



Interstitial Lung Disease Guideline

Appendix 8

Patient Information for Sarcoidosis

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PATIENT INFORMATION FOR SARCOIDOSIS

What is sarcoidosis?

Sarcoidosis (also known as sarcoid) is a disease resulting in small nodules of inflammation and scarring (called granulomas) throughout the body. Sarcoidosis most commonly affects the lungs and skin but other organs can be affected.

What causes sarcoidosis?

We do not know the cause of sarcoidosis but it probably results from something in the environment causing the disease in a patient who is susceptible, probably as a result of their genes. Sarcoidosis is not hereditary and cannot be passed on to children. Occasionally, more than one family member may have sarcoidosis, but there is no evidence that the condition can be passed on from one person to another. Sarcoidosis is a relatively rare disease occurring in 1 in 10,000 people in the UK. The disease affects all races and ages but is most commonly found in those between 20-40 years of age.

What are the symptoms of sarcoidosis?

Sarcoidosis may range from a very minor illness to a more severe condition. Each patient with sarcoidosis is different and most will only have a few of these symptoms.

General symptoms

Many patients with sarcoidosis experience fatigue or tiredness.

Respiratory (lung) symptoms

Sarcoidosis commonly affects the lungs but may not cause any symptoms. If they do occur, the common symptoms are dry cough, breathlessness and sometimes a discomfort in the centre of the chest.

Lymph glands

Sarcoidosis commonly affects lymph glands causing them to swell. For example you may notice swollen neck glands.

Skin

Sarcoidosis often affects the skin causing small bumps (nodules or papules) anywhere on the skin or just under the surface of the skin. Sometimes, at the start of sarcoidosis a red/purplish rash, called erythema nodosum, may occur on the front of the shins.

Other symptoms

Sarcoidosis can affect the eyes, causing them to be red and sore. Bones and joints may become inflamed and painful. The heart is sometimes affected and this may cause irregularities in the heart-beat or affect the heart function causing breathlessness. Sarcoidosis can cause the level of calcium in the blood to go up and this can lead to problems with kidney function. Blood tests may show that the liver has been affected by sarcoidosis. Sometimes sarcoidosis causes problems with nerves causing weakness or abnormal sensation.

How is sarcoidosis diagnosed?

Sarcoidosis is diagnosed in different ways according to which organ is affected. In most cases evidence of sarcoidosis is visible on a chest x-ray or CT scan of the lungs. In many cases tissue from the affected organs is sampled (called a biopsy) and examined under the microscope to confirm the presence of sarcoidosis. Biopsies from the lung may require a procedure called a bronchoscopy, in which a telescope is passed into the lung, or sometimes an operation is needed to obtain lung samples.

Once sarcoidosis is diagnosed, patients may require further investigation to see if the disease is present in different organs and how severely these have been affected. The tests will vary according to your symptoms but often includes lung function (breathing) tests which indicate if the lungs has been affected and heart tests including an ECG (heart tracing). Patients with sarcoidosis usually have blood tests to look at blood cells, calcium levels and liver and kidney function.

How is sarcoidosis treated?

Not all patients with sarcoidosis need drug treatment. Sarcoidosis may often be active for a period of months to years and then improve without treatment and cause no further problems. Because of this it is common for doctors to observe a patient's symptoms and tests for a period of some months before considering treatment. In some patients where symptoms are severe or an organ is seriously affected treatment will be started straight away.

Steroid treatment for sarcoidosis

Steroids are the commonest and most effective treatment for sarcoidosis. Prednisolone is the most commonly used drug and usually a moderate to high dose is given for 6-12 weeks and gradually reduced according to the response. Treatment is usually given for between six months and two years and if the disease appears inactive after this time may be cautiously withdrawn. Steroids may have significant side effects including blood pressure, diabetes, osteoporosis, weight gain, bruising, and your doctor will discuss the benefits and risks of steroids with you.

Other drugs for sarcoidosis

In patients steroids are ineffective or cause unacceptable side-effects. In such cases, other drugs can be used to try and help control the disease. Commonly used drugs are methotrexate, azathioprine and hydroxychloroquine. All of these drugs have different types of side effects and your doctor will discuss these with you in detail should they be required for your condition.

Other treatments

Occasionally other treatments are required including treatment of severe lung fibrosis due to sarcoidosis which may need oxygen and in rare cases lung transplantation. Damage to the conducting system or other parts of the heart can require treatment including a pacemaker or other treatments for heart failure. Specific treatments may also be used in the eyes and skin.

What is the prognosis for patients with sarcoidosis?

Sarcoidosis is often not a serious disease and in some cases will resolve with or without treatment. However sarcoidosis can occasionally cause major handicap depending on which organs are involved and rarely sarcoidosis can be life-threatening. Some patients with sarcoidosis will therefore need to be followed up for many years by specialists in the hospital.

Further information

This sheet contains general information about sarcoidosis. As the disease affects different people in different ways, it is best to discuss your disease with your own doctor.