

Patient information from BMJ

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Sarcoidosis

Sarcoidosis is a rare condition that causes small lumps to grow in some organs in the body, usually the lungs. It can also cause red patches to appear on the skin.

Not everyone needs treatment, but medications can help with the symptoms. If you have sarcoidosis, you can use our information to talk with your doctor about what treatments are best for you.

What is sarcoidosis?

If you have sarcoidosis, small lumps or patches grow on some of your internal organs and often on the skin. These lumps and patches are called **granulomas**. They can affect your health by damaging the affected organs.

Sarcoidosis is a rare condition that usually affects people when they are aged between 20 and 40. We don't know what causes it. But it seems to be more common in some groups of people, including:

- women
- people with a family history of sarcoidosis
- black people, and
- people with Scandinavian heritage.

The symptoms of sarcoidosis can vary from mild to very severe. And it can sometimes cause death, although this is rare.

In about half of people, the condition gets better by itself after a while. But the more severe your symptoms are, the less likely you are to recover.

In most people, sarcoidosis affects the lungs, the lymph nodes (small glands in the armpits, neck, and groin, among other places), and the skin. But it can affect most organs, especially the heart, eyes, and nervous system.

What are the symptoms?

The symptom of sarcoidosis that you are most likely to notice is red patches (granulomas) on the skin.

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Because the lungs are usually affected, you will probably also have symptoms similar to those caused by asthma, such as:

- coughing
- wheezing
- shortness of breath, and sometimes
- chest pain

Depending on what other organs are affected, you could have other symptoms, which could include:

- tiredness that doesn't go away after you rest or sleep (called chronic fatigue)
- weight loss
- mild fever
- sensitivity to bright light
- painful, red eyes (this is called **ocular sarcoidosis**), and
- pain and stiffness in the joints.

If you have sarcoidosis that affects the nervous system (called neurosarcoidosis) you might have other symptoms, such as:

- headaches
- weak muscles in the face (called facial palsy), and
- seizures.

If you see your doctor with any of these symptoms, he or she will probably want to do some tests. These might include:

- a chest x-ray, so your doctor can look at your lungs
- blood tests
- an electrocardiogram (ECG) to test whether your heart rhythm is normal
- tests to see how well your lungs are working. This will probably involve checking how much air you can blow out in one breath
- a biopsy of any organs affected by sarcoidosis. This involves taking a small amount of tissue with a needle, for testing. You will probably only need this test if your doctor is sure that you have sarcoidosis. So it won't be one of the first tests you have.

What treatments work?

Not everyone with sarcoidosis needs treatment. Doctors usually only recommend treatment for people with symptoms that are causing them problems.

In many people, the condition gets better after a while without any treatment. But this is less likely to happen the more severe your symptoms are.

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For most types of sarcoidosis the main treatment is medications called **corticosteroids**. These are drugs that reduce inflammation (swelling). This helps to control the granulomas, which can help the affected organs to work normally.

For example, reducing inflammation in the lungs can help with breathing symptoms. And treating the skin with corticosteroids can make it less red and inflamed.

Of course, with any condition that affects the lungs, your doctor will strongly advise you to stop smoking if you haven't already. If you need help to stop smoking, ask your doctor.

Corticosteroids can be taken as pills, or they can be applied as cream for granulomas on the skin and around the eyes.

Side effects of treatment

If you take them for long periods or in high doses, corticosteroids can cause serious side effects in some people, including weakened bones, high blood pressure, diabetes, weight gain, and thinning skin.

So, depending on how severe your symptoms are, your doctor will suggest that you use the lowest dose possible for your symptoms, and that you sometimes have spells when you don't use these drugs.

Your doctor might also recommend that you also take vitamin D and calcium supplements to keep your bones strong. But you should not take more than your doctor recommends, as this can cause problems.

If you can't take corticosteroids for any reason (for example, because of side effects), or if you need to stop using them for a while, there are other drug options that you might be able to try.

Severe symptoms

In most people with sarcoidosis, the **lungs** are affected in some way. Some people have only mild symptoms, such as occasional wheezing. But others have more serious breathing problems.

If you have severe lung symptoms, you might need more intensive treatments, such as:

- higher doses of corticosteroids, possibly through an intravenous (IV) drip for a while
- oxygen to breathe through a mask when you need it, and
- other medications to help your lungs work more normally.

Some people with severe sarcoidosis in the lungs have a lung transplant. This is a major operation and a big decision. You can discuss all these treatments with your doctor to decide which are the best options for you.

If you have sarcoidosis that affects your **eyes**, the main treatment is corticosteroid eye drops. But other treatments can help with more severe symptoms. For example, your doctor might suggest corticosteroid pills as well as, or instead of, drops.

Your doctor might also refer you to an ophthalmologist (eye specialist) to check for problems that sarcoidosis can cause, such as cataracts, glaucoma, and vision problems.

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Sarcoidosis that affects the nervous system is usually treated with higher doses of corticosteroids. But other drugs can be used when needed.

If you have sarcoidosis that affects your heart, your doctor should refer you to a cardiologist (heart specialist) to manage the problems that this can cause. For example, you might need to take extra medications to manage your blood pressure.

What will happen?

The severity of sarcoidosis varies hugely from person to person. Some people have mild symptoms that don't need any treatment. And most of them will get better after a while.

For people with more severe symptoms, it's less simple. Many people still get better, but it's less likely. And some people with very severe symptoms will die because of the damage to the organs that are affected by sarcoidosis.

It's not possible to say what will happen to you as an individual, though. But your doctor should monitor you every few months to check on how you're doing. This could include checking:

- your blood
- how well your liver and other affected organs are working, and
- your lungs.

Your doctor will also check your bone strength every couple of years. This is because corticosteroids can make some people's bones weaker.

For this reason you will probably need to take vitamin D and calcium supplements for as long as you have sarcoidosis. But you shouldn't take more than your doctor recommends, and you will need to take a urine test to check that you don't have too much calcium in your system, as this can cause problems, including kidney stones.

There are various charities and support groups for people with sarcoidosis. For example, in the UK, Sarcoidosis uk (sarcoidosisuk.org) offers information and practical help to people with the condition.

Your doctor might be able to direct you to a group in your area. Or you could easily search online.

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