

Sarcoidosis

Sarcoidosis is a condition in which abnormal nodules, called sarcoid granulomas, appear in the body's tissues. Sarcoidosis can involve any organ in the body, but affects the lungs or the lymph nodes of the chest in about 90 per cent of cases. It can develop at any age, but mostly affects people in their late 20s to early 40s.

Sarcoidosis is not cancer, and is not related to tuberculosis, which is a serious and potentially fatal bacterial infection of the lungs. Most people get better within one to three years and may not need any medical treatment other than close observation by their doctor.

Symptoms of sarcoidosis

Many patients with sarcoidosis don't have any symptoms. The condition may be diagnosed by chance during medical tests for an unrelated health problem. When symptoms do occur, they depend on which body part is affected.

Typical symptoms may include:

- Cough
- Fever
- Chest pain or discomfort
- Shortness of breath
- Tiredness and lethargy
- Facial swelling
- Arthritis, particularly of the large joints
- Painful red lumps called erythema nodosum on the front of the legs.

Sarcoid granulomas

The small inflammatory nodules present in sarcoidosis are known as sarcoid granulomas. They comprise groups of immune cells, which are normally part of the body's defence system. Sarcoidosis usually affects the lungs or the lymph nodes near the lungs. The reason for this is not known. Lymph nodes elsewhere in the body such as the neck or armpits may be involved. In about 10 per cent of cases, sarcoidosis can involve other organs or tissues within the body, including the salivary glands, liver, eyes or skin.

Complications of sarcoidosis

Occasionally, sarcoidosis may develop in the brain or heart, which can lead to serious complications:

- If the brain is affected, symptoms may include headaches, weakness, numbness, and blurred vision
- If the heart is affected, symptoms may include palpitations, dizziness or chest pain.

Very occasionally, sarcoidosis can trigger high levels of calcium in the blood, causing thirst and kidney damage. An increase in calcium levels in the urine can put the person at risk of kidney stones.

Cause of sarcoidosis

The cause of sarcoidosis is not known. It appears to be more common in cooler climates, but the reason for this is unclear. Occasionally, sarcoidosis runs in families, which suggests that genes may play an important role. Current thinking suggests that the cause may be an infective agent or an allergy working in combination with susceptible genes. However, there is no evidence to support this theory. Research is ongoing.

Diagnosis of sarcoidosis

Sarcoidosis can usually be diagnosed on the basis of symptoms, x-ray results and blood tests, although it is sometimes difficult to diagnose. It is important to differentiate sarcoidosis from other conditions that can enlarge the lymph glands and cause shadows on chest x-rays.

In most cases, however, the doctor will want to confirm the diagnosis with a biopsy. Lung biopsies are performed using a fibre-optic bronchoscope placed down the trachea via the mouth. Sometimes, the bronchoscope is inserted into a small incision in the neck or between the ribs. The biopsy specimen is sent to a pathologist, who examines it under the microscope.

Your doctor may wish to arrange for other medical tests such as:

- Blood tests
- Urine tests
- Breathing tests
- Electrocardiogram (ECG)
- Echocardiogram (ECHO)
- CT scans
- Neurological tests
- Eye tests.

Treatment for sarcoidosis

In Australia, sarcoidosis is usually a mild condition. Most patients get better within one to three years and may not need any medical treatment at all. However, your doctor will wish to monitor you closely during your recovery, so expect regular health checkups. Your doctor may refer you to a specialist.

Medical treatment is needed in serious or progressive cases. Steroid medication, such as prednisolone or cortisone, is the most common therapy. Rarely, other drugs may be needed. Initially, the dose of steroids may be high. The dose can often be reduced once the condition is under control.

Once sarcoidosis appears to be improving, relapse is rare unless the medication is stopped. Never suddenly stop taking the medication. When resolved, sarcoidosis rarely returns.

Long-term outlook for sarcoidosis

About one person in three with sarcoidosis will have some degree of organ damage. Without treatment, chronic and severe sarcoidosis of the heart, brain or lungs can have serious health consequences, including death. However, it is important to remember that serious complications are rare in Australia. Most people recover fully and have no lasting ill effects. Discuss any concerns and fears with your doctor or specialist.

Your doctor can recommend lifestyle changes, if necessary. Occasionally, too much sunshine can cause high calcium levels in the blood and urine, which can lead to kidney problems. If you are a smoker, you should quit. Generally speaking, you can expect to lead a normal active life.

Pregnancy is not affected by sarcoidosis. Women with the condition who become pregnant usually get a little better. Very occasionally, the condition worsens after the baby is born.

Where to get help

- Your doctor
- The Australian Lung Foundation Tel. 1800 654 301

Things to remember

- Sarcoidosis is a condition in which abnormal nodules, called sarcoid granulomas, appear in the body's tissues.
- The lungs are most commonly affected, causing symptoms such as coughing and shortness of breath.
- Most people get better within one to three years and may not need any medical treatment other than close observation by their doctor.

This page has been produced in consultation with, and approved by:

Australian Lung Foundation

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