Managing Lupus

Practical steps to help you live well with lupus

LUPUS FOUNDATION OF AUSTRALASIA

Your diagnosis [1-7]

What is lupus?

Lupus (systemic lupus erythematosus) is an autoimmune condition where the immune system mistakenly attacks healthy tissue, leading to inflammation and organ damage.

It can affect almost any part of the body including the skin, joints, blood, kidneys, lungs, heart, and brain.

How does it affect my life?

Lupus affects everyone differently, but it can impact your work, relationships, and daily activities. There's still a lot you can do to stay involved in the things you enjoy.

Small steps can ease the load and help you build a life that still feels like yours.

Is there a cure?

Lupus has no cure, but with the right treatment and some lifestyle adjustments, most people with lupus can live full, active lives. The key is understanding your condition, following your treatment plan, and knowing when to reach out to your care team.

How is lupus treated?

Lupus can look different in every person, so treatment is tailored to manage your specific symptoms and to protect any organs or tissues that are affected.

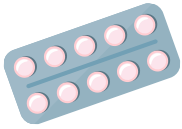
Management focuses on controlling inflammation, protecting organs or tissues that are affected, and improving quality of life.

Who is involved in my care?

Your care is a team effort. Your GP, specialist, nurses and wider healthcare team work together to manage your care and support your overall wellbeing.

A specialist will adjust your treatment as needed and may refer you onto other specialists to treat specific symptoms.

Medication is typically used to reduce inflammation, control flares, and prevent long-term damage.



Lupus treatment and monitoring [4-11]

Your treatment plan

Your specialist will tailor treatment to your symptoms, organ involvement, and response over time.

Common medications used in lupus include:

- **Antimalarial drugs (like hydroxychloroquine)**- reduce flares/symptoms/and organ damage, improve energy levels, increase remission rates, decrease heart attacks/strokes/blood clots, and increases life-span
- **Non-steroidal anti-inflammatory drugs (NSAIDs)-** for pain, pericarditis, and fevers
- **Corticosteroids-** anti-inflammatory medications to control lupus flares
- **Immunosuppressants-** work to calm the immune system
- **Biologics-** targeted therapies that block specific immune pathways

Each medication has different actions and side effects, and you may be prescribed more than one. Medications or doses may also be changed as symptoms improve or flare. Your doctor will work with you to find the right combination.

Monitoring your condition

Regular monitoring by your doctor helps detect changes and prevent flares:

- Blood tests- to assess inflammation, kidney and liver function, immune markers, cholesterol and blood sugar
- Urine tests- to check for early signs of kidney involvement
- Blood pressure checks
- Assessment of skin and joints
- Review of symptoms and medication effects
- Annual eye checks if you're on certain medications

Some symptoms can develop gradually but only manifest at a late stage. That's why attending scheduled appointments with both your GP and specialist is important, even when you're feeling well.

Your GP and specialist will share information about your test results and symptoms, so any changes can be managed promptly.

If any new or worsening symptoms present, discuss these with your doctor. Even minor concerns are still worth raising if they're impacting your life.

Supporting your well-being [2,4,5,12-20]

Sun protection

Ultraviolet light exposure (especially from the sun, but also even from inddor lighting) can trigger lupus flares. This means being sun-smart:

- Wear SPF 70+ sunscreen every day, even when indoors, and even in winter and on cloudy days
- Wear long sleeves, dark colors, tightly-woven fabrics, a wide-brimmed hat, and sunglasses outdoors
- Stay out of direct sun for long periods
- Tell your doctor if light exposure makes you feel poorly

Sleep and rest

Fatigue is one of the most common challenges of living with lupus. Your may feel you need to rest more. Listen to your body and know your limits. Getting enough sleep can help reduce flares and support your immune system.

Practising good sleep hygiene- regular bedtimes, a dark room, and limiting screens (TV, smart phones, computers) before bed- can improve sleep. Pace yourself on high-activity days and don't feel guilty about resting.

Staying active

Regular gentle exercise helps with mood, fatigue, joints, and heart health. There is no hard-and-fast rule- swimming, yoga, pilates, lifting weights, walking the dog, gardening, or kicking a ball around with the kids, all count! The goal is to simply keep moving.

On days when symptoms are flaring, rest and gradually build back up once you're feeling better.

Eating well

Eating well can make a real difference to how you feel, and to your long-term health. Focus on:

- Plenty of vegetables, fruit, fish, and whole grains (a Mediterranean-style diet is a great guide)
- Calcium-rich foods and vitamin D- especially important if you're on steroids, which can affect bone strength
- Avoid highly processed foods, which have been associated with increased autoimmunity
- Eat less salt, which can raise blood pressure
- Limit alcohol, which can interact with some medications

Stress, flares, and warning signs [4, 18-21]

Managing stress

Stress can trigger flares, and living with a chronic illness is stressful in itself- a cycle that can be hard to break.

Strategies that help include:

- Talking to a psychologist or counsellor who focuses on lupus or chronic illness
- Trying to practice mindfulness and relaxation techniques daily
- Journaling
- Going for a walk or having a coffee with a friend or family member
- Opening up to trusted people about what you're going through
- Connecting with a lupus support group– in person or online

If you smoke...

Smoking does make lupus much harder to control and reduces how well your medicines work. It also significantly increases your heart disease, stroke, blood clots, and lung cancer risks.

If you smoke, it's important to seek counselling to cut down or quit smoking.

Your GP can also help with strategies and medication support.

Recognising flares

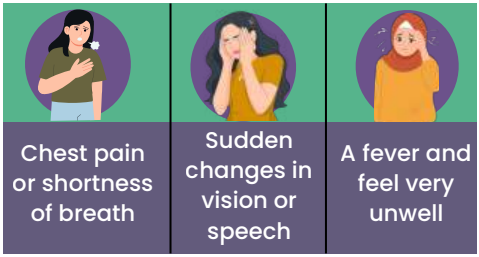
Lupus symptoms can be constant in some or come in waves, with active symptoms (flares) followed by periods where things settle (remission).
Stress, sun exposure, and infections can all trigger a flare.

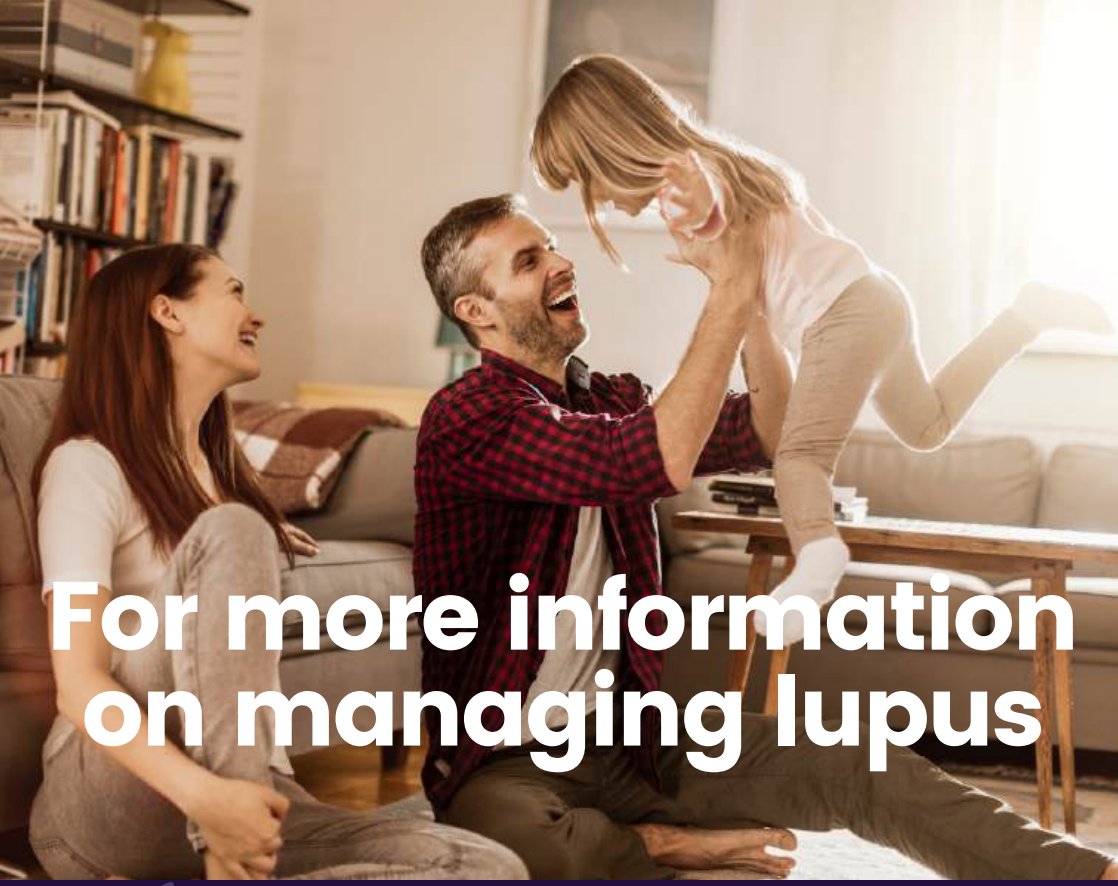
Some people learn when something doesn't feel right, while others find that flares can creep up without notice.

Watch out for these signs:

- Headaches or unusual tiredness that doesn't improve with rest
- New/worsening joint pain or swelling
- A rash, especially across the cheeks and nose
- Swollen ankles or changes in your urine (foamy or dark)

Seek medical attention right away if you experience:





For more information on managing lupus

Please visit The Lupus Foundation of Australasia at:

www.lupusfoundationaustralasia.org/understanding-lupus

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