

Treatment of Sarcoidosis

There is currently no known cure for sarcoidosis.

Treatment is often necessary for patients whose sarcoidosis is causing severe symptoms or is preventing the affected organ(s) from functioning normally. Sometimes simple painkillers (paracetamol or non-steroidal anti-inflammatory such as ibuprofen) may help to ease the symptoms.

The drugs used to treat sarcoidosis do so by reducing inflammation in the body. These are known as immunosuppressants. The most commonly used drugs are corticosteroids. These can be taken as a tablet (prednisolone) or given at a higher dose via a vein (methylprednisone). Treatment with corticosteroids is often required for at least 6 to 24 months.

Sometimes corticosteroids may not be completely effective, or cause side effects. Other immunosuppressants may be used, either alone or in combination, to help reduce the steroid dose. These medications include Methotrexate, Azathioprine and Mycophenolate.

Healthy Living

Sometimes patients' symptoms may suddenly get worse, also known as a 'flare-up'. This may be triggered by stress, illness or nothing recognisable. Make sure you eat healthily, pace yourself, talk to friends and family and recognise mental health problems early. Contact SarcoidosisUK or your GP for further professional support.

Who We Are

SarcoidosisUK provide support and information to anyone affected by sarcoidosis. We also raise awareness and fund research. Contact Us for information on our Support Groups Network and free Nurse Helpline.

How You Can Help:

Donate:

www.sarcoidosisuk.org/donate

Get involved in medical research:

www.sarcoidosisuk.org/research/get-involved-sarcoidosis-research/

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SARCOIDOSIS OVERVIEW

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What is Sarcoidosis?

Sarcoidosis is a condition where lumps called granulomas develop at different sites within the body. Granulomas are made up of clusters of cells involved in inflammation. If many granulomas form in an organ, they can prevent that organ from working properly.

Sarcoidosis can affect many different parts of the body. It often affects the lungs but can also affect the skin, eyes, joints, nervous system, heart and other parts of the body.

Who Develops Sarcoidosis?

Sarcoidosis is uncommon. About 15 in 10,000 people in the UK have sarcoidosis – every year around 4,000 people are diagnosed. It can occur at any age, but most commonly affects adults in their 30s or 40s.

What Causes Sarcoidosis?

The exact cause of sarcoidosis is not known. It probably involves a precise combination of genetic and environmental factors. The condition does run in some families.

So far, a single factor causing sarcoidosis has not been identified.

What Parts of the Body are Affected?

Sarcoidosis can affect almost any part of the body. The lungs and lymph glands in the chest are most commonly involved, affecting 9 in 10 patients with sarcoidosis.

Other parts of the body that may be commonly involved are the skin, eyes and lymph glands elsewhere in the body. The joints, muscles and bones are involved in 1 in 5 patients.

The nerves and nervous system are involved in about 1 in 20 patients. The heart is involved in about 1 in 50 patients.

What are the Symptoms of Sarcoidosis?

The symptoms of sarcoidosis depend on which part of the body is affected. They can include:

- cough
- feeling breathless
- red or painful eyes
- swollen glands
- skin rashes
- pain in joints, muscles or bones
- numbness or weakness of the face, arms, or legs

Patients with sarcoidosis may feel tired and lethargic (fatigued), lose weight or suffer with fevers and night sweats.

Sometimes, the symptoms of sarcoidosis start suddenly and don't last long. In other patients, the symptoms may develop gradually and last for many years.

Some people don't have any symptoms at all and are told they have sarcoidosis after having a routine chest X-ray or other investigations.

How is Sarcoidosis Diagnosed?

There is no single or specific test to diagnose sarcoidosis. A detailed history and examination by your doctor is the most important first step in diagnosing sarcoidosis. They will determine which parts of your body may be affected.

Blood tests Your doctor may arrange blood tests to look for signs of inflammation, to check your kidney and liver function, and your calcium levels. They may also check a marker in

your blood called angiotensin-converting enzyme (ACE), which is sometimes raised in patients with sarcoidosis.

Lungs If your doctor suspects your lungs may be affected, they will usually arrange a chest X-ray and breathing tests (spirometry).

Scans Your doctor may also arrange imaging scans (CT scan or PET CT scan) to look for other parts of your body that may be affected but might not be causing you any symptoms. The scans will look for inflammation (granulomas).

Biopsy In order to help make a definite diagnosis of sarcoidosis a sample of tissue (a biopsy) is taken from one of the areas of inflammation (granuloma) using a bronchoscopy.

As sarcoidosis can affect many different parts of the body, your doctor may ask other specialists (who specialise in the part of your body affected by sarcoidosis) to look after you as well. SarcoidosisUK has other leaflets with more information on different types of sarcoidosis (see *Read more* overleaf).

The Outlook

Sarcoidosis gets better without treatment in most patients (around 60%). In others, the condition persists and may require some treatment. In the minority of patients that develop a more serious form of the disease, more aggressive and prolonged treatment is sometimes required.

A much smaller proportion of patients present with life-threatening symptoms, particularly in those with pulmonary fibrosis (lung scarring) or heart or neurological involvement.