

# Systemic Lupus Erythematosus (SLE)

## Frequently Asked Questions

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### Q 1: What is lupus (SLE)?

Systemic lupus erythematosus (SLE), also known as lupus, is a disease of the immune system, which is estimated to affect more than 20,000 people in Australia and New Zealand.

Symptoms can be vague and vary between people, and diagnosis can be difficult. However, once diagnosed, a combination of prescribed treatment and lifestyle adjustments enables most people to enjoy a normal life.

The main role of the immune system is to produce antibodies which protect the body against illness caused by bacteria, moulds, and viruses. In an autoimmune disease such as lupus, the immune system produces antibodies that attack the body's own healthy tissue. This causes inflammation, tissue damage and pain. Lupus is caused by a combination of environmental and genetic factors.

### Q 2: Who is affected by lupus?

Around 90% of people with lupus are women, and most develop the condition between the ages of 15 to 45 years. When lupus occurs in children it is usually diagnosed during puberty. Lupus is more common and severe in indigenous Australians, Polynesians and families from Southeast Asia.

### Q 3: Is there more than one type of lupus?

There are two main types of lupus, which differ significantly in the type and severity of symptoms:

- **Systemic lupus erythematosus (SLE)** can affect almost any organ or system of the body. In most people only the skin and joints are affected. In some people SLE can also affect the kidneys, lungs, heart, blood vessels or brain. Symptoms may increase in severity (flare ups) and then improve (remission).
- **Discoid lupus** (also known as chronic cutaneous lupus erythematosus) is generally milder than SLE. Discoid lupus usually appears as a red scaly rash on sun exposed areas such as the face, scalp, arms, legs or trunk. Most people only develop skin symptoms, and others may develop SLE.

Other milder forms of lupus include:

- **Subacute cutaneous lupus** where the main symptoms are skin rashes, sun sensitivity and joint aches.
- **Drug induced lupus** usually develops as a reaction to certain medications and clears up when the medications are ceased.

### Q 4: What are the symptoms of lupus?

Lupus can cause many symptoms including:

- Joint pain or swelling, which is seen in approximately 50% of people with lupus.
- Skin rashes that get worse with sun exposure are seen in approximately 20% of people with lupus.

- Fever.
- Loss of appetite and weight loss.
- Feeling tired and weak affects approximately 10% of people with lupus. This may be severe.

Most people with lupus will not experience all these symptoms, and no two people seem to experience identical symptoms.

Lupus is an unpredictable disease. For some people, symptoms will subside after treatment of the initial acute attack. Others may experience periods of improvement (remission), followed by brief flares of disease symptoms.

### Q 5: What causes lupus symptoms to flare?

Symptom flare ups may be caused by:

- Hormones
- Certain types of medication
- Chemicals
- Viral and bacterial infections
- Exposure to UV light (sun exposure)
- Dietary factors
- Stress
- Pregnancy

### Q 6: How is lupus diagnosed?

Early diagnosis is important. The diagnosis of lupus is usually suspected based on clinical symptoms and signs, and then confirmed by laboratory tests ordered by your GP.

Blood tests will usually include an Anti-Nuclear Antibody (ANA) test, which measures the presence of antibodies that may attack the body's own healthy tissue.

Not all people with SLE have a positive ANA result, and many with a positive ANA result do not have SLE. For example, close relatives of SLE patients may have a positive ANA without developing SLE themselves. You may be referred to a specialist for additional tests to confirm the diagnosis and to monitor the activity of SLE.

### Q 7: What treatments for lupus are available?

The aim of lupus treatments is to reduce inflammation in tissues and to improve quality of life. Treatments will be different for each person and will depend on the severity of their disease.

There are five main groups of drugs that are used:

- **Non-steroidal anti-inflammatory drugs** (NSAIDs) such as aspirin, ibuprofen, naproxen and COX-2 inhibitors reduce inflammation and can relieve the fevers, muscle aches, and arthritis that accompany lupus. They do not alter the course of the disease, or the underlying immune process.
- **Anti-malaria drugs** (such as hydroxychloroquine and chloroquine) are often used to reduce joint pains, skin rashes and fatigue.
- **Corticosteroids** (such as prednisolone) are very effective anti-inflammatory medications and are the drugs of choice for treating serious complications of lupus, such as those affecting the heart, lungs and nervous system.

- **Immune suppressing drugs** (such as methotrexate) suppress the immune system and are generally used when serious disease is present, and steroids alone are not enough to control the disease.
- **Cytotoxic drugs** (such as cyclophosphamide) are potent immunosuppressive agents that are used to treat serious manifestations of SLE, especially kidney inflammation (glomerulonephritis).

### Q 8: How can lupus be managed during pregnancy?

It is important to talk to your doctor before planning to get pregnant to discuss any potential risk for you and your baby. Planning pregnancy while lupus symptoms are in remission reduces the risk of a disease flare occurring during pregnancy.

Lupus flares occurring during pregnancy are usually mild and occur in the first three months (first trimester). In the first few weeks after birth new mothers may experience lupus flares but this can be controlled with corticosteroids.

It is important to discuss therapy options with your doctor to ensure that any current medication taken will not affect the pregnancy. Although lupus does not usually lower fertility, some women with lupus are at increased risk of blood clots and recurrent miscarriages.

### Q 9: How can I manage my symptoms and improve my quality of life?

There is currently no cure for lupus, but there are effective medications that will bring the disease under control, often permanently. The outlook for most people with lupus is good.

Early detection, effective treatment and some lifestyle adjustments mean most people with lupus feel well and enjoy good quality of life.

Lifestyle adjustments that can reduce lupus symptoms include:

- Resting before allowing yourself to become fatigued. This may mean restructuring your schedule and avoiding stressful situations.
- Starting a program of regular moderate exercise (without becoming fatigued) as this will improve well-being and prevent muscle wasting.
- Avoiding excessive exposure to the sun by wearing broad brimmed hat, long sleeves and long trousers. Always use maximum strength sun block that protects against UVA and UVB rays.
- Avoiding contact with people who have known infections.
- Finding out as much about lupus as you can to help gain control and remove fear.
- Visiting your doctor regularly (particularly if you feel that your symptoms are worsening) and keep a list of your symptoms and questions you might have for your doctor.
- Always taking your medications as you have been instructed and keep a record of your medications.
- Not smoking.
- Drinking alcohol in moderation (up to two standard drinks daily).

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