Diagnosing Lupus

Your guide to understanding and testing for lupus

LUPUS FOUNDATION OF AUSTRALASIA

How is lupus diagnosed [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.

Is it hard to diagnose?

Lupus can take time to diagnose because symptoms often overlap or mirror other conditions and diseases. They may also come and go, which can inherently delay diagnosis further.

Currently, there is no single test for lupus.

Symptoms doctors look for

You don't need to tick every box to have lupus. Doctors often look for patterns of symptoms, such as:

- Fatigue and joint pain/swelling
- Rashes, skin sensitivity, hair loss
- Fever, headaches, chest pain, swelling in hands, feet and eyes
- Blood problems such as anaemia, clots, or Raynaud's phenomenon (fingers and toes turning different colours when exposed to cold or stress)

What your doctor might ask

Your doctor may collect information on your symptoms such as:

- when they began, how often they occur and what makes them better or worse
- whether they affect your daily life

They may also ask about family history of lupus or autoimmune diseases.

Who diagnoses lupus?

Your GP is your initial point of care. If lupus is suspected, they will usually refer you onto a specialist for further investigation of your condition.

While a GP or specialist can both diagnose lupus, a specialist typically makes the final diagnosis once all tests have been completed.

The role of specialists [5,8-10-16]

What specialist will I see?

Specialists are doctors with advanced training in a specific area of medicine.

Rheumatologists specialise in autoimmune conditions and primarily diagnose and manage lupus. Children and adolescents are seen by a **paediatric rheumatologist** who has completed additional specialist training in rheumatic diseases in young people.

Several other types of specialists may be involved, depending on which organs are affected:

- **Immunologists** manage immune-system disorders, including complex antibody patterns seen in lupus
- **Dermatologists** can perform skin biopsies and diagnose and manage lupus of the skin
- **Nephrologists** are typically involved if lupus causes kidney issues
- **Neurologists** assess lupus symptoms affecting the brain or nervous system

It's common to see more than one specialist if multiple organs are affected.

What to expect from the consultation

Your specialist will consider:

- the information provided by your GP
- your medical history
- current symptoms and medications
- any prior tests or investigations

This helps to build a clear picture of your overall health and what may be causing your symptoms.

Once you've received a diagnosis, your specialist will create a treatment plan, working closely with your GP to arrange ongoing monitoring and care.

Specialist care is guided by your test results, imaging, and the symptoms you report during the consultation.

Report all symptoms to your specialist, not just the ones you think are most important.

The road to diagnosis [11,16-17]

Navigating the diagnostic process can feel overwhelming- we're here to help guide you through it.

Your GP is the best first contact for new or unexpected symptoms, prescriptions, and general health concerns.

Your specialist manages lupus activity, treatment decisions, and any changes to your care plan.

> Don't hesitate to ask your treating doctors any questions - understanding the diagnosis is the first step forward.

Who is responsible for what?

GP

- Orders the first blood and urine tests
- Refers you to a specialist for further assessment
- Helps monitor your blood pressure, blood tests and overall health
- Works with specialist, nurses, and healthcare team to coordinate monitoring and treatment

Specialist

- Orders specialised tests and imaging to confirm lupus
- Interprets results and manages your treatment plan
- Arranges biopsies if required and checks for organ inflammation
- Communicates updates on care, treatment and test results to your GP

Referral and investigations [2, 4, 16-19]

Blood tests

Blood tests are usually the starting point for lupus. They measure signs of inflammation, immune activity, or changes in your blood counts.

Common blood tests include:

- **Complete blood count and platelets -** red blood cells, white cells, and platelets
- **Antibody tests -** checks markers like ANA to see if your immune system is attacking healthy tissue
- **Clotting tests -** show if lupus is affecting your blood's ability to clot
- **Complement levels -** low levels may point to inflammation or active disease
- **Other blood tests**- Kidney function, ESR, and CRP ... markers)

Over 95% of people diagnosed with lupus have positive ANA results.

A specialist can arrange additional tests for other autoantibodies (such as dsDNA and Smith antibodies), and conditions like antiphospholipid syndrome, a condition affecting blood clotting that can occur alongside lupus.

Urine test (urinalysis)

A urine sample can detect blood, protein, or abnormal particles that can indicate inflammation or damage in the kidney's filtering units (glomeruli). Repeat samples can be analysed over time to monitor for changes. In some cases, a 24-hour urine collection may be required to accurately measure protein levels.

Biopsies

Biopsies are samples of tissue taken to analyse for disease. Your specialist uses an ultrasound-guided needle to remove a sample from your skin or kidney. This is sent to the lab to look for inflammation or organ damage under the microscope.

Imaging

- **Ultrasound-** scan kidneys, joints and soft tissue for inflammation
- **X-rays-** assess joints, lungs and heart
- **CT scans-** takes multiple different images of the brain, lungs, or kidneys
- **Echocardiograms-** ultrasounds assessing heart function and structure
- **MRI scans-** more detailed than CT assessing brain and nervous system

Following diagnosis [5,6,17,20,21]

I've just been diagnosed with lupus. What happens now?

Your specialist may commence you on treatment for lupus soon after diagnosis.

Common types of medicines used to manage 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

Medicines or dosages can be changed, if you experience any side effects, or if symptoms flare and then improve. Talk to your doctor about the pros and cons of each medication and what might work best for you.

Is there any support available?

Nurses are central to your care. They carry out tests ordered by your doctor, help explain results and manage your symptoms and medications

Allied health professionals (psychologists, physiotherapists, and social workers) can help with day to day challenges, and support with fatigue, mobility and stress.

Your family and friends also play a big role. Whether it's attending appointments, helping around the house, or simply being there to listen.

Local lupus support groups also offer shared experiences, information, and connection with others who understand your journey.

Helpful resources

Arthritis Australia

Arthritis NZ

Australian Rheumatology Association

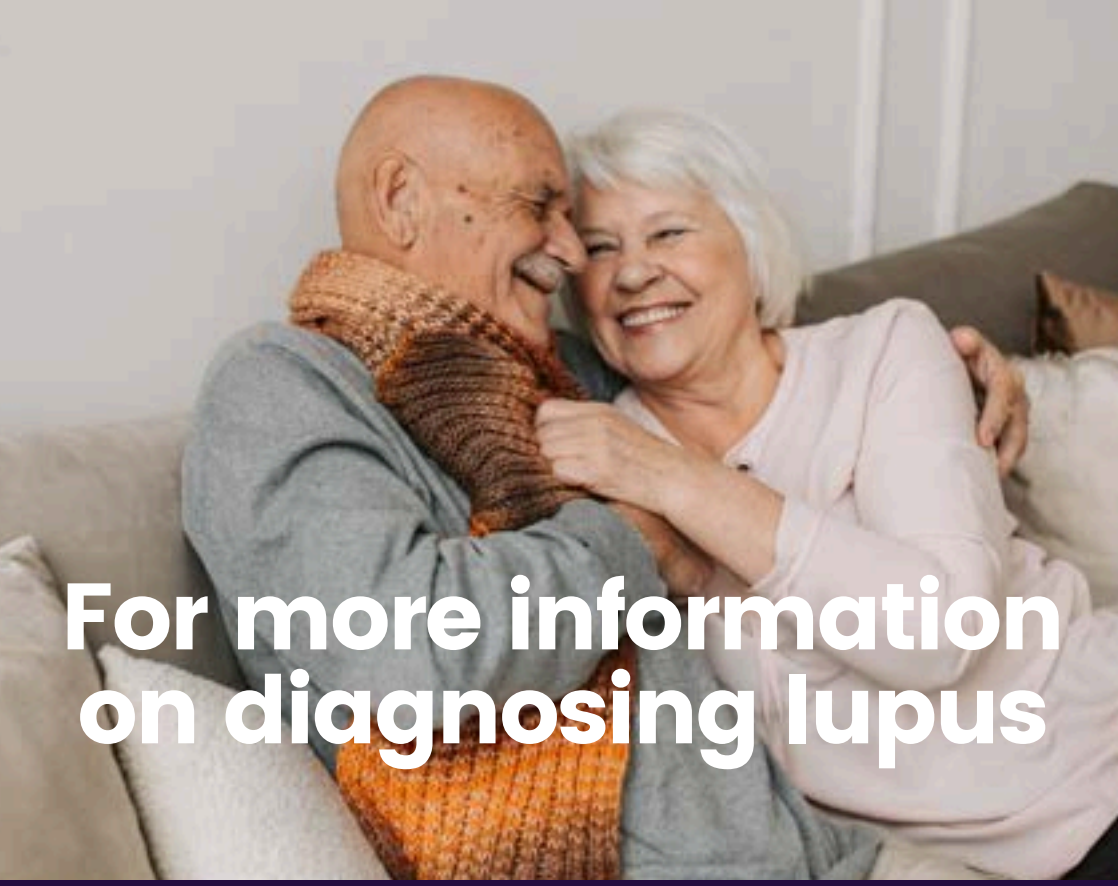
New Zealand Dermatological Society

Lupus Association of NSW

Lupus Victoria

Asia Pacific Lupus Collaboration

Lupus WA



For more information on diagnosing lupus

Please visit the Lupus Foundation of Australasia at:

www.lupusfoundationaustralasia.org/understanding-lupus

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