



STAYING MOVING, STAYING STRONG

LUPUS SYSTEMIC LUPUS
ERYTHEMATOSUS (SLE)



WHAT IS LUPUS?

- Lupus, also called systemic lupus erythematosus or SLE, is an autoimmune condition.
- This means the body's immune system thinks that body parts need healing even when they don't. This causes swelling (inflammation) in the body.
- Lupus can affect many parts of the body including joints, skin or other organs like the lungs and kidneys.
- It is not known what causes lupus. But you're more likely to get it if it runs in your family, if you are a woman or have a long period of illness or stress.

WHAT DOES LUPUS FEEL LIKE?

People can have good and bad days. Bad days (e.g. when feeling tired and sore) are called 'flare ups'.

People with lupus can feel:

- Sore and swollen joints
- Tired
- Sad or depressed
- Fevers
- Rashes
- Mouth sores
- Lupus can affect your body, mind and spirit.

Everyone with lupus has a different story.

"People get it inside, people can get it on the outside. I can have butterfly rashes on my face some days and then some days I won't, but I still have pain inside"
— Yindjibarndi woman, aged 48



HOW DO I KNOW IF I HAVE LUPUS?

- Have a yarn with your doctor.
- To diagnose lupus, your doctor might ask you to get blood or urine tests.
- Your doctor may also send you to a specialist doctor called a rheumatologist.



HOW CAN I LOOK AFTER LUPUS?

MEDICINES

- Medicines are an important way to control lupus.
- Yarn with your rheumatologist and doctor about the right medicines for you.
- The right medicines depend on how lupus affects you and which body parts are involved (e.g. your joints, skin, organs)

These can include:

- Medicines to calm your immune system, including antimalarials (e.g. hydroxychloroquine, or immunosuppressants e.g. mycophenolate).

- Medicines to help swelling (inflammation) and pain (e.g. ibuprofen, celecoxib, cortisone).
- Medicines to stop blood clots (anticoagulants).
- When starting medicines, check in with your doctor every 1-3 months about how you're feeling. After this, check in every 6 months.
- Tell your doctor if you are pregnant or plan to get pregnant.

"When I was diagnosed I had to start rethinking about my health and changing my lifestyle. Changing my food intake, take all my medications and trying to do a lot of exercise and walking" — Nhanda woman, aged 68

BUSH MEDICINES

- Bush medicines may help alongside Western medicine. Yarn with your local Aboriginal health service or Cultural Elder to find out more.

MANAGING TRIGGERS

- Knowing your triggers can help you avoid flare ups.
- Common triggers are feeling stressed, being sick or having an injury, being pregnant or using some medicines.
- Sunlight can be a trigger and your skin may be extra sensitive. Sun protection is important. Wear sunscreen, cover your skin, wear a hat and sunglasses when outdoors.

LIVE HEALTHY

- Staying active and eating healthy will help your lupus.
- Cut down, or if you can, get off the smokes.
- Not sleeping well can make pain worse. Good sleep at night can help your joint pain and keep your mind healthy too.
- Look after your moods and stress. Yarn about your feelings with family, your doctor or staff at your Aboriginal health service.



Don't be shame about asking questions

The more you know about your lupus, the more you can be in charge of your health and wellbeing.

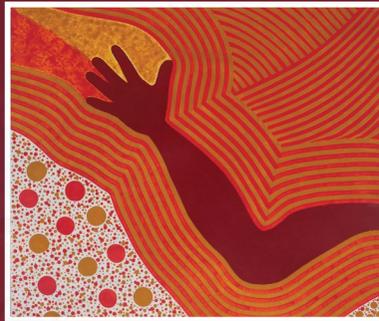
Some questions you could ask your doctor:

- What causes lupus?
- Why do I get flare ups?
- What can I do to look after my lupus?
- What is going to happen in the future?
- What medicines can help me?
- What can be side effects of these medicines?
- How often do I need to see a doctor or specialist?

ABOUT THE ARTIST

THOMAS MARKS – LIVING WITH ARTHRITIS

Thomas 'Marksey' Marks is a proud Wotjobaluk/ Gunaikurnai man from Gippsland. Being one of many Stolen Generations children, he wasn't able to grow up on his traditional Country. As an adult, he is now proudly reclaiming his Aboriginal identity through art. In his artwork 'Living With Arthritis' Thomas tells the story of his struggle with arthritis and the journey he is on to fight back against the pain. It's also a story for others who experience arthritis and go through life followed by this lingering pain.



NICOLE DICKERSON – HEALING TOGETHER

Nicole is a Yamaji Woman from Geraldton Western Australia with connections to the Amangu, Naaguja, Wilunyu and Ngarluma People. Nicole grew up interested in art with her creative ways coming from her Dad. Nicole's art is her form of healing, strength, her words when she cannot speak, and most importantly it's her story. In 'Healing together' Nicole tells the story of how the rain falls on the land, connecting people, cleansing the mind, body & soul, from one place that connects two, to support Healing Together on one land.



WHERE CAN I GO FOR HELP?

If joint pains are stopping you from living well, have a yarn with your doctor, health worker or physio.

If you'd like help finding your local Aboriginal health service have a look at these links:

<https://askizzy.org.au>

<https://www.naccho.org.au/naccho-map>

WANT TO KNOW MORE ABOUT LUPUS?



Scan here
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This brochure was developed with funding from the Australian Government and support from Arthritis Australia