

Treatment of Sarcoidosis

Part 2

Sarcoidosis (sar-coy-DOE-sis) is a disease of unknown cause in which inflammatory (white blood) cells clump together and form tiny lumps of cells in various organs and tissues of the body. These lumps are called granulomas (gran-yu-LO-mas). Sarcoidosis most often affects the lungs and its surrounding lymph nodes but can also involve other areas of the body including the eyes, skin, sinuses, liver, kidneys, brain and heart. Sarcoidosis varies in how active and how severe it is for each person and over time. The inflammation in sarcoidosis may resolve spontaneously, even without treatment, or it may persist, causing symptoms and organ damage that may get worse over time. The granulomas, when active, can cause short term and long term damage to the organ involved. This fact sheet reviews treatment of sarcoidosis. For more information about sarcoidosis see 'What is Sarcoidosis' at www.thoracic.org/patients.



How serious is sarcoidosis?

The course of sarcoidosis varies greatly among people and over time for an individual. In many cases, sarcoidosis is mild and self limited. A short time after appearing, the granulomas may stop growing or shrink. Symptoms may go away within a few years without treatment.

Sarcoidosis starts with active, ongoing inflammation. Granulomas (lumps) form and grow. Symptoms develop, and scar tissue can form in the organs where the granulomas are growing. In most patients, the inflammation decreases, and the granulomas stay the same size or shrink within a few years. But any old scars will remain and can still cause symptoms. However, for some patients, sarcoidosis can become chronic, lasting life long.

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, sinuses, heart or other organs. Between 20 and 30 percent of people with pulmonary sarcoidosis end up with permanent lung damage.

The scarring from sarcoidosis is often in upper portions of the lungs. The lungs are at risk of infection due to fungus or bacteria, including mycobacteria. A 'fungus

ball' can form and a person may cough up blood (hemoptysis) as a result of the fungus.

There are two reasons to treat sarcoidosis: concern for developing organ damage (including respiratory failure) and/or to improve quality of life.

Treatment is aimed at maintaining good function of the organ involved, reducing symptoms, improving quality of life, and preventing organ damage. Talk with your healthcare provider about how sarcoidosis is affecting your health and what treatment you may need.

What medicines are used to treat sarcoidosis?

Medications to treat inflammation in sarcoidosis include:

- **Corticosteroids.** The most common corticosteroid prescribed for sarcoidosis is prednisone. Initially, higher doses may be used to control the inflammation. Once your symptoms are better, your healthcare provider may decrease the dose slowly.
- **Methotrexate.** This medicine may be given with or in place of corticosteroids.
- **Azathioprine, hydroxychloroquine, mycophenolate** are other drugs that may be used if corticosteroids and methotrexate are not effective. Thalidomide and minocycline may be used in skin sarcoidosis.

- **Infliximab** and **adalimumab** are newer treatments that have proved useful for chronic sarcoidosis when standard treatments have failed.

Research continues to try to find new treatment for sarcoidosis. Other drugs are currently being tested in clinical trials.

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 healthcare provider.

Other medicines used for symptoms in sarcoidosis

Some medications may help improve the symptoms from sarcoidosis without treating the sarcoidosis itself. Sarcoidosis associated fatigue may be treated with neurostimulants such as methylphenidate and modafinil. Small fiber neuropathy may be treated with medicines such as gabapentin.

Is there any role for lung transplantation in sarcoidosis?

Some people with advanced lung disease because of sarcoidosis may be eligible to receive a lung transplant. Many factors go into deciding if you need a transplant and will be able to tolerate the surgery. Your healthcare provider can refer you to a lung transplant center for further testing and information. For additional information on lung transplantation, go to www.thoracic.org/patients/.

What else can I do to stay as healthy as possible 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 you are not taking any medications and have no symptoms from your sarcoidosis, you should visit your healthcare provider for a checkup at least once a year for at least the first few years.
- See a medical eye specialist (an ophthalmologist) for an eye exam each year.
- Don't smoke. While smoking doesn't cause sarcoidosis, it can make your lung function worse. For help quitting smoking, go to www.thoracic.org/patients.

- 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. A pulmonary rehabilitation program is a good way to gradually increase your exercise capacity. Research has shown that a supervised pulmonary rehabilitation program may reduce fatigue and improve a person's quality of life. For more information, see ATS Patient Information Series "Pulmonary Rehabilitation at www.thoracic.org/patients".

Authors: Ganesh Raghu, MD; Jeffrey S. Berman, MD; Praveen Govender, MD

Reviewers: Marianna Sockrider MD, DrPH; Hrishikesh S. Kulkarni, MD; Ginger Spitzer

Rx Action Steps

- ✓ Talk with your healthcare provider about whether you need treatment for sarcoidosis and what options you have.
- ✓ Do not smoke and try to avoid being around tobacco smoke.
- ✓ Take action to stay healthy and watch for early changes with sarcoidosis.

Healthcare Provider's Contact Number:

Additional Lung Health Information

Foundation for Sarcoidosis Research

<http://www.stopsarcoidosis.org>

American Thoracic Society

www.thoracic.org/patients

National Heart, Lung and Blood Institute

<http://www.nhlbi.nih.gov/health/health-topics/topics/sarc>
(also available in Spanish)

American Lung Association

<http://www.lung.org/lung-health-and-diseases/lung-disease-lookup/sarcoidosis/learn-about-sarcoidosis.html>

American Lung Association of Canada

<http://www.lung.ca/lung-health/lung-disease/sarcoidosis-1>

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