SYSTEMIC LUPUS ERYTHEMATOSUS (SLE)
ASCIA Education Resources patient information

Lupus is a disease of the immune system, which affects more than 17000 Australians. 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?
Lupus is an “auto-immune” disease, in which the immune system produces antibodies that attack the body’s healthy tissue. These antibodies cause inflammation, tissue damage and pain.

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

- **Discoid** lupus (also known as “cutaneous lupus”) is generally a milder disease than SLE and usually appears as a red scaly rash on sun-exposed areas such as the face, scalp, arms, and legs.
- **Systemic** Lupus Erythematosus (SLE) – This type can affect the skin as well. In addition, SLE can manifest as inflammation in joints, kidneys, lungs, heart, blood vessels and brain.

The cause of Lupus is unknown
An interplay of genetic and environmental factors contribute to the formation of the antibodies that lead to SLE. SLE is characterised by flare-ups and remissions. Some of the possible triggers of disease flare-ups include hormones, certain medications and chemicals, viral and bacterial infections, exposure to UV light, dietary factors, stress and pregnancy.

Lupus is most common in young women
Around 90% of lupus patients are women. Most develop the condition between 15 and 45 years. When lupus occurs in children, it is usually diagnosed during puberty.

Symptoms may be vague, variable and unpredictable
Lupus can cause many symptoms, including joint pain or swelling (seen in 50% of patients), skin rashes that get worse with sun exposure (20% of patients), fever, loss of appetite and weight loss. Fatigue, weakness and lethargy affects 10% of patients and may be severe. Most patients will never experience all the symptoms and no two patients seem to experience identical symptoms. A subset of patients with lupus are at increased risk of blood clots and recurrent pregnancy loss.

The course of lupus is usually unpredictable
For some people, 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 systemic lupus have a positive ANA 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 necessary to confirm the diagnosis and to monitor the activity of SLE.

**Effective treatment is available for lupus**
The aims of treatment are to reduce inflammation in tissues and to improve quality of life. Treatment must be individualised, taking account of the severity of the disease.

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

- **Non-steroidal anti-infliammatory drugs** (NSAIDs) such as Aspirin, ibuprofen, naproxen, Celebrex and Vioxx. NSAIDS reduce inflammation. They can relieve the fevers, muscle aches, and arthritis that accompany lupus. They do not, however, alter the course of the disease or the underlying immune process.
- **Anti-malaria drugs** such as hydroxychloroquine. Anti-malaria drugs are often used to reduce joint pains, skin rashes and fatigue.
- **Corticosteroids** such as Prednisolone. Corticosteroids are very effective anti-inflammatory medications. They 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 azathioprine, methotrexate, cyclosporin A, tacrolimus. These 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** like cyclophosphamide. 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 patients to feel well and live normal lives. It is only a small minority of patients who find the condition substantially reduces their quality of life.

**Lupus and pregnancy**
Patients 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. Discuss therapy 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, but a small proportion of women will suffer recurrent miscarriage.
Some tips to help people with lupus to lead normal lives
The following tips may assist people with Lupus to lead normal lives:

- Take rests before allowing yourself to become fatigued - this may mean re-structuring your schedule and avoiding stressful situations.
- Commence a program of regular moderate exercise (without becoming fatigued) - this will improve well-being and prevent muscle wasting.
- Sun exposure can trigger flare ups – avoid excessive exposure to the sun by wearing a broad brimmed hat, long sleeves and long trousers and always use maximum strength sunblock that protects against UVA and UVB rays.
- Avoid contact with people who have known infection.
- 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.
- Drink alcohol in moderation only (around two standard drinks daily).
- Make contact with a local support group – you are not alone!

There are currently no ‘cures’ for lupus, but there are effective medications that will bring the disease under control – often permanently. As you grow older, it is likely that the disease will improve. There are a number of Lupus Associations and Support Groups in Australia, which provide support and information to patients and their families, as well as promoting understanding and awareness of the condition in the community. These groups also organise funding for further research into lupus and its management.

Lupus Association of NSW
Ph: (02) 9878 6055

Lupus Group of Western Australia
Ph: (08) 9224 3144

Victorian Lupus Association
Ph: (03) 9650 5348

Lupus Australia, Queensland
Ph: (07) 3878 9553

Lupus Association of Tasmania
Ph: (03) 6330 1313

Lupus/Scleroderma Group
Arthritis Foundation of South Australia
Ph: (08) 8379 5711

Your hospital may also have a Lupus support group. An example is the Scleroderma/Lupus Resource & Support Centre, Royal Newcastle Hospital, NSW.
Ph: (02) 4923 6146

References

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The Australasian Society of Clinical Immunology and Allergy (ASCIA) is the peak professional body of Clinical Allergists and Immunologists in Australia and New Zealand.

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