

Employment and sickle cell disease

Information and advice for patients and employers

Sickle Cell & Thalassaemia Centre

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 (crescent shaped). 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 symptom 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 patients with 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, and 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 (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.

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Advice on benefits

Information regarding benefit entitlements can be obtained, free of charge from your local Job Centre (or Job Centre Plus) or social security office. Leaflets on housing benefit and council tax benefit are available from local councils. You can also find further information by visiting www.gov.uk/benefitsadviser.

Personal independence allowance has now replaced Disability living allowance (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

0121 212 9209

OSCAR Sandwell

www.oscarsandwell.org.uk

0121 525 0556

Contact details

If you have any questions or concerns please contact the Sickle Cell and Thalassaemia Centre.

Sickle Cell & Thalassaemia Centre

Sandwell & West Birmingham Hospitals

City Hospital

Dudley Road

Birmingham

B18 7QH

Tel: 0121 507 6040

Monday, Wednesday

& Thursday 9am – 5pm

Tuesday 9am – 6pm

Friday 9am – 4pm

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For further information

Birmingham Sickle Cell & Thalassaemia Service

Soho Health Centre
247-251 Soho Road Handsworth
Birmingham B20 9RY
0121 545 1655
bchc.sicklecellresults@nhs.net

The UK Thalassaemia Society

19 The Broadway
Southgate Circus
London, N14 6PH
Tel: 0208 882 0011
www.ukts.org

Thalassaemia International Federation

PO Box 28807
2083 Acropolis – Strovolos
Nicosia
Cyprus
www.thalassaemia.org.cy

For more information about our hospitals and services please see our websites
www.swbh.nhs.uk and www.swbhengage.com, follow us on Twitter @SWBHnhs and like us
on Facebook www.facebook.com/SWBHnhs.

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Sources used for the information in this leaflet

- Sickle Cell Society, 'Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK', 2008.
- National Institute for Health and Care Excellence, 'Sickle cell disease', 2010.
- Sickle Cell Society, 'Employment Advice for Sicklers', May 2009.
- Sickle Cell Society, 'Advice to Employers', May 2009.
- Atkin K. and Anionwu E.N., Race Equality Foundation, 'The social consequences of sickle cell and thalassaemia: improving the quality of support', February 2010.

If you would like to suggest any amendments or improvements to this leaflet please contact the communications department on 0121 507 5495 or email: swb-tr.swbh-gm-patient-information@nhs.net



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