



Lupus

- Lupus is a chronic condition that results from a malfunctioning immune system
- There are different types of lupus; the most common is systemic lupus erythematosus (SLE)
- Symptoms include skin rashes, joint and muscle pain and fatigue
- While there's no cure, lupus can be managed with medication and lifestyle changes

Systemic lupus erythematosus is an autoimmune condition that results from a malfunctioning immune system.

Your immune system is designed to identify foreign bodies (e.g. bacteria, viruses) and attack them to keep you 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.

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

Causes

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

Symptoms

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/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 and/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 (e.g. 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 light.

Diagnosis

Lupus is a difficult condition to diagnose. There's 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 diagnosis your condition using a combination of exams and tests including:

- discussing your symptoms and medical history with you
- a 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 – dipstick test for blood and protein
- chest x-ray and electrocardiogram/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 outcome.

Treatment

While there's currently no cure for lupus, 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

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's no 'one size fits all' treatment.

You might need to take a combination of different medications that could include:

- pain relievers (or analgesics) – can provide temporary pain relief.
- non-steroidal anti-inflammatory drugs (NSAIDs) – short-term use helps control inflammation and provide temporary pain relief. NSAIDS should be avoided by people with kidney disease.

- corticosteroids – are used to quickly control or reduce inflammation. They're generally used to treat more serious cases of the disease 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.
- anti-malarials - originally used to treat malaria, these medications have been found to be very effective at controlling immune system activity in conditions like lupus. People who take anti-malarials 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 work 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 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 side effects.

It's also important that you discuss any other medications, or complementary therapies you're taking - they can potentially affect your lupus medications.

Self-management

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 (e.g. what triggers flares, how to manage pain and fatigue) the more control you'll 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). You should also cover your skin and wear a hat and sunglasses when outdoors. Less commonly, UV light from fluorescent lights, including low energy light bulbs, may cause rashes in some people with lupus.

Exercise – regular physical activity has many health benefits, including helping you to manage your symptoms (e.g. pain, joint stiffness). When you start exercising regularly you should notice an improvement in the quality of your sleep, increase in energy levels, a reduction in fatigue, and improvements in 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 the things that work 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 particular lupus medications.

Ask your GP about your vitamin D, calcium and cholesterol levels – get your levels checked to see if you need supplements/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 or stay at work.

Support for people with lupus

It's natural to feel overwhelmed when you're diagnosed with lupus, as there's 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 support group and speak to other people who also have lupus and know what you're going through.

Where to get help

- Your doctor
- Your specialist/s (often a dermatologist, rheumatologist, nephrologist, immunologist)
- Musculoskeletal Australia
www.msk.org.au
MSK Help Line: 1800 263 265

How we can help

Call our MSK Help Line and speak to our nurses. Phone 1800 263 265 or email helpline@msk.org.au.

We can help you find out more about:

- lupus and musculoskeletal conditions
- ways to live well with these conditions
- managing your pain
- upcoming webinars, seminars and other events.

More to explore

- Versus Arthritis <https://www.versusarthritis.org>
- Lupus Foundation of America www.lupus.org
- Lupus UK www.lupusuk.org.uk
- Better Health Channel
www.betterhealth.vic.gov.au

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