NHS
University Hospitals of Liverpool Group

Patient information

Sickle Cell Disease (SCD)
Work, Employment and Education Advice

Haematology Department

This leaflet is intended to provide general guidance and advice for Employees/Students – Employers/ Educational Establishments. Each person with SCD will have their own issues and coping mechanisms related to their SCD. There can be a huge range and variation from person to person. It is recommended that the person affected with SCD works closely with either Employers/ Educational Establishments and health care professionals to ensure that any changes/measures are identified and acted upon in a timely manner.

For University Student it is advised that you contact the University health Centres and Student Engagement officers.

What is Sickle Cell Disease/Sickle Cell Disorder (SCD)?

Sickle cell disease (SCD) is a collective term given to a group of related, inherited conditions that affect the red blood cells. It can cause many health issues including severe pain, anaemia and long-term organ damage. It is more prevalent in people who originate from Africa, The Caribbean, Middle East, India and The Mediterranean though it can be found in other ethnic groups too. SCD is currently the most common severe inherited disorder in the UK with approximately 17,000 people in the UK having the condition.

Individuals with SCD are not all alike and the severity of the disorder can vary tremendously from individual to individual and also day to day within the same individual. SCD is associated with episodes of severe pain called sickle cell painful crises/vaso-occlusive crises. A complex combination of factors can cause the red blood cells to become blocked in the blood vessels, causing acute pain. Premature destruction of red blood cells also leaves the person with SCD severely anaemic and chronically fatigued. Many systems of the body can be affected: different key organs can be damaged over time and multiple symptoms can occur in different parts of the body.

The main types of SCD are sickle cell anaemia, haemoglobin SC disease and sickle beta-thalassaemia.

With the appropriate support, people with sickle cell disease can achieve well in education and the workplace.

Is SCD a disability in law?

The Equality Act 2010 [Section 6(1)] states a person has a disability if they have a physical or mental impairment and "the impairment has a substantial and long-term adverse effect on [the person's] ability to carry out normal day-to-day activities." In law, a diagnosis of sickle cell disorder (SCD) is not automatically a disability, though SCD meets several of the criteria given in guidance. These include:

- Some normal day-to-day activities (lifting, walking, repetitive movements, sitting or standing for long periods) cause pain.
- Some normal day-to-day activities (lifting loads, walking, long hours, shift work) cause fatigue.
- Chronic pain is strongly associated with depression, so some with SCD who develop depression will also meet the legal criterion of mental impairment, which further impacts their abilities.

Where the effect of the impairment is controlled by medication (sickle cell pain relief); by medical treatment (hydroxycarbamide, penicillin, or regular blood transfusions), or by aids (compression socks to reduce risk of deep vein thrombosis) the effect of these is ignored in considering if the impairment is a disability, so SCD workers will still be considered disabled even if their condition is controlled. The law states that the adverse effect must be 'substantial', but guidance to the act states that this simply means it must be more than minor or trivial. This may mean not just being unable to do an activity but also only being able to do an activity with difficulty:

- The difficulty might arise from stress (e.g. targets, working beyond hours, insufficient or poorly scheduled breaks) as stress could trigger a sickle cell painful crisis.
- The difficulty might develop under certain temperatures (e.g. sickle cell crises are triggered in cold environments or by use of air conditioners).

Given the nature of SCD it is likely that most people with the diagnosis will fall within the definition of disabled for the purposes of the Equality Act 2010.

Reasonable Adjustments

A student or employee who has a condition such as SCD is entitled to expect their university/ employer to make reasonable adjustments to ensure that they are not at a disadvantage whilst at university or work. These adjustments can be to premises or can involve the provision of equipment (such as a specialist chair), or there can be adjustments to study/work practices which people with SCD may struggle to comply with. In all cases it is necessary to identify what it is that puts the SCD student/employee at a disadvantage as a result of their condition and consider what can be done to remove that disadvantage.

How can the symptoms of SCD be prevented?

Certain factors are more likely to precipitate a painful sickle cell crisis. These include working /studying in cold lecture theatres/laboratories, working outdoors in windy/cold conditions, air-conditioning, pollution, infections, dehydration, strenuous exertion, stress, sudden changes in temperature, and drinking alcohol.

Advice to people living with SCD on preventing crises includes keeping warm, eating healthily, taking moderate exercise, resting when tired, taking plenty of fluids, seeking urgent medical advice if they have a fever, avoiding smoking and alcohol, keeping up to date with medications and vaccinations, and living a stress-free life where possible. As well as treatment for acute symptoms some people with SCD may have hospital appointments for regular treatments such as exchange blood transfusions or blood tests. Nevertheless, it is important to emphasize that even where such precautions are taken people with SCD may have unanticipated episodes of illness.

Areas of Good Practice

Travel to Work:

Many students/workers with SCD face a challenge in commuting to university or work. They may already have chronic anaemia and fatigue, so a punishing commute leaves them tired even before work begins. Loss of function of the spleen means they are especially vulnerable to respiratory infections when in close contact with other commuters. Exposure to cold in waiting outside for public transport or switching between warm and cold environments in using public transport, is a risk for triggering a sickle cell painful crisis. Access to a car, to a parking space closest to the building where the person works, to a disabled parking space at work, and to flexitime to avoid the rush hour can all help.

Water and Toilet Breaks:

All people with SCD are recommended to have an intake of water of at least 3 litres per day. Ensure a ready supply of fresh drinking water is available to employees close to workstations. In someone with SCD, the kidneys cannot concentrate urine effectively, so people with SCD need to pass large quantities of dilute urine and may require more frequent toilet beaks than other workers. Neither access to drinks nor toilet breaks should be restricted for students/employees with SCD.

Flexible Working/Working from Home:

Some students/employees with SCD can be severely anaemic, and may be tired, lethargic and not always able to concentrate fully. Flexible working can help in a number of ways. Tiredness from anaemia may be worsened because of night-time pain, sleep disorder or priapism. Permitting late starts times can help, as can flexible working, and working from home. If hospital and medical appointments are granted as paid leave, then the person with SCD is less likely to become tired and stressed from using up annual leave to cover medical appointments necessary to maintain good health. For those who have regular exchange blood transfusions the person may be more tired in the week prior to the transfusion. Scheduling work to reduce work towards the end of this blood transfusion cycle may help.

Stress:

Stress is a recognized trigger to illness in someone with SCD. Avoid excessive monitoring, and adjust targets and deadlines so some flexibility is built in. Allow the student/ employee to work at their own pace. If required, relax dress codes as formal attire may be uncomfortable, and permit modifications to uniforms to enable the worker to remain warm and well. Always consult the student/worker about any proposed “away-day” activities or team-building exercises to minimize disruption and stress. For students, Tutor’s/ University should be aware of increase stress around work submission and exam times.

Temperature:

People with SCD need to keep warm to remain well. Examples of possible reasonable adjustments might include raising the overall temperature of workplaces; providing health-and-safety inspected individual portable heaters for employees with SCD; consulting students/employees about use of air-conditioning (as rapidly cooled skin is a key trigger for a sickle cell crisis); consulting with the student/employee about the potential usefulness or not of heated chairs or heated jackets; considering allocation to workstations nearest the heating source or furthest away from outside cold. As with all reasonable adjustments it is important to consult the employee concerned from the outset, and to revisit and review the efficacy of the adjustment after a period of time.

Workers Individual Support Plans (WISP):

It is recommended all workers with SCD should have a Worker's Individual Support Plan (WISP), which should be reviewed regularly, as required. As SCD has numerous possible complications affecting many systems of the body, it is important, where possible, to include views of the students/employee's specialist sickle cell nurse in drawing up this plan.

Drawing up a worker individual support plan in consultation with the student/employee may help. Although there are some key preventive measures that will apply to all people with SCD, SCD is a variable and complex condition, and different people will be affected by different complications of the condition and to varying degrees.

The plans are individual but cover as a minimum: preventive measures to keep the person well at work; arrangements for working whilst taking pain medication; what constitutes an emergency and what to do; key contacts, especially the hospital healthcare team who will be the key health professionals caring for the student/worker.

The plan is reviewed each year, or as needed, as people may develop new complications arising from SCD and individuals may themselves not know how their condition may develop.

Medical Issues and Medical Emergencies for Sickle Cell Disease/Disorders (SCD)
Acute painful episodes or sickle cell crises:

These acute episodes of pain may occur in any part of the body and may be brought on by cold, stress, over-exertion, dehydration, or without any obvious precipitating factors. The pain may last a few hours or up to 2 weeks or even longer and may be so severe that a person needs to be hospitalized. It is important to listen to the person with SCD who will come to know whether the pain is mild and will pass (where employers can promote inclusion in the workplace by permitting rest and re-integration into work later that day) or moderate (where rest at home may prevent a more serious crisis and reduce overall work time lost) or severe when they need to go to hospital.

Acute chest syndrome:

Signs include chest pain, coughing, difficulty breathing, and fever. It can appear to be similar to flu like symptoms. However, it is important to liaise with appropriate healthcare team immediately.

Chronic Pain:

Some people with SCD experience chronic pain, that is, pain that is long-term, lasting over months or years and beyond a time frame that suggests healing or final resolution of the pain will occur. This is different from, and in addition to, acute painful crises. People with SCD may be involved in pain management courses and/or psychological therapies to help learn how to recognise types of pain and how to manage them.

Fever:

People with sickle cell disorder are at increased risk for certain bacterial infections. A fever of 38° Celsius or higher, could signal an infection. People with sickle cell disorder and fever should be seen by the appropriate healthcare team without delay.

Haemolysis:

In people with SCD their red blood cells are destroyed prematurely and only last 10-20 days in the bloodstream rather than the usual 120 days. This means they are anaemic and are therefore more likely to suffer fatigue, be lethargic or have difficulty concentrating. Those who have regular exchange blood transfusions every 4-6 weeks may become tired towards the end of the transfusion cycle.

Strokes:

The risk of stroke is much higher in people with SCD. Apply the FAST approach:

Facial weakness: can the person smile, or has their mouth or eye drooped?
Arm: can the person raise both their arms above shoulder height?
Speech problems: can the person speak clearly and understand what you say?
Time: to dial the emergency number for an ambulance.

It can be difficult to differentiate the symptoms of stroke from those of a sickle crisis, where pain can result in restriction of movement.

Areas of Good Practice

Sickness Absences:

Since SCD is a chronic, life-long and unpredictable variable condition, it is possible that a student/ worker with SCD might have a series of absences. In such circumstances, to apply HR sickness absence interviews and to trigger disciplinary warnings for each sickle cell-related absence could be regarded as an example of “discrimination arising from disability”. [Section 15 of the Equality Act 2010 makes it unlawful for an employer to treat an employee unfavourably because of something “arising in consequence of” his or her disability where the employer knows that the employee has a disability].

In these circumstances employers should adjust their sickness absence policies to ensure that they do not unfairly penalize SCD students/workers.

Pain:

SCD is an unpredictable condition, variable over time and between different people. This creates uncertainty for the person affected. The painful crises can come on quite suddenly.

Pain can make a person grumpy, unresponsive and uncooperative. The pain of a sickle cell crisis can be mild, moderate, severe or excruciating. Since pain is such a common experience for people with SCD it is vital that the university/workplace recognize this and develop a plan to support the student/employee when in pain.

No Pain					Most Severe pain
	Self-medication or individual techniques	Self-medication or individual techniques plus "time-out" in quiet, safe environment	A couple of day's rest at home in order to prevent a worse crisis	Can go home and manage their own referral to a day care unit	Dial 999 Know which hospital is their main treatment centre.

Only the Person with SCD is an Expert in Their Own Pain and Only They Can Say How Severe Their Pain is at Any Given Time. Always Listen to The Them.

Medical Appointments:

In order to remain well people with SCD may have commitments to medical appointments. These may be regular (monthly-six monthly) outpatient appointments for checks with their consultant. The consultant may order laboratory tests or scans that then require further hospital attendance. If the person with SCD is taking the anti-sickling drug hydroxycarbamide, they may have appointments as part of safety monitoring of that drug.

They may also have regular (every four - six weeks) exchange blood transfusions that help keep them well. Transfusions may mean attendance at hospital a couple of days before the transfusion, in order to have blood cross-matched, and attendance on another day for the transfusion itself. The person may be tired the day following a transfusion and may need a day off to rest and be able return to work. Employers should allow them to attend these appointments without requiring that they count it as sickness absence or holiday.

Further Information
National Sickle Cell Society - **www.sicklecellsociety.org**
Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK – 2018 - **www.sicklecellsociety.org/resource/sicklecellstandards/**
A Guide for Employers and Employees on Work, Employment and Sickle Cell Disorder (SCD) - **www.sicklecellwork.dmu.ac.uk** or **www.sicklecellsociety.org/resource/employment/**
EQUALTY ACT 2010 – **www.legislation.gov.uk**
UK Thalassaemia Society - **www.ukts.org**
Reference
A Guide for Employers and Employees on Work, Employment and Sickle Cell Disorder (SCD) - **www.sicklecellwork.dmu.ac.uk** or **www.sicklecellsociety.org/resource/employment/**

Feedback

Your feedback is important to us and helps us influence care in the future.

Following your discharge from hospital or attendance at your outpatient appointment you will receive a text asking if you would recommend our service to others. Please take the time to text back, you will not be charged for the text and can opt out at any point. Your co-operation is greatly appreciated.

Specialist Haemoglobinopathy Team:

Consultant Haematologist
Advanced Practitioner
Clinical Nurse Specialist x 2
Haematology Specialist Registrar (Rotational Position)
Psychologist

Contact Details:

Specialist Haemoglobinopathy Team
Tel: 0151 706 3397
Textphone Number: 18001 0151 706 3397

Author: Haematology Department
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All Trust approved information is available on request in alternative formats, including other languages, easy read, large print, audio, Braille, moon and electronically.

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