has been stable for at least six months.
- Pregnancy can lead to a lupus flare. Build a strong rapport with your rheumatologist and obstetrician during your pregnancy.
- 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. It is best to plan your pregnancy for a time when your lupus is stable or quiet.
- Your pharmacist can help you weigh the risks and benefits of medicines you can take during your pregnancy.
- You should not get pregnant while taking certain medicines like Mycophenolate, Methotrexate, or while on infusion therapies.

Quit smoking

Smoking is a known lupus trigger. Be sure to ask your doctor about the many options available to help you quit smoking.

Therapies for Common Issues Affecting Lupus Patients

Oral ulcers

- Alum powder. Apply for 60 seconds and spit. (Do not swallow). Do not rinse with water for 24 hours. Studies have not reported any side effects but avoid excessive use as there can be risk of aluminum toxicity.
- Oral hygiene. Brush your teeth twice a day with fluoride toothpaste and floss daily.
- Quit smoking. Smoking increases your risk for gum disease and oral ulcers.
- Magic Mouthwash®. Apply for 60 seconds and spit. (Do not swallow) Apply up to three times daily. Avoid using too often to prevent side effects from excessive use of lidocaine.
- Benzocaine®. Apply to affected areas up to four times daily and do not swallow. Common side effects are mucosal irritation, burning or itching. Avoid excessive use.
- If your ulcers do not improve, talk with your doctor about other elixirs (steroid elixirs, lidocaine elixirs) that can be prescribed.

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. Your body needs 13 vitamins to grow and develop normally. Take a multivitamin daily.

Joint Pain

- Omega-3 Supplements. This is a polyunsaturated fatty acid 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 and Black Pepper®. Turmeric is an ancient herb used in cooking. Curcumin is the active ingredient, which some people believe can help reduce inflammation in joints. Turmeric is generally considered safe but high doses or long-term use may cause gastrointestinal issues and blood thinning. If you are pregnant or on blood thinners, talk to your doctor before you start this herb.