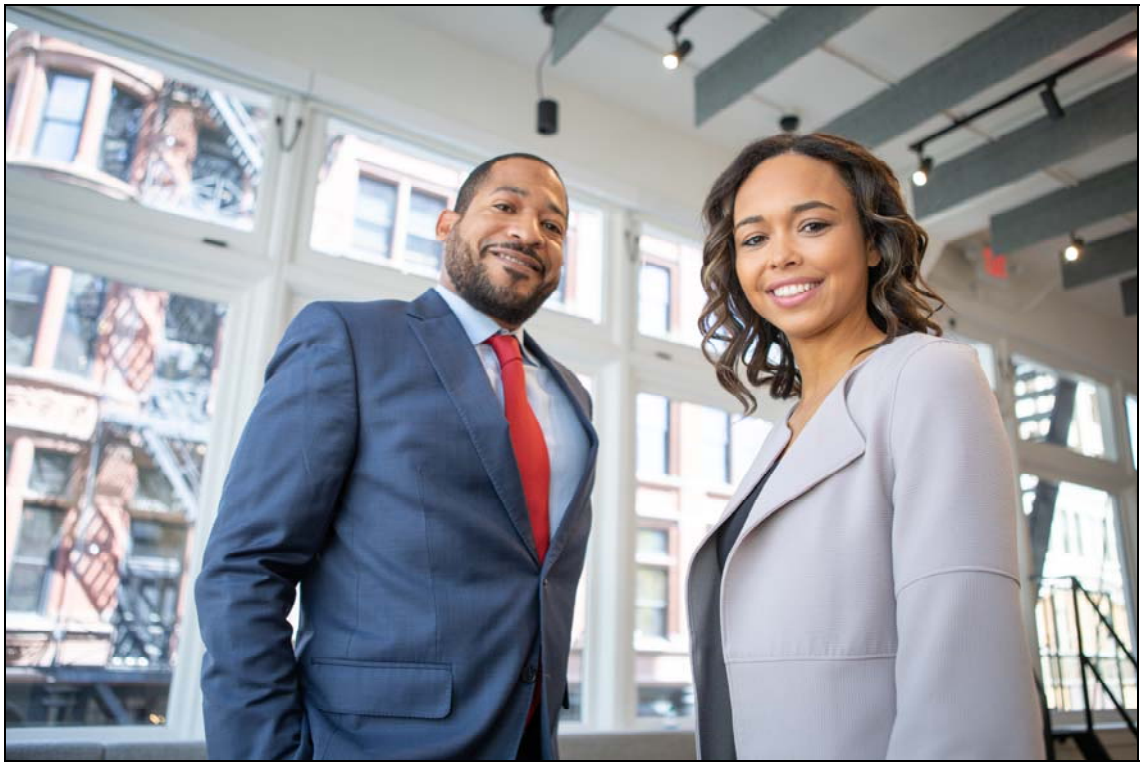
SICKLE CELL DISORDER

(SCD)

A-Z OF SYMPTOMS, COMPLICATIONS AND REASONABLE ADJUSTMENTS IN THE WORKPLACE



2019

SICKLE CELL DISORDER (SCD)

Sickle cell disorder (SCD) is an umbrella term for a group of genetic haemoglobin disorders including sickle cell anaemia, haemoglobin SC disease and sickle beta thalassemia. It affects approximately 15,000 individuals in the UK. Normal red blood cells are round, with a concave centre, and move easily through the blood vessels in the human body. Normal red blood cells last approximately 120 days. In SCD, the red blood cells become 'sickle' shaped, similar to a crescent moon. These sickle shaped red blood cells are hardened, sticky, and become trapped within the walls of the blood vessels and interrupt normal blood flow. Sickle shaped red blood cells have a life cycle of approximately 20 days. Individuals affected with SCD cannot produce red blood cells quickly enough to replace the sickle shaped red blood cells that die and become severely anaemic.

ANAEMIA

Anaemia is one of main characteristics of sickle cell disorder (SCD), due to a lack of red blood cells. Fatigue and shortness of breath can occur as a result of a shortage of red blood cells in the body.

Reasonable adjustment

Allow the person with SCD to work at their own pace. Avoid over-exertion and working beyond set hours. "Time out" periods in designated safe spaces at work when needed should also be provided, permitting a period of rest before resuming work activities. Employees who have long commutes to work should be supported by providing disabled car parking spaces at work.

BLOOD TRANSFUSIONS

A low red blood cell count owing to premature destruction of red blood cells is a symptom of SCD. Some employees may have regular blood transfusions as a key part of their medical treatment in order to maintain optimal health and manage acute symptoms of sickle cell disorder.

Reasonable adjustment

A reasonable adjustment includes permission to undergo blood transfusions as part of working time. This means that the employee does not have to use evenings, weekends or annual leave to undertake preventive medical treatment that maintains optimal health and attendance at work.

CIRCULATION

Sickled red blood cells are unable to flow smoothly through the blood vessels in the body as a result of their abnormal shape and viscosity. Blood coagulation increases as a result of sickling of red blood cells, resulting in complications such as deep vein thrombosis (DVT) which may eventually lead to more serious complications such as a pulmonary embolism (PE).

Reasonable adjustment

All employees, particularly those who disclose previous medical history of blood clots, would benefit from short intervals to mobilise around designated spaces in the workplace, in order to promote blood circulation.

DRUG THERAPY

Sickle cell disorder (SCD) is a lifelong condition with multi-faceted complications requiring medical intervention to treat acute and chronic complications. Healthcare professionals prescribe oral drug therapies both to prevent illness and to treat acute pain and associated chronic complications.

Reasonable adjustment

Employees should be permitted to take prescribed medication during working hours when necessary. Employees may be prescribed opiate drugs when discharged from hospital. Employers need to recognise that employees need time to recover even after they are discharged from hospital.

Employers need to know (and employees need to act responsibly) in that they should not operate machinery or drive vehicles when taking opiate medications. Requirements to operate machinery or driving should be suspended, and alternative work activities assigned for a period of time.

EYES

Individuals with sickle cell disorder, particularly those with haemoglobin SC disease can experience eye complications (sickle cell retinopathy). Sickled red blood cells become trapped within blood vessels and interrupt blood supply to the retina (thin layer of tissue inside the eye) and cause vision loss.

Reasonable adjustment

Provide a larger PC monitor, and reduce glare from fluorescent lighting. Visual aids including electronic magnifier devices for presentation boards, portable electronic magnifiers, and in-built electronic magnifiers for desktop workstations may help employees with reduced vision. Employees who work from home would benefit from laptops with in-built electronic magnified devices.

FATIGUE

Fatigue is a major symptom of sickle cell disorder. Sickled red blood cells have difficulty passing through blood vessels and transporting sufficient oxygen around the body, causing symptoms including tiredness. Fatigue can also occur as a result of experiencing pain, which interferes with sleep.

Reasonable adjustment

Assumptions should not be made about employees with SCD taking part in away-day or team-building exercises, especially at short notice. Employees should not over-exert themselves, and some outdoor activities may be unsuitable for workers with SCD. Flexible working hours, particularly late starts, may support employees with chronic fatigue. Rest periods during working hours can increase energy and enable tasks to be completed proficiently. Working from home is also another reasonable adjustment that may support employees in managing fatigue. Working beyond hours should be avoided.

GALLSTONES

Gallstones are a complication of SCD. Bilirubin is a substance made by the body during the breakdown of red blood cells. Sickled red blood cells are constantly breaking down in individuals with SCD due to their shorter than average life span. Breakdown of red blood cells lead to excess bilirubin production and the formation of gallstones.

Reasonable adjustment

Employees, particularly those who work shifts, long hours or whose job requires standing for long periods would benefit from resting periods for sitting down due to the fact that gallstones can cause abdominal pain. Flexible working hours and suitable alternative roles and in the workplace should also be considered. Employees may require surgery as a medical intervention. Therefore, scheduled time off from work to undergo surgery and during the recovery period is necessary.

HOSPITALISATION

Hospitalisation is a complication of certain symptoms associated with SCD. Acute pain complications often require hospitalisation, with medical intervention including oral and intravenous fluids, as well as intravenous analgesics. Hospital admissions and length of stay varies from individual to individual, therefore, all employees with SCD must be treated on an individual basis.

Reasonable adjustment

Employees who are absent from work should have a nominated emergency contact person, for example a relative or healthcare professional, who will ring the workplace to inform the relevant line

manager in the event of an acute pain episode that required admission to hospital. An employee should not be expected to contact the workplace themselves during hospital admission.

INFECTIONS

Infections are a complication of SCD. Sickled red blood cells interrupt blood supply to the spleen and cause permanent organ damage. Individuals with SCD are susceptible to bacterial infections due to impaired spleen function.

Reasonable adjustment

Indoor work environments should have good ventilation systems that provide clean air for employees. Personal protective equipment (PPE) such as gloves and face masks will minimise exposure to pollutants and harmful substances. Kitchen areas and fridges should be meticulously clean to avoid infection risks. Employers should consider permitting employees to travel to work by car, to reduce their exposure to respiratory infections whilst using public transport.

JOINT DISORDERS

Joint disorders are a complication of sickle cell disorder. Sickled red blood cells interrupt blood flow to joints. Poor blood flow to joints can cause chronic pain, swelling and restricted mobility.

Reasonable adjustment

Ergonomically designed workstations, PCs, swivel chairs, foot stools, as well as ergonomic pens and associated stationery should be provided. Mobility aids including arthritis gloves, knee braces, and compression socks worn in the workplace may reduce pain and discomfort, and enable work activities to be undertaken with greater ease. Other options for employees may also include flexible working hours, flexible job duties, or working from home.

KIDNEYS

Kidney disease is a complication of SCD that occurs as a result of sickled red blood cells interrupting blood flow to the kidneys (sickle cell nephropathy). Poor blood flow to the kidneys eventually impairs renal function. Individuals with SCD also produce large quantities of urine as a result of renal complications associated with the condition, and need more frequent toilet breaks.

Reasonable adjustment

Staying hydrated is a requirement for employees with SCD. Oral fluids are also an essential preventive measure for acute pain episodes. Employees should have water readily available within easy reach of their workstation. Employees should have toilet breaks permitted at any time during working hours.

LIVER

Liver impairment is a complication of sickle cell disorder that occurs as a result of iron overload (sickle cell hepatopathy). Excess levels of iron in the body may occur as a result of frequent blood transfusions.

Reasonable adjustment

Abdominal pain or discomfort can occur as a result of liver inflammation or liver impairment. Employees should have resting periods during working hours to manage abdominal pain. Job duties that do not require standing for long periods may be an alternative option to consider.

MENTAL HEALTH

Chronic illness, pain and mental health are closely linked together. Mental ill health can often be a

secondary complication of sickle cell disorder. Acute and chronic pain can have a long lasting and negative impact on psychological health and can be associated with mental health conditions such as depression and anxiety. Stress is also a recognised trigger factor for acute pain episodes in SCD.

Reasonable adjustment

A workplace environment that understands the correlation between chronic illness and psychological health is important. Employees should not have time-limited targets that place stress and pressure on employees, as well as exacerbate underlying mental health conditions. Flexible working hours, and working from home are alternative options to consider. Time off for counselling should be considered.

NECROSIS

Necrosis refers to the death of bone, as a result of poor blood supply. Osteonecrosis is common in individuals with SCD and usually affects the femoral head of the hip. Osteonecrosis can also affect the shoulder, elbow, wrist, knee and ankle. Interrupted blood supply to the affected joint can cause arthritis, chronic pain, and restricted mobility. A hip replacement operation may be required.

Reasonable adjustment

Employees should have ergonomically designed chairs for hip pain and discomfort, and vertical and click-less mouse and keyboard wrist aids. Employees should also have good accessibility to buildings and ground floor offices or workstations. Toilet facilities with height-adjustable toilet frames should be provided. Reserved parking spaces within close proximity to the workplace should be provided.

ORGAN DAMAGE

Organ damage is a complication of SCD as a result of poor blood supply to organs. Sickled red blood cells become trapped within the blood vessels and interrupt blood flow to multiple organs in the body.

Reasonable adjustment

Medical intervention such as surgery may be required to address severe clinical manifestations of affected organ. Employees should have scheduled time off from work to undergo surgical procedures and subsequent recovery period. Annual leave should not be used to cover absent periods from work.

PAIN

A spectrum of mild, moderate, severe and excruciating pain is characteristic of SCD. Sickled red blood cells can interrupt blood flow within the blood vessels, cutting off blood supply and oxygen, causing pain in several areas of the body. Acute pain episodes, often known as a 'sickle cell crisis' are unpredictable and may happen at any time, even when precautions are taken. Chronic pain can also occur as a result of long-term complications of SCD.

Reasonable adjustment

In the event of a severe or excruciating acute pain episode at work, employees may require immediate medical intervention, including making a 999 emergency call. Employers should have an emergency plan for someone with SCD who has a sickle cell crisis, including informing next of kin. Employees should not be placed on sickness targets or face dismissal from employment as a result of absences from work due to acute pain episodes.

QUALITY OF LIFE

Employees with sickle cell disorder live with a chronic medical condition with acute and chronic complications which may adversely affect their overall health and quality of life. Quality of life refers to factors such as health and happiness.

Reasonable adjustment

Employers should help employees maintain their physical and psycho-social wellbeing. This refers to supporting employees maintain their physical and psychological health, as well as creating a workplace environment that supports social well-being.

RED CELL EXCHANGE TRANSFUSIONS

A high percentage of sickled red blood cells in the body is a complication of SCD. Employees who have repeated acute pain episodes require red blood cell exchange transfusions to reduce the high percentage of sickled red blood cells in the body, and replace them with healthy red blood cells. This reduces the frequency of acute pain episodes.

Reasonable adjustment

Most employees will have red cell exchange transfusions to address repeated hospitalisation for acute pain episodes. Scheduled time off from work should be arranged for employees who receive this therapy to maintain optimal health. This refers to scheduled dates during the year for cross matching of blood (one appointment) and the red cell exchange transfusion itself (another appointment).

STROKE

Stroke is an important potential complication of SCD. Sickled red blood cells can interrupt blood flow to the brain and cause brain cells to die. This is known as a cerebral infarction. Blood vessels can also rupture and cause localised bleeding in the brain. This is known as a brain haemorrhage.

Reasonable adjustment

Good accessibility to buildings should be provided for employees who have a medical history of stroke. Lifts and wheelchair access are reasonable adjustments. Employees who work in offices would benefit from ergonomically designed products such as wheel-less chairs, PC screens with magnifying devices, assistive technology, assistive software, ergonomic keyboards, or voice-activated software.

TEMPERATURE

Hot or cold temperatures are trigger factors for acute pain episodes. Cold temperatures can cause blood vessels to constrict (vasoconstriction), and restrict blood flow around the body and trigger an acute pain episode. Employees who travel abroad as part of their work activities may require oxygen therapy on flights, as high altitudes can trigger an acute pain episode due to a lack of oxygen. Extreme hot temperatures can cause dehydration, which can also cause an acute pain episode.

Reasonable adjustment

Employees should have warm environmental conditions to work in. Good heating systems, as well as individual portable heaters should be provided for employees. Air-conditioners should only be used with caution during hotter periods, and the person with SCD should not sit in direct line of these. Employees who undertake outdoor work activities, work near chillers or work in other cold conditions should be permitted to wear extra layers of clothing and/or considered for alternative work assignments. Adjustments to work uniforms should be permitted.

ULCERS (LEG)

Leg ulcers are a complication of sickle cell disorder, and occur as a result of poor blood circulation to the skin. A leg ulcer is an open sore that often appears on the inside of the leg, and may take a long time to heal, up to months or in some cases years.

Reasonable adjustment

Employees in office and administrative type roles should be permitted to take analgesics for pain management. Employees with venous leg ulcers should be allowed to attend appointments for compression therapy. Lifts should be available and periods standing up avoided.

VACCINATIONS

Susceptibility to bacterial and viral infections are complications of SCD. Individuals with sickle cell disorder have a compromised immune system. They require vaccinations over the course of their lives as a preventive measure to maintain good health.

Reasonable adjustment

Employees should be provided free mandatory vaccinations as part of occupational health policy. This should include annual flu vaccinations.

WATER

An acute pain episode is a complication of SCD often triggered by dehydration. Dehydration causes the blood to become thicker and affect blood circulation around the body. Water is an essential preventive measure for acute pain episodes.

Reasonable adjustment

Employees should have water within reach during working hours. This enables employees to stay hydrated and also to take oral medications when necessary.

X-RAYS AND SCANS

Sickle cell disorder is a medical condition with acute and chronic clinical manifestations. Employees may require x-rays and scans as part of diagnostic tests to confirm the presence or absence of illness.

Reasonable adjustment

Employees should be given permission to attend appointments for x-rays and scans. Scheduled time off should not count as an absence or as a sick day off work. Annual leave should also not be used as a method to cover time off work for hospital appointments that are vital to maintain good health.

YELLOW TINT (EYES)

Yellow tint to the whites of the eyes (jaundice) is a complication of SCD. When red blood cells breakdown, a yellow substance called bilirubin is produced. High levels of bilirubin cause a yellow tint to the eyes and skin. Jaundice can cause symptoms including abdominal pain, fever and fatigue.

Reasonable adjustment

Employees should be allowed to reduce working hours, or undertake work activities from home as an alternative option. Employees with GP/hospital appointments should have time off from work to attend.

ZINC AND OTHER MINERAL DEFICIENCIES

Individuals with sickle cell disorder are often deficient in vitamins including zinc, folate, vitamin B12 and vitamin D. Vitamins play a vital role in health and wellbeing.

Reasonable adjustment

Employers could also consider implementing healthy eating options for employees at work. Canteens should offer healthy options for employees to consume during working hours.

This guidance was produced as part of the project **Barriers and Enablers to Employment: Black Disabled Peoples Living with Sickle Cell Disorder Project** (2018-2020) funded by The Big Lottery and Disability Research Independent Living and Learning and conducted by De Montfort University, The Sickle Cell Society and OSCAR Sandwell. The guide was produced by Dorcas Oyeyiola, working as part of De Montfort University's paid internship scheme DMU Graduate Champions. We thank Dr Amy Webster, Consultant Haematologist, University Hospitals of Leicester NHS Trust for reviewing this document.

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