Sickle Cell Work and Employment

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

http://sicklecellwork.dmu.ac.uk

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Work, Employment and Sickle Cell

This guide is based on research examining the experiences of people with sickle cell disorder (SCD) in work and employment in England. There are duties on employers under the **1996 Employment Rights Act** to provide a contract and not to dismiss employees unfairly. There are also duties under the **Equality Act 2010** to make reasonable adjustments to enable the inclusion of disabled workers in the workplace, and, since SCD disproportionately affects BME communities, not to engage in direct or indirect racist discrimination, nor in harassment/victimization. If people with SCD are given appropriate support they are able to carry out their jobs.

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

Sickle cell disease/disorder (SCD) is a collective name for a set of inherited chronic conditions. People with SCD cover a spectrum from milder to severe forms of SCD, but with support they can achieve well in work. SCD is associated with episodes of severe pain called sickle cell painful 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. Main types of SCD are sickle cell anaemia, haemoglobin SC disease and sickle beta-thalassaemia.

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 has to 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

An employee who has a disability such as SCD is entitled to expect their employer to make reasonable adjustments to ensure that they are not at a disadvantage at work. These adjustments can be to premises or can involve the provision of equipment (such as a specialist chair), or they can be adjustments to 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 worker 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 in cold offices, 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. 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.

Good Practice: Job Applications
A person with SCD is not obliged to disclose their SCD upon application. However, an employer is not in a position to make reasonable adjustments unless the person with SCD informs them. An employer is not permitted to ask about a disability, nor about restrictions arising from a disability, as part of the job application process. However, an applicant may ask for reasonable adjustments as part of the job application/interview process. A disability-confident employer might provide written copies of interview questions in advance to reduce stress and/or provide a taxi to enable attendance at interview. They might collect data, separated from the actual job application, in order to monitor equal opportunities. It is difficult to know whether and if so when to disclose a disability during the recruitment process. A good point to ask for reasonable adjustments is the point at which a written offer of the job has been made by the employer. These reasonable adjustments should be in place when the person commences work.

***Travel to Work*:** Many workers with SCD face a challenge in commuting to work. They 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 flexi-time to avoid the rush hour can all help.

Good Practice: Travel to Work
One employer has a comprehensive policy on travel to work. As an exception to overall green travel policies, the employee with SCD has a guaranteed parking space at work. This space is a disabled driver space, or the space nearest the relevant work building usually reserved for senior managers, so that the person with SCD does not have to walk long distances. Car park attendants and security staff are briefed about SCD so that they do not discriminate by challenging the use of a disabled parking space by someone with a hidden disability or condition. In addition, combined with effective use of flexible working hours, the person can reduce travel to work time by avoiding the rush hour at the beginning and end of the day. The *Access to Work* scheme can also provide assistance.

Good Practice: 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 employees with SCD

Good Practice: Flexible Working/Working from Home
Some 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.

Good Practice: 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 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 worker about any proposed "away-day" activities or team-building exercises to minimize disruption and stress.

Good Practice: 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 employees about use of air-conditioning (as rapidly cooled skin is a key trigger for a sickle cell crisis); consulting with the 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.

Worker's Individual Support Plans (WISP): We recommend 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 employee's specialist sickle cell nurse in drawing up this plan.

Good Practice: Workers Individual Support Plans
Drawing up a worker individual support plan in consultation with the 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. One employer works with the local specialist sickle cell nurse, as well as HR, the occupational health nurse, and the person with SCD themselves, to draw up these plans. 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 consultant who will be the key health professional caring for the worker; and a list of workplace colleagues who have attended a professional update on sickle cell. 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 see a consultant 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 recognize 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 101° Fahrenheit (38° Celsius) or higher, could signal an infection. People with sickle cell disorder and fever should be seen by a consultant without delay.

Haemolysis: In people with SCD their red blood cells are destroyed prematurely and only last 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.

Obstructive Sleep Apnoea some people with SCD experience hypoxia or low oxygen levels at night which may contribute to poor quality sleep or no sleep at all, leaving them still tired in the morning. This is in addition to tiredness arising from their anaemia.

Priapism*:* An unwanted painful erection of the penis, unrelated to thoughts about sex. Again, priapism may also contribute to poor quality sleep. Urgent medical help should be sought if it lasts more than two hours.

Good Practice: Sickness Absences
Since SCD is a chronic, life-long and unpredictable variable condition, it is possible that a 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 workers. One employer suspended their return-to-work interviews for sickle cell-related absences as these were causing the person with SCD unnecessary distress. Discussions as to whether there are further adjustments that might reduce risk of triggering illness episodes in the future are more appropriately conducted as part of a Worker's Individual Support Plan (WISP) rather than as part of a disciplinary process. In the unfortunate event an employee with SCD is hospitalized for a sickle cell crisis, the period of absence needs to include perhaps a week post-discharge to enable proper recuperation. Returning to work too soon may mean a relapse and further time off that could have been prevented. As the employee may be in extreme pain and on opiate drugs, permit sickness notification by another person (a family member or a nurse) and allow the worker to text or email their notification of absence rather than requiring a telephone call.

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 workplace recognize this and develop a plan to support the employee when in pain. The worker's support plan needs to be worked out individually for each person, with input from the employee, occupational health, sickle cell medical or nurse specialist, and a union representative if requested by the employee.

Medication: A key part of the Worker's Individual Support Plan should include agreed procedures for undertaking a health and safety check and assessing suitability of specific job roles (such as operating machinery or driving) when taking strong painkillers. The key is to listen to the person. Where pain is mild or moderate the aim should be to keep the person in the workplace. This may be achieved by combining pain medication with opportunities for rest and, for example, time out in a safe environment so that they can return to work later in the day. Some people with SCD use opiate painkillers when they have severe pain. These should not be used when driving or operating machinery and may impair decision-making.

Good Practice: 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 4-6 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. A good employer will not deduct pay for time spent on appointments, although it is not definite that the Equality Act requires them to do so.

A Framework for a WORKER'S INDIVIDUAL SUPPORT PLAN for Someone with Sickle Cell Disorder

Name: Date of Birth: Workplace(s): Current work group: **Condition 1:** Sickle Cell Anaemia (HbSS) **Condition 2:** **Condition 3:** [People with SCD may develop other long-term conditions] Date of Plan: Review Date: [Suggest annual review]	 Photograph [taken when the person is well and free from pain]
NEXT OF KIN CONTACTS **Contact Name:** **Relationship:** **Contact number:** **Contact Name:** **Relationship:** **Contact number:**	**CONTACT NUMBERS** **Emergency Contact Name:** **Emergency Contact number:** **Hospital Consultant Name:** **Hospital Consultant Number:** **Specialist Nurse Name:** **Specialist Nurse Number:**
RESPONSIBLE IN WORKPLACE: Name: Building/Department: Contact Number:	**WORKPLACE**

REASONABLE ADJUSTMENTS:

Generic
Key worker to ensure that each workstation is aware of importance of following preventive measures: a warm environment, unrestricted access to water and toilet breaks.

Person-Specific Adjustments

Example 1: Provided height-adjustable chair and foot stool to help with necrosis of the hip and post hip-replacement surgery

Example 2:

Example 3:

MEDICATION

A person with SCD may be prescribed opiate-strength medication as part of overall pain management in hospital. Strong medication such as morphine has side effects and the person may have difficulty sleeping, and may have withdrawal-like symptoms such as sweating, being confused, and feeling dizzy. In some cases they may be prescribed reducing doses for a few days post-discharge to wean off the drugs slowly. Hospital staff and GPs can help by ensuring fit notes cover the week following hospital discharge. HR and managers should respect the need for time to recover, as returning to work too soon without recuperation time can lead to a relapse.

PAIN MANAGEMENT

The aim is to strike a balance between responding appropriately to medical emergencies and maintaining an inclusive work environment where a person with SCD is not frequently off work for all episodes of pain. Many people with SCD experience mild pain at work and have developed the resilience to cope with this and carry on. Sometimes if the pain is moderate this may entail self-medicating with painkillers or using individually tailored pain management strategies such as use of hot water bottles, self-massage, or distraction techniques (e.g. watching TV, listening to music). In some cases a period of rest at work in a quiet safe area may be sufficient to recover and even return to work the same day. In other cases being permitted to go home and rest for the remainder of the day and perhaps the next day may (or flexibility such as working from home the next day) can prevent a full sickle cell crisis developing and much greater time off then being required. In cases of severe pain the person may need to go home or refer themselves to hospital. In cases of excruciating pain an ambulance should be called immediately.

NO PAIN					MOST 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 for an ambulance. Know which hospital is their main treatment centre.

ONLY THE EMPLOYEE IS AN EXPERT IN THEIR OWN PAIN AND ONLY THE EMPLOYEE CAN SAY HOW SEVERE THEIR PAIN IS AT ANY GIVEN TIME. ALWAYS LISTEN TO THE WORKER.

OTHER PARTICULAR NEEDS/ISSUES

This section can contain information specific to the person’s individual condition (for example, information about mental health, strokes, leg ulcers, eye problems, hip problems, priapism, headaches, seizures, deep vein thrombosis or other possible complications of sickle cell disorder).

Stakeholders in drawing up a Workers Individual Support Plan [WISP]

Name of Person:	Signature:	Date:
Occupational Health:	Signature:	Date:
Sickle Cell Specialist Nurse:	Signature:	Date:
Human Resources Manager:	Signature:	Date:
Union Representative:	Signature:	Date:

Space for a relevant list. If requested by the worker this might include a list of medications they have been prescribed. Alternatively it might be space to note which relevant staff have attended a Sickle Cell Awareness Education Session:

e.g. Name of Prescribed Drug — Dosage
e.g. Name of Staff Member — Date of Attendance

Space to include examples of good practice developed by the workplace:

Illustrative Example 1

[Name of Employer] has joined the Disability Confident Employers Scheme to embed continuous improvement in disability practice into the organization

Example 2

.....

.....

Example 3

.....

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Further Information

RESEARCH

For a link to the research evidence underpinning the production of this information, please visit:
http://sicklecellwork.dmu.ac.uk

This site includes resources on employment and sickle cell including:
A-Z of SCD Symptoms and Possible Reasonable Adjustments
Examples of completed social security benefits applications for someone with SCD

SICKLE CELL VOLUNTARY GROUPS

The Sickle Cell Society
http://www.sicklecellsociety.org

Organization for Sickle Cell Anaemia Research and Thalassaemia Support
http://www.oscarsandwell.org.uk http://www.oscarbirmingham.org.uk

OTHER RESOURCES

ACAS
http://www.acas.org.uk An attempt at conciliation is necessary before bringing a case to an employment tribunal. If conciliation fails, ACAS will issue an *Early Conciliation Notification Form*

Chartered Institute of Personnel and Development has guidance on mental health support at work
https://www.cipd.co.uk/knowledge/culture/well-being/mental-health-support-report

Disability Confident Employers Scheme
https://www.gov.uk/guidance/disability-confident-how-to-sign-up-to-the-employer-scheme#how-to-become-disability-confident

Disability Law Service
https://dls.org.uk/ Can provide employment advice and, in some cases, support an employee in going to an employment tribunal

EQUALTY ACT 2010 *covers, amongst other issues, racist discrimination*
https://www.equalityhumanrights.com/en/advice-and-guidance/race-discrimination#act

Maternity Action Advice on rights on pregnancy and work
https://maternityaction.org.uk/

UNISON *Proving Disability and Reasonable Adjustments*
https://www.unison.org.uk/content/uploads/2019/02/25362.pdf

Trades Union Congress *practical advice for trade union reps on issues they are likely to encounter when dealing with the range of issues that can arise in the workplace*
https://www.tuc.org.uk/union-reps
Resources for Equality and Discrimination: Age, Disability, Gender, LGBT+, Race, Religion
https://www.tuc.org.uk/union-reps/equality-and-discrimination

A downloadable copy of this leaflet is available at:

http://sicklecellwork.dmu.ac.uk
http://www.sicklecellanaemia.org

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