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**

Call our National Help Line on 1800 263 265

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 - including the skin, joints, kidneys and lining of the heart and lungs - causing ongoing inflammation and pain.

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.

While pain and inflammation of the skin and joints can impact on your quality of life, the damage that lupus may cause to your major organs, such as the kidneys or nervous system, is much more serious.

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 African-American women and Asians.

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
- mouth and nose ulcers
- chest pain (as a result of inflammation of the lining of the heart or lungs)
- anaemia (a lack of healthy red blood cells)
- poor kidney function
- seizures or visual disturbances (resulting from inflammation of the nervous system)
- fever.

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.

Cause

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

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.

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

Early diagnosis is important (as soon as possible after the appearance of symptoms), because internal organs such as the kidneys can be affected.

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 killers (or analgesics) – medications like paracetamol can provide temporary pain relief.
- non-steroidal anti-inflammatory drugs (NSAIDs) – e.g. naproxen and ibuprofen help control inflammation and provide temporary pain relief.
- corticosteroids – such as prednisolone are used to quickly control or reduce inflammation. They're used in the early days of your condition, or if you're going through a flare, to get the inflammation under control. They do have side effects if used for long periods, so your doctor will closely monitor you while you're taking them.
- hydroxychloroquine - medications such as Plaquenil 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 conditions like 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 work on controlling your overactive immune system. They help relieve pain and inflammation, and can also reduce or prevent joint damage.
- immunosuppressants - these medications including azathioprine, mycophenolate mofetil, cyclosporine, leflunomide, methotrexate and cyclophosamide suppress your overactive immune system. Each of these medications has particular effects on lupus and 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, as 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 'slip, slop, slap' by wearing UVA and B sunscreen every day. You should also cover your skin and wear a hat 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, 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.
- 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 support that's available.

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 *MOVE muscle, bone & joint health* for information and contact details.

Where to get help

- Your doctor
- Specialist (often a dermatologist, rheumatologist, nephrologist or immunologist)
- *MOVE muscle, bone & joint health*
  National Help Line: 1800 263 265

Things to remember

- Lupus is a chronic condition that results from a malfunctioning immune system
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- There's no cure, however lupus can be managed with medication and lifestyle changes

This information has been produced in consultation with and approved by: MOVE muscle, bone & joint health Ltd.

How we can help

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

Visit our website move.org.au for information on:

- muscle, bone and joint conditions
- ways to live well with a muscle, bone and joint condition
- our new resource *Managing your pain: An A-Z guide*
- programs and services
- peer support groups
- upcoming webinars, seminars and other events.

More to explore

- **Arthritis Research UK**
  www.arthritisresearchuk.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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