What is Lupus

A guide on what lupus is, who it affects, and what living with it looks like

LUPUS FOUNDATION OF AUSTRALASIA

Lupus explained [1-6]

What is lupus?

Lupus (systemic lupus erythematosus or SLE) is a chronic autoimmune condition where the immune system, designed to protect you from diseases and infections, mistakenly attacks healthy tissue. This leads to inflammation and organ damage.

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

Who develops it? Is it rare?

Lupus isn't rare, but it can take time to diagnose, especially when symptoms often resemble other conditions and diseases.

Women between 15-45 account for 90% of lupus cases. However, children, men, and the elderly can also develop lupus. While anyone can develop it, some people are more likely to have it than others.

Does lupus affect everyone the same?

The short answer is no- every person experiences lupus differently.

This is because lupus keeps the immune system stays active, even when there's no infection to fight. Ongoing immune activity leads to inflammation in different parts of the body, which is why no two people have the exact same experience.

What are the symptoms and do they subside?

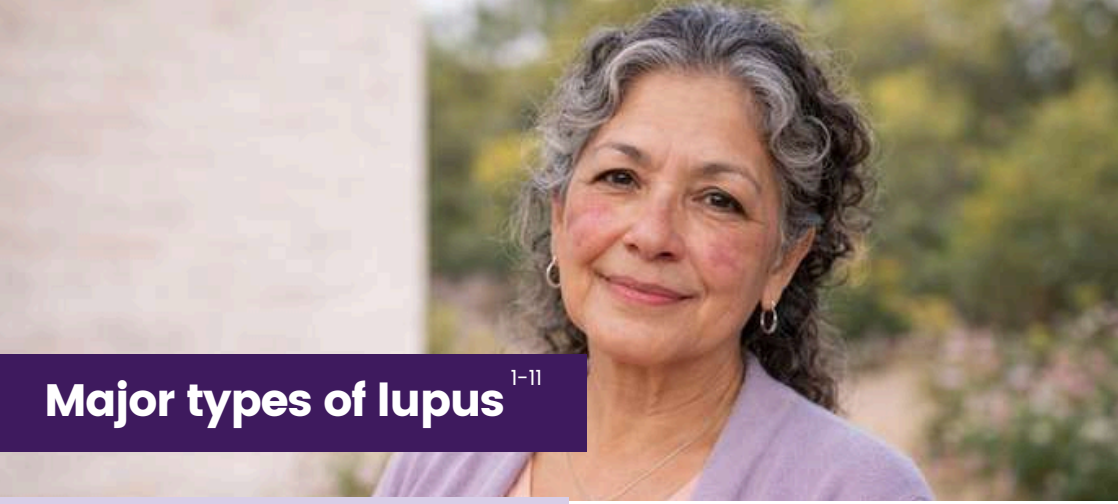
Some people have common symptoms like fatigue, joint pain, fever, or skin rashes, while others experience more serious complications.

Symptoms can come and go in **'flares'** or **'flare-ups'**, which is when symptoms worsen or new ones appear. Between flares, symptoms may ease or disappear completely **(remission)**.

Flares can also be triggered by a number of factors such as UV exposure, infections, and stress.

Fast facts about lupus

- 20,000 people across Australia & New Zealand have lupus
- Often diagnosed in women aged 15–45
- More common in Asian, African, Hispanic & First Nations people
- Affects men, children, and people of any age
- Family history of autoimmune diseases, smoking, stress, & some prescription medications increase risk



Major types of lupus[1-11]

SLE is the most severe form of lupus, affecting body parts other than just the skin (known as cutaneous lupus).

Problems can range from brain fog and anaemia (low red blood cell count) to poor appetite.

Common symptoms include:

- fatigue
- fever
- weight loss
- mouth ulcers
- skin rashes
- joint pain

There are more serious symptoms that indicate inflammation in organs like the kidneys (lupus nephritis) or nervous system. In such cases, you may be referred to a nephrologist (kidney specialist) for further assessment.

Cutaneous lupus erythematosus (CLE)

This is lupus that affects the skin. Rashes often, but not always, develop on sun-exposed areas (face, scalp, chest, or arms), with some forms leading to scarring if left untreated.

It can occur with SLE (often as the first sign of disease), or in isolation. Joints and organs may also be involved.

Major subtypes of CLE include:

- **Discoid lupus erythematosus** is a type of **chronic CLE (CCLE)** characterised by red or dark, scaly, disc-shaped ('discoid') rashes on the scalp and face that can leave discolored areas, scars, and hair loss.
- **Subacute CLE** presents as red or dark-colored, ring-shaped or scaly lesions which are often sun-sensitive and can lead to permanently discolored skin.
- **Lupus profundus or lupus panniculitis** is inflammation in the fat of the skin causing firm, painful lumps that can leave skin indentations after healing.
- **Acute CLE (ACLE)** is a transient, acute rash seen in active SLE, often as a 'butterfly rash' on the face or widespread, red rashes. **Bullous lupus** is a blistering form of ACLE.

ANA-negative SLE

This type of lupus occurs when antinuclear antibody (ANA) is negative. ANA is an immune marker that is usually positive in SLE. Often, other autoantibodies are positive, such as anti-dsDNA and anti-SSA. ANA can also be negative in one lab test method but positive in another.

Lupus and skin [5-12]

Lupus can affect the skin in many ways. Some rashes are caused directly by immune activity, others by the broader impact of the disease.

Rare types of CCLE

These are less common and have different patterns and triggers, compared with discoid or subacute rashes:

- **hypertrophic or verrucous lupus-** thick, wart-like skin growths
- **tumid lupus-** smooth, swollen red patches
- **chilblain lupus-** painful or itchy lumps on fingers, toes, ears & face, brought on by cold weather
- **comedonal or comedogenic lupus** - acne-like cysts and scars on sun-exposed areas, primarily the face
- **lichen planus–like lupus (overlap syndrome)**- flat, purple-red scaly patches that mimic lichen planus leaving colour changes as they heal
- **mucosal lupus-** recurrent red patches or ulcers in lining of mouth or nose

Non-specific cutaneous SLE

Some skin changes seen in lupus can also appear in other conditions.

They may include:

- Changes in the small blood vessels near the nails (nail fold capillaries)
- Raynaud's phenomenon- fingers or toes turning white in the cold
- small blood clots blocking vessels at the fingertips and reducing blood flow
- Widespread hair thinning
- Hives or raised itchy rashes (urticaria) indicating potential inflammation in the blood vessels
- A net-like pattern on the skin (livedo reticularis)
- Skin thickening or bumps caused by deposits under the skin (mucin or calcium)

Understanding lupus [6-13]

Drug-induced lupus

- Caused by certain prescription medications
- Mimics SLE symptoms (e.g. joint pain, fever, rash) but usually resolves once the medication is stopped

Neonatal lupus

- Rare form of lupus affecting newborns whose mothers carry specific autoantibodies (anti-SSA/Ro and anti-SSB/La) which cross the placenta
- May cause temporary skin rashes or liver abnormalities
- In rare cases, can affect the baby's heart rhythm, requiring a pacemaker and monitoring by a cardiologist

Childhood-onset SLE

- Also known as paediatric lupus, it is SLE in children
- More aggressive than in adults with earlier onset of systemic organ damage
- Higher risk of kidney and nervous system involvement, and more frequent flares
- Requires paediatric specialist care due to treatment side effects on growth & development

Sometimes, it's not lupus.

Symptoms that look like lupus can be caused by other conditions such as thyroid problems, anaemia, infections, or other autoimmune diseases like Sjögren's or rheumatoid arthritis.

While overlapping symptoms are common, it can take time to work out whether a symptom is due to lupus itself or something else.

Further tests may be conducted when symptoms change or don't match your usual pattern. Its important to speak to your doctor if you notice any new or changing symptoms.

Understanding the different types of lupus can help you make sense of your symptoms, treatment options, and what to expect over time.

Lupus and reproductive health [16-18]

Lupus can affect sexual and reproductive health, depending on factors like age, gender, disease severity, and treatment.

Women's health

Women with lupus may experience irregular periods or hormonal imbalances, especially during flares or when taking certain medications. Some medications in particular can affect hormone levels and lead to early menopause or fertility problems.

Lupus and male fertility

Low testosterone levels or reduced sperm quality may occur in men with lupus, sometimes as a result of the disease or medications. A fertility specialist can help assess your fertility and reproductive health and discuss next steps before starting certain treatments.

Sexual health and intimacy

Fatigue, joint pain, mood changes, vaginal dryness and skin issues, and erectile dysfunction can all affect intimacy. Communicating openly with your partner, and engaging in counselling, and pelvic physiotherapy are proactive ways to improve intimacy.

Fertility and family planning

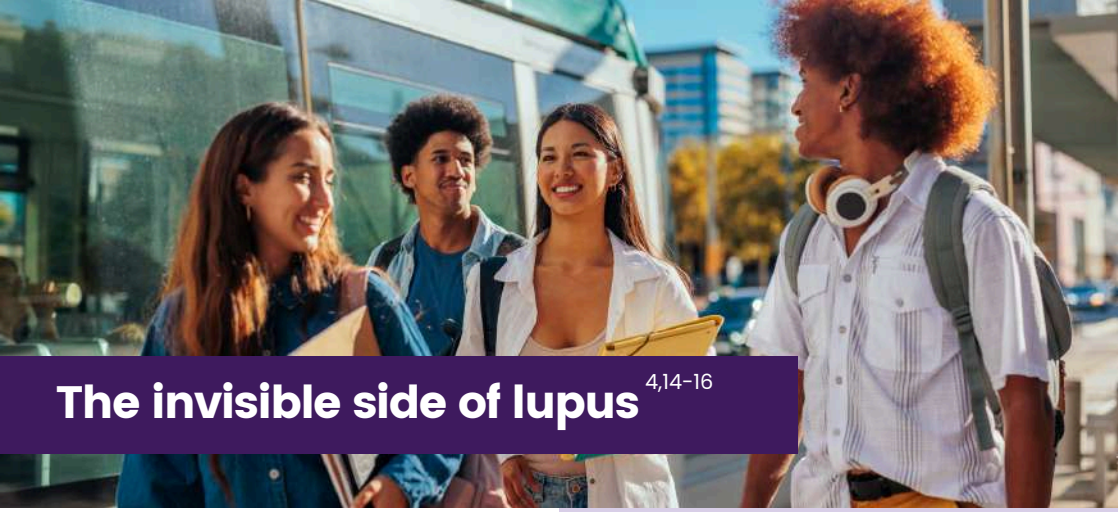
Women with lupus can conceive, but timing and planning are crucial. Planning a pregnancy when symptoms and condition is stable and while under specialist care can minimise risk. Some medications aren't safe to take during pregnancy and may be ceased before trying to conceive.

If pregnancy is not planned, safe and effective contraception is especially important to avoid exposing a developing pregnancy to potential harmful side effects from medications.

Lupus and pregnancy

A healthy pregnancy is possible, though lupus increases the risk of complications, like high blood pressure, blood clots, preterm birth, miscarriage, or neonatal lupus. This risk is increased if you have active disease, kidney involvement, or certain antibodies are present (e.g. antiphospholipid, anti-Ro/SSA).

With regular monitoring, your specialist can help manage your treatment and risk during pregnancy.



The invisible side of lupus [4,14-16]

What are invisible symptoms?

Many people with lupus experience symptoms that are not visible to others, such as fatigue, pain, or difficulty concentrating. These can occur even when tests appear normal or someone looks well on the outside, significantly impacting daily life, work, and relationships.

Because of this, people with lupus may feel misunderstood or dismissed. Feeling unheard can be incredibly distressing, which is why it's important to recognise these symptoms as a real part of lupus and discuss them openly with your healthcare team.

Mental health and wellbeing

Lupus can take a gradual toll on your mental health, impacting how you feel, think, and cope.

Many people with lupus experience anxiety and depression, not just from the disease itself, but as a side effect of medications, or from the ongoing stress of managing a chronic condition.

Stress can worsen symptoms or trigger flares, so it's important to be aware of signs that you may not be coping:

- Feeling constantly overwhelmed or low
- Difficulty sleeping or eating
- Withdrawing from others
- Trouble concentrating or making decisions
- Loss of interest in usual activities

Support is out there

Looking after your day-to-day wellbeing starts with noticing and discussing symptoms:

- Tell your healthcare team how you feel
- Seek support from your GP or a mental health professional if low mood or anxiety persists
- Accept practical support from trusted family and friends
- Engage in gentle exercise or mindful activities like tai chi, yoga, painting, listening to music or walking the dog
- Prioritise sleep and manage daily activity
- Listen to your body and pace yourself, especially during periods of fatigue or emotional strain

Diagnosis, management & care [4,6,17,19-23]

Diagnosing lupus

Your GP may perform a physical examination, initial tests, and refer you to a specialist such as a rheumatologist, for further assessment.

Blood tests often include an ANA test, which looks for immune antibodies linked to lupus. Results are interpreted alongside symptoms and other findings to build a complete picture. A skin biopsy may also be performed to diagnose certain types of CLE.

A specialist confirms the diagnosis and assesses your symptoms, along with disease activity and severity.

Managing lupus

Your GP and specialist will work together to develop a treatment plan, which may include medications, lifestyle modifications, and regular monitoring. This may be adjusted as symptoms improve, flare, or change.

Care is collaborative and supported by nurses and the wider healthcare team.

Healthy ways to manage lupus

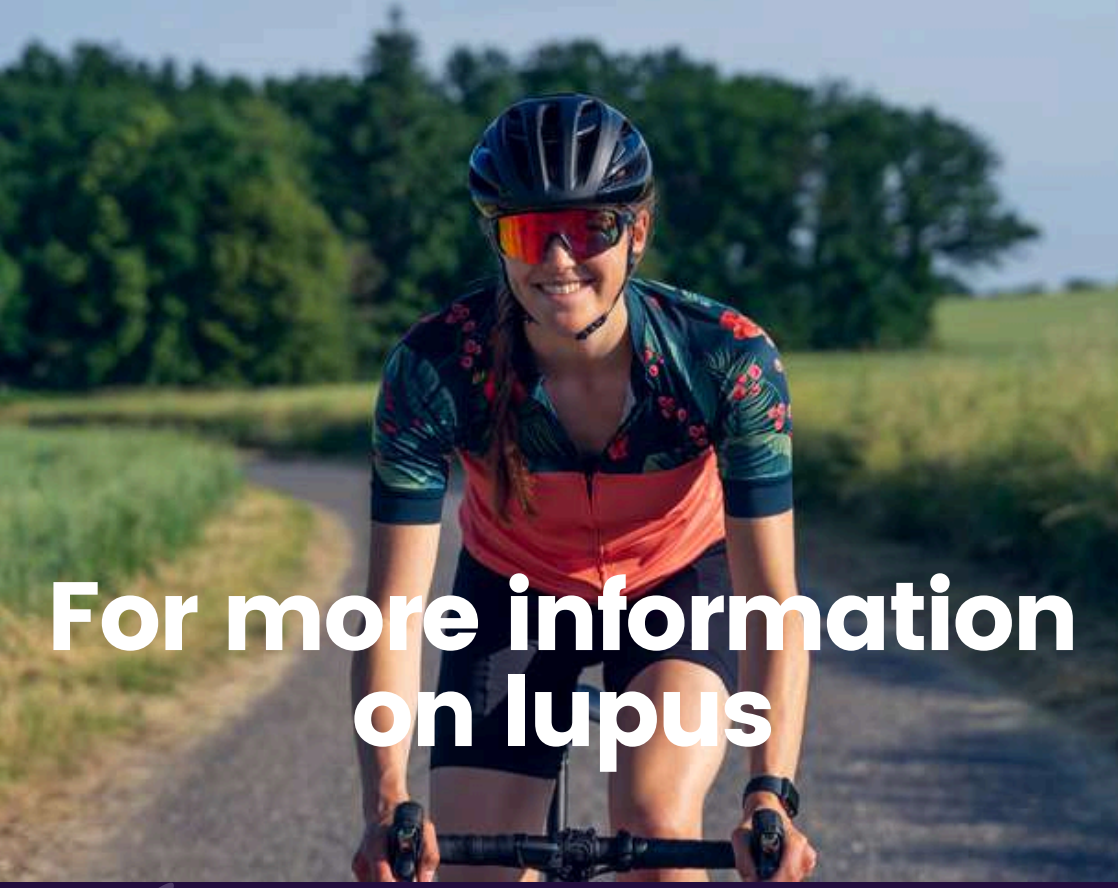
Living well with lupus isn't just about taking medications. It's about adopting everyday habits to support your overall health.

Strategies include:

- Eating a balanced diet rich in seeds, legumes, and green leafy vegetables
- Limiting highly processed, fried or high-sugar foods
- Exercising regularly
- Reducing sun exposure and maximising sun protection
- Managing stress where possible
- Avoiding smoking

It also means staying consistent with:

- Taking your medications as prescribed
- Prioritising your mental health
- Maintaining a healthy body weight
- Visiting your GP regularly



For more information on lupus

Please visit The Lupus Foundation of Australasia at:
www.lupusfoundationaustralasia.org/understanding-lupus

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