

Systemic Lupus Erythematosus (SLE)

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 from person to person, and consequently diagnosis can be difficult. However, once diagnosed, a combination of prescribed treatment and lifestyle adjustments enables most people with lupus to enjoy an almost normal life.

What is lupus?

The main role of the immune system is to fight foreign invaders such as bacteria, moulds and viruses. In autoimmune diseases the immune system produces antibodies that attack the body's own healthy tissue. Lupus is an autoimmune disease, and the antibodies produced by the immune system in lupus cause inflammation, tissue damage and pain.

Who is affected by lupus?

Around 9 in 10 people with lupus are women and the majority develop the condition between 15 and 45 years. When lupus occurs in children it is usually diagnosed during puberty.

There are two main types of lupus

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

- **Systemic lupus erythematosus** (also known as SLE) is characterised by flare ups and periods of improvement (remissions), and can affect almost any organ or system of the body. In most people only the skin and joints are affected. However, in some people SLE can also affect the kidneys, lungs, heart, blood vessels or brain.
- **Discoid lupus** (also known as chronic cutaneous lupus erythematosus) is generally milder than SLE and usually appears as a red scaly rash on sun exposed areas such as the face, scalp, arms, legs or trunk. Most people with discoid lupus have symptoms only on their skin. However, a small number of people with discoid lupus will develop SLE.

Other milder forms of lupus include:

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

The cause of lupus is unknown

A combination of genetic and environmental factors contribute to the formation of the antibodies that lead to lupus. Possible triggers of disease flare ups include:

- Hormones
- Certain medications and chemicals
- Viral and bacterial infections
- Exposure to UV light
- Dietary factors
- Stress
- Pregnancy

Lupus symptoms may be vague, variable and unpredictable

Lupus can cause many symptoms, including:

- Joint pain or swelling - seen in ~50% of people with lupus
- Skin rashes that get worse with sun exposure - seen in ~20% of people with lupus
- Fever
- Loss of appetite and weight loss
- Fatigue, weakness and lethargy - these affect ~10% of people with lupus and may be severe

Most people with lupus won't experience all of these symptoms and no two individuals seem to experience identical symptoms.

The course of lupus is usually unpredictable

For some people with lupus, symptoms will subside after treatment of the initial acute attack. For others, periods of improvement (remission) are punctuated by brief flares of disease.

Early diagnosis is important

The diagnosis of lupus is usually suspected on the basis of clinical symptoms and signs and confirmed by laboratory tests.

Blood tests will usually include an Anti-Nuclear Antibody (ANA) test, which measures antibodies to self-tissues. Whilst this is a good screening test, not all people with SLE have a positive ANA result and many people with a positive ANA do not have SLE. For example, close relatives of SLE patients may have a positive ANA without developing SLE themselves. Additional blood tests are therefore necessary to confirm the diagnosis and to monitor the activity of SLE.

Effective treatments are available for lupus

The aim of lupus treatments is to reduce inflammation in tissues and improve quality of life. Treatments must be individualised, taking into account the severity of the disease.

There are five main groups of drugs that are used to treat lupus:

- **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, but 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).

Diagnosis, treatment and lifestyle changes are important

The outlook for most people with lupus is good. Early detection, effective treatment and some lifestyle adjustments enable most people with lupus to feel well and live normal lives. It is only a small minority of people who find that lupus substantially reduces their quality of life.

Lupus and pregnancy

Women with lupus should talk to their doctor before considering pregnancy. They should be made aware of any potential risk for themselves and the baby. It is preferable for lupus to be in remission, as this 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 (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 adversely affect the pregnancy. Women should have no difficulty becoming pregnant as lupus does not usually lower fertility. However, a small proportion of women with lupus are at increased risk of blood clots and recurrent miscarriages.

Some tips to help people with lupus to lead normal lives

- Take rests before allowing yourself to become fatigued, which may mean restructuring your schedule and avoiding stressful situations
- Commence a program of regular moderate exercise (without becoming fatigued) as this should improve well being and prevent muscle wasting
- Sun exposure can trigger flare ups so avoid excessive exposure to the sun by wearing a broad brimmed hat, long sleeves and long trousers, and always use maximum strength sun block that protects against UVA and UVB rays
- Avoid contact with people who have known infections
- Find out as much about lupus as you can to help gain control and remove fear
- Visit your doctor regularly (particularly if you feel that your symptoms are worsening) and keep a list of your symptoms and any questions you might have for your doctor
- Always take your medications as you have been instructed and keep a record of your medications
- Do not smoke (for your health and well being)
- Drink alcohol only in moderation (up to two standard drinks daily)

There are currently no cures for lupus, but there are effective medications that will bring the disease under control, and often permanently. As you grow older, it is likely that the disease will improve.

There are a number of organisations which provide support and information to people with lupus and their families, as well as promoting understanding and awareness of the condition in the community. These organisations are listed on the ASCIA website www.allergy.org.au/patients/patient-support-organisations

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