

What is sarcoidosis?

Sarcoidosis (sar-coy-DOE-sis) is a disease that most often involves the lungs but can involve any other organ in the body including the lymph nodes, skin, liver, heart, eyes, brain, salivary glands and the bone marrow. It causes inflammation in those organs producing tiny clumps of cells called granulomas.

What causes sarcoidosis?

Doctors don't completely understand what causes sarcoidosis. 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. Sarcoidosis does appear in some families suggesting that there may be a hereditary component. It is not contagious.

What are the symptoms of sarcoidosis?

Many people with sarcoidosis do not have any signs or symptoms. Others have only vague symptoms that can be seen in many other illnesses, such as weight loss, fever, loss of appetite, night sweats, fatigue, and sleep problems.

Symptoms that may arise from involvement of 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.
- 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.
- Eyes: Burning, itching, tearing, redness, sensitivity to light, dryness, seeing black spots, blurred vision, reduced color vision, and, in rare cases, blindness.

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.

- 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
- Spleen and Liver: fever, fatigue or itching. There can be pain in the upper right part of the abdomen, under the ribs.





How is Sarcoidosis diagnosed?

There is no specific diagnostic test to diagnose sarcoidosis. Doctors suspect sarcoidosis based on signs and symptoms mentioned above. Tests to help the diagnosis and rule out other conditions that may mimic sarcoidosis may include:

- A chest X-ray to look for enlarged lymph nodes and small round spots in the lungs. A CT scan of the chest may show enlarged lymph nodes and changes in the lungs that might not be visible on a regular chest X-ray.
- Breathing tests to provide an indication of how well the lungs work and the extent of involvement by the sarcoidosis.
- A biopsy—taking a small piece of tissue to examine under a microscope to look for evidence of the disease. In the lung, this is usually obtained through the airways using a procedure called bronchoscopy. Bronchoscopy is also useful to help rule out infections that can cause granulomas and thereby mimic sarcoidosis.
- An eye exam with a special lighted tool allows the doctor to look inside the eye for possible signs of sarcoidosis.
- An electrocardiogram (EKG) –a test that records a tracing of the electrical activity of the heart.



How is sarcoidosis treated?

Not all patients with sarcoidosis need treatment. Sarcoidosis can be subclinical (meaning no symptoms) and in many cases can resolve without medications. Doctors treat sarcoid to improve quality of life or if there is a threat to life. Those who do need treatment are given medicine to reduce inflammation and slow the growth of the granulomas. 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.
- Azathioprine, 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

Will my sarcoidosis get worse?

The course of sarcoidosis varies greatly among people. In many cases, sarcoidosis is mild and may resolve spontaneously. 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. 1 in 4 people with pulmonary sarcoidosis end up with permanent lung damage.

Do you have questions for the physician or nurse? Take a few moments to write down questions you may have to ask at your next visit.



Get Support and Learn More:

You are not alone in this journey!

*For research and clinical studies please visit:
<http://www.inova.org/healthcare-services/lung-transplant/research/index.jsp>

*For appointments concerns contact the front desk at: 703-776-3281

*For issues concerning disability, oxygen and/or work letters: please contact our social worker, Susan Perry at 703-776-5776

*For issues concerning insurance and bill related issues: please contact Lori Hill at 703-776-2577

Rx Action Steps

- If your sarcoidosis is active, follow regularly with your doctor.
- 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

To learn more:

American Thoracic Society
<http://www.thoracic.org/sections/education/patienteducation/index.html>

National Heart, Lung and Blood Institute:
www.nhlbi.nih.gov/health/dci/Diseases/sar.what.html

World association of sarcoidosis and other granulomatous disorders
<https://www.wasog.org/patient-information/patient-information.html>