

Practical Advice for Employers

The following advice will help facilitate and maintain a productive and positive working relationship with an employee who has sarcoidosis.

Employees may find that continuing to work is helpful to their recovery and improves their quality of life. Simple adjustments can make a big difference in helping them to stay at work in an appropriate capacity. Together, you might consider:

- changing the work environment (e.g. ensuring high air quality) or working hours (e.g. part-time/flexible hours and breaks);
- changing the role (e.g. using less demanding equipment, reducing physical exertion);
- phased return to work after sickness absence;
- planning for hospital appointments/surgery;
- adjusting performance targets and/or redistributing work;
- managing anticipated busy periods.

Always remember to prioritise your employee's physical and mental health and ensure they are fairly valued based on their realistic working capacity.

Sarcoidosis activity in the body changes over time, for better or worse. However, damage to the affected organ(s) is often permanent. It is important to monitor progress and check that any special arrangements you make remain appropriate. If an employee takes time off work, maintain regular contact. Clear communication is very important.

Legalities

Employees with sarcoidosis may have statutory protection regarding their employer's legal duty to make work and workplace adjustments. Sarcoidosis may be considered a life limiting disease and therefore a disability by the Department of Work and Pensions. Not taking an employee's rights into proper consideration could lead to legal action under the Equality Act (2010).

Who We Are

SarcoidosisUK is the UK Sarcoidosis Charity. We're here to provide support, information and to fund research. The vast majority of our funds go towards researching a cure. We run support services across the UK – please contact us for more information.

How You Can Help:

Donate to fund research:
www.sarcoidosisuk.org/donate

Join our registry for the opportunity to participate in medical research:
www.sarcoidosisuk.org/patient-register

Further Information:

Workplace Health Advice and Guidance
www.nhs.uk/Livewell/workplacehealth/
www.acas.org.uk/index.aspx?articleid=4203

Workplace Rights
www.citizensadvice.org.uk/work/

Mental Health
www.mind.org.uk/workplace/mental-health-at-work/

Occupational Health
www.fitforwork.org/employer/
www.nhshealthatwork.co.uk/find-providers.asp

Contact Us

SarcoidosisUK, 49 Greek Street,
London, W1D 4EG

Phone: 020 3389 7221

Email: info@sarcoidosisuk.org

Web: www.sarcoidosisuk.org

Facebook: facebook.com/groups/sarcoidosisuk

Twitter: [@sarcoidosisuk](https://twitter.com/sarcoidosisuk)

SarcoidosisUK
Charity number: 1063986

SARCOIDOSIS INFORMATION for EMPLOYERS

Basic information about sarcoidosis and practical advice for managing an employee with this condition.



What is Sarcoidosis?

Sarcoidosis is an inflammatory disease characterised by the accumulation of white blood cells (known as granulomas). The condition can affect any organ and often affects multiple organs simultaneously.

Lungs are involved in 90% of cases (pulmonary sarcoidosis); 30% of patients have extrapulmonary disease (outside of the lungs).

Sarcoidosis also commonly affects the bones and joints (40% patients), skin (25%), eyes (30%) and is also known to affect the liver, endocrine system, kidneys, heart, and central nervous system.

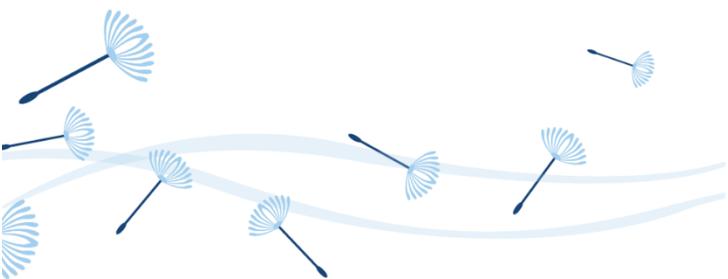
Sarcoidosis is a long-term health condition - currently it cannot be cured but can be managed using medication. Although sarcoidosis symptoms may persist over many years their impacts may be significantly reduced by the patient pacing their activities and managing their working life in an appropriate manner.

What causes Sarcoidosis?

It is not known exactly what causes sarcoidosis. The condition is most probably triggered by the interaction between various genetic and environmental factors.

How common is Sarcoidosis?

It is estimated that 1-2 people per 10,000 have sarcoidosis in the UK.



What is the impact of Sarcoidosis?

Sarcoidosis is an auto-immune condition - the immune system attacks healthy cells in the affected organ(s). The impact is often debilitating. Quality of life is often severely affected, particularly by fatigue and difficulty breathing.

Symptoms vary widely depending on which organ(s) are affected. Symptoms may not be immediately obvious or indeed visible and may be picked up by a routine scan or examination.

Common symptoms may include:

- cough, chest pain and difficulty breathing (pulmonary sarcoidosis)
- aching/tender joints, fatigue, and weight loss (commonly experienced)
- skin plaques, visual impairment, kidney failure, cardiac arrhythmias, amnesia (organ specific)

Chronic and acute

There are two basic types of sarcoidosis, chronic and acute. Acute conditions develop suddenly and usually clear within a few months or years. Chronic conditions develop gradually and worsen, patients become severely affected and quality of life is reduced dramatically.

Fatigue and sleeping

Many sarcoidosis patients experience extreme fatigue and sleep disordered breathing (SDB). This hugely reduces quality of life and can make normal working very difficult, sometimes dangerous.

Mental health

Lack of awareness and knowledge has meant sarcoidosis is poorly understood by both the medical profession and public. Patients can feel isolated in dealing with their condition. As a result mental health problems such as anxiety and depression are common.

Course of the Disease

Spontaneous remission occurs in 60-70% of cases. However, a substantial number of patients develop a more serious chronic disease. A small proportion will present life threatening symptoms, particularly those with cardiac or neurological involvement. Sarcoidosis can be fatal.

Each case of sarcoidosis is unique and should be assessed on an individual basis. It is not known why the disease spreads into different organs in the body.

Flare ups

Sarcoidosis may spread, regress and 'flare up' over time. A flare up is when symptoms are suddenly experienced more severely - it is not known what triggers this.

It can be tempting for patients to 'push-through' these flare-ups and continue working as normal. However this is likely to exacerbate and prolong symptoms. There may be long periods of incapacity if flare ups persist.

Treatment

As yet there is no known cure for sarcoidosis.

The treatment options available for sarcoidosis act only to suppress symptoms and do not cure the disease.

The first line general treatment is oral corticosteroids. This suppresses the inflammation and granuloma formation. Immunosuppressive drugs may be necessary for patients who require high doses of these steroids for prolonged periods.

Sarcoidosis treatments can cause severe side effects - sometimes these can be as debilitating as the disease itself. For example immunosuppressive drugs can make the individual more susceptible to infection and other illnesses on top of sarcoidosis.