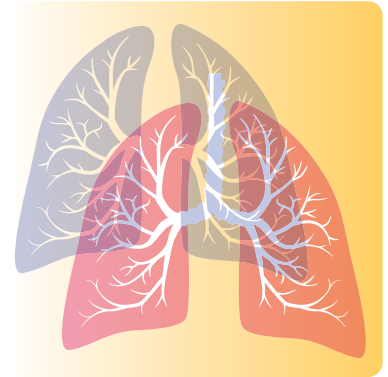


## What is Sarcoidosis?

Sarcoidosis (sar-coy-DOE-sis) is a disease in which inflammation produces tiny lumps of cells in organs throughout the body. The lumps, called granulomas, most often appear in the lungs, but they also can occur in the lymph nodes, eyes, skin or other areas of the body.



If these tiny lumps grow in an organ, they can affect how well the organ works. When sarcoidosis affects the lungs (pulmonary sarcoidosis), the disease can reduce the amount of air the lungs can hold, cause abnormal stiffness of the lungs, and, therefore, cause breathing problems.

### What causes sarcoidosis?

The cause of sarcoidosis is unknown. The disease can affect people of every race, sex and age. Sarcoidosis is more common in African-Americans, and those of German, Irish, Scandinavian, Asian and Puerto Rican origin. It appears most often in young people between 20 and 40 years of age. It is not contagious. Sarcoidosis does appear in some families, but further research is needed to determine if there is a hereditary component.

### What are the signs and symptoms of sarcoidosis?

Many people with sarcoidosis do not have any symptoms. Others have only vague symptoms that can be seen in many other illnesses, such as weight loss, fever, loss of appetite, depression, night sweats, and sleep problems. Symptoms that may come from problems with a specific organ include:

- **Lungs:** Shortness of breath, wheezing or dry cough that may disappear over time.
- **Lymph nodes:** Enlarged and sometimes tender lymph nodes, most often in the neck and chest, but sometimes under the chin, arm pits or groin.
- **Eyes:** Burning, itching, tearing, redness, sensitivity to light, dryness, seeing black spots, blurred vision, reduced color vision, and, in rare cases, blindness.
- **Skin:** Bumps, ulcers, or rarely, flat areas of discolored skin that appear mostly near the nose or eyes or on the back, arms, legs and scalp. Painful and tender bumps can also appear on the ankles and shins.
- **Bones and Joints:** Bone lumps (nodules), causing pain in the hands and feet and sometimes pain and swelling in the ankles or other joints.
- **Spleen and Liver:** fever, fatigue or itching. There can be pain in the upper right part of the abdomen, under the ribs.

- **Heart:** Shortness of breath, swelling in the legs, wheezing, coughing, and chest pain. One may have a feeling of an irregular or fast heart beat at times, or even pass out without warning.

- **Salivary Glands:** Swelling (which may make the cheeks look puffy) and an overly dry mouth and throat.

- **The Nervous System:** Headaches, vision problems, weakness or numbness of an arm or leg, drooping of one side of the face, loss of movement in the arms or legs, weakness, pain or a “pins and needles” feeling.

### How is sarcoidosis diagnosed?

Any of these signs and symptoms may lead a healthcare provider to suspect sarcoidosis.

There is no one diagnostic test to diagnose sarcoidosis. The healthcare provider is likely to perform a variety of tests, which may include:

- Medical history and physical exam to look for signs of sarcoidosis and rule out other diseases.
- A **chest X-ray** to look for enlarged lymph nodes and small round spots in the lungs
- **Pulmonary function tests** to give an indication of how well the lungs work. (For additional information on pulmonary function tests, see ATS Patient Information Series: Bronchoscopy (<http://www.thoracic.org/sections/education/patient-education/index.html>))
- A **tissue biopsy**—taking a small piece of tissue to examine under a microscope to look for signs of disease. In the lung, this is usually done through the airways using a procedure called bronchoscopy. A bronchoalveolar lavage (BAL) to get lung fluid may also be done. For further information on bronchoscopy or BAL, see ATS Patient Information Series: Bronchoscopy (<http://www.thoracic.org/sections/education/patient-education/index.html>)
- An **eye exam** with a special lighted tool allows the doctor to look inside the eye for possible signs of sarcoidosis.
- **Blood tests** can show changes in some organs such as the liver, kidney and bone marrow.
- A **CT scan** of the chest may show enlarged lymph nodes

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and scars in the lungs that a regular chest X-ray may not.

- A **Gallium scan** is a special type of X-ray scan that can help show active sarcoidosis in many organs.
- An **electrocardiogram (EKG)** is a test that records a tracing of the electrical activity of the heart. It shows how regularly the heart beats and may show if there is any strain on the heart.

## How serious is sarcoidosis?

The course of sarcoidosis varies greatly among people. In many cases, sarcoidosis is mild. It makes a brief appearance, and then the granulomas may stop growing or shrink. Symptoms may go away within a few years without treatment.

In the moderate form of sarcoidosis, inflammation remains but does not worsen. People with moderate sarcoidosis may have symptoms or flare-ups and only need treatment at times.

The severe form of sarcoidosis slowly worsens over a period of years, and can cause permanent organ damage. Treatment can help, but the disease may still leave scar tissue in the lungs, skin, eyes or other organs. Between 20 and 30 percent of people with pulmonary sarcoidosis end up with permanent lung damage. For some patients, sarcoidosis can become chronic, lasting for many years.

Sarcoidosis has active and inactive phases. In active phases, granulomas (lumps) form and grow. Symptoms develop, and scar tissue can form in the organs where the granulomas are growing. In inactive phases, the disease is not active. The inflammation decreases, and the granulomas stay the same size or shrink. But any old scars will remain and can still cause symptoms.

## How is sarcoidosis treated?

For some sarcoidosis patients, their condition will improve without any treatment. Those who do need treatment are given medicine to reduce inflammation and slow the growth of the granulomas. Treatment is aimed at maintaining good lung function, reducing symptoms and preventing organ damage.

Medicines commonly used to treat sarcoidosis may cause side effects. Side effects range from those that are mild, to those that are severe and potentially dangerous. If you are taking one or more medicines for sarcoidosis, you will need to be monitored closely by your doctor. Medications for sarcoidosis include:

- **Corticosteroids.** The most common corticosteroid prescribed for sarcoidosis is prednisone.
- **Methotrexate.** This medicine may be given to people who cannot take corticosteroids. It also may be used with corticosteroids if needed.
- **Azathioprin, hydroxychloroquine, chlorambucil, cyclophosphamide and pentoxifylline** are other drugs that may be used if corticosteroids and methotrexate are not effective. Thalidomide and minocycline have been used in some cases of skin sarcoidosis.

- **Infliximab** is a new treatment that has proved useful for chronic sarcoidosis, but is currently a drug to use only when standard treatments have failed.

For further information on sarcoidosis medications, please visit <http://www.thoracic.org/sections/education/patient-education/index.html>

## Can I live a normal life with sarcoidosis?

Many people with sarcoidosis can lead normal lives, and are able to carry on with their usual social, intellectual, artistic and athletic activities. There are several important steps a person with active or inactive sarcoidosis can take to keep healthy:

- If your sarcoidosis is active, have frequent medical check-ups so your doctor can monitor your illness and adjust your treatment if needed.
- If your sarcoidosis becomes inactive and/or you have no symptoms, you should visit your healthcare provider for a checkup at least once a year.
- See a medical eye doctor (an ophthalmologist) for an eye exam each year.
- Don't smoke. While smoking doesn't cause sarcoidosis, it can make it worse.
- Avoid dust, chemicals, fumes and other substances that can harm your lungs.
- Exercise and be as active as you can, but don't strain yourself.

### Additional Lung Health Information

#### **American Thoracic Society:**

<http://www.thoracic.org/sections/education/patient-education/index.html>

#### **National Heart, Lung and Blood Institute:**

[www.nhlbi.nih.gov/health/dci/Diseases/sar.whatis.html](http://www.nhlbi.nih.gov/health/dci/Diseases/sar.whatis.html)

#### **American Lung Association:**

[www.lungusa.org](http://www.lungusa.org)

#### **American Lung Association of Canada:**

[www.lung.ca/diseases/sarcoidosis.html](http://www.lung.ca/diseases/sarcoidosis.html)

#### **ATS Public Advisory Roundtable:**

<http://www.thoracic.org/sections/about-ats/par.html>

## Rx Key Points

- ✓ If you are having symptoms or signs of sarcoidosis, go to a healthcare provider promptly.
- ✓ See your healthcare provider and medical eye doctor regularly to monitor your condition.
- ✓ Do not smoke and try to avoid being around tobacco smoke.

#### **Doctor's Office Telephone:**