Sarcoidosis, or sarcoid, is a disease in which certain inflammatory cells clump together and form nodules known as granulomas in various parts of the body. The most common organs to be affected by sarcoidosis are the lungs, the skin and the eyes, although in some people almost any part of the body can be involved.

In most cases the body’s immune system heals the granulomas over a few years. Sometimes, for reasons that are not understood, this does not happen and scar tissue is formed. This is called fibrosis and can result in permanent damage.

How many people have sarcoidosis?

Sarcoidosis is an uncommon condition, although the number of people diagnosed varies from country to country. It is difficult to be sure how many people have sarcoidosis throughout the world, as many do not know they have it and sometimes it can be mistaken for other diseases. In the UK, about 3,000 new cases of sarcoidosis are diagnosed each year. It can affect people of any age, but is more common in young adults and is slightly more common in women. In some populations, such as Afro-Caribbean, Irish and Swedish people, it can affect up to 60 out of every 100,000 people.

What causes sarcoidosis?

Nobody knows the cause of sarcoidosis even though much scientific research is being carried out to answer this question. It is also not clear why sarcoidosis affects different people in different ways. Some scientists think it may be due to an environmental toxin or a virus that triggers the body to react in a certain way. A person’s individual genetic make-up may also be important.

Despite these uncertainties, if you are a patient who has been diagnosed with sarcoidosis, you can be reassured by some of the following facts:

- The majority of people with sarcoidosis get better without specific treatment within 12 to 18 months and lead perfectly normal lives
- Sarcoidosis is not infectious; you cannot catch it and it cannot be passed between people
- Sarcoidosis is not a form of cancer

The most common symptoms in people with sarcoidosis include:

- Shortness of breath and a dry cough
- A flu-like illness with fever, tiredness and joint pains
- A painful red rash usually occurring on the arms or legs
- Eye irritation and visual problems
- Swollen glands, which can be felt in the neck or around the face
How do I know if I have sarcoidosis?

It can be discovered by chance, for example, when chest X-ray is done for other reasons, such as for an employment medical.

How will my condition be diagnosed?

The diagnosis of sarcoidosis can be difficult and may take time, because other diseases closely resemble sarcoidosis. In some cases tissue samples or biopsies are needed. These are usually taken from the lungs, glands in the neck or chest, or from the skin. If a biopsy is needed it will usually be straightforward and be done under local anaesthetic.

Tests in hospital help to show how severe the disease is and what parts of the body are affected. Many people do not need treatment and can be simply monitored regularly. Your doctor will discuss with you whether you need treatment for your sarcoidosis and advise you on the best options.

<table>
<thead>
<tr>
<th>Test</th>
<th>Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chest X-ray</td>
<td>Determines whether the lungs and lymph glands in the chest are involved</td>
</tr>
<tr>
<td>Heart tracing (ECG) and scan (ECHO)</td>
<td>Used to monitor if sarcoidosis has affected the heart</td>
</tr>
<tr>
<td>Blood tests</td>
<td>Help to identify which organs are involved and can exclude other diseases</td>
</tr>
<tr>
<td>CT scan of the chest</td>
<td>Gives more detailed information about the lungs and glands in the chest</td>
</tr>
<tr>
<td>Lung function tests</td>
<td>Used to check if sarcoidosis is affecting the function of the lungs</td>
</tr>
</tbody>
</table>

How will I be treated?

Systemic treatment is usually recommended when sarcoidosis affects the brain or heart and when sarcoidosis is affecting lung function. For eye and skin involvement, treatment decision depends on the extent of the area involved. The most common drug used is prednisolone (a steroid). Sarcoidosis responds very well to steroids, although they do not cure the disease, which may relapse after the steroids are stopped. Steroids can also cause side effects, such as weight gain, diabetes, thinning of the bones, and thinning of the skin and easy bruising. Therefore, the decision to use steroids must be carefully considered and your doctor will help you balance the risk and benefits of treatment. If a decision is made to start steroids, your doctor will help you to find the lowest dose of steroids that control your symptoms by gradually lowering the dose you take: this is called tapering. There are other drugs available, but these are generally less effective than steroids.

Useful websites

World Association of Sarcoidosis and Other Granulomatous Disorders (WASOG): www.wasog.org