



Sarcoidosis

What is sarcoidosis?

Sarcoidosis – also called sarcoid – is a condition where cells in your body clump together to make small lumps called granulomas. These **granulomas** can develop in any part of your body. They are most commonly found in the **lungs** and the **lymph glands** which drain the lungs. They can also affect your skin, heart, nervous system, liver, spleen, muscles, nose, sinuses and eyes.

When lots of granulomas develop in one area, they begin to affect how well that part of your body works. This causes symptoms.

Sarcoidosis affects people in lots of different ways. It can cause symptoms in just one part of your body or many parts at the same time. Though sarcoidosis isn't always a lung condition, the lungs are affected in about 90% of cases. When the lungs are affected, it's called **pulmonary sarcoidosis**.

You can get sarcoidosis at any age, but it commonly affects adults in their 30s or 40s. It's unusual for children to get sarcoidosis. The NHS estimates that sarcoidosis affects around one person in every 10,000 in the UK.

What causes sarcoidosis?

We don't know what causes sarcoidosis, but we do know it's related to your immune system behaving in a way it shouldn't.

Normally your immune system fights infections by releasing white blood cells into your blood to destroy germs. This causes the affected part of your body to become inflamed, making it swollen or red. Researchers think that sarcoidosis could be caused by something in the environment that stops your immune system working properly. Instead of attacking germs, it attacks healthy parts of your body.

Research also suggests that, for some people, the risk of getting sarcoidosis is related to their genes. Sometimes, more than one family member can get sarcoidosis. But there's no evidence that it's infectious.

Symptoms

Your symptoms depend on what part of your body is affected. They can include:

- feeling short of breath
- a cough which is often dry
- tiredness and feeling ill
- red or sore eyes
- painful red lumps on your shins
- swollen glands in your face, neck, armpits or groin
- rashes – usually on your upper body
- painful joints, bones and muscles
- an abnormal heart rhythm
- sweats

In some cases, symptoms come on suddenly, but don't last very long. This is called **acute sarcoidosis**. Common symptoms of acute sarcoidosis are swollen glands, fever, tiredness, joint pains and lumps or rashes on the legs.

If your symptoms develop gradually and last longer, this is called **chronic sarcoidosis**. This means that the condition is long term. People with long-term sarcoidosis often have fewer symptoms, but the symptoms can get worse over time.

Some people don't experience any symptoms. In this case, you may only discover you have sarcoidosis if you have a chest X-ray for another reason.

Diagnosis

Sarcoidosis can be difficult to diagnose. It shares symptoms with lots of other diseases and you may not even have any obvious symptoms. This means it can take a while to get a diagnosis.

You might need to have a few different tests, depending on which parts of your body are affected.

Pulmonary sarcoidosis

If it looks like sarcoidosis is affecting your lungs, you'll probably have a **chest X-ray** or **CT scan**. A CT scan uses a special X-ray machine to produce a detailed image of the inside of your body. In most cases, this is enough to find out if you have sarcoidosis.

In some cases, the doctor may want to examine the inside of your lungs more closely by doing a **bronchoscopy**. This is done using a bronchoscope – a thin, flexible tube with a light and a very small camera at one end. The tube is passed through your nose or mouth, down your windpipe and into your lungs.

The procedure isn't painful, but it can cause coughing. It's often done under sedation with a local anaesthetic. Your doctor will be able to give you more details when they discuss the test with you.

During the procedure, your doctor may take a sample of tissue from your lungs. This can be examined under a microscope to see if there are any granulomas. This is called a **biopsy**.

Some centres prefer to do this using an **EBUS-TBNA procedure**. The doctor uses a special kind of bronchoscope with ultrasound to see inside your lungs and take a tissue sample. This procedure takes slightly longer than a standard bronchoscopy. But in centres which perform the test regularly, it's more likely to give a clear diagnosis than a standard bronchoscopy.

Sarcoidosis in other parts of your body

You may have **blood tests**, **urine tests** or a **biopsy** of the affected area. You may also have an **electrocardiogram**, sometimes called an **ECG**, which is a simple test that records the rhythm of your heart.

If you're diagnosed with sarcoidosis in one part of your body, other parts of your body may also be affected. Further tests will help to show how different parts of your body are affected.

Treatment

Sarcoidosis will often get better without medication. Only a small number of people with sarcoidosis need treatment. This means it's normal for your doctor to keep an eye on your symptoms for a few months before talking about treatment options. It's usual to have regular chest X-rays, breathing tests and blood tests to monitor your condition.

Most people with acute sarcoidosis, which is short term, won't need specific treatment. If your sarcoidosis is causing you pain, such as muscle or joint pain, a painkiller such as ibuprofen or paracetamol can help.

If your symptoms continue and tests show your condition is getting worse, you may need treatment. The aim of treatment is to **improve your symptoms** and to **prevent scarring and damage** to the affected parts of your body.

Steroids

Steroids are an effective treatment. Sometimes they can be used directly on the part of your body that's affected. For example, you can use eye drops for eye symptoms. More usually, you'll take them as a course of tablets.

If you take high doses of steroids for a long time, you can experience side effects. These can include increased appetite and weight gain, indigestion, heartburn and difficulty sleeping. They can also cause a weakening of the bones called osteoporosis.

For this reason, you'll usually take a high dose of tablets for a short time, followed by a lower dose over a much longer period. If you stop taking steroids too soon, your condition might become active again and cause more scarring. So you'll often need to continue the treatment for up to two years.

Usually you'll only need one course of steroids, but sometimes you might need to take a second course. Only a small number of people with sarcoidosis need long-term treatment with steroids. If you take steroids long term, most centres will recommend a bone density scan. This may be repeated if you take steroids for over two years.

Other medication

For a very small number of people, steroids are not enough to control their symptoms. These people may take other medications called **immunosuppressants**. These help control your body's immune system.

Looking after yourself

If you currently smoke, the most important thing you can do to look after your health is to quit. For more advice on giving up smoking, go to blf.org.uk/smoking or call our helpline on **03000 030 555**.

Getting regular exercise and enough sleep is very important.

It's also important to eat well and maintain a healthy weight. Avoid sugar and processed foods where possible. Drink plenty of fluid to keep hydrated. Foods and fluids contain essential nutrients to help control your symptoms and keep you feeling as strong as possible. Find out more at blf.org.uk/healthyeating

If you have sarcoidosis, you might have a tendency to develop high levels of calcium in your urine or blood. Don't take any calcium or vitamin D supplements unless they're specifically recommended for you by your doctor. You should be able to get all the calcium and vitamin D you need from a balanced diet.

Before you make any major changes to your diet, you should always talk to your doctor or another health care professional.

What is the outlook?

Sarcoidosis affects people in very different ways. It can last for just a few weeks or months (**acute**), or it can last for years (**chronic** or **long-term**).

Chronic sarcoidosis can last a long time, but might not get any worse. Sometimes, you might get **flare-ups** of your symptoms and need treatment. A flare-up is when your symptoms suddenly get worse.

Though sarcoidosis can affect many parts of the body, it's unusual for people with long-term sarcoidosis to develop the condition in a part of their body that hasn't been affected before. If sarcoidosis does flare up, it's usually in the same area of your body and with the same symptoms as when it first started.

Over time, sarcoidosis can cause damage and scarring in the affected parts of your body. In the lungs this can cause you to feel more and more out of breath. If sarcoidosis is diagnosed early, it may be possible to manage it to minimise damage or scarring to the affected area.

Most people who have long-term sarcoidosis eventually improve and can have an active life. But in some cases, long-term sarcoidosis gets worse over many months or years. This can cause permanent damage to the affected parts of your body. Sadly, people can die from heart or lung sarcoidosis, but this is very rare.

Get in touch with us to find support near you.

Helpline: 03000 030 555

Monday to Friday, 9am-5pm

Ringing our helpline never costs more than a local call and is usually free, even from a mobile.

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We value feedback on our information. To let us know your views, and for the most up to date version of this information and references, call the helpline or visit blf.org.uk