

WHAT ARE THE AIMS OF THIS LEAFLET?

This leaflet has been written to help you understand more about sarcoidosis of the skin. It will tell you what it is, what causes it, how it is diagnosed, how it can be treated and where to find out more about it.

WHAT IS SARCOIDOSIS?

Sarcoidosis is a disease that affects approximately 1 in 10,000 people and can affect one or more organs of the body. Most commonly it affects the skin (approximately 1 in 4 people), lungs, lymph nodes, or eyes. Less often, it can affect the joints, the nervous system, the liver and the kidneys. Sarcoidosis causes a type of inflammation known as a 'granuloma', which consists of a cluster of cells that can cause raised lumps on the skin. Involvement in one part of the body does not necessarily mean it will extend to other organs.

WHAT CAUSES SARCOIDOSIS?

The cause of sarcoidosis is not fully understood, although it is thought to be due to genetics, environmental factors, infections, and in some cases, autoimmune conditions (when the immune system attacks the body). The specific roles of these factors are unclear.

Sarcoidosis is not infectious and cannot be passed from person to person. It is not a cancerous condition. It can affect people of all ages and races. The number of people affected by sarcoidosis in a given population is not completely understood but is affected by ethnicity and geographical location.

WHAT DOES SARCOIDOSIS LOOK AND FEEL LIKE?

People with sarcoidosis may experience many different symptoms, or in its early stages there may be no symptoms. Symptoms can be vague (or not very specific) but may include feeling tired, fever, aches and pains in the joints, persistent dry cough, shortness of breath, and losing weight. When sarcoidosis affects the skin, it can have several different appearances (please see below).

HOW DOES SARCOIDOSIS AFFECT THE SKIN?

- Papules and plaques (raised areas): This is the most common presentation for sarcoidosis on the skin. It is in the form of small, raised bumps (papules) or larger plaques. Plaques can be smooth or scaly. They may be purplish red or brown in colour. They can occur anywhere on the body, including the face.
- Erythema nodosum: These are painful deep red lumps (nodules) that often occur on the shins. As they fade, they may leave behind a bruise-like discolouration of the skin. Some people experience fever, sore joints and feel unwell when erythema nodosum first appears. One in 4 people affected by sarcoidosis will have this skin condition.
- Lupus pernio: This refers to dark red, purplish or brown swollen areas that appear on the nose, cheeks, ears or fingers. This can be difficult to treat successfully and can result in scarring when it settles down. Lupus pernio is often linked with sarcoidosis in other parts of the body such as the lungs.

When sarcoidosis affects the skin, it may cause a number of specific issues including:

- Tattoo/Scar sarcoidosis: This is a rare type of sarcoidosis in the skin, where an existing scar or tattoo becomes red, raised and firm compared with the skin around the scar. Frequency of this problem is not known at present.
- Scalp: when the scalp is involved it may involve hair loss.

- Nail: the nails may be affected which can cause thickening, ridging and rarely scarring or loss of the nail.
- Oral disease: Rarely sarcoidosis can affect the mouth and may cause localised swelling or raised lumps or nodules.

HOW IS SARCOIDOSIS IN THE SKIN DIAGNOSED?

To diagnose sarcoidosis in the skin, a small sample (biopsy) is taken from the affected area by your doctor, and then looked at under the microscope. Your doctor may perform blood tests to check the level of calcium and angiotensin-converting-enzyme (ACE) in the blood. Both can be elevated in sarcoidosis. Depending on your symptoms, your doctor may also perform additional tests to look for other affected areas. This may include assessment of the heart, lungs and eyes. Your specialist may also recommend referral to other specialists depending on the extent of symptoms and signs of the condition.

CAN SARCOIDOSIS BE CURED?

At present there is no known cure for sarcoidosis. The aim of treatment is to suppress the condition. However, in 6 out of 10 people affected by sarcoidosis, the disease will completely settle down within 2 to 5 years.

HOW CAN SARCOIDOSIS BE TREATED?

Not all people affected by sarcoidosis require treatment. The disease can remain stable or settle down by itself without any treatment.

For sarcoidosis that is only affecting the skin, the most common form of treatment is the application of strong topical corticosteroids (steroid creams or ointments) to the affected area of skin. Your doctor may sometimes inject steroid in liquid form directly into the skin lesion to help it settle down – this is called intralesional steroid therapy.

If these methods are ineffective, or if large areas of the skin are affected, your doctor may consider oral medicines that dampen down the immune system. These include oral corticosteroids (for example, prednisolone) or steroid-sparing tablets (e.g. methotrexate).

WHERE CAN I GET MORE INFORMATION ABOUT SARCOIDOSIS?

Sarcoidosis UK

Tel: 020 3389 7221 0800 014 8821 (Freephone) Web: www.sarcoidosisuk.org/

Please note that the British Association of Dermatologists (BAD) provides web links to additional resources to help people access a range of information about their treatment or skin condition. The views expressed in these external resources may not be shared by the BAD or its members. The BAD has no control of and does not endorse the content of external links.

This leaflet aims to provide accurate information about the subject and is a consensus of the views held by representatives of the British Association of Dermatologists: individual patient circumstances may differ, which might alter both the advice and course of therapy given to you by your doctor.

This leaflet has been assessed for readability by the British Association of Dermatologists' Patient Information Lay Review Panel

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