

MEDfacts

An Educational Health Series From National Jewish Health®



SARCOIDOSIS

Sarcoidosis is a chronic disease that can affect any organ in the body, but most commonly affects the lungs. Very small (microscopic) clusters of inflammation or white cells, called granulomas, are seen in the organs affected with sarcoidosis. These granulomas may clear up on their own, or may cause permanent scarring and organ dysfunction. While there is no cure for sarcoidosis at this time, the disease can be managed to minimize organ dysfunction. Sarcoidosis is likely to have more than one cause.

Sarcoidosis is most common in young people between the ages of 20 and 40 but can affect any age group and race. About 10 to 40 of 100,000 people develop sarcoidosis. Sarcoidosis is not contagious.

What are the Signs and Symptoms?

Sarcoidosis symptoms can vary greatly, and up to half of people with sarcoidosis have no symptoms when the illness is diagnosed. A person with sarcoidosis may have:

- no symptoms (asymptomatic)
- only vague symptoms of a general nature such as weight loss and fever
- symptoms associated with the specific organ that is involved

The lungs are the most common organ affected by sarcoidosis, but any organ can be affected, and more than one organ can be involved. Signs and symptoms associated with specific organ involvement can include:

Lungs

Inflammation in the lungs can cause shortness of breath, wheezing or cough (often a dry cough). In some people, the symptoms go away. In others, there can be permanent scarring and persistent symptoms.

Lymph Nodes

Enlargement of various lymph nodes can occur, especially the lymph nodes in the chest.

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Eye

Inflammation of the eye can lead to redness, pain, dry eyes, and sensitivity to light. Blurred vision also can occur. In some cases there can be eye involvement with no obvious visual problems. It is important that an eye doctor perform an eye exam regularly to determine if there is eye involvement.

Skin

Skin may appear as raised, pink or purplish areas or as painful nodules under the skin.

Bone

Bone involvement is usually detected incidentally, but occasionally can cause pain and rarely fractures.

Spleen and Liver

Enlargement of the spleen or liver that a doctor can feel during a physical exam can occur. The only abnormality may be seen on liver blood tests.

Heart

Heart involvement is thought to occur in up to 40% of sarcoidosis patients and can be difficult to diagnose. Heart involvement can occur without symptoms, can present with heart rhythm abnormalities (too fast or too slow) and can affect the ability of the heart muscle to pump blood.

Brain and Nervous System

Granulomas can develop in the brain and the nerves and cause many symptoms, including loss of sensation, loss of muscle strength, headaches, and dizziness. Only about one in 100 people with sarcoidosis are affected.

Salivary Gland

The salivary gland can be involved with granulomas. People with salivary involvement of their sarcoidosis may have trouble with a dry mouth.

How is sarcoidosis diagnosed?

The first step in diagnosing sarcoidosis is a proper and thorough evaluation. The inflamed microscopic granulomas seen in the affected organ with sarcoidosis are similar to those in other diseases such as tuberculosis, fungal diseases, berylliosis and farmer's lung. Because of this, a careful evaluation is necessary to rule out other diagnoses that can look like sarcoidosis. Only after the known causes of granulomas have been ruled out is the diagnosis of sarcoidosis made.

An evaluation to detect sarcoidosis should include the following:

Thorough Medical Examination: This can help rule out other diseases that may be similar to sarcoidosis.

Chest X-Ray: Doctors look at chest X-rays for evidence of enlarged lymph nodes and small round spots in the lung caused by the clusters of inflammation. "Staging" can help the doctor determine the degree of lung involvement in sarcoidosis. A scale of 0-4 is commonly used, with 4 having the highest amount of lung involvement.

Pulmonary Function Tests: These standard [breathing tests](#) give an indication of the severity of lung disease. There is nothing unique about sarcoidosis on these tests, so they do not substitute for other, more specific tests. Pulmonary function tests can show obstruction of airflow out of the lungs, restriction of the lung's ability to take in air, and a decrease in the transport of oxygen from the lung into the blood stream. The most important types of breathing tests in sarcoidosis are [spirometry](#), lung volumes, and

diffusing capacity. In some cases, measurement of blood oxygen levels during an exercise test should also be done.

Tissue Biopsy: A microscopic examination of tissue samples from the lungs or other affected organs is also needed to be absolutely sure of the diagnosis and exclude other causes. A bronchoscopy can obtain this tissue. A bronchoscopy is an outpatient procedure in which the doctor places a narrow tube through the nose and into the airways. Sometimes the diagnosis is made by obtaining tissue samples from the skin, liver, or enlarged lymph nodes.

Bronchoalveolar Lavage: When a bronchoscopy is done, a small part of lung can be washed (lavaged) in order to obtain some cells of the immune system from the lung. By counting the types of cells in lavage fluid, it is possible to get an estimate of how inflamed the lungs are and whether the type of inflammation is characteristic of sarcoidosis.

Eye Examination: A slit lamp examination by an eye doctor (ophthalmologist) is an important part of an eye examination to detect inflammation.

CT Scan: A CT scan is a detailed type of X-ray. The CT scan may make it possible to see lymph nodes and scars in the lung when regular chest X-rays sometimes cannot.

Calcium Levels in the Blood and Urine: Regulation of calcium may be disturbed in sarcoidosis and this results in too much calcium in the blood and/or urine. Exposure to the sun, calcium and vitamin D supplementation and high dairy intake can further stimulate this process. It may be necessary to collect a urine sample for 24 hours to measure the calcium level in the urine as well as collect a blood sample for blood levels of calcium. High calcium levels in the blood can be associated with symptoms that may include fatigue, abdominal pain/constipation, mental fogginess and can also lead to kidney dysfunction.

PET (Positron Emission Tomography) Scan: This is a special kind of scan where a patient is given radioactive labeled sugar intravenously and then is placed in a special scanning machine to see where the radioactive labeled sugar accumulated. Areas of active inflammation take up the radioactive labeled sugar and are detected with the scanning machine, giving your doctor a better idea of which areas or organs might be involved with sarcoidosis.

Heart Testing: The doctor might order an electrocardiogram to evaluate the electrical system of the heart and an echocardiogram to evaluate the structure and function of the heart. Occasionally, the doctor might order further tests for the heart if there is suspicion of possible heart involvement with sarcoidosis. These tests might include a holter monitor and/or a heart MRI (Magnetic Resonance Imaging).

What is the treatment?

Up to one half of the people diagnosed with sarcoidosis improve without treatment. Those who do not improve are often placed on medicine to reduce inflammation. Many people will recover, but some will get worse despite treatment.

The goals of treatment are to:

- Maintain good organ function
- Lessen symptoms
- Prevent organ damage

Medication

Several medicines are used to treat sarcoidosis.

Corticosteroids: Corticosteroids, which work to reduce inflammation, are the main treatment. Generally, prednisone (a tablet) is given daily or every other day, depending on the symptoms. Prednisone can decrease symptoms, improve lung function, reduce granuloma formation, and possibly lessen scarring of the lungs. Prednisone can be associated with a number of side effects. Because of this, a doctor should carefully monitor people on corticosteroids. Prednisone is not the drug of choice for long-term management of sarcoidosis.

Methotrexate: For long-term management of sarcoidosis, steroid-sparing agents are typically used. Methotrexate is an anti-inflammatory medicine and is often used as a second-line medicine. It may be used with corticosteroids or after stopping corticosteroids.

Other Medicines: Other medicines are used if corticosteroids and methotrexate are not effective. These other medicines are not used often, since their effect on sarcoidosis is not as well understood. They also can have side effects. These medicines include azathioprine, hydroxychloroquine, mycophenolate mofetil and remicade.

Oxygen Therapy

Oxygen therapy may be an important part of a treatment plan for people with severe sarcoidosis. It can help reduce heart and lung side effects of low oxygen levels.

Pulmonary Rehabilitation

For people who develop chronic, progressive sarcoidosis, pulmonary rehabilitation also may be helpful. This includes exercise, healthy eating and education.

Because treatment is so important, a person can improve the outcome of sarcoidosis by seeing a doctor when the symptoms first appear. This can help prevent damage to the lungs, eyes, heart, and other organs. Also, people with sarcoidosis should continue to follow up with their doctor after they have been diagnosed to monitor if the disease is progressing.

Sarcoidosis at National Jewish Health

National Jewish Health is recognized by the World Association for Sarcoidosis and Other Granulomatous Diseases (WASOG) as a WASOG Sarcoidosis Clinic. This designation provides formal recognition of our team's commitment to meet the needs of sarcoidosis patients and efforts to keep abreast of the ongoing advances and findings.

National Jewish Health is currently involved with ongoing research regarding sarcoidosis. This research may be applied to develop better diagnosis and treatment for people with sarcoidosis.

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