

Sarcoidosis of the lungs



Sydney
Local Health District

What is sarcoidosis of the lungs?

Sarcoidosis is a chronic inflammatory condition in which clusters of cells involved in inflammation (called granulomas) form in different organs in your body. Although sarcoidosis can affect the eyes, skin, heart and nervous system, it mostly affects the lungs and lymph nodes. 90% of sarcoidosis cases involve the lungs, which is known as pulmonary sarcoidosis, or sarcoidosis of the lungs. Only a small proportion will progress to develop significant lung disease.



20% of people with sarcoidosis may progress to develop Interstitial Lung Disease (ILD), which involves scarring of the lung tissue.

What causes sarcoidosis?

Currently, the exact cause of sarcoidosis is unknown, although it is thought that a combination of various factors may contribute to its development, including occupational, environmental, genetic risk factors or an underlying atypical infection.

What are the signs and symptoms of sarcoidosis?

The symptoms of sarcoidosis often depend on which organs are affected and can vary from one person to another. While the majority of people may not experience any symptoms, others may experience a sudden start to their symptoms which can resolve quickly or may experience a more gradual build-up over time. Along with general symptoms such as fatigue, people with sarcoidosis of the lungs may experience a persistent dry cough, breathlessness, chest discomfort or wheezing.

Some of the common signs and symptoms are listed below, but it is important to note that you may experience different symptoms to these:



Persistent dry cough, shortness of breath, wheezing, chest pain



Skin changes including rash or reddish-purple bumps, sores or lesions on your nose, cheeks or ears, colour changes or growths under the skin



Blurred vision, pain, burning, itching or dry eyes, severe redness or sensitivity to light



Irregular, rapid or fluttering heartbeat or fainting



General symptoms including fatigue, swollen lymph nodes, weight loss, pain and swelling in your joints, such as the ankles.

How is sarcoidosis diagnosed?

Sarcoidosis is often difficult to diagnose as people may only have a few symptoms early in the disease. When symptoms do occur, they often resemble other conditions. Your healthcare professional will need to rule out other more common conditions and then determine which organs may be affected by sarcoidosis.

Diagnosis of sarcoidosis may involve:



A physical examination and discussion with your healthcare professional about your symptoms, work and medical history



Blood and urine tests to check your overall health and how well your kidneys and liver are working. Angiotensin Converting Enzyme (ACE) test to look for markers of sarcoidosis



A chest X-ray or CT scan to look at your lungs, and a Positron Emission Tomography (PET) scan or Magnetic Resonance Imaging (MRI) to determine if sarcoidosis is affecting your heart or central nervous system



Breathing tests to measure how well your lungs are working



Electrocardiogram or echocardiogram to detect any heart problems



Eye exam to check for vision problems that may be caused by sarcoidosis



Biopsy sample of the lymph node or organ involved to look for granulomas. Your doctor will make an assessment and advise you on the best and safest area to biopsy.

How is sarcoidosis treated?

As sarcoidosis presents differently in people, treatment is not standardised. For many people, no treatment is required and the condition remains stable or improves on its own. Some people however, may require treatment to suppress their immune system, reduce inflammation and prevent their condition from getting worse over time.

Although there is no cure for sarcoidosis, there are a range of different medications that may help reduce inflammation. These include:

- Corticosteroids, or prednisone, which reduce inflammation
- Medications that suppress the immune system and reduce inflammation such as methotrexate, azathioprine or mycophenolate mofetil
- TNF inhibitors, which are biologic drugs used to treat inflammation - including infliximab, abatacept or adalimumab
- Treatment with inhalers may be used if sarcoidosis of the lungs primarily affects the airways.

Your doctor will discuss your treatment options with you and help decide how to best manage your condition.

As part of your management plan, there are a range of things you can do to help maintain your health and help feel your best, including:



Participating in daily exercise to help stay fit



Participating in a pulmonary rehabilitation program



Maintaining a healthy diet and lifestyle



Keeping up to date with vaccinations



Using oxygen therapy if prescribed by your doctor



Staying connected with your healthcare team



Staying connected with your family and friends and ensure you seek support when you feel you need it.

For more information on looking after yourself and maintaining a healthy lifestyle, you can also refer to the [Life with Pulmonary Fibrosis \(PF\)](#) booklet and the [Living with PF: Non-pharmacological treatments](#) resources.

I've been diagnosed with sarcoidosis, what next?

Sarcoidosis is different for everyone, so once you have received a diagnosis, your treating healthcare team will prescribe a treatment and follow up plan that is individualised to suit you. Regardless of your symptoms or your treatment, you will need to see your doctor regularly so they can monitor any symptoms, check if your condition is progressing and continue to assess any medications and treatments you may be receiving.

What support is available?

If you have been diagnosed with sarcoidosis, it is important to remember that you are not alone. Stay connected to your healthcare team and reach out to friends and family or support groups. Seeking support through professional counselling services or a psychologist can also help you manage difficult feelings or emotions that may arise.

LUNG FOUNDATION AUSTRALIA SERVICES



Information and Support Team



Lung disease information resources



Education webinars



Support groups



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Referral to pulmonary rehabilitation and Lungs in Action exercise programs



E-newsletter

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