

Understanding Sarcoidosis

What is sarcoidosis?

Sarcoidosis is an inflammatory disease that starts in the lungs and is characterized by granulomas (small rounded outgrowths made up of blood vessels, cells and connective tissues) that can produce many different symptoms. They are called granulomas because they look like grains of sugar or sand. These tiny granulomas can grow and clump together. If too many granulomas form in an organ, they can affect how the organ works.

Sarcoidosis can occur in almost any part of the body, although it affects some organs more than others. It usually starts in either the lungs or lymph nodes, especially the lymph nodes in the chest cavity.

Sarcoidosis is generally a chronic (long-term) disease, lasting for several years or a lifetime. Some people, however, may have a type that only lasts a few months.

What causes it?

It is believed that sarcoidosis develops when a person's immune system overreacts to something in the environment (bacteria, viruses, dust, chemicals, etc.) or perhaps mistakenly turns on the body's healthy cells (called autoimmunity). Although the exact reason for this overreaction is unknown, suspected causes include:

- A viral or bacterial infection
- A defect in the body's immune system
- An unidentified toxic substance
- An unknown environmental cause
- An inherited or genetic factor

Who gets sarcoidosis?

Sarcoidosis was once thought to be an uncommon condition, but it is now known to affect tens of thousands of people. Sarcoidosis can occur at any age, but it is most common in young adults between 20 and 40, with 70 percent of patients being under 40. African Americans and people of Scandinavian, German or Irish descent are particularly at risk. Although sarcoidosis affects white men and women about equally, African American women get the disease twice as often as African American men.

What are its symptoms?

Sometimes sarcoidosis develops gradually and produces symptoms that last for years or it may appear suddenly and then disappear just as quickly. In either case, symptoms can vary, depending on which organs are affected and how long a person has had the disease.

Sarcoidosis that affects only the lungs, for example, may cause few, if any, symptoms. In fact, many people do not know they have the disease until it shows up on a routine chest x-ray. More advanced forms of the disease may cause shortness of breath and a cough that won't go away.

Other signs and symptoms of sarcoidosis include:

- A vague feeling of discomfort and fatigue and an overall feeling of ill health
- Fever, night sweats

- Sleep problems
- Loss of appetite or weight loss
- Small red bumps on your face, arms or buttocks, a condition more common in blacks than in whites
- Red, watery eyes
- Arthritis in the ankles, elbows, wrists and hands, commonly associated with bumps in the skin over the shins (erythema nodosum)

How is sarcoidosis diagnosed?

Sarcoidosis produces few symptoms in its early stages. When symptoms do occur, they often resemble those of other illnesses. For that reason, doctors will usually diagnose sarcoidosis only after ruling out diseases with similar features, such as lymph cancer, tuberculosis, rheumatoid arthritis, rheumatic fever and fungal infections.

No single noninvasive test can positively identify sarcoidosis, but initially, doctors are likely to order a chest x-ray. Depending on the results, a patient may then have additional tests to confirm the diagnosis, including a transbronchial biopsy, which uses a flexible scope to collect lung tissue specimens.

How serious is it?

In many people, sarcoidosis is mild and the inflammation that causes the granulomas may get better on its own. For some, the inflammation comes and goes or remains but doesn't get worse.

For a small percentage of patients, sarcoidosis slowly gets worse over the years and can cause permanent organ damage. Although treatment can help, sarcoidosis may leave scar tissue in the lungs, skin, eyes or other organs. The scar tissue can affect how the organs work. In some serious cases in which vital organs are affected, sarcoidosis can result in death.

How is sarcoidosis treated?

Treatment may not be needed if sarcoidosis is only affecting the lungs and nearby lymph nodes. Since sarcoidosis often disappears on its own at this stage, doctors are more likely just to monitor the patient and recommend physical therapy.

When chest x-rays reveal more widespread areas of lung inflammation, the doctor may monitor the disease for 3 to 12 months and begin treatment only if the inflammation hasn't improved or has progressed.

Treatment with medications is usually recommended if the patient's heart, eyes or central nervous system is involved or if blood-calcium level is elevated. Doctors with special expertise in sarcoidosis should manage patients who are on regular prednisone therapy.

More information about sarcoidosis

A patient's own lung specialist is the best source for information about sarcoidosis.

Other sources include:

The American Lung Association

www.lungusa.org

National Institutes of Health, National Heart, Lung and Blood Institute

www.nhlbi.nih.gov

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