

Lupus

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**ARTHRITIS
NEW ZEALAND**

KAIPONAPONA AOTEAROA

*Improving the lives of
people affected by arthritis*

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kua pōngia e te kaiponapona*

I've just been told I have Lupus...

So you've just been informed that you have Lupus (Systemic lupus erythematosus or SLE), or there is a suspicion that you have Lupus.

You had probably never heard of the word. Your doctor has doubtless tried to explain things to you, but you may not have taken it all in due to being surprised by this somewhat strange name, *Lupus*.

While there is no specific cure, there are all kinds of things that can be done to help you manage it.

And by the way, don't worry, it is not contagious. You haven't caught it from anyone and no-one can catch it from you. And unless a severe complication develops well down the track, it is unlikely you will need to go to hospital for other than tests and treatment.

What is Lupus?

Lupus is a form of arthritis. As you will know by now, it can affect joints, muscles and even the skin.

It is an auto immune disease. By auto immune, we mean that antibodies are produced in your system which fight with certain of your healthy body tissues resulting in painful inflammation.

Whilst you are probably not that interested right now in where the name came from, for the record it's the Latin word for *wolf*. Please don't think you're going to turn into a wolf. We'll explain more about that shortly.



What causes Lupus?

We hope that one day researchers will find the answer to that question. But for now we can only go on suspicion. We suspect that genetic factors might have something to do with it, meaning you were born with a pre-disposition to the disease. But we don't rule out environmental factors either. Environmental factors that may contribute to the triggering of the disease could be such things as viruses, exposure to the sun, drugs and chemicals in the environment. Stress may have something to do with it and female hormonal activity. This has yet to be proven by research.



Who gets Lupus?

About ten times more women than men get it. It is usually first diagnosed in the child-bearing years. In New Zealand, Lupus is three to four times more common in Māori and Pacific women. Lupus is also more common in Chinese women.

What are the symptoms?

Lupus can mimic many other conditions. Because of this, it can sometimes be difficult to diagnose. It usually starts with joint pains, especially in the small joints of the hands and feet. And it may “flit” from one set of joints to another quite quickly. Tiredness is one of the most prominent features of Lupus.

Other symptoms may include:

- Skin rashes
- Recurring mouth ulcers
- Dryness of the eyes and mouth
- Fatigue
- Fevers
- Hair loss
- Headaches
- Depression

It is the skin rashes, by the way, that brought about the connection with wolves in the name of the disease. Hundreds of years ago, people tended to link the names of conditions with things seen in the world of nature. In fanciful and exaggerated fashion, some saw a certain form of skin rash on the cheeks and the nose as resembling the colouration of the face of a wolf. Let us say it again, they were grossly exaggerating.

How is it diagnosed?

No specific tests can diagnose Lupus. Your doctor will make the diagnosis based on the history of your illness, a physical examination and blood tests.

How is Lupus treated?

As we said, there is no specific cure. But for the vast majority of people living with Lupus, there is effective treatment that makes life so much more comfortable, and for some, even close to normal.

Medications

These may include non-steroidal anti-inflammatory drugs (NSAIDS), immunosuppressive drugs, prednisone, new biologic treatments and preparations for the skin.

Lifestyle Changes

Giving up smoking is one of the most important things you can do to reduce the risk of more serious complications. It can be extremely difficult to stop but treatments are available that can help you. Talk to your GP or call a smoking helpline for advice.

Lifestyle changes can help minimise symptoms and aid an improved sense of well-being. Preventive measures can reduce the risk of flares. For photosensitive patients, avoidance of (excessive) sun exposure and/or the regular application of sunscreens will usually prevent rashes. Regular exercise can help prevent muscle weakness and fatigue. Immunisation will protect against specific infections and maintaining a healthy lifestyle by getting enough rest, reducing stress, eating a balanced diet, and quitting smoking all helps.

Lupus is a difficult condition to live with and it may give you many challenges, especially during periods of your life when you may need more energy. Meeting others with Lupus can help by sharing your thoughts and concerns with someone else who is going through the same process.

Contraception

If you have lupus you should use contraceptive pills that contain only progesterone or low-dose oestrogen. You may prefer to consider physical/barrier methods of contraception. This is because oestrogen can increase the chances of a flare-up, although this is more commonly seen in people with a more severe disease.

For more information visit:

- www.arthritis.org.nz
- Arthritis Research UK – www.arthritisresearchuk.org/arthritis-information/conditions/lupus.aspx
- National Institute of Arthritis and Musculoskeletal and Skin diseases – www.niams.nih.gov
- Australian Rheumatology Association – www.rheumatology.org.au
- Medsafe – www.medsafe.govt.nz

Where can I learn more?

www.arthritis.org.nz

Regional offices

Northern (Auckland) 09 523 8900

Midland/Central (Wellington) 04 472 1427

Southern (Christchurch) 03 366 8383

National office

Level 2, 120 Featherston Street

PO Box 10020, The Terrace

Wellington, 6143

Phone 04 472 1427

Fax 04 472 7066

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