

SarcoidosisUK Patient Information

Sarcoidosis and Calcium and Vitamin D

What is calcium and vitamin D?

Calcium is a mineral that makes up our bones and is essential for a healthy skeleton. Calcium levels are regulated by vitamin D, which we produce in our skin using sunlight, and obtain in our diet through foods like oily fish.

Low levels of calcium and vitamin D can contribute towards osteoporosis (thinning of the bones) which is common as we age (<https://nos.org.uk/about-osteoporosis>). Certain medications contribute to osteoporosis including corticosteroids, which are often used to treat sarcoidosis.

Having too much calcium or vitamin D can be a bad thing. High calcium levels can cause stomach pain, constipation, confusion and occasionally, kidney damage. For most people, calcium and vitamin D supplements are very safe, but for some people with sarcoidosis, there is a risk of supplements increasing blood levels of calcium and vitamin D.

What causes high blood levels of calcium in sarcoidosis?

Sarcoidosis is a condition where lumps (nodules) called granulomas develop at different sites within your body. These granulomas are made up of clusters of cells involved in inflammation. If many granulomas form in an organ, it can prevent that organ from working properly.

Activated cells within the sarcoid granulomas increase the activity of an enzyme (1 α -hydroxylase) that converts inactive vitamin D (25-hydroxy vitamin D) to its active form (1,25-dihydroxy vitamin D). This active form of vitamin D is essential in helping the body absorb and use calcium; in fact, the body cannot absorb calcium at all without some vitamin D. Overproduction of this enzyme (1 α -hydroxylase) is responsible for the development of high calcium levels in the blood of patients with sarcoidosis.

How common are high blood levels of calcium in sarcoidosis?

An elevated blood calcium level is seen in approximately 1 in 10 patients with sarcoidosis.

Who should have calcium and vitamin D supplements?

Vitamin D levels are commonly measured in the general population, and your doctor may well check your vitamin D and calcium level as part of a routine checkup. Measuring PTH (parathyroid hormone levels) with



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a PTH test is helpful in understanding the cause of high calcium, especially in patients with sarcoidosis. If vitamin D levels are low, a doctor would usually recommend supplementation.

If you have sarcoidosis there is an increase chance you would experience side effects from taking vitamin D and calcium supplements. It is essential that you have your calcium 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). This should be using the 1,25 dihydroxyvitamin D (1,25-DHCC). However your doctor may first check your calcium level and the 25-hydroxyvitamin D (25-DHCC) before proceeding with further tests.

SARCOIDOSIS PATIENTS REMEMBER: Always mention to your doctor that you have sarcoidosis if they recommend you have any calcium or vitamin D supplements, and if in doubt discuss with your sarcoidosis specialist.

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