

Condition Insight Report (CIR)

Sarcoidosis
Version 1.0

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Overview

What is the condition usually called/ any abbreviations used?

- Sarcoidosis, sometimes abbreviated to sarcoid.
- Sometimes specific organs are referenced: Pulmonary Sarcoidosis, Cardiac Sarcoidosis, Skin Sarcoidosis, Ocular Sarcoidosis, Neurosarcoidosis, Hepatic Sarcoidosis, Renal Sarcoidosis or Multi-system Sarcoidosis.
- Occasionally Löfgren Syndrome is used to describe an acute form of sarcoidosis.
- Occasionally Heerfordt-Waldenstrom Syndrome is used to describe a rare subacute variant of sarcoidosis.

Brief overview of the condition.

Sarcoidosis is classified as a rare disease (most specialists agree that around 1 in every 10,000 people in UK have it). It manifests itself differently in each patient (known as a 'snowflake' disease because no two patients are alike), with different amounts of inflammatory cells –known as granulomas - clumped together damaging organs, sometimes permanently with fibrosis.

Symptoms can be extremely varied between claimants, and I have listed some of these on the enclosed Condition Insight Report. However, it is near impossible to capture all of these symptoms and weigh their possible effect on daily living and mobility, and to explain the likelihood of someone with sarcoidosis having a particular symptom or not. Also, there is a combination/cumulative effect of symptoms that must be considered.

Presenting Symptoms

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. It is important to note that sarcoidosis is a multi-organ (systemic) condition and it can affect any part of the body.

Symptoms can include;

- Fatigue (extreme chronic tiredness that isn't relieved by rest)
- Violent 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.

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.

Whilst mental health may or may not be directly related to sarcoidosis itself, some research as well as anecdotal evidence is showing that some patients with sarcoidosis struggle with their mental health. Issues include:

- Challenges of chronic disease and inadequate pain relief, severe fatigue, excessive daytime sleepiness, breathlessness, etc.
- Medical professionals, family and/or friends not understanding the disease or symptoms
- Trouble or inability to do things one could before
- Extreme difficulty getting diagnosed

Fluctuations



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.

POINTS TO REMEMBER

- Flares can last a few days, several months or longer and may or may not require additional treatment or medication changes.
- **Even when not in a 'flare' the claimant is likely to still be experiencing symptoms that will impact function.**
- Being active one day is not an accurate account of their illness as it often results in increased pain, exhaustion and a 'flare'.
- **it is imperative that you take a longer view of function, for instance 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.

Reliability

What specific areas should be covered to ensure a complete, reflective report?

SAFETY



Do they have any symptoms which could cause a safety consideration?

If someone reports severe fatigue in combination with brain fog, you must explore their ability to safely complete activities. Specifically those that require a level of concentration and focus.

Furthermore, neurosarcoidosis can cause an inability to walk and problems with limbs. Cardiac sarcoidosis can also cause fainting episodes which must be considered.

TIMELY



For any activities where restriction is reported how long does it take them to complete these activities? Has how long it takes them changed over time?

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 let alone anything more. Consequently, you must be considering how long it takes someone to actually complete an activity when their fatigue and breathlessness impacts them substantially.

ACCCEPTABLE
STANDARD



How have they adapted to completing tasks over time – is this different to what might be considered 'normal'?

For some, severe lung issues can make walking even very short distances extremely painful and debilitating. They may be reporting they are completing activities, especially if they have a longstanding condition. However, you must consider if this is being completed to an acceptable standard.

REPEATEDLY



Are they able to repeat a task as often as required? Is this the same every day?

When someone experiences symptoms of fatigue, breathlessness and pain they may have extensive difficulties repeating an activity. If someone tells you then can wash themselves, how do they feel after? Can they move onto another activity? Could they complete the same activity later in the day? Surface level function is not adequate and must be explored further.

Sensitivities & Customer Care



Watch a video [HERE](#) on
a patients experience of
Sarcoidosis

- ❖ Stress can worsen sarcoidosis symptoms, so the stress caused by the assessment process is likely to cause particular 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.
- ❖ People are likely to benefit from having someone with them in the assessment, for example a friend, family member or advocate, in order to ensure that the claimant's 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.

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

Particular problems might come with toileting and continence problems, 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 their impact on their daily life.



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's, EKG's, MRI, ultrasounds – all help build a picture, but rarely reveal everything.

Although 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.

Tell me more....

It is 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.

Sarcoidosis often comes hand in hand with other conditions, such as Chronic Fatigue Syndrome, Fibromyalgia, chest infections, diabetes and many more.

There are significant side effects to the medication, in particular immunosuppression – including increased risk of shingles, gout, flu, pleural effusions, pneumonia etc. This further complicates the picture, making it harder for the claimant to fully realise the impact their health condition has on them.

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 1: Preparing food

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 let alone cook a simple meal. They may also report being able to complete the activity, but that it has a substantial impact on how they feel after when they do. It also cannot be underestimated the level of pain most sarcoidosis patients suffer - and the debilitating effects this will have. This can cause problems with joints, muscles, bones: these issues can occur at the time and be worse later.

If someone is experiencing exhausting they may present as a risk in the kitchen with knives or flames.

Remember in PIP...

Can someone prepare and cook a simple meal for one? How long can they stand in the kitchen? Can they chop and peel vegetables? Can they lift pans? Does completing this activity increase breathlessness or fatigue? How do they feel after the activity? How long does it take to recover? Do they experience pain?

Activity 2: Taking nutrition

It is imperative that someone with Sarcoidosis has a well balanced diet to provide them with the vitamins and minerals they need.

As people with sarcoidosis have such a varied range of symptoms, it is extremely important that you explore if their condition impacts swallowing. Furthermore, if they have joint pain, can they physically cut their own food and bring it to their mouth?

Remember in PIP...

Can they chew, swallow and bring food to their mouth? Can they physically cut food? Do they have any aids to assist such as adapted cutlery? Can they eat solid food? Do they have any risk of choking? Can they complete this activity in a timely manner?

Activity 3: Managing therapy and monitoring a health condition

People on weekly immunosuppressants such as methotrexate/ azathioprine or steroids (Prednisolone)" may also underestimate or fail to mention the problems or additional symptoms they have around their medication day.

If they report joint pain, they may have difficulties removing medication from packets or administering their own medication. Equally, if they have any therapy in the home to manage their condition, do they require

assistance with this?

Remember in PIP...

Therapy is only considered within the scope of the activity if received in the home environment. If they do have therapy at home, do they require assistance? If so, why and how long does this take?

Regarding their medication, can they manage this themselves? Can they administer their own medication? Can they remember to take it and physically remove it from packaging?

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 4: Washing and Bathing

Sarcoidosis can be extremely restricting especially because of fatigue. They may also report being able to complete the activity, but that it has a substantial impact on how they feel after when they do. Breathlessness and pain will also likely impact their ability to wash and bathe. It may be that they are washing but can only physically do this once or twice a week due to symptoms, so it is important this is explored.

Furthermore, if there are co-existing mental health conditions secondary to their sarcoidosis, they may lack motivation.

Remember in PIP...

You must explore how someone is managing the activity. How do they get in and out of the bath? Do they have any aids? Can they wash their entire body? How long does it take and how do they feel after? Does this activity increase their symptoms? How long does it take to recover? Do they need assistance with upper or lower body? Are they motivated to wash regularly?

Activity 5: Managing toileting needs and incontinence

Pain, breathlessness and fatigue may all impact someone's ability to reliably manage their toilet needs.

Some patients also report urgency in relation to toileting needs. Neurosarcoidosis patients can experience continence issues.

Remember in PIP...

You must explore how someone gets onto and off the toilet and how they clean themselves. Does doing this make them more breathless? We do not consider ability to mobilise to the toilet. Also explore if someone has incontinence on majority of days and how they manage this.

Activity 6: Dressing and undressing

Sarcoidosis can be extremely restricting especially because of fatigue. They may also report being able to complete the activity, but that it has a substantial impact on how they feel after when they do. You must consider if someone is avoiding this activity on the majority of days due to their condition. Breathlessness and pain may also limit their ability to dress and undress.

Furthermore, if there are co-existing mental health conditions secondary to their sarcoidosis, they may lack motivation.

Remember in PIP...

You must explore someone's ability to dress and undress within the scope of STAR. How long does it take them? Can they dress upper and lower body? Does this increase symptoms of breathlessness and/or fatigue? Do they require assistance or use any aids? Can they dress reliably whilst seated? Are they motivated to dress daily or change clothes?

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 7: Communicating Verbally

Some people living with sarcoidosis will experience brain fog. This may mean they struggle to express what they want to say or understand what is being said to them.

Remember in PIP...

Can someone express and understand both basic and complex verbal information? Who do they speak to? Can they use a mobile phone? Do they have any cognitive or sensory impairments that may impact their ability to complete this activity? Can they understand the information?

Activity 8: Reading and understanding signs and symbols

Brain fog can often impact a persons ability to fully understand what they are reading. They may also struggle to focus on reading.

Sarcoidosis of the eyes also causes problems with vision

Remember in PIP...

Concentration is not considered within the scope of the activity. However, someone must be able to not only read complex written information, but also understand it. What can they read? What do they have difficulties with and why? How do they overcome this?

Activity 9: Engaging with others face to face

Sarcoidosis often causes social isolation – so there can be a great deal of stress and anxiety with social situations, meeting others or basic activities.

You must ensure you explore any co-existing mental health conditions that may impact their ability to engage with people.

Remember in PIP...

Who do they engage with on a regular basis? How do they feel meeting unfamiliar people? If they have anxiety with unfamiliar people, who can support them?

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 10: Budgeting

If someone reports brain fog secondary to their sarcoidosis, it may be that this impacts their ability to manage their household finances.

Furthermore, if they have co-existing mental health conditions, they may lack motivation to complete this activity.

Remember in PIP...

Can someone manage their household finances? Do they do online banking or shopping? Could they plan for future purchases? Could they understand change in a shop?

Activity 11: Planning and following a journey

If someone reports brain fog secondary to their sarcoidosis, it may be that this impacts their ability to manage journeys. Sarcoidosis patients can also suffer neurological symptoms, which impact planning skills.

Planning journeys can be extremely difficult for those with sarcoidosis - especially going to new places. The longer the condition lasts, the worse this can become. Increasing isolation can lead to anxiety, loss of confidence and panic attacks.

Remember in PIP...

Can someone reliably plan and follow both familiar and unfamiliar journeys? How do they get around? Can they use public transport? Could they follow a diversion? If there is co-existing MH conditions, does their anxiety meet OPD threshold? If so, what symptoms do they experience and how is this managed? Can they go out of the home on the majority of days?

Activity 12: Moving Around

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. If someone experiences fatigue, even walking short distances may require a prolonged period of recovery. Furthermore, they may struggle to repeat the distance.

Remember in PIP...

You must explore STAR when asking about someone's ability to mobilise. It is not sufficient to simply indicate a distance or time someone can walk for.

Firstly, establish when someone is walking, do they require an aid? If so, what aid? Was this prescribed or self purchased?

How far can they walk and how long does this take? How does walking make them feel? Does breathlessness/fatigue increase each time they walk? When they walk a second time, does pace reduce or distance reduce? If they experience fatigue, how do they feel later in the day? How many times could they repeat the distance they walk?

How long does it take to recover from mobilising?

Lived examples are also extremely beneficial. How do they manage up and down the stairs? How do they manage with chores? How do they manage their shopping? How many aisles can they walk and how long does it take? If they go to their GP surgery or hospital, how far is it from the car? How long does it take them to get to the required department and how far is this?

Additional reading or other resources

EXTERNAL

[SarcoidosisUK - Information, Support, Research & Awareness](#)

[SarcoidosisUK Patient Information Leaflets - Overview, Lungs, Fatigue...](#)

[Sarcoidosis: Causes, Symptoms, Diagnosis & Treatment \(clevelandclinic.org\)](#)

[SarcoidosisUK – YouTube](#)

[Health-Related Quality of Life \(HRQoL\) in Sarcoidosis: Diagnosis, Management, and Health Outcomes - PMC \(nih.gov\)](#)

[Sarcoidosis, What is it? - Foundation for Sarcoidosis Research \(stopsarcoidosis.org\)](#)

[Morbidity and Mortality in Sarcoidosis - PMC \(nih.gov\)](#)