

# Employment and Sickle Cell Disease

Information and advice for patients

## Sickle Cell and Thalassaemia Centre

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Sickle cell disease (SCD) is an inherited blood condition which is caused by the blood cells changing shape. Rather than being round in shape, the red blood cells have a sickle shape. As a result of this, these sickle-shaped blood cells block the blood flow in small blood vessels and this can result in pain (this is the most common result of a sickle cell crisis). Therefore, patients with SCD have periods of ill health in between periods of good health.

Some people have mild infrequent crises which they can manage at home whereas others have more severe crises for which they require hospital admission. In addition, some people have long term complications which may require more specialist treatments such as long term blood transfusions.

### Considerations for patients with SCD at work

- Patients will usually be aware of the ways in which they can avoid a crisis. Common causes are infections, exposure to extremes of temperature, physical and mental stress, and dehydration.
- Patients with SCD need to drink about 3 litres of fluid/day. This is because the kidneys in SCD do not function as effectively and therefore individuals may need to urinate frequently.
- SCD does not affect a person's intelligence unless they have had a stroke.
- Time off work may be required to attend routine hospital/doctor appointments for tests, assessments, treatments. Some patients may also require time off work because of unplanned hospital appointments. Most patients will know how to manage their pain using medications as well as other therapies (for example, hot water bottles).
- Some individuals may not disclose their illness for fear of stigmatisation, or having their capabilities underestimated.

### Considerations for an employer

As an employer, knowledge of SCD can help you to understand how the employee is managing in the work environment and also what adjustments need to be considered to minimise ill health. For example, this would include avoidance of draughts, being able to decide what tasks can be done or avoided and being able to offer support. Other considerations would be the same as for non-sickle patients such as flexible working.

## **Advice on benefits**

Information regarding benefit entitlements can be obtained, free of charge from a local job centre plus office, social security office or job centre. Leaflets on housing benefit and council tax benefit are available from local councils.

**[www.gov.uk](http://www.gov.uk)**

**[www.gov.uk/benefitsadviser](http://www.gov.uk/benefitsadviser)**

Personal independence allowance has now replaced DLA, for advice phone:

**New claims: 0800 9172222**

**Claim in progress: 0845 850 3322**

**Already in receipt of DLA: 08457123456**

The Citizens Advice Bureau (CAB) will advise on a range of earnings-related and other benefits which a person may be entitled to, whether they are working or not. This may include housing, welfare and state benefits. They will advise on whether the person is entitled to family income support, invalidity care allowance, disability living allowance, family fund and a range of means and non means-tested benefits.

Local organisations that can help are:

**OSCAR Birmingham**

**[www.oscarbirmingham.org.uk](http://www.oscarbirmingham.org.uk)**

0121 212 9209

**OSCAR Sandwell**

**[www.oscarsandwell.org.uk](http://www.oscarsandwell.org.uk)**

0121 525 0556

## **Contact details**

If you have any questions or concerns please contact the Sickle Cell and Thalassaemia Centre on 0121 507 6040

## **Opening hours**

Monday - Thursday 9am – 5pm

Friday - 9am – 4pm

Saturday - blood transfusion service only

For more information about our hospitals and services please see our website

**[www.swbh.nhs.uk](http://www.swbh.nhs.uk)**, follow us on X **@SWBHnhs** and like us on Facebook

**[www.facebook.com/SWBHnhs](http://www.facebook.com/SWBHnhs)**.

## Sources used for the information in this leaflet

Sickle Cell Society. (2018). *Standards for the clinical care of adults with sickle cell disease in the UK*. Sickle Cell Society.

Sickle Cell Society. (2019). *Sickle Cell Work and Employment A Guide for Employers and Employees on Work, Employment and Sickle Cell Disorder (SCD)*. Sickle Cell Society.

National Institute for Health and Care Excellence. (2012). *Sickle cell disease: managing acute painful episodes in hospital Clinical guideline [CG143]*.

Atkin, K., & Anionwu, E. (2010). *The Social Consequences of Sickle Cell and Thalassaemia: improving the quality of support*. London: Race Equality Foundation.

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