Sickle Cell and Trait: A Guide to Higher Education Policy

Higher Education, Health and Wellbeing


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We wish to thank the people who participated in research and who shared their experiences to make this guide possible. We would like to thank all the students who anonymously gave feedback on first drafts of this guide. We would also like to thank the following for their critical comments:
-Louise Hayden, Haemoglobinopathies Clinical Nurse Specialist, Leicester Royal Infirmary
-Tina Sharpe, De Montfort University
-Hulda Lopanda, De Montfort University
-Omotola Dehinde, SC Advocate

Higher Education and Sickle Cell

This booklet has been produced based on research examining the school and employment experiences of people living with Sickle Cell Disorders (SCD) in England. We discovered that issues affecting employment trajectories often began in schools and higher education. By Higher Education (HE), we include tertiary or post-secondary educational institutions such as colleges and universities.

Good practice: People living with SCD should be encouraged to follow their educational dreams and employment aspirations. They can be aided in this through mentorship and seeing examples. Encourage people living with SCD, who have gone to HE, to come and talk to those pupils thinking about it. If you are a teacher or lecturer, motivate your students and talk through their fears and aspirations. In our research, we found that there was always that one key teacher who believed in the abilities of a student or gave them some extra support. That could be foundational for setting that student on the path to HE and later employment.

What is Sickle Cell?

Sickle cell disorder (SCD) is a collective name for a series of inherited blood disorders that can affect all systems of the body. SCD is one of the most common genetic conditions in the world, as carrying the sickle cell gene (having SCD trait) offered a genetic advantage and protection against malaria. SCD is commonly found in people whose origins are from the equatorial belt region, such as West-Africa, the Mediterranean, Latin-America, Caribbean, Middle East and Indian sub-continent.

Good practice: It's important to know your students and prepare for their inclusion. In the United Kingdom (UK), most people who have SCD are British but have an African or African-Caribbean heritage. If the college or university has a lot of international students, students with SCD can be from a range of differing countries, such as, from Nigeria, Brazil, Saudi Arabia, or Greece. It is important to understand if those students are here without their families and to know who to contact if they become unwell. They might also want to be in contact with voluntary sector organisations who can offer advice and support, such as national organisations: Sickle Cell Society (https://www.sicklecellsociety.org/) or local, like OSCARs (https://www.oscarsandwell.org.uk/). This includes international students who become parents of a child with SCD.

People living with SCD have a type of haemoglobin (called haemoglobin S, HbS or sickle haemoglobin) which differs from normal adult haemoglobin (haemoglobin A or HbA). This can cause red blood cells to change shape and form a sickle or banana shape. These can become blocked in the blood vessels, causing acute pain. Many systems of the body can be affected, meaning that different key organs can be damaged and differing symptoms can occur. The main types of SCD are sickle cell SS which is viewed as more serious and haemoglobin SC disease and sickle beta-thalassaemia which tend to be milder. Despite its name sickle beta-thalassaemia is a sickle cell disorder and is distinct from beta-thalassaemia major. Each person's experience of SCD is unique and can not be predicted. People have periods where they are very well but also times in their lives when they might need to be hospitalised.

Sickle Cell Trait

There is a difference in having SCD which is a serious medical condition and carrying the sickle cell trait or gene. Having the SCD trait means you are healthy, and it is typically asymptomatic. However,

some people with sickle cell trait can have issues with dehydration, extreme physical exertion and high altitudes which can cause blood cells to form sickle-like shapes. There is also an extremely rare form of kidney cancer that can affect people with sickle cell trait. It is called renal medullary carcinoma and symptoms can include blood in urine and feeling pain between the ribs and hips.

Good practice: Students with sickle cell trait can compete at the highest physical levels including professional sports. However, if students with sickle cell trait are taking part in activities that can cause extreme physical exertion such as in sports competitions or during hot summer days, they need to stay well-hydrated by drinking water and have breaks to rest.

If you want to understand if you carry the sickle cell gene (or have the trait), you can ask to get a blood test from your GP. In the UK, all babies have a blood spot test and you may also find out as a parent that your child carries the sickle cell gene. Knowing your trait status is important. If you have the sickle cell trait and you have a child with another person who has sickle cell trait, you have a 1 in 4 chance, in each and every pregnancy, of having a child with SCD. A child with sickle cell trait is perfectly healthy.

Good practice: People who had the sickle cell trait in the UK did not have a lot of education about what this entailed, where they could get tested nor how they could find out more information. This was in contrast to students, from places like Nigeria, who felt they were well informed but said that they could experience stigma. All students appreciated getting impartial information, which was not just medical in nature but also about the social aspects of having sickle cell trait.

Higher Education and Inclusiveness

HE is becoming increasingly diverse and it has certain duties to ensure inclusion and diversity is respected. The **2010 Equality Act** identifies protected characteristics, such as, age, disability, sex, sexual orientation, gender reassignment, pregnancy and maternity, religion or belief, marriage and civil partnership and 'race'. Universities also have duties to ensure no discriminations, equality of opportunity and thus have to provide reasonable adjustments or accommodations, for instance, in ensuring exams are accessible for students with differing disabilities, chronic and medical conditions. The United Nations **Convention on the Rights of Persons with Disabilities** (CRPD), Article 24, also affirms the rights of persons with disabilities to education. All states must ensure non-discrimination and equality of opportunity and inclusion in education and life-long learning.

Good practice: We found that people living with SCD often do not go to universities of their choice because they prefer to be close to their families, and especially the hospitals where they receive their care. As well as checking on the colleges and universities of their choice, students and parents might want to contact the sickle cell services in that city and ask to speak to a specialist nurse. They can also check with the **disability services (they are a part of equality and diversity services at a college or university)** to understand what happens if a student becomes unwell or has a pain crisis. Once accepted at a college or university, we would recommend **you ask your consultant to refer you to local team in the city** you will be attending. Even if you don't want to transfer all your care to the hospital near your institution, it is a good idea they meet you and aware you're living in the area. This is in case you require support whist in the city. It might be useful to ask your consultant to contact the consultant in that city, so they are aware of your medical history. You might ask your consultant if they can inquire if you can tour the A&E department. Some universities make sure that students with SCD have a special medical identification, enabling ambulance services to access where they are on campus in a quick way. Disability services would check that your

lecturers and security team would also be aware of what to do and how important immediate medical support would be. Some universities also make sure that students with SCD are in accessible university accommodation and they can stay there past the first year. In good practice, we heard of one university where security staff ensured ambulances could get to accommodation quickly where a student with SCD lived. The university allowed the student to stay on campus which also reduces the need for commuting. The impact of commuting to colleges and universities was a significant cause of fatigue. Ask if you can visit accommodation to check it is accessible to your needs.

Universal Design for Learning

HE has an obligation to ensure **Universal Design for Learning (UDL**) which means that colleges and universities will engage in differing learning and teaching styles to engage a variety of learners in the classroom. They will use digital methods and innovative technologies to allow inclusion and accessibility of learning. They will also ensure flexibility and have duties to **reasonable adjustments** in the classroom and during assessments.

Good practice: Many people living with SCD spoke about studying in hospital or pushing themselves to attend class when they were in pain, fatigued or at risk of infection. We also heard from parents of children with SCD missing classes because they needed to attend hospital appointments. With UDL and having all the learning materials available virtually, this issue has decreased and students can stay home if needed and learn in their own time. Students said they appreciated when lecturers asked if they needed tutorials or made extra materials, like videos, available that they could follow in their own time to catch-up.

Decolonisation

As HE has become increasingly diverse, students and staff have begun to think about decolonisation and what this should look like in the classroom, during lectures and on campus. Students and staff have asked for more representation in the visual imagery, the texts and stories that we tell and a reappraisal of all our histories. That includes ensuring that sickle cell is part of HE and all our educational learning as one of the major recessively inherited genetic conditions in the UK and globally.

Good practice: Students felt it was hard to have to explain what sickle cell was to their tutors, lecturers or fellow students. This necessitated disclosure and explaining a complicated medical condition. An inclusive atmosphere takes this burden away from students by ensuring everyone is informed and campus are inclusive to all students living with disabilities, chronic illnesses and medical conditions. Colleges and universities should teach about sickle cell in medical and nursing degrees but also as part of our social and cultural history of diversity in the UK, and as global citizens. The story of sickle cell is about global social justice, anti-racism and the fight for health equality. It should be part of the entire curriculum in all HE institutions. Decolonisation is also about holding space for students and encouraging them to celebrate all parts of their heritage, for example, through creation of their societies, celebration of Black history month and affirming role-models.

Disability

People living with SCD may see themselves as having a chronic or medical condition and not view themselves as having a disability. How a person with SCD self-identifies is very personal but in order to get reasonable adjustments, rights to disability accommodations and ensure that a college or university is aware of their condition, they should get in touch with disability services, disability officer or learning support coordinator. Disability services at colleges and universities can give you information about what support is available and also act as a liaison to lecturers so they are aware. In the UK, if you are a British citizen, you are entitled to a **Disability Student Allowance (DSA)** which helps students with medical conditions, learning difficulties or disabilities. Even if you are not a British citizen, it is important to contact disability services, as they can also ensure assistance with practical issues, as well as give information about what to do in case of any emergency situation. They will also be aware of extra support, like **university financial support or hardship funds** which students with SCD can apply to for additional support such as with heating, specialist diet or because they are unable to work. Specialist sickle cell nurses or the voluntary sector will also be able to signpost to support available.

Good practice: Disability services can be useful to ensure that students do not have to disclose personally but there is an awareness in their lecturers and personal tutor of their condition, while protecting their privacy to other students. As SCD can sometimes be episodic or manifest as a disability, it might be that students are fine for several months but might have to contact services for specific issues. For example, with getting a note-taker, Dictaphone or specialist speech to text software, in case of pain crises that were affecting the joints in the fingers. It's good practice to review if a student living with SCD needs any reasonable adjustments every 3-6 months.

Ableism

Students living with SCD stated that an important reasonable adjustment that they needed was time. They do not lack ability but absences meant that they could miss lectures, seminars or workshops. The nature of HE is of productivity, working to deadlines and ensuring that assignments are done on time. The idea that HE is designed for able bodies is termed ableism.

Good practice: Ensure that students can catch-up with provision of tutorials or extra self-directed tutorial time. If students need extensions or deferrals because of illness, hospital appointments or fatigue, explain that there is no issue with that. Everyone works at their own pace.

Higher Education and Reasonable Adjustments

Symptoms of Sickle Cell

People living with SCD mostly look fine which is why having sickle cell is sometimes described as an **invisible disability**. There are mild and severe versions of SCD but it affects every person differently. People can have a range of symptoms which they learn how to cope with, such as anaemia, jaundice, fatigue and a range of pain. However, there can also be more serious issues like stroke or pain developing into a 'crisis' needing immediate medical treatment. People living with SCD might also need to go the hospital or clinic on a regular basis, for example, for blood transfusions. They might also have chronic complications that affect their mobility such as joint pains, necrosis of the hip or leg ulcers.

Good practice: If you are a personal tutor with a student living with SCD, ensure you give face-to-face or virtual meetings as required by the student. Ask students about their needs for adjustments or accommodations to attend class or follow lectures. Assure them that their privacy will be kept but the team is aware of their condition and knows what to do if they ever become unwell or have a pain crisis. Understand that you will need to call the emergency services in such a situation. As well as academic life, ask them about joining societies and social life. Students are not their medical conditions and often want to experience life as a student.

How can the symptoms of sickle cell disorders (SCD) be prevented?

Certain factors have been identified as more likely to precipitate a painful sickle cell crisis. These include infections, cold and/or damp conditions, pollution, dehydration, strenuous exertion, stress, sudden changes in temperature, alcohol, caffeine, drugs and smoking. Advice to people living with SCD on preventing pain crises includes keeping warm, eating healthily, taking moderate exercise, drinking plenty of fluids, seeking medical advice if they have a fever, avoiding smoking, drugs and alcohol, keeping up to date with medications and vaccinations, and trying to live a stress-free life.

Good practice: Going to HE can be exciting but stressful, as students begin to understand how to manage their conditions themselves. Sometimes, they are still learning, for instance, to listen to the signs of their bodies, how to cook for themselves and when to rest. They have to look after their physical and mental health and it's good to signpost those services. They can do moderate exercise under supervision, for example, in a gym. Students can also struggle with homesickness, anxiety and even depression living away from home. They should know how to get in touch with the mental health and wellbeing services. This also includes sexual health services. Students with SCD should discuss such issues with a consultant. Students may have heard of the use of marihuana to cope with pain but this can have a negative impact on the body and should be discussed with a consultant. Generally, the use of any alcohol, smoking, vaping, drugs and even staying out or up all night are very dangerous to people living with SCD.

HE absences: There will be times when students living with SCD might need support due to absences. They should be able to catch up with the work in their own time. Lecturers usually allow for that by ensuring lectures are recorded and also available online. Students with SCD generally feel that they can catch up with work or follow the material online if they need to have absences or to work from home or hospital. A big issue for them is when absences from illness happen around exams or periods when they will have assessments.

Good Practice: Anecdotally in our research, it seemed as if there was a correlation between going into a crisis and stressful periods of time, like exams, when assessments were due. Students reported that there were some reasonable adjustments that were especially helpful. They appreciated as much preparation as possible and knowing that they could have an extension or deferral if needed. Lecturers can put in place reasonable adjustments for assessments, for example, presenting via video-link if someone cannot be on campus or ensuring a quiet room to take an exam to reduce stress. Do not schedule back-to-back exams without adequate rest and toilet breaks. Ensure that students can drink water and have access to supervised toilet visits during exams. Exam rooms should be warm in the winter and cool in the summer.

***Water*:** Students living with SCD need to be well hydrated to reduce the likelihood of becoming ill. Ensure a policy of allowing all students to drink water in class. Ensure water fountains on campus are working and kept in the highest state of cleanliness so young people living with SCD are not put off using them and risk of infection is kept to a minimum. People living with SCD produce large quantities of dilute urine and need to go to the toilet more often. Do not restrict toilet breaks for students.

Good practice: Ensure that students can readily have water in class and are allowed to leave the classroom for toilet breaks. Lecturers can ensure that there is a break after an hour's lecture for all students. When students with SCD had to do bench work in laboratories, lecturers agreed with the students that they could have a stool to sit down and have regular timed breaks.

Fatigue: The person with SCD may experience severe anaemia. This may mean they feel tired, have fatigue, are lethargic and unable to concentrate. They may feel tired to the point where they feel they need to sleep. They might also be drowsy due to pain medication or because they are due a blood transfusion. Climbing numerous flights of stairs several times per day to get to and from a lecture or walking to campus can be very physically demanding. Students are also increasingly working, as well as studying during a cost-of-living crisis, affecting fatigue and energy levels.

Good practice: Try to ensure that classrooms are timetabled close to each other for students living with SCD. Rooms should be well-ventilated and warm during winter. Allow students to wear coats and scarves in cold auditoriums. In summer, do let students sit away from air-conditioning or windy areas. Ensure that students are housed in warm and well insulated accommodation within walking distance to campus. If needed, make it possible for students living with SCD to stay in university accommodation on campus, to reduce their commute. Colleges should also be mindful of the impact of commuting and working on their students. Be aware jobs requiring heavy manual labour, working in freezers or evening shifts might take a toll on a student's health and are discouraged.

Pain: SCD is an unpredictable condition, variable over time and between different people. This creates uncertainty for a student. A painful crisis 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 or severe and it's important to listen to the expertise of students living with the condition.

Good practice: If a student says that they are in pain, encourage them to go home and rest. If they say they want to stay on campus, they can go to quiet rooms or breathing spaces and see if they can manage the pain. If the pain is moderate, they might want to go to a pain clinic to manage their pain. If they do not have access to a pain clinic, they can visit the GP or nurse on campus. If the pain is severe and they go into crisis, you have to call an ambulance immediately.

Medication: Where pain is mild or moderate, a key aim should be to keep the student in HE, by combining pain medication with an opportunity for rest and time out in a safe environment. This is so students can return to lessons when they feel better. Sensitivity around gender and pain is also required as women might feel pain correlated to periods. Men due to priapism which can cause painful erections. These are involuntary, very painful and not sexual in any way. If they last for longer than 2 hours, urgent medical care should be sought. In the UK, you can get a prescription prepayment certificate, allowing you to save money if you know you will need prescribed medicines for pain or other issues. Disability services or the voluntary sector can give more information.

Medical Emergencies for Sickle Cell Disorders

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 as soon as possible.

Organ damage: Sickle cell affects all systems of the body any organ can be affected. Signs of organ damage can include nausea, paleness (jaundice), fatigue, and rapid pulse.

Fever: Children 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. Children with sickle cell disorder and fever should be seen by a consultant without delay. If you are an adult and have a fever you should also see your consultant.

Painful crises: These may occur in any part of the body and may be brought on by cold or heat or dehydration. 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 hospitalised. It is important to listen to the student who will come to know whether the pain is mild or moderate and will pass or whether they need to go to hospital.

Pulmonary Hypertension: Some people living with SCD can be at high risk for pressure in their lungs. They can have difficulty breathing, fatigue, chest discomfort, feel light headed and have swelling in their arms, legs or stomachs.

Stroes*:* Apply the FAST approach:

Facial weakness: can the person smile, or has their mouth or eye drooped?

Arm: can the young 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.

Vision: People with SCD and especially SC should be aware of any changes in vision and go to A&E urgently if they have an increase of floaters or there is any change in vision.

Leg ulcers: Can occur due to poor blood flow**.** They will need treatment and changing of bandages, sometimes under medical supervision.

Priapism*:* An unwanted painful erection of the penis, unrelated to sexual thoughts. Urgent medical help should be sought if it lasts more than two hours.

Life away from home: HE is often the first time that a student lives away from home and their support networks. This can be a challenging but also a very rewarding time in a person's life. It is a time of transition and it's good to discuss that each step of the way with those who will support. We have developed the following HE plan below to allow the student living with SCD/parents to begin to prepare and to put into practice some of the advice contained in this guide.

Planning for Higher Education

Consultant/Haematology team:

-Can they prepare a letter for you explaining your (child's) condition?
-Can they make contact on your behalf with the team in the city you are going to or send your medical records there?
-Is there a sickle cell centre or pain clinic?
-Can you have a tour of the A&E department and do you know who your new consultant will be?

Disability Services:

-What educational reasonable adjustments do you need? In the classroom? During assignments?
-What information do they need about your condition? Do you have any additional learning needs?
-Do you need any equipment or support?

Accommodation:

-If you are living at home, have you tested the commute? Do you need any support?
-If you going to live on campus, is the accommodation warm, quiet, accessible? Have you met the security staff?

Personal Tutor:

-Do you need to let them know about any personal or academic issues?
-Any reasonable accommodations that need to be put place? Any caregiving responsibilities or times when you might need to be away from class?
-How do you best learn?

Family, guardians and friends:

-Have you got your support network ready? Who is going to have a chat with you each week to check-in?
-Have you got a text or voice message ready in your phone that you can press in case you (your child) go into crisis?
-Have you discussed what will happen if you go into a hospital by yourself?

This leaflet was first produced in 2011 on the basis of research funded by the United Kingdom's Economic and Social Research Council (RES-000-23-1486) a research grant held by Simon Dyson, Lorraine Culley, Sue Dyson (De Montfort University), Karl Atkin (University of York) and Jack Demaine (Loughborough University). It is also based on research conducted in 2018-2020 funded by the Big Lottery and DRILL (Disability Research Independent Living and Learning, reference 2C1\100045) on a grant held by Simon Dyson and Maria Berghs (De Montfort University).

Version 3.2 **Date:** 31st July 2024