

Sarcoidosis



What is sarcoidosis?

Sarcoidosis – also called sarcoid – is a condition where inflamed cells 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, eyes, joints, heart, nervous system, liver, spleen, muscles, nose and sinuses.

When lots of granulomas develop in one area, they begin to affect how well that part of your body works. This causes symptoms. The inflammation, which is usually reversible, can sometimes progress to scarring, which isn't reversible.

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 not a common condition: in the UK 4,500 people were diagnosed with the condition in 2012. It's very rare for **children to get sarcoidosis** (blf.org.uk/support-for-you/sarcoidosis-in-children).

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. This is probably a response to various triggers in the environment.

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.

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.

What are the symptoms of sarcoidosis?

Your symptoms depend on what part of your body is affected.

Symptoms of sarcoidosis include:

- feeling short of breath
- a cough which is often dry
- tiredness
- feeling ill or feverish
- red, painful eyes with impaired eyesight
- painful red lumps on your shins
- swollen glands in your face, neck, armpits or groin
- skin rashes
- painful joints, bones or muscles
- an abnormal heart rhythm or chest pain
- sweats
- fatigue that, when severe, can be extreme

Tiredness and fatigue

Feeling tired or fatigued occurs early on and is often the last symptom to go away. Fatigue is often hard to treat. It's important people around you understand this. Take fatigue seriously- it's a sign you should see a sarcoidosis specialist.

Symptoms such as heart palpitations and unexplained breathlessness must also be taken very seriously. They may be due to heart disease, including sarcoidosis affecting the heart.

Acute sarcoidosis

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.

Chronic sarcoidosis

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

Are there always symptoms?

Some people never experience any significant symptoms. In this case, you may only discover you have sarcoidosis if you have a chest X-ray for another reason.

How is sarcoidosis diagnosed?

Sarcoidosis can be difficult to diagnose. It shares symptoms with lots of other diseases and you may not 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. This is because there is no single specific test to diagnose sarcoidosis.

Pulmonary sarcoidosis

If it looks like sarcoidosis is affecting your lungs, you'll probably have **lung function tests** and a **chest X-ray** or **CT scan**.

A CT scan uses a special X-ray machine to make a detailed image of the inside of your body. In some cases, this may be enough to find out if you have sarcoidosis, but doctors will often need more information.

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 make you cough. 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**.

Many centres now prefer to do this using an **EBUS-TBNA procedure**. The doctor uses a special kind of bronchoscope with ultrasound at the tip to see inside your lungs and take a tissue sample. This procedure takes slightly longer than a standard bronchoscopy. But 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.

How is sarcoidosis treated?

Sarcoidosis can get better without medication. This means it's normal for your doctor to keep an eye on your symptoms for a few months before talking about treatment. It's usual to have regular chest X-rays, **breathing tests** and blood tests to monitor your condition.

Many people with sarcoidosis don't need treatment.

But treatment may be needed if:

- symptoms are affecting your quality of life
- scarring in your organs is severe enough to be potentially dangerous

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.

Treatment for sarcoidosis is aimed at **improving your symptoms** and **preventing inflammation from causing 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 often, 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, mood disturbance and difficulty sleeping. They can also cause thinning of the bones, or 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.

Often 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 health care centres will recommend a bone density scan. This may be repeated if you take steroids for over 2 years.

Other medication

For a very small number of people, steroids are not enough to control their symptoms, or the dose needed to control symptoms in the longer term is too high. These people may need to take other medications called **immunosuppressants** that help control your body's immune system, such as methotrexate, azathioprine, hydroxychloroquine and mycophenolate mofetil (MMF).

These all require careful monitoring with regular blood tests and may increase your risk of infection. Some have side effects that you should discuss with your health care professional.

Looking after yourself

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 sarcoidosis specialist. You should be able to get all the calcium and vitamin D you need from your diet.

As with any lung condition, it's important to eat well and maintain a healthy weight. Stress often triggers sarcoidosis symptoms. It's helpful to think carefully about your lifestyle. Talk to your friends or family or a health care professional about how you feel, and try to find ways to reduce stress in your life. Getting regular exercise and enough sleep is very important.

If you smoke, the best thing you can do to look after your health is to quit. Find out more at blf.org.uk/smoking

What is the outlook for those with sarcoidosis?

Sarcoidosis affects people in very different ways:

- acute sarcoidosis can last for just a few weeks or months.
- chronic (or long-term) sarcoidosis can last for years, 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.

Sarcoidosis can affect many parts of the body and research has shown it's possible for it to develop in places not previously affected. But usually, if sarcoidosis does flare up, it will be in the area of your body where it first started, with the same symptoms.

How can sarcoidosis affect you over time?

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

Most people who have long-term sarcoidosis eventually improve and can have an active life. But in some cases, when long-term sarcoidosis gets worse over months or years, there can be permanent damage to the affected parts of the body. People with sarcoidosis that affects the heart or lungs can die from sarcoidosis, but this is rare.

Further information and support

You can call our helpline on **03000 030 555**, where our friendly staff will be happy to talk to you about your concerns and answer your questions.

SarcoidosisUK has more information about sarcoidosis. Visit the **SarcoidosisUK** (www.sarcoidosisuk.org) website or call **020 3389 7221**.

Get in touch with us to find support near you.

Helpline: **03000 030 555**

Monday to Friday, 9am-5pm

Ringing our helpline will cost the same as a local call.

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blf.org.uk

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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**