

KNOW SARCOIDOSIS / SUPPORT RESOURCES

# SARCOIDOSIS FACT SHEET

## WHAT IS SARCOIDOSIS?

Sarcoidosis ("sar-coy-DOE-sis") is a condition that involves inflammation in your body. The inflammation forms tiny clumps of cells. These are called granulomas. They are so tiny that only a microscope can see them. Even though they are so small, these clumps can cause a lot of problems. They can affect any organ in your body. Most often they affect the following ones:

- LUNGS
- LYMPH NODES
- EYES
- SKIN

Doctors do not know for certain what causes sarcoidosis, but there are some theories:

Environmental factors: Since it often affects the lungs, eyes, and skin, sarcoidosis may be triggered by something in the environment. An example might be an airborne substance that you take in and that causes your body to react against itself.

Genetics: Certain genes may also play a role. But exactly which gene or group of genes may be involved is still not known.

Both genetic and environmental factors may be involved in sarcoidosis. Some people may have certain genes that make them more prone to sarcoidosis when they are exposed to a certain substance. More research is needed in this area.

Diagnosis: About 20% of people with sarcoidosis will see a doctor more than 6 times before getting diagnosed.

### SIGNS AND SYMPTOMS OF SARCOIDOSIS

Sarcoidosis symptoms can differ from person to person. They vary depending on which organs may be affected:



Lungs: More than 90% of people with sarcoidosis have lung problems. These problems may include shortness of breath, wheezing, dry cough, or chest discomfort. Up to 30% of people with sarcoidosis-related lung issues develop chronic sarcoidosis. This can potentially lead to longterm symptoms.



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**Eyes:** About 25% of people with sarcoidosis have eye-related problems. These symptoms include burning, itching, tearing, redness, or dryness. Eyes may also become sensitive to light. Seeing black spots, blurred vision, or reduced color vision can also occur. In rare cases, loss of vision can occur as well. Eye-related problems can potentially lead to serious, long-term complications.



**Skin:** About 25% of people with sarcoidosis will have some form of skin-related symptoms. These may include a painless rash; painful, reddish bumps (near the nose or eyes, or on the back, arms, legs, or scalp); hair loss; or painful bumps on the ankles or shins. Scarring of the skin may also occur in some cases.



**Joints:** Some people (about 10-15%) have symptoms that affect bones, muscles, and joints. These include painful, bony lumps in the hands and feet, and pain and swelling in the ankles or other joints. Arthritis and changes in bone structure may also occur.



**Heart:** Roughly 28% of people with sarcoidosis develop heart problems. But only 5% experience symptoms related to the heart. These symptoms include shortness of breath, swelling in the legs, wheezing, coughing, or chest pain. An abnormal or fast heartbeat may also occur. Fainting without warning can also be a sign of heart symptoms. Problems in the heart can potentially lead to serious, long-term complications.



**Lymph nodes:** Sarcoidosis may affect the lymph nodes, causing tenderness or swelling in the area around the neck, chest, chin, armpits, or groin.



Liver: Sarcoidosis affects the liver in about 50-80% of cases. Even so, symptoms that are related to the liver do not usually occur. These problems can be silent. If symptoms do occur, they may include fever, fatigue, itching, or pain below the ribs, usually in the upper-right part of the belly.



**Kidneys:** Sarcoidosis can affect the way your kidneys manage calcium in your body. In 2-10% of patients, this causes too much calcium in the blood. In 21% of patients it causes too much calcium in the urine. Sarcoidosis may also cause kidney stones and other problems.



**Nervous system:** Up to 5-10% of people may have problems with their nervous systems. These symptoms may include headaches, vision problems, weakness, numbness, loss of movement in an arm or leg, or drooping of one side of the face. General weakness or pain, or a "pins and needles" feeling, may also occur. Issues in the brain can potentially lead to serious, long-term complications.



**Spleen:** Though rare, sarcoidosis can affect the spleen. Symptoms may include an enlargement of the spleen, fever, fatigue, itching, weight loss, and pain in the upper right part of the midsection.



**Salivary glands:** Sarcoidosis can affect the salivary glands. It can cause swelling, pain, and dryness in the mouth and throat.



Male reproductive organs: About 5% of males with sarcoidosis have problems with their reproductive organs. Symptoms may include pain and swelling in or near these organs. Problems may include infertility and erectile dysfunction (ED).



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### **HEALTHY TIPS FOR LIVING WITH SARCOIDOSIS**

There are some healthy tips you may try if you have sarcoidosis. Check with your doctor if he or she recommends these.

For active sarcoidosis: Have frequent medical check-ups. This allows your doctor to monitor your illness and, if needed, adjust your treatment.

For inactive sarcoidosis: See your doctor at least once a year for a check-up.

**Get a yearly eye exam.** It's important to schedule regular check-ups with an eye doctor (ophthalmologist) if you have sarcoidosis.

Try to stay active and exercise when you can. Start any new exercise routine slowly. Take your time and never push yourself. **And always talk with your doctor** before starting any new exercise plan. He or she can help you determine the type of exercise that may be right for you.

Maintain a healthy diet. Whether you have sarcoidosis or not, it's important to make healthy choices when it comes to your diet and nutrition.

Studies have shown that the right diet may lead to some potential health benefits. For example, a diet that's rich in fruits and vegetables, low-fat or non-fat dairy foods, and whole grains may reduce your risk of some major health problems.

REMEMBER: ALWAYS TALK WITH YOUR DOCTOR FIRST BEFORE MAKING A CHANGE IN YOUR DIET OR STARTING A NEW EXERCISE ROUTINE.

**Avoid smoking.** Smoking is not believed to cause sarcoidosis. If you are a smoker, it's important to talk to your doctor about quitting.

Try avoiding substances that may be harmful to your lungs. Certain substances in the air may worsen chronic lung disease. If possible, try to avoid harmful inhalants.

**Stress may impact sarcoidosis.** In fact, it may cause it to become worse. It's important to stay in touch with your feelings. It's also important to try and learn how to spot severe stress when it arises and manage it.

Mallinckrodt intends this document to be informative, but you should remember the contents are general in nature and not meant to substitute for specific advice from professionals that may be necessary based on your individual questions and needs. We have made reasonable efforts to provide helpful and accurate information, however we make no guarantees and you should not solely rely on the information included in this document.

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