

SYSTEMIC LUPUS ERYTHEMATOSUS (SLE)

We Are Here To Help!



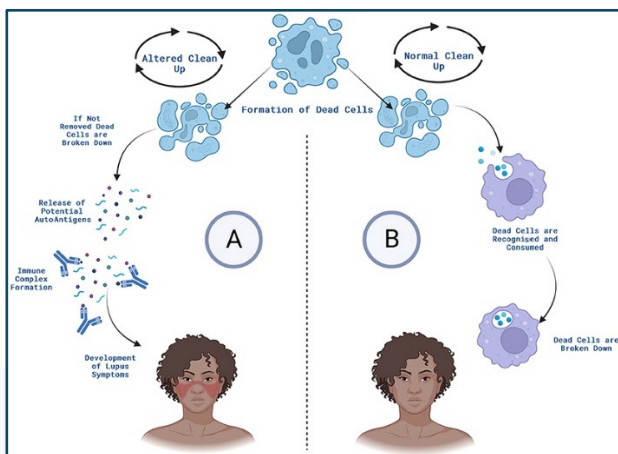
This information leaflet is published by the Arthritis Foundation as part of its continuing education programme for all people with arthritis.

WHAT IS SYSTEMIC LUPUS ERYTHEMATOSUS?

Systemic lupus erythematosus, often called SLE or lupus, is a long-term autoimmune condition. This means the body's immune system, which normally protects you from infections, starts attacking healthy tissues by mistake. Lupus can affect the skin, joints, blood cells, kidneys, lungs, heart, brain, and other organs. Symptoms are different in every patient. There are times when the condition is quiet (remission) and times when it becomes more active (flares). Early diagnosis and regular follow-up can help control active disease, and flares and thus protect your organs.

WHY LUPUS HAPPENS

There is no known single cause of lupus. A person may have a higher chance of lupus because of their genes. A trigger such as sunlight, infection, stress, hormones, or some medicines may switch the disease on. The immune system becomes overactive and confused. The body makes proteins called autoantibodies and immune complexes. These can settle in tissues and cause inflammation. This leads to symptoms and flares in different parts of the body.



A diagram explaining the immune system in SLE



A patient with
an acute malar rash



Raynaud's
syndrome



Discoid
lupus rash

COMMON SYMPTOMS OF LUPUS?

- Tiredness or fatigue that does not improve with rest.
- Joint pain, swelling, or stiffness.
- Skin rashes, especially after sun exposure.
- A rash across the cheeks and nose called a butterfly rash.
- A discoloured rash, called discoid lupus that can cause scarring of the skin.
- Mouth or nose ulcers.
- Hair thinning or hair loss (alopecia).
- Fever.
- Chest pain or shortness of breath.
- Headaches or difficulty concentrating.
- Swelling in the legs, feet, or around the eyes.
- Changes in fingers or toes colour in the col (Raynaud's phenomenon).

HOW IS LUPUS DIAGNOSED?

Lupus can be difficult to diagnose because its symptoms vary from person to person and can look like other illnesses. There is no single test for lupus. Your healthcare team may use your medical history, a physical examination, blood tests such as an ANA test, urine tests, and sometimes scans or a biopsy if an organ such as the kidney or skin is affected.

LUPUS AND THE KIDNEYS, SKIN, AND JOINTS

Kidneys

What lupus may do

Inflammation can damage the kidney filters. This is called lupus nephritis and may lead to protein or blood leaking into the urine.

Symptoms to watch for

Swelling of the feet, ankles, legs, or around the eyes, foamy urine, passing less urine, tiredness, high blood pressure. Some people have no early symptoms.

Monitoring and what helps

Regular urine and blood and BP checks are important. Early treatment can help prevent long-term kidney damage.

Skin

What lupus may do

Lupus can cause rashes, sun sensitivity, mouth or nose ulcers, fragile skin, and hair thinning or hair loss. Some skin changes may scar or leave light or dark marks.

Symptoms to watch for

Butterfly rash over the cheeks and nose, round or patchy rashes, hair loss, skin sensitivity to sunlight.

Monitoring and what helps

Use sunscreen daily, wear a hat and protective clothing and report new rashes to your doctor.

Joints

What lupus may do

Lupus can cause joint pain and swelling, especially in the hands, wrists, knees, ankles, and feet.

Symptoms to watch for

Pain, stiffness, or swelling, often worse in the morning or after resting, difficulty walking, writing, dressing, or holding objects.

Monitoring and what helps

Treatment to control inflammation, regular gentle movement, rest during bad flares, warm compresses.

Raynaud's phenomenon

What lupus may do

Small blood vessels in the fingers and toes can narrow too much in response to cold or stress. This can reduce blood flow to the fingers or toes for a short time.

Symptoms to watch for

Fingers or toes turning white, blue, or red, numbness, tingling, pain, especially in cold weather or during stress.

Monitoring and what helps

Keep warm, avoid smoking, manage stress, and tell your healthcare team if episodes become frequent, painful, or lead to sores. Your doctor may check circulation and review medicines if needed.

LUPUS AND THE HEART, LUNGS, AND NERVOUS SYSTEM

Heart

What lupus may do

Inflammation can affect the tissue around the heart, and less commonly, the heart muscle or valves. It can also increase the long-term risk of high blood pressure, blood clots, and early heart disease.

Symptoms to watch for

Chest pain, palpitations, swelling, unusual shortness of breath, or dizziness.

Monitoring and what helps

Report symptoms early, attend regular check-ups, control blood pressure, avoid smoking, and follow your treatment plan.

Lungs

What lupus may do

Lupus can inflame the lining around the lungs causing fluid in the lungs, or the lung tissue itself.

Symptoms to watch for

Chest pain with deep breathing, dry cough, shortness of breath, breathlessness, or reduced exercise tolerance.

Monitoring and what helps

Tell your doctor about these symptoms.

Nervous system and brain

What lupus may do

Lupus can affect the brain, spinal cord, or nerves. In some people, symptoms may be linked to inflammation, poor blood flow, or blood clots.

Symptoms to watch for

Headaches, dizziness, memory or concentration problems, mood changes, numbness, weakness, seizures, trouble speaking, or vision changes.

Monitoring and what helps

Tell your healthcare team urgently about new or worsening neurological symptoms because they may need quick assessment.

LUPUS AND THE BLOOD CELLS, PREGNANCY, AND ANTIPHOSPHOLIPID SYNDROME

Blood

What lupus may do

Lupus can cause anaemia, low white blood cells, or low platelets.

Symptoms to watch for

Tiredness, weakness, dizziness, shortness of breath, infections, easy bruising, nosebleeds, bleeding gums, heavy periods, or tiny red or purple skin spots.

Monitoring and what helps

Regular blood counts help find problems early, even when you do not yet feel unwell.

Pregnancy

What lupus may do

Many people with lupus can have healthy pregnancies, but active lupus, kidney disease, or certain antibodies can increase risks.

Symptoms to watch for

Possible concerns include miscarriage, pre-eclampsia, premature birth, and lupus flares.

Monitoring and what helps

Plan pregnancy when lupus has been quiet for several months, review medicines before conception, and have close follow-up with your lupus team and pregnancy team.

Antiphospholipid syndrome (APS)

What lupus may do

Some people with lupus have antiphospholipid antibodies that can make the blood more likely to clot. When these antibodies are linked to clots or certain pregnancy complications, this is called APS.

Symptoms to watch for

Blood clots in the legs or lungs, stroke, heart attack, miscarriage, stillbirth, or pre-eclampsia.

Monitoring and what helps

Your doctor may do blood tests if APS is suspected. Treatment may include low-dose aspirin, blood thinners, and careful monitoring, especially during pregnancy.

WHAT ARE THE TREATMENT OPTIONS FOR LUPUS?

Treatment depends on which parts of the body are affected, and whether any organs are at risk. The goals are to control symptoms, prevent flares, reduce inflammation, protect organs, and improve quality of life. Many people need a combination of medicines, and treatment may change over time depending on how lupus behaves. Your doctor will usually try to use the lowest amount of steroid possible and may add other immune-suppressing medications.

Pain relievers and anti-inflammatory medicines: These may help with joint pain, fever, and mild inflammation.

Chloroquine: This is one of the most important long-term medicines for lupus and is often recommended for most people with SLE. It can help with fatigue, joint pain, rashes, and flare prevention. It may take weeks to months to work fully, so it is important to take it regularly. Because it can rarely affect the eyes after long-term use, regular eye checks are important.

Corticosteroids (steroids): Medicines such as prednisone work quickly to calm inflammation and are often used during flares or when organs are affected. Because steroids can cause side effects such as weight gain, raised blood pressure, raised blood sugar, weaker bones, thinning of the skin, and infection risk, doctors usually aim to use the lowest dose for the shortest possible time.

Immunosuppressant medicines: These medicines calm an overactive immune system and may be used when lupus is more severe, when kidneys or other organs are affected, or when doctors want to reduce the need for steroids. Examples include azathioprine, methotrexate, mycophenolate mofetil, tacrolimus and cyclophosphamide. These medicines need regular blood tests because they can affect the liver, kidneys, or blood counts and can increase the risk of infection.

Biologic medicines: These are newer treatments that target specific parts of the immune system. They may be used when lupus remains active despite standard treatment, or in some types of moderate to severe disease. Your healthcare team will discuss whether these medicines are suitable for you and what monitoring is needed.

Treatment for specific problems: Some people also need medicines for blood pressure, kidney protection, bone health, cholesterol, blood-thinning, or pregnancy-related care. Vaccinations, infection prevention, and regular monitoring are also an important part of treatment when you are taking immune-calming medicines.

LOOKING AFTER YOURSELF

- Take your medicines exactly as prescribed.
- Regular visits to your treating doctor for examination including blood and urine tests.
- Protect yourself from the sun by using sunscreen, wearing protective clothing, and avoiding strong midday sun where possible.
- Get enough rest and pace your activities when you feel tired.
- Choose regular gentle exercise, such as walking or stretching, if your healthcare team says it is safe.
- Eat a balanced diet and stay hydrated.
- Avoid smoking.
- Speak to your doctor before becoming pregnant, or if you are planning a pregnancy.
- Keep a record of your symptoms and possible flare triggers.
- Ask for support if you are feeling anxious, low, or overwhelmed.

DIET AND EXERCISE

There is no special diet that will treat or cure lupus, but healthy eating can help your body. Try to eat a balanced diet with vegetables, fruit, whole grains, beans, nuts, and healthy proteins. Drink enough water and limit sugary drinks, salty foods, and highly processed foods. If lupus affects your kidneys, ask your doctor if you need special diet advice.

Gentle exercise can help with stiffness, mood, strength, and energy. Walking, stretching, swimming, or cycling may help. Start slowly, do what feels safe, and rest during flares. Speak to your healthcare team if exercise makes your symptoms worse.

In general:

- Eat regular, balanced meals and stay hydrated.
- Choose more vegetables, fruit, whole grains, and healthy proteins.
- Limit salty, sugary, and highly processed foods.
- Try to have gentle activity most days, even for a short time.

SELF-CARE FOR RAYNAUD'S ATTACKS

Keep your hands and feet warm as well as your body in general. Avoid cold exposure in general but also direct exposure such as taking things out of the freezer, or working in cold water. Try to stay calm during attacks, and do not smoke. Tell your healthcare team if attacks become more frequent, more painful, last longer, or cause sores.

SEEK URGENT MEDICAL HELP IF YOU HAVE

- Severe chest pain, or trouble breathing.
- New confusion, seizures, or severe headache.
- Sudden swelling, reduced urine, or blood in the urine.
- High fever, or signs of infection.
- Severe weakness, dizziness, or fainting.
- Rapid worsening of your usual symptoms.

QUESTIONS YOU MAY WANT TO ASK YOUR HEALTHCARE TEAM

- Which parts of my body are affected by lupus?
- What tests do I need and how often?
- What side-effects should I watch for with my medicines?
- How can I reduce the chance of flare-ups?
- What symptoms should make me seek urgent help?
- Is it safe for me to exercise, work, travel, or become pregnant?

GLOSSARY OF TERMS USED

What these useful terms mean in simple language

ANA

A blood test that may be positive in lupus. It can support the diagnosis, but it does not by itself prove that someone has lupus.

Nephritis

Inflammation of the kidneys. In lupus, this is called lupus nephritis.

APS

Short for antiphospholipid syndrome, a condition in which certain antibodies can make blood clots or pregnancy complications more likely.

Autoantibodies

Proteins made by the immune system that attack the body's own tissues by mistake.

Immune complexes

Small clusters formed when antibodies attach to substances in the blood. In lupus, they can settle in tissues and cause inflammation.

Flare

A time when lupus becomes more active and symptoms get worse.

Remission

A time when lupus is quieter and symptoms improve, or may almost disappear.

Immuno suppressant

A medicine that calms down an overactive immune system.

USEFUL WEBSITES



arthritis.org.za
**Arthritis Foundation
of South Africa**



saraa.co.za
**South African Rheumatism
& Arthritis Association**



lupusfoundationsa.co.za
The Butterfly Foundation



andreasgiftfoundation.org
Andreas Gift Foundation



autoimmune.org/about-us
Autoimmune Association



lupusresearch.org
Lupus Research Alliance



creakyjoints.org/lupus-help-center



arthritis-uk.org/about-us

This pamphlet is for general patient education. It does not replace medical advice, diagnosis, or treatment from your doctor or clinic. If you are worried about your symptoms or medicines, please contact your healthcare provider.

We Are Here To Help!

GET IN TOUCH

Email: info@arthritis.org.za

YOU CAN ALSO:

Become a member of the Arthritis Foundation.

Donate or leave a bequest
towards AFSA work/services:

Account Name:

Arthritis Foundation of South Africa

Bank:

Standard Bank

Account Number:

070965226

Branch code:

020909

Swift Code:

SBZAZAJJ

HELPLINE: +27 86130 30 30



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