

Systemic lupus erythematosus (SLE or lupus)

This sheet has been written for people affected by lupus. It provides general information to help you understand how you may be affected and what you can do to manage it. It also tells you where to find further information and advice.

What is lupus?

Systemic lupus erythematosus (also called SLE or lupus) is an autoimmune condition. The normal role of your body's immune system is to fight off infections and diseases to keep you healthy. In an autoimmune disease like lupus, your immune system starts attacking your own healthy tissues. For some people lupus may just affect the skin and/or joints. In other people the lungs, kidneys, blood vessels, brain or other parts of the body may also be affected.

What are the symptoms?

The symptoms of lupus vary from person to person. Symptoms may come and go at different times. Although many parts of the body can be affected, most people usually have involvement of only a few parts. The most common symptoms are:

- joint pain and/or swelling, especially in the hands or feet
- skin rashes, made worse by being in the sun
- sores in the mouth or nose
- anaemia (low number of red blood cells).

What causes it?

It is not known what causes lupus. It is believed to be the result of a combination of factors, including genetics, viruses, sunlight, stress and hormones acting together. This is yet to be proven in research.

How is it diagnosed?

If you have symptoms of lupus you should see your doctor. Your doctor will diagnose lupus on the basis of your symptoms, a clinical examination and various tests. These can include blood and urine tests, as well as tests to check organs such as your heart and lungs. There is

no one single test that can tell whether you have lupus. It can be difficult, and often takes time, to diagnose lupus as the symptoms can be similar to other types of arthritis.

What will happen to me?

With close follow-up and the right treatment, most people with lupus can expect to live a full and active life. However it can cause serious and even life-threatening problems in some cases. Many people with lupus have 'flares', periods when their symptoms get worse. 'Flares' can happen with no obvious cause. There is no way of knowing their severity or how long they will last. They can occur more commonly during times of stress, or may be triggered by sun exposure, infections, and pregnancy. People with more severe forms of lupus can have serious problems with organs such as the kidneys, lungs and heart. If these organs are affected, you may need to see other specialists (for example, a kidney specialist if your kidneys are affected).

Is there a cure for lupus?

Currently there is no cure for lupus. However treatment for lupus has improved dramatically, with new medicines that are extremely helpful in controlling the condition. Be wary of any products or therapies that claim to cure lupus.

What treatments are there for lupus?

Your doctor will tailor your treatment to your symptoms and the severity of your condition. There is no way of predicting exactly which treatment will work best for you. Your doctor may need to trial several different treatments before finding the one that is right for you and may include medicines, such as:

- corticosteroids, when the kidneys or other organs are involved
- non-steroidal anti-inflammatory drugs (NSAIDs)
- disease-modifying anti-rheumatic drugs (DMARDs).

For more information see the Australian Rheumatology Association's Patient Medicine Information or the *Medicines and arthritis* information sheet.

What can I do?

See your doctor for treatment and advice. Your doctor will help coordinate your treatment. As lupus is a life-long disease, it is important to see your doctor regularly to make sure it stays under control. Your doctor may also send you to a rheumatologist, an arthritis specialist, for further tests and treatment. If you have lupus and have not seen a rheumatologist, ask your doctor about a referral. See the *Working with your healthcare team* information sheet.

Learn about lupus and play an active role in your treatment. Not all information you read or hear about is trustworthy so always talk to your doctor or healthcare team about treatments you are thinking about trying.

Reliable sources of further information are also listed in the section below. Self management courses aim to help you develop skills to be actively involved in your healthcare. Contact your local Arthritis Office for details of these courses.

Protect yourself from the sun. If your skin is sensitive to the sun, make sure you avoid the sun during peak hours, and wear sunscreen, a hat and protective clothing.

Live a healthy life. Stay physically active, eat a healthy diet, stop smoking and reduce stress to help your overall health and wellbeing. See the *Healthy eating* and *Physical activity* information sheets.

Acknowledge your feelings and seek support. As there is currently no cure for lupus and it can affect many parts of your life, it is natural to feel scared, frustrated, sad and sometimes angry. Be aware of these feelings and get help if they start affecting your daily life. See the *Arthritis and emotions* information sheet.

CONTACT YOUR LOCAL ARTHRITIS OFFICE FOR MORE INFORMATION SHEETS ON ARTHRITIS.

Learn about lupus and your treatment options.

Lupus is a complex condition but can be well controlled.

For more information:

Books Wallace, Daniel J 2005, *The lupus book: A guide for patients and their families*, Oxford University Press, Melbourne.

Holden, Triona & Hughes, Graham 2004, *Talking about lupus: What to do and how to cope*, Piatkus, London.

Lahita, Robert G & Phillips, Robert H 2004, *Lupus Q&A*, Avery, New York.

Websites Australian Rheumatology Association - information about medicines and seeing a rheumatologist www.rheumatology.org.au

Arthritis Research UK www.arthritisresearchuk.org

American College of Rheumatology www.rheumatology.org

Arthritis Foundation (US) www.arthritis.org