

Fatigue, or extreme tiredness, is one of the most common complaints for sarcoidosis patients. It can have a very negative effect on their quality of life.

What is fatigue?

Fatigue has no simple definition but includes a lack of physical or mental energy or motivation. People describe it as an overwhelming sense of tiredness with no obvious cause. Fatigue cannot be exactly measured or shown with medical equipment.

Fatigue during sarcoidosis

The majority of sarcoidosis patients display symptoms of fatigue at the time of diagnosis. This is probably caused by the inflammatory process of the disease. Certain proteins (cytokines) are produced by the immune system as a result of the disease. These proteins may cause symptoms of fatigue.

The majority of patients, both men and women, suffer from fatigue. The severity of sarcoidosis seems to have no influence on the degree of fatigue experienced.



Symptoms of fatigue

Fatigue cannot be tested and there is not always a professional to consult. This can make it complicated to explain your fatigue to friends, family, colleagues and health and social care professionals. They may unhelpfully ask you to 'make a bit more effort' or 'stop being lazy.' It can make the problem worse that patients may still be able to be active and sociable some of the time. This can lead to tension at work and social situations.

It is often the case that patients in remission from sarcoidosis still feel tired. When these symptoms last for longer than 6 months, it may be called 'chronic fatigue'. It is not known exactly how many sarcoidosis patients suffer from chronic fatigue.

Chronic fatigue

Although it is clear that chronic fatigue associated with sarcoidosis begins during the illness, the precise cause of the fatigue remains unknown. Chronic fatigue after sarcoidosis is often accompanied by these symptoms:

- pain (throat, head, lymph nodes, joints)
 - concentration and memory problems
 - sickness after exertion
 - anxiety and depression
 - uncomfortable walking
 - decreased muscle strength
 - less physical activity
- As such, chronic fatigue after sarcoidosis decreases quality of life significantly.

Treatment

There is no cure for fatigue. The only proven therapy is combining cognitive behavioural therapy (CBT) alongside slowly building physical activity with the guidance of a physiotherapist.

However, there are a number of lifestyle choices that will combat fatigue: Live healthily - Eat a healthy, varied diet. Do not smoke. Drink alcohol and coffee in moderation.

Look to the future and make plans - It is helpful to look towards the future. Talk to loved ones and find out about your nearest SarcoidosisUK Support Group for inspiration.

Maintain a healthy sleeping pattern - Try to sleep during the day as little as possible (or not at all) especially if you experience restless or light sleep overnight.

Consider your mental health - Having sarcoidosis is tough and can contribute to mental health conditions. Call the SarcoidosisUK Nurse Helpline or consider talking to a mental health specialist if you are concerned.

Finally, stay active - Stay as active as possible, not only physically but also mentally and socially. If you can, exercise for 30 minutes a day at moderate intensity, 5 days per week.