Lupus

Summary

- Lupus is a chronic condition that results from a malfunctioning immune system.
- There are different types of lupus. The most common type is systemic lupus erythematosus (SLE).
- Symptoms can vary and may include: skin rashes, joint and muscle pain and fatigue.
- There is no cure, but lupus and its symptoms can be managed with medication and lifestyle changes.

Systemic lupus erythematosus (SLE), otherwise known as lupus, is a chronic condition that results from a malfunctioning immune system. The immune system is designed to identify foreign bodies (such as bacteria and viruses) and attack them to keep us healthy. However in the case of lupus, your immune system mistakenly attacks healthy tissue, causing inflammation in parts of the body such as the skin, joints, kidneys, heart and lungs.

Types of lupus

There are different types of lupus. The most common type is systemic lupus erythematosus (SLE).

Other types of lupus are:

- discoid lupus erythematosus (DLE) – a chronic skin condition that appears as reddened and round scaly patches that tend to develop in sun-exposed areas such as the face and hands. Sometimes lesions can develop across other areas of the body, including the neck and upper back. There is no cure, but the skin lesions can be managed with medication and by avoiding exposure to sunlight
- drug-induced lupus – some medications can provoke SLE-like symptoms, which then disappear once the medications are stopped. Medications that are known to cause lupus-like symptoms include certain medications used to treat high blood pressure and medications for heart abnormalities
- neonatal lupus – this is a rare form of temporary lupus that affects a foetus or newborn baby. It occurs when the autoantibodies of a mother with SLE are passed to her child before birth. These autoantibodies can affect the skin, heart and blood of the baby.

This fact sheet will focus specifically on systemic lupus erythematosus (SLE or lupus).

Systemic lupus erythematosus (SLE or lupus)

Systemic lupus erythematosus is a systemic condition, which means that it can affect the entire body. Lupus can affect the skin, joints, kidneys, brain, and other organs.

Lupus can range from mild to life-threatening. This very much depends on the parts of the body that are being attacked by the immune system.

The most common forms of lupus are milder forms, and most people enjoy a full life, even though they may need to take medications. Lupus is only life threatening in rare cases.

Women in their child-bearing years are most likely to develop lupus. However lupus can affect men, children and older people.

Certain ethnic groups are also more likely to develop lupus, such as those of Afro-Caribbean and Asian ancestry.

Symptoms of lupus

The symptoms of lupus can vary and may include:

- skin rashes (both on the face and body)
- joint and muscle pain
- hair loss
- fatigue
- fever
- headaches or migraines
- confusion and memory problems
- anxiety and depression
- mouth and nose ulcers
- blood and blood vessel problems, such as high blood pressure, anaemia and increased risk of blood clots
- chest pain or breathlessness (as a result of inflammation of the lining of the heart or lungs)
- poor kidney function
- seizures or visual disturbances (a rare symptom resulting from inflammation of the nervous system)
- abdomen pain (a less frequent symptom caused by inflammation of the gut, pancreas, liver or spleen).

It's unlikely that one person will experience all of these symptoms. At times the symptoms you experience as a result of your lupus (such as rash, pain, fatigue) will become more intense. This is called a flare. Flares are unpredictable and can seem to come out of nowhere. They're often triggered by stress and exposure to ultraviolet (UV) light.

**What causes lupus?**

We don't know what causes lupus. However, it appears that genes may play a role, as well as environmental triggers such as an illness or a period of stress.

**How is lupus diagnosed?**

Lupus is a difficult condition to diagnose. There is no single medical test that will diagnose lupus. Symptoms can vary greatly from one person to another and are often similar to those of other conditions. It may take months or years to get a definitive diagnosis of lupus.

Your doctor will diagnose your condition using a combination of exams and tests including:

- discussing your symptoms and medical history with you
- physical examination – including your joints and skin to look for any signs of change, inflammation and rashes
- blood tests that highlight the presence of inflammation or particular antibodies
- urine testing – this is a dipstick test for blood and protein
- chest x-ray and electrocardiogram or echocardiogram – to see how well your heart is working
- a biopsy of tissue to determine the presence of lupus – depending on what organs are affected.

Test results also help rule out other conditions that may have similar symptoms.

Early diagnosis and treatment is important for the best possible health outcomes.

**How is lupus treated?**

There is no cure for lupus, however there are different medications that can help to control it very effectively. If your condition is controlled early, the likelihood of later complications may be reduced.

There are also many strategies you can use to manage your condition, including physical activity and other lifestyle changes.

**Medication for lupus**

Medication can help manage your symptoms and assist in controlling your overactive immune system. Because people with lupus experience different symptoms, and to varying degrees, there is no ‘one size fits all’ treatment. You might need to take a combination of different medications that could include:

- pain-relieving medication (analgesics) – medications such as paracetamol can provide temporary pain relief
- non-steroidal anti-inflammatory drugs (NSAIDs) – such as naproxen and ibuprofen. Short-term use of NSAIDs can help control inflammation and provide temporary pain relief. Do not use NSAIDs if you have kidney

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- corticosteroids (such as prednisolone) – these are used to quickly control or reduce inflammation. Corticosteroids are generally used to treat more serious cases of lupus or to control inflammation if you are going through a flare. They do have side effects if used for long periods, so your doctor will closely monitor you while you’re taking them

- hydroxychloroquine medications – these are referred to as ‘anti-malarials’ because they were originally used to treat malaria. We now know that they’re very effective at controlling immune system activity in chronic conditions such as lupus. Hydroxychloroquine is effective in treating skin and joint problems associated with lupus. People who take hydroxychloroquine are less likely to have flares, so many people with lupus will take these medications long term

- disease modifying anti-rheumatic drugs (DMARDs) – this group of medications works on controlling your overactive immune system. They help relieve pain and inflammation, and can also reduce or prevent joint damage

- immunosuppressants – in moderate to severe cases these medications (including azathioprine, mycophenolate mofetil, cyclosporine, leflunomide, methotrexate, and cyclophosphamide) may be used to suppress your overactive immune system. These medications can present particular side effects, so your specialist will closely monitor the effects they have on you.

All medications can have side effects. It’s important you discuss these with your doctor, and know what to do if you experience any. It’s also important that you discuss any other medications or complementary therapies you are taking, as they can potentially affect your lupus medications.

Self-management of lupus

Other things you can do to manage lupus include:

- learn about your condition – you need to understand your condition in order to manage it well. The more you know about your condition (for example what triggers flares, and how to manage pain and fatigue) the more control you will have. Understanding your condition means you’ll be able to make informed decisions about your healthcare and play an active role in its management

- manage your exposure to ultraviolet (UV) light – UV light, especially sunlight, can cause a flare. This can include skin rashes in sun-exposed areas. Remember to wear 50+ UVA and B sunscreen every day (even if it's cloudy). Cover your skin and wear a hat and sunglasses when outdoors. Less commonly, UV light from fluorescent lights, including low energy light bulbs, may induce rashes in some people with lupus

- exercise – regular physical activity has general health benefits. It can also help you manage the symptoms of your condition. Regular exercise can help improve the quality of your sleep, as well as increasing your energy levels, reducing fatigue, and improving your overall strength and fitness. Exercise can also help prevent long-term consequences of lupus such as heart disease and osteoporosis

- learn ways to manage pain – there are many things you can do to manage pain, and different strategies will work for different situations. For example, heat packs can help ease muscle pain, cold packs can help with inflammation, and gentle exercise can help relieve muscle tension. Try different techniques until you find what works best for you

- manage your stress – stress can aggravate your lupus symptoms. Things you can do to manage stress include planning your day and setting priorities, using relaxation techniques such as going for a walk or listening to music, and avoiding people and situations that cause you stress

- don’t smoke – smoking cigarettes can worsen your lupus symptoms and reduce the effectiveness of some lupus medications

- ask your GP about your vitamin D, calcium and cholesterol levels – get your levels checked to see if you need supplements or medications or regular monitoring

- balance rest and activity – plan your activities to make the most of your energy by alternating periods of activity with rest. Break large jobs down into small achievable tasks so that you don’t overdo things

- eat well – eating a balanced diet can help provide you with better energy levels, help to maintain your weight, and give you a greater sense of wellbeing

- stay at work – it’s good for your health and wellbeing. Talk to your doctor or allied healthcare professional about ways to help you to get back to work or stay at work.
Support for people with lupus

It’s natural to feel overwhelmed when you’re diagnosed with lupus, as there is currently no cure and it can affect many parts of your life. You may feel scared, frustrated, sad or angry.

It’s important to acknowledge these feelings and get help if they start affecting your daily life. Your doctor, specialist or other health professional will be able to provide you with information about available support.

You might also find it helpful to contact a Lupus Peer Support Group and speak to other people who also have lupus and know what you’re going through. Contact Musculoskeletal Australia for information and contact details.

Where to get help

- Your GP (doctor)
- Specialist (such as a rheumatologist, dermatologist, nephrologist or immunologist)
- Musculoskeletal Australia National Help Line Tel. (03) 8531 8000 or 1800 263 265
- Arthritis Australia Tel. 1800 011 041

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