Sarcoidosis

Overview of the health condition or disability

What is the condition usually called?
Sarcoidosis.

Are there any alternate names?
It is sometimes abbreviated to sarcoid.
Specific organs may also be referenced: pulmonary sarcoidosis, cardiac sarcoidosis, skin sarcoidosis, ocular sarcoidosis, neurosarcoidosis, hepatic sarcoidosis, renal sarcoidosis, multisystem(ic) sarcoidosis.
Occasionally, Löfgren syndrome is used to describe an acute form of sarcoidosis and Heerfordt-Waldenström syndrome to describe a rare subacute variant of sarcoidosis.

What is the generally preferred term when referring to someone with this condition?
A person with sarcoidosis. People sometimes refer to themselves as ‘sarkies’, however this is never to be used in a professional capacity.

Common areas of daily life where functional restriction occurs

What areas of daily life may a person with this particular health condition or disability find challenging?
People are likely to experience some level of functional restriction in most areas of daily living, particularly preparing and cooking food, washing and bathing, dressing and undressing, managing treatments/medication, working, socialising and moving around.

Sarcoidosis can be extremely restricting especially because of fatigue. Some patients describe being unable to get out of bed, or barely able to walk to the kitchen.

Sarcoidosis often causes social isolation – so there can be a great deal of stress and anxiety with social situations, meeting others or basic activities. For some, severe lung issues can make walking even very short distances extremely painful and debilitating. Cardiac sarcoidosis can make any activity extremely problematic or impossible. Ocular sarcoidosis can stop people being allowed to drive. The range of sarcoid can make any element of life extremely challenging.

Are there any areas that a Health Professional should ask about specifically to ensure a complete report?

• Reliability and repeatability for any area of daily life, due to the impact of fatigue. Ability to complete tasks in a timely manner.

• To realise the full extent the sarcoidosis has had on the claimant’s life, it might be useful to compare their life before diagnosis with their present situation.

• It is also important to realise that a sarcoidosis patient who is said to have “dormant sarcoidosis” can still present with significant exhaustion, pain and multi-system afflictions. There are also ongoing side effects from the medication, and most of the time secondary conditions.
Commonly reported variability in functional restrictions

Do people with this particular health condition or disability find its impact on daily life can vary from time to time?

Sarcoidosis often presents as a ‘flaring’ condition, with episodic worsening of symptoms. These episodes or flares vary from patient to patient and are unpredictable in both timing and duration, but usually involve a worsening of current symptoms, or a reappearance of previous symptoms. Occasionally they involve the appearance of new symptoms. This means that people with sarcoidosis often experience variation in the impact their condition has on their daily life. Flares can last a few days, several months or longer and may or may not require additional treatment or medication changes.

Some people with longer term sarcoidosis need to rest for days before being able to do things – and rest again afterwards. This has to be taken into account with any assessment. Being active one day is not an accurate account of their illness as it often results in increased pain, exhaustion and a ‘flare’.

What aspects of daily living can be worse and what might be constant?

Any aspects of daily living might be worse, depending on the symptoms involved and their severity. Functional restrictions vary widely between people with sarcoidosis, due to the multi-organ (systemic) nature of the condition and the wide range of symptoms people experience.

Fatigue/extreme exhaustion can stop all activities of daily living. Sarcoidosis patients often describe needing to sleep all day and still wake up tired. If they fight this, their symptoms get progressively worse.

Common misconceptions about the health condition or disability

What kind of areas might a claimant with this health condition or disability find hard to mention or perhaps understate the importance?

Particular problems might come with toileting and continence issues, fatigue, and reliability and repeatability of tasks/activities. People with sarcoidosis often underestimate the impact their condition has on them, particularly if an assessment is carried out on a day when they are feeling more able.

People underestimate the impact their condition can have on their ability to socialise and interact with other people. The unpredictability of symptoms can lead to people becoming isolated.

People on weekly medications such as methotrexate may also underestimate or fail to mention the particular problems or additional symptoms they have around their medication day.

Brain fog can also be a major issue with sarcoidosis patients, meaning it is particularly difficult for them to recall or fully explain symptoms or the impact on their daily life.

What areas of this health condition or disability are least well understood or hardest to identify and which might impact on daily living?

Fatigue is a particularly problematic symptom which often persists even when the condition is considered to be medically under control. It is important to understand that this fatigue is absolute exhaustion, not something that can be overcome. Living with fatigue can become normalised, so people underestimate the impact it is having on their daily lives even when those impacts are profound.

There is a common misconception about fatigue which is temporary and symptomless. This does not reflect the reality faced by many sarcoidosis patients.

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How is it best to ask about these areas?

Take a longer view, over the course of a week or a month. Ask people when they were last able to do something purely for leisure, for example going out with friends or family, and what effect this had on them in the following days. People with sarcoidosis often talk about ‘pushing through’, but this may well leave them needing recovery time which may take several days.

What kind of medical evidence is likely to best convey the impact of this health condition or disability on an individual?

A full evaluation of all medical records can build up a picture – but the individual nature of sarcoidosis cannot be underestimated. For instance, though sarcoidosis most often affects the lungs, in 5-10% of cases it does not. This in no way reduces the seriousness of the condition, especially as it can affect the...
heart and other major organs and be more devastating than pulmonary sarcoidosis.

It is important to note that there is not one specific test for sarcoidosis. The ACE blood test is only accurate in around 60% of cases, so it is notoriously difficult to reach a diagnosis or assess the true state of the sarcoidosis. A combination of lung function tests, x-rays, CT scans, PET-CT scans, ECG/EKG, MRI scans, ultrasounds – all help build a picture, but rarely reveal everything.

**Presenting symptoms**

Please describe any common symptoms that an individual with this health condition or disability might exhibit when presenting at a face-to-face consultation.

Sarcoidosis is known as “The Great Mimic” in that it presents in a similar way to other conditions. This complicates and delays diagnosis and treatment.

Symptoms can include fatigue (extreme chronic tiredness that isn’t relieved by rest), cough, breathlessness, joint and/or bone pain, visceral pain, skin rashes/symptoms, night sweats, sensitivity to cold, palpitations, irregular heartbeat, chest pain, ‘brain fog’, eye problems including dryness, burning, blurred vision, light sensitivity. Pain is common but often under reported to health professionals. It can be difficult to treat.

People with sarcoidosis often additionally experience symptoms relating to the organ affected, so, for example, people with neurosarcoidosis are likely to experience neurological symptoms such as numbness, paralysis, headache, changes in mood and behaviour, memory loss or impairment, aphasia, or paraesthesia. (For a list of morbidities relating to organ involvement, please see table 1 in this paper.

Sarcoidosis is not always well understood by health professionals treating the condition. People may experience symptoms which are not acknowledged by their medical team, or are ascribed to mental health conditions, particularly anxiety.

**Recommended communication approach to a claimant at a face-to-face consultation**

What are the best communication approaches necessary to engage someone with this health condition or disability?

Stress can worsen sarcoidosis symptoms, so the stress caused by the assessment process is likely to cause difficulty for people who experience fatigue, brain fog, and other neurological symptoms. People may need more time to process questions and formulate their response, and supplementary questions should be used to check that the answer given is full and complete and accurately represents the person’s abilities.
Etiquette and common courtesies

People are likely to benefit from having someone with them in the assessment, for example a friend, family member or advocate, to ensure that their difficulties are accurately reported and to reduce the stress experienced.

A basic general knowledge of sarcoidosis from the assessor would make a massive difference in helping the claimant explain their condition. Correct pronunciation of sarcoidosis will also be helpful.

Further reading:

Click on the links below for further information.

- SarcoidosisUK
- SarcoidosisUK - Patient information leaflets
- SarcoidosisUK's YouTube channel features Q&A's with specialists and videos from their helpline nurses
- Cleveland Clinic
- National Library of Medicine - Morbidity and Mortality in Sarcoidosis
- National Library of Medicine - Health-Related Quality of Life (HRQoL) in Sarcoidosis
- Foundation for Sarcoidosis Research