

Rarely sarcoidosis can affect the adrenal glands directly with granulomas disrupting the normal functioning of the gland.

If the adrenal glands cannot produce enough hormones this is adrenal insufficiency or secondary adrenal failure.

Symptoms

- Fatigue
- Weight loss
- Low blood pressure (which can cause dizziness or fainting, especially when standing up.)

Adrenal insufficiency can be difficult to recognise and cause you to be unwell at short notice. You should have a steroid card and have instructions about precautions you, and people helping you, need to follow if you are unwell.

Pancreas involvement

Very rarely, sarcoidosis may involve the pancreas either because granulomas in the pancreas, or lymph nodes nearby, affect its function producing and draining bile and enzymes for digestion. Even more rarely, the pancreas' ability to make insulin can be damaged, leading to diabetes mellitus.

The steroids used to control sarcoidosis can irritate the pancreas, which can damage both its digestive function and its insulin production. The steroids can also contribute to weight gain, increasing the demands on the pancreas which can lead to diabetes mellitus.

Treatment

When sarcoidosis affects the hypothalamus and pituitary, thyroid, adrenal or pancreas, treatment focuses on medications to treat sarcoidosis and medications to replace the hormones that your body is not producing.

Who We Are:

SarcoidosisUK provide support and information to anyone affected by sarcoidosis. We also raise awareness and fund research. Contact Us for information on our Support Group network and free Nurse Helpline.

How You Can Help:

Donate:

www.sarcoidosisuk.org/donate

Get involved in medical research:

www.sarcoidosisuk.org/research/get-involved-sarcoidosis-research

Thanks to:

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SARCOIDOSIS ENDOCRINE SYSTEM

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Sarcoidosis, your metabolism, and your hormones

Sarcoidosis and calcium

An increased level of calcium in the blood and/or urine is common in sarcoidosis. We see high blood calcium in 1 in 10 people with sarcoidosis.

Why is calcium and vitamin D important?

Calcium is essential for a healthy skeleton but it is also important for nerve and muscle function. Calcium levels are regulated by vitamin D, which we produce in our skin using sun light, and obtain in our diet through foods like oily fish.

Low levels of calcium and vitamin D can contribute towards thinning of the bones (osteopenia or osteoporosis) which becomes more common as we age. Medications used to treat sarcoidosis including steroids, affect the calcium metabolism and contribute to osteoporosis.

High levels of calcium in sarcoidosis

In sarcoidosis, clusters of cells called granulomas develop at different sites within your body. The inflammation in sarcoidosis increases the activity of an enzyme which converts inactive vitamin D to its active form. This is essential for the body's absorption and use of calcium. Too much active vitamin D can cause the body to absorb too much calcium, elevating the blood and urine calcium levels.

Symptoms

High calcium levels can cause:

- stomach pain
- constipation
- fatigue, depression and even confusion
- kidney stones and kidney damage (rare)

Preventing high calcium

For most people, calcium and vitamin D supplements are very safe, but for some people with sarcoid, there is a risk of supplements increasing blood levels of calcium and vitamin D.

It is essential that you have your calcium in the serum and urine and vitamin D level measured before you start any supplements, and that these levels are monitored whilst you remain on therapy (usually with a blood test two months after starting therapy).

Sarcoidosis and hormone production

1. Hypothalamic-Pituitary Involvement:

Hypothalamic-pituitary sarcoidosis occurs in less than 1 in 20 people with sarcoidosis.

Granulomas can form in the brain at the hypothalamus and pituitary gland. These glands are involved in your body's hormone system. The hypothalamus is a control centre that sends signals to the pituitary gland to release hormones that control growth, temperature, libido, periods, erections, metabolic rate, blood pressure, and other vital functions.

Symptoms

If sarcoidosis affects these parts of the body, it can cause swelling. This might lead to headaches and changes in vision. It can lead to different symptoms if it affects the controls or production of hormones.

- changes in menstrual cycles for women,
- problems with sexual interest and function
- changes in your energy and/or weight
- increase in thirst and urination (called diabetes insipidus)

Steroid treatment for sarcoidosis can also affect how the hypothalamus and pituitary function.

Diagnosis of hypothalamic-pituitary sarcoid

This often involves a combination of blood tests, imaging studies like MRI scans, and rarely a biopsy.

2. Thyroid gland involvement

Sarcoidosis can sometimes directly involve the thyroid gland in your neck which makes hormones that control your metabolism. These hormones affect processes like heart rate, body temperature, and weight.

In sarcoidosis, granulomas can form and disrupt the normal functioning of the thyroid leading to either hypothyroidism (low thyroid function) or hyperthyroidism (high thyroid function).

Granulomas in the thyroid may need investigating to distinguish them from other lumps in the thyroid – this is usually done with an ultrasound scan but sometimes with a needle biopsy.

3. Adrenal gland involvement

The adrenal glands sit on top of each kidney and produce important hormones: cortisol (which helps your body respond to physical stress) and aldosterone (which helps control blood pressure).

Steroid treatment for sarcoidosis can affect your body's own steroid production. This happens mainly in the hypothalamus and pituitary, which are parts of the brain that control the adrenal glands. This can influence how much cortisol and aldosterone your adrenal glands make.

Steroids are very important to control the sarcoidosis so your doctors will want to find the lowest possible dose to both control the disease but minimize the effect on your adrenal glands.