Treatment of Sarcoidosis

There is no known cure for sarcoidosis. The disease may resolve spontaneously without the need for medication in around 60% of patients.

Treatment is often necessary for others who experience symptoms or where their condition is affecting the functioning of body organs. Sometimes simple painkillers (paracetamol or non-steroidal anti-inflammatory such as ibuprofen) may help to ease the symptoms.

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

Sometimes corticosteroids may not be effective, or cause side effects. Other immune medications may be used, either alone as an alternative drug or in combination, to reduce the steroid dose. These medications include Methotrexate, Azathioprine or Mycophenolate.

**Healthy Living**

Sometimes patients’ symptoms may suddenly get worse (‘flare-up’). This may be triggered by stress, illness or nothing recognisable. Make sure you eat healthy, pace yourself, talk to friends and family and recognise mental health problems early. Please contact SarcoidosisUK or your GP for professional support.

Who We Are

SarcoidosisUK provide support and information to anyone affected by sarcoidosis. We also raise awareness and fund research. The vast majority of our funds go towards researching a cure. Contact us for information on our Support Groups network and free Nurse Helpline.

How You Can Help

**Donate** to fund research: www.sarcoidosisuk.org/donate

**Get involved** in medical research: www.sarcoidosisuk.org/research/get-involved-sarcoidosis-research/

Thanks to:

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What is Sarcoidosis?
Sarcoidosis is a condition where lumps called granulomas develop at different sites within the body. These granulomas are made up of clusters of cells involved in inflammation. If many granulomas form in an organ, it 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 body parts.

Who Develops Sarcoidosis?
Sarcoidosis is rare. About 1 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 is probably a rare combination of genetic and environmental factors. The condition does run in some families.

So far, no single cause triggering sarcoidosis has 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 test to diagnose sarcoidosis.

A detailed history and examination by your physician is the most important first step in diagnosing sarcoidosis. They will determine which parts of your body may be affected.

Blood tests Your physician may arrange some 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 physician suspects your lungs may be affected, they will usually arrange a chest X-ray and breathing tests (spirometry).

Scans Your physician 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 make a definite diagnosis of sarcoidosis a sample of tissue (biopsy) is taken from one of the areas of inflammation (granuloma).

As sarcoidosis can affect many different parts of the body, your physician 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.

The Outlook
Sarcoidosis resolves spontaneously in most patients. In others, the condition may persist but does not require treatment.

In the minority that do develop a more serious form of the disease, more aggressive and prolonged treatment is sometimes required. An even smaller proportion of patients present with life-threatening symptoms, particularly in those with heart or nerve involvement.