

What is sarcoidosis?

Sarcoidosis causes clusters of abnormal tissue to form in the body, called granulomas. Granulomas can grow in different organs like the lungs, skin, eyes, liver, kidneys or other areas of the body.

There are many theories on what causes sarcoidosis but the exact cause is not known. Some believe it is related to genes or something in the environment.

What are the symptoms of sarcoidosis?

Symptoms include fever, feeling tired and losing weight. Sarcoidosis can cause other symptoms depending on the organ involved. For example, if sarcoidosis is in the lung you may cough, feel short of breath or have chest pain.

How is the diagnosis of sarcoidosis made?

There is not one test to diagnose sarcoidosis. Other diseases can cause granulomas to form in the body and have symptoms like sarcoidosis. Your provider will do blood tests, xrays and a biopsy of the granuloma to help make the diagnosis.

What happens after the diagnosis is made?

After you are first diagnosed with sarcoidosis, tests will need to be done to see which organs in your body have sarcoidosis. These tests include:

1. History and physical exam
2. Chest X-ray
3. Pulmonary function tests (PFT or breathing tests)
4. Blood draw: for blood counts, calcium level, liver function and kidney function tests, TB test, immunoglobulins (immune cell levels), fungal tests
5. Electrocardiogram (ECG - tracing of the heart rhythm)
6. Ophthalmologic (eye) exam

How is sarcoidosis treated?

Many people with sarcoidosis do not need treatment and the disease will go away or stabilize on its own. There is no medicine to cure sarcoidosis.

Medicines are used if you are having lots of symptoms caused by sarcoidosis. Medicines are used if sarcoidosis is in the eye, kidney, heart or nervous system, even if symptoms are mild.

The most common medicine used to treat sarcoidosis is glucocorticoids (steroids). Usually prednisone is started at high doses and cut down slowly over time. Medicine is given for at least 12 months even if you start feeling better before then. You will be watched closely after the medicine is stopped to see if your symptoms come back (relapse). Other medicines can be used with steroids for stronger effect or used in place of steroids if you are having side effects to the steroids.

Below are some of the medicines used to treat sarcoidosis and their side effects:

1. Glucocorticoids (steroids): Prednisone is the most common steroid used. It has many side effects so the lowest dose to stop your symptoms is used.

Common side effects: weight gain, acne, swelling in the hands or feet, mood swings, problems sleeping. If you take this medicine for a while you can get diabetes, thin skin, osteoporosis (weak bones), cataracts, high blood pressure, stomach ulcers, avascular necrosis (problem in the hip joint) or infections.

Don't take NSAIDs (Advil, Motrin, Ibuprofen, aspirin) or drink alcohol (wine, beer, liquor) while on this medicine.

2. Methotrexate: lowers inflammation in the body and can be used with steroids. It is taken once a week in pill form.

Common side effects include: nausea, vomiting, headache, rash, hair loss or mouth sores. Rare side effects include liver damage, kidney damage, low blood counts or lung damage. If you take this medicine for a long time you are at risk of lymphomas (blood cancers).

Take folic acid 1 mg every day to help cut down on the side effects.

Don't take NSAIDs (Advil, Motrin, Ibuprofen, aspirin) or drink alcohol (wine, beer, liquor) while on this medicine. Don't take this medicine if you are pregnant or breast-feeding. Always use birth control while you are on this medicine.

Before starting the medicine your blood will be checked for: liver function, hepatitis, blood counts and kidney function. After your dose is stable your blood will be checked every 1-2 months.

3. Azathioprine: lowers the immune system and can be used with steroids. This medicine is used if methotrexate does not work.

Common side Effects: nausea, vomiting, diarrhea, rash, fever, feeling tired. Rare side effects include liver damage or low blood counts. If you have had a kidney transplant you may be at risk for cancer on this medicine.

Always use birth control while you are on this medicine.

Before starting the medicine your blood will be checked for: liver function, kidney function and blood counts. After your dose is stable your blood will be checked every 2 months.

4. Leflunomide: cuts down on symptoms of sarcoidosis and can be used by itself or with other medicines.

Common side effects: nausea, diarrhea, stomach pain, liver damage, rash or nerve pain.

Always use birth control while you are on this medicine and for 2 years after you stop the medicine. Don't drink alcohol (wine, beer, liquor) while taking this medicine.

Before starting the medicine your blood will be checked for: liver function, hepatitis, blood counts, kidney function. After your dose is stable your blood will be checked every 1-2 months.

There are other medicines that can be used if you do not get better on these medicines.

What to expect during and after treatment?

The medicine should make you feel better. If you have sarcoidosis of the lung your breathing tests (PFT) and chest x-ray should get better. In severe cases, the tests may not get better but the medicine keeps the sarcoidosis from getting any worse.

Sometimes symptoms come back (relapse) when the medicine is stopped but should go away if the medicine is started again. The prognosis is good when you have sarcoidosis. Permanent organ damage can happen in 10-20% of people with sarcoidosis. About 1-5% of people die from sarcoidosis which is more likely if sarcoidosis is in the lungs or heart.

Where to find more information or get involved in advocacy groups?

www.stopsarcoidosis.org (Foundation for Sarcoidosis Research)

<http://www.nlm.nih.gov/health/health-topics/topics/sarc/> (NIH summary on sarcoidosis)

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References

--Joint ATS, ERS and WASOG Executive Committee. Statement on Sarcoidosis. American Journal of Respiratory and Critical Care Medicine 1999; 160: 736-55.

--King T. Treatment of Pulmonary sarcoidosis with alternatives to glucocorticoids. www.uptodate.com. 2012.