

# Sickle Cell & Thalassaemia

A comprehensive guide to education policy and best practice in supporting children and young people (CYP) diagnosed with Sickle Cell and/or Thalassaemia (SCaT) in educational settings (2024)



Adapted from Sickle Cell Consortium Parent to Parent initiative and by Simon Dyson's, "Sickle Cell and Thalassaemia: Education, Health and Care, A Guide to School Policy" 2016

**Created by OSCAR Birmingham & Birmingham City Council  
Children & Families Directorate**

**Supported by: BSoL ICB SCaT Development Steering Group**

## Background Information

### Education, Health and Care in School

This guidance has been produced based on the most recent collective views of children, young people and carer's own experiences relating to Sickle Cell and Thalassaemia conditions in education settings across Birmingham and Solihull. An important part of school inclusiveness is recognising the importance of offering appropriate education provision to children and young people with long-standing illnesses, particularly since a large proportion of childhood is spent attending school.

**Section 100 of the 2014 Children and Families Act** in England places a duty on the appropriate school authority (for example, board of governors or proprietor), to reasonable adjustments to support pupils in school with medical conditions. Pupils with Sickle Cell or Thalassaemia come under this legislation and guidance.

[Supporting pupils with medical conditions at school - GOV.UK](#)

### What is Sickle Cell?

Sickle Cell is a name for a series of serious inherited invisible blood conditions that can affect all systems of the body. It is one of the most common genetic conditions with almost 300 babies born in the UK with Sickle Cell each year. People with sickle cell have a rare type of haemoglobin which causes red blood cells to change shape and become blocked in the blood vessels, causing severe acute pain and risk of life-threatening complications. Sickle Cell disproportionately affects communities from Black African, Caribbean, South Asian and Middle Eastern Heritage.

### Impact

CYP with Sickle Cell will present different symptoms including pain crises, resulting in key organs being damaged, fever, priapism, swelling in joints and bone aches, extreme fatigue and delayed growth. Children and young people are at high risk of a stroke especially between the ages of 2-16 years old. Children on average can miss up to 16 days of school each year. They may also be on regular treatment such as blood transfusions or exchange, oral medications, iron and ongoing treatment with hospital appointments. There are many types of Sickle Cell conditions which a specialist nurse can provide further information.

### What is Beta-Thalassaemia Major?

There are different types of Thalassaemia with Beta-thalassaemia Major the most serious inherited blood condition which affects the production of haemoglobin in red blood cells. Treatment involves blood transfusions every 2-4 weeks for the rest of their lives, iron chelation therapy and ongoing hospital appointments.

### Impact

Each CYP is unique, and symptoms may differ but will include severe tiredness, pale, shortness of breath due to lack of oxygen in body and anaemia. Iron overload can damage liver, heart and lungs if not safely removed. Some children may experience delayed growth, puberty and fragile bones. Pupils with Beta Thalassaemia Major will require close monitoring and treatment to prevent life threatening complications.

# Checklist:



Ensure that the family, CYP, education staff and specialist nurses are invited to the annual meeting to develop and review the health care plan (HCP).



Ensure each plan is personalised and unique to the CYP as sickle cell and thalassaemia can impact different children in different ways.



Ensure that a copy of the HCP is shared with relevant educational staff, including all teaching and non-teaching staff who will be responsible for the care and supervision of the pupil, on and off site.



Ensure this document is reviewed at least annually, or as necessary if there are changes based on risk factors such as frequent hospitalisation, school absences, changes to medications. Any update of HCP should be based on healthcare recommendations.



Ensure that you seek further guidance from parents/carers or supporting health professionals.



Note: Most pupils will have an understanding of their condition at an age-appropriate level and should be included in planning and discussions.

# **Key Roles and Responsibilities**

## **The Role of the education setting**



Some children and young people require provision to be carried out during the day when they are at nursery, school or college. The responsibility for the education provision will be down to education staff - with a medical overview (HCP) with input from health professionals, HCP and risk assessment where necessary. Sickle cell and Thalassaemia are serious long-term conditions and require lifelong care and treatment.

There are different variations of this condition. Symptoms and pain will vary across every young person and will not always be predictable or visible. Complications will impact their learning, home environment and attendance. It is important the school collaborates with carers, health professionals and pupil to understand the severity of the condition, and feel confident in implementing good practice, preventative measures to support pupils and what to do in a medical emergency. Being confident, consistent in decision making and making reasonable adjustments will help pupils to feel safe, supported, included and enable them to reach their fullest potential.

A CYP's attendance can be affected by their complex health needs. Absences, including those for appointments connected with a CYP's medical condition need to be effectively managed and appropriate support put in place to limit the impact on the CYP's educational attainment and emotional and general wellbeing.

## **The Pupil's Role**



CYP should share any issues and concerns with parents, school and health professionals about their care and treatment, especially if this is affecting their access and attendance to education. Pupils should try to be resilient, gain more understanding about their condition whilst striving to do their best in school.

Pupils should seek help if they are struggling with education and /or wellbeing.

Pupils should be confident, open and honest in speaking about their condition with adults and peers.

## **Parent/Carer Role**



The parent/carers play an integral part for their child. They are the only people present for every medical appointment, managing symptoms and hospital admission.

Education settings should involve parents and carers as you have a wealth of knowledge and information regarding their child's condition and how it affects them.

Parent/carers understand their child and should be included in all stages of their child's education especially if health has an impact on child's learning,

## **The Hospital's Role**



The Specialist Haematology Team at Birmingham Women and Children's Hospital, supported by a consultant, provide comprehensive care and treatment to children and young people. Specialist teams are responsible for the personal care plan. They have extensive clinical expertise and can provide teaching and learning for both teaching and non-teaching staff. Refer to them as a point of contact for information, guidance or child's condition impacts their wellbeing and education.

## **Educational Implications and Provision Advice for Supporting Children and Young People with Sickle Cell and Thalassaemia.**

CYP with Sickle Cell and Thalassaemia need to be well supported throughout their education so they are included and make appropriate academic progress alongside their peers, despite their medical condition.

### **Individual Education, Health, and Care Plans**

- All children with Sickle Cell and Thalassaemia (SCAT) should have a health care plan in school (HCP). This should be reviewed at least annually. It is important to include the CYP, parent/carer and a supporting health professional in developing and reviewing this plan. The HCP needs to be shared with relevant education staff in the setting, and it is especially important to consider how relevant information will be shared with cover teachers.
- Schools should also work with CYP and their families to ensure the provision detailed in their healthcare plan is appropriately implemented in the education setting so that the CYP is effectively supported to play a full and active role in school life, remain healthy and achieve their academic potential.

## **SCHOOL ABSENCE DUE TO HEALTH NEEDS**

**CYP with Sickle Cell or Thalassaemia may miss teaching and learning time due to their condition; this might be to attend appointments, due to ill health and /or due to pain and fatigue needs.**

- A CYP's own school can usually well support absences. Schools should look to explore flexible options around blended learning, including online opportunities. Maintaining linking opportunities with their peers at school is also beneficial. Such arrangements best support CYP to continue to make progress when they are unable to attend school but are still well enough to learn. These approaches also contribute to CYP, and their families' feeling connected with their school and well supported at what can be a difficult time in their lives.
- Schools should arrange further education provision if a CYP is too unwell to attend school for the longer term. They can refer to the Local Authority arrangements for educating pupils out of school.
- If attendance drops below 90% during school term, due to absences related to their condition the appropriate supporting health professional should be informed.
- Schools should adopt supportive approaches to absence in circumstances where significant health needs have been appropriately evidenced.
- Reasonable adjustments to usual attendance policies when supporting CYP with significant health needs might be required . Reasonable adjustments would not include authorisation for a holiday in term time but schools should avoid warnings of potential legal action for poor attendance where there is ample evidence that the child has a serious medical condition and schools should not penalise children for their attendance record if their absences are related to their medical condition, e.g. hospital appointments.

## CURRICULUM ACCESS DUE TO HEALTH NEEDS

CYP with Sickle Cell and Thalassaemia may experience severe anaemia. They may have less energy, feel tired and lethargic and find it difficult to concentrate throughout the school day. CYP with transfusion dependent thalassaemia are also likely to be tired towards the end of their 4-week cycle of transfusions.

### Curriculum Provision

- Prioritise learning to best support CYP to make progress at times when they are most fit and well and able to attend to school.
- Provide more motivating tasks for periods of when CYP has more pain and fatigue.
- The use of ICT supports efficient recording and helps with the management of fatigue.
- School needs to consider access arrangements for any assessments and examinations and be aware that additional stress around this time may trigger further pain and fatigue.

## GETTING AROUND SCHOOL

For some CYP with Sickle Cell or Thalassaemia their ability to mobilise can be affected. Mobilising longer distances can be painful and/or tiring.

### Education Provision

- Reduce unnecessary walking around school.
- Issue a lift pass.
- Ensure CYP can take the shortest route.
- Consider walking distance in timetable and room allocations where possible e.g. ensure form room at secondary school is easily accessible.
- Ensure CYP has time to move around school – they may prefer to leave lessons 5 minutes early with an early leave pass.

## WATER/HYDRATION

All CYP should be encouraged to drink water throughout the school day. Good hydration reduces the likelihood of becoming unwell. CYP with Sickle Cell require more water than the average person and certainly need to be well hydrated. Dehydration can cause pain.

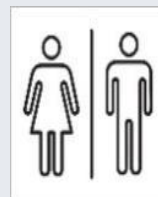
### Education Provision

- A filled water bottle must always be with the student.
- Ensure access to drinking water, even in class.
- CYP might need to be encouraged/prompted to drink water regularly.
- Ensure any water fountains are working and clean or ensure there is an alternative way to fill water bottles.



## USING THE TOILET

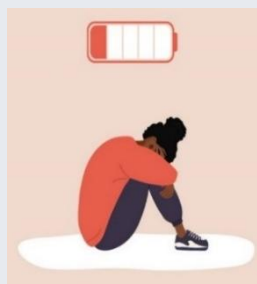
Sickle Cell affects the kidneys, and it is more difficult for CYP to concentrate their urine. In addition, CYP living with SC require more fluids to stay hydrated. This combination often leads to an increased need to urinate frequently.



### Education Provision

- CYP need to be able to use the toilet as and when needed/requested, even if this is during lesson time.
- A toilet pass may need to be provided to allow a student to leave the lesson or to discreetly explain a late arrival to a lesson due to having to go to the toilet on the way.
- Some students might need a regular discreet adult prompt/timetabling to remind them.

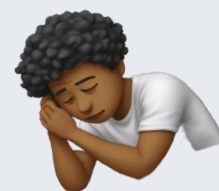
## FATIGUE & TIREDNESS



A CYP with Sickle Cell or Thalassaemia may experience severe anemia. This may mean they feel tired, lethargic and unable to concentrate. They could feel tired to the point where they feel they need to sleep.

Education settings should implement within school strategies to support fatigue needs and avoid the need for a pupil having to go home just for a rest break where possible.

### Absence Arrangements Education Provision Education Provision



- Reduce unnecessary walking around school – see section on mobility.
- Plan for busy activities to be followed by quiet activities.
- Provide an indoor space at break time where the student can take a rest – this should still provide an opportunity for CYP to have a social break time alongside friend/s.
- Provide a discreet and appropriate area where a CYP can lie down and rest /sleep in the school day if required.
- Provide a more flexible curriculum as and when needed - additional rest breaks, motivating activities and flexible homework arrangements for times when CYP is more fatigued.



# PAIN

Pain may occur in any part of the body and may be brought on by triggers such as cold, heat, stress or fever. Educational settings must listen to CYP when they report pain and respond appropriately and according to the advice in the HCP. The goal for school is to find a balance between responding appropriately to a medical emergency and not constantly sending CYP home for minor pain episodes.



## Education Provision

- Ensure CYP is aware of who to report their pain issues to.
- Seek advice from supporting health professionals to discuss if a pain scale is an appropriate and useful tool in school. This tool might support school/CYP to take appropriate actions.
- Refer to HCP regarding strategies /medication that can be administered to alleviate pain.

## SCALE FOR PAIN

Only applicable for children and young people treated for Sickle Cell

0	1/2	3/4	5/6	7/8	8-10
I am not in pain anymore	I am in a little bit of pain but don't need medication	I feel if I have my medication, I can be in class	I feel the need to have time out and my parent to be contacted	I feel the need to go home or hospital	I am in so much pain and need immediate medical attention



## PHYSICAL ACTIVITIES



Extended periods of time in cold or wet weather may trigger episodes of illness and strenuous exercise involving exertion could precipitate a sickle cell crisis. CYP may tire more easily and need rehydration during physical activity.

CYP with Sickle Cell or Thalassaemia should enjoy the positive aspects of physical activity alongside their peers.

Moderate exercise should be encouraged.

Approaches to including CYP with these conditions in physical activities should be individually planned and adapted.

Advice from parents, CYP and supporting health professionals should be implemented. Schools should also be aware that CYP may also have a blood test or cannula site which can be sore or bruised.

Please refer to HCP for more information.

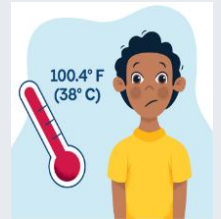
### Education Provision

- It is important to listen to CYP and follow advice from parent /carer and supporting health professionals around inclusion in physical activity.
- The CYP should participate at their own level.
- CYP should have the opportunity to take rest breaks as needed but should not be standing around inactive in cold weather.
- Additional layers /adapted PE kit might be required - i.e., jogging bottoms and warm fleece can be provided. Extra layers /blanket can be taken outside.
- CYP should ensure they have access to water and stay hydrated throughout the lesson.
- Appropriate alternative indoor PE opportunities might need to be provided in cold and wet weather.

## TEMPERATURE



Young people with Sickle Cell may become ill if they are too hot or too cold. It is good for all children to go outside in the fresh air, but additional provision should be considered.



### Education Provision

- CYP should be encouraged to wear appropriate layers of clothing for the temperature outside.
- CYP should have the opportunity to come back in from break early if they become too cold.
- An alternative indoor venue should be provided in cold weather if required, this should still enable the CYP to have social playtime with their friend/s.
- Encourage CYP to wear hat, scarf and gloves in cold weather and provide time for CYP to put these on before going out to play allowing them to go out to play at the same time as their peers.

## SCHOOL TRIPS/RESIDENTIALS

All CYP, including those with Sickle Cell and Thalassaemia should be supported to ensure they have full access to all the wider opportunities education provides and that includes school trips and residential.



### Education Provision

- It is always important to gather the views of CYP, parent /carers and supporting health professionals when planning the inclusion of CYP with Sickle Cell and Thalassaemia in a school trip/residential.
- Individual planning incorporating all the advice is required to safely include CYP in school trips.
- This planning should begin well in advance of the date of the trip.

# SWIMMING

Children living with Sickle Cell and Thalassaemia can enjoy swimming and should learn to swim. CYP with Sickle Cell are advised not to become too cold. This may happen when going swimming with school – in the pool and/or when getting changed afterwards.



## Education Provision

It is always important to listen to the views and gather advice of CYP, parent carers/ and supporting health professionals before planning inclusion in swimming/water activities. Individual planning is required to safely include CYP in school swimming sessions. This planning should begin at least a term ahead of the swimming lessons.

Planning considerations should include:

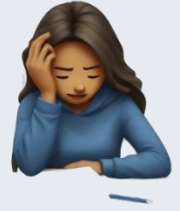
- Some schools may have the opportunity to consult with the swimming baths to increase the water temperature in the swimming pool used.
- Visit the venue ahead of time so that information about water temperature and the heating in the changing rooms can be assessed and discussed with CYP, parent and supporting health professional.
- Consider moving the swimming visit to the summer term.
- Provide a towel on the poolside. Consider allowing CYP to wear a wet suit.
- Consider the need to reduce the time spent in the water. This arrangement should be flexible and adjusted on the day according to the needs of CYP.
- Ensure the CYP is fully active for the session i.e. not standing at the side of the pool waiting for a turn.
- Ensure CYP has easy fastenings and loose clothing to make the task of changing after swimming easier and quicker.
- Ensure CYP has a toweling robe/spare towel to help keep them warm once out of the pool.
- CYP should remain hydrated during the session and access to a water bottle should be on the poolside.

# OTHER HEALTH & MEDICAL CONSIDERATIONS

## WELLBEING AND MENTAL HEALTH



Living with Sickle Cell and Thalassaemia can be very difficult for CYP. This will impact self-esteem, confidence and general mood. It is common for CYP to feel worried, stressed at one time or another depending on what is happening around them in their lives or related to their condition.



***Chronic pain can lead to psychological distress. Physical pain and emotional well-being are closely linked and a change in one area can affect the other.***

CYP who experience chronic sickle cell pain are often presented with various difficulties including:

- Difficulties with relationships, social life, memory and concentration.
- Problems with school, mood and anxiety issues.
- Sleep disturbance, isolations and stigma living with the condition.
- Coping with their frequent hospital admissions.
- Children may develop behavioural and emotional difficulties due to neuropsychological dysfunction and stress caused by their condition.
- Delayed puberty and physical development.

**Promoting wellbeing is a key part of keeping CYP safe, helping them develop and ensuring positive outcomes (Public Health 2021).**

**Best practice, provision and tips include:**

Provide a safe space for CYP to have conversations and talk about feelings.

### **Take time out to relax**

CYP should take deep breathes or have calm thoughts when feeling stressed. Seek additional support from external organisations.

**Support CYP to identify, learn and become experts in managing their condition when they reach an appropriate age**

Explore supportive interventions to help build their resilience and setbacks.

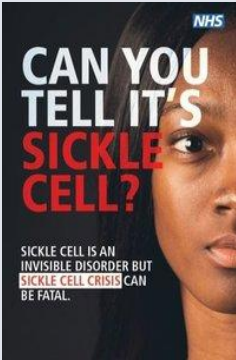
### **Encourage healthy eating and positive lifestyle choices**

Prevent and challenge discrimination in and out of school.

**Provide opportunities and reasonable adjustments where possible for pupils to catch up coursework and for exams.**



## ACUTE PAIN & CHEST SYNDROME



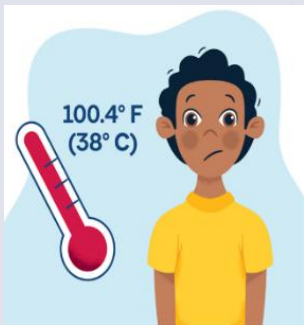
Pain can be either chronic or acute. Listen to CYP when they state they are in pain. Acute Chest Syndrome is a pain crisis in the lungs. This is life threatening. Follow the pain management protocol.

**Acute and severe pain is a medical emergency and requires immediate hospital.**

These are the most common reasons why hospital admission may be required and time away from school.

## FEVER AND INFECTIONS

**Children with sickle cell disorder are at increased risk for certain bacterial infections including sepsis.**



A high temperature could signal an infection. Children with sickle cell disorder and fever should be seen by consultant without delay.

Painful swelling of the hands and feet (Hand-foot syndrome) , plus fever. It is most likely to occur in children under five.

## PRIAPISM



**An unwanted painful erection of the penis unrelated to thoughts about sexual desire.**

Urgent medical help should be sought if it lasts more than two hours.  
First experience

## STROKE

**Children and young people are at higher risk of a stroke especially between the ages of 2-16 years old.**

It can be difficult to differentiate the symptoms of stroke from those of a sickle crisis, where pain can result in restriction of movement. Children with Sickle Cell have a Transcranial Doppler Scan yearly from age 2 to assess risk of stroke. It is important to liaise with the young person's medical consultant to investigate if such changed behaviour is owing to a silent stroke.

Blood cells tend to stick together and clump the blood vessels. This can lead to clot forming, moving to the brain, causing a stroke. A stroke can also be caused by damage to blood vessels in the brain caused by Sickle Cell.

### **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

## TACKLING INEQUALITIES

It is important to understand that Sickle Cell and Thalassaemia predominantly disproportionately impact those from Black African, Caribbean and South Asian communities including migrant families new to area. **This group also experiences racial bias, structural racism and have been affected by COVID-19 pandemic, both directly through infections and deaths, and indirectly economically, socially with poor housing conditions and poverty (BLACHIR Report 2023)**


**Provision:** Review educational approach and opportunity for targeted intervention to increase academic achievement for this group. Refer and/or work with local Sickle Cell Charity or with Early Help Teams if any CYP needs more help from public services or community groups in their locality.

# Generic Care Plan

## A Guide for an Individual Education Health & Care Plan for Someone with Sickle Cell Disorder or Thalassaemia

Sickle Cell (HbSS) or (HBSC) or (HBS/Bthal)

(Note- This is an example of a plan. BWCH will use their own more comprehensive care plan,  
where parent/carers & education settings contact them in respect of a child's individual needs)

<p>Name:</p> <p>Date of Birth:</p> <p>School:</p> <p>Current Class/Group:</p> <p>Condition 1:</p> <p>Condition 2:</p> <p>Condition 3:</p> <p>Date of Plan:</p> <p>Review Date:</p>	 <p>Photograph</p>
<p><b>PARENT/GUARDIAN/CARER CONTACTS</b></p> <p><b>Contact Name:</b></p> <p><b>Relationship:</b></p> <p><b>Contact number:</b></p> <p><b>Contact Name:</b></p> <p><b>Relationship:</b></p> <p><b>Contact number:</b></p>	<p><b>CONTACT NUMBERS</b></p> <p><b>Emergency Contact Name:</b></p> <p><b>Emergency Contact number:</b></p> <p><b>Hospital Consultant Name:</b></p> <p><b>Hospital Consultant Number:</b></p> <p><b>Specialist Nurse Name:</b></p> <p><b>Specialist Nurse Number:</b></p>
<p><b>KEYWORKER RESPONSIBLE IN SCHOOL:</b></p> <p><b>Name:</b></p> <p><b>Building/Department:</b></p> <p><b>Contact Number:</b></p>	<p><b>GENERAL PRACTITIONER:</b></p> <p><b>Contact Name:</b></p> <p><b>Contact number:</b></p>
<p><b>Date of Health and Safety Risk Assessment Carried out by School:</b></p>	



**PREVENTION:**

**Key worker to ensure that each member of school staff is aware of importance of following preventive measures....**

- Unrestricted access to drinking water during class time
- Unrestricted access to use of the toilet, including during class time
- Keeping warm: permitting coat/hat/gloves indoors, not sending outside in break
- Not forcing them to undertake exercise if they say they are tired or in pain

**MEDICATION**

**Name of medication:**

**Reason for medication:**

**Dosage:**

**Time of medication:**

**Special Considerations:**

**Medication will be stored:**

**Arrangement for Delivery to School:**

**Written Records Arrangement:**

**PAIN MANAGEMENT**

The aim is to strike a balance between responding appropriately to medical emergencies and maintaining an inclusive school environment where a pupil with sickle cell disorder is not constantly sent home for episodes of minor pain. Ask the specialist sickle cell nurse or hospital consultant if there is a pain scale suitable for use in getting the young person with sickle cell disorder to say how severe the pain they are in. There are scales in which a young person is shown drawings of a series of cartoon faces ranging from happy (no pain) to sad and crying (most pain). Such a scale could be included in the individual education, health and care plan. The following scale is for illustrative purposes only and any scale used should have the approval of the young person's hospital consultant.

<b>0</b>	<b>2</b>	<b>4</b>	<b>6</b>	<b>8</b>	<b>10</b>
I am not in any pain	I am in a little pain but don't need my medication	I feel if I have My medication I can be in class	I feel I need to have time out but may feel better later	I feel I need to go home	I feel I need to go to hospital

**OTHER PARTICULAR NEEDS/ISSUES**

- This section can contain information specific to the young person's individual condition (for example, information about silent strokes, leg ulcers, priapism, headaches, seizures or other possible complications of sickle cell disorder).

**Stakeholders in drawing up IHCP**

Name of Person: Signature: Date:

Guardian/Carer: Signature: Date:

School Nurse: Signature: Date:

Sickle Cell/Thalassaemia Specialist Nurse:

Signature: Date:

Teacher: Signature: Date:

**School staff Who Have Received Sickle Cell/Thalassaemia Awareness Session:**

Name:	Date:

**Space to include examples of good practice developed by the school:****Water**

[Name] is allowed to take his water bottle into assembly. He sits at the end of the row to be able to access this discreetly.

**Exams**

Ensure the plan is in place should they need additional time. Consider a small, well-heated room and supervised access to toilet during exams.

**(For Beta-Thalassaemia Major or Sickle Cell Disorder) Blood Transfusions**

Work with the hospital to schedule regular blood transfusions so that [name] is most energized at beginning of exams.

## **Further Information for Education Settings/Local Schools**

### **OSCAR Birmingham**

Established local Sickle Cell and Thalassaemia charity offering a range of projects, interventions, information and advice on a range of issues to professionals, wider public, children, young people and families across Birmingham and Solihull.

<https://oscarbirmingham.org.uk/mentoringsupport>  
<https://oscarbirmingham.org.uk/services-for-carers>

Email: [admin@oscarbirmingham.org.uk](mailto:admin@oscarbirmingham.org.uk) Tel: 0121 212 9209

### **Clinical and Medical Support**

Haemoglobinopathy Specialist Team for Sickle Cell and Thalassaemia at Birmingham Women and Children's NHS Foundation Trust. Medical team involved in the care and treatment of children and young people diagnosed with SCaT across Birmingham and West Midlands. This team is responsible for CYP personal care plans.

Tel: 0121 333 8862 (Specialist Liaison Sisters)

### **West Midlands Sickle Cell and Thalassaemia Network**

This is a network is led by healthcare professionals, including consultants, nurses, vascular scientist, psychologist and other NHS specialists.

<https://westmidsstn.nhs.uk>

### **Mental Health support for young people**

Forward Thinking Birmingham provides care pathway and mental health assessment and support for young people from 0-25 years old.

<https://www.forwardthinkingbirmingham.nhs.uk>

### **Sandwell and West Birmingham NHS Trust**

Psychology Service for SCaT patients aged 16 plus only and need to be referred by a consultant or specialist nurse.

## **National Charities**

### **The Sickle Cell Society**

<https://www.sicklecellsociety.org>  
<https://www.sicklecellsociety.org/priapism>

### **UK Thalassaemia Society**

<https://www.ukts.org>

## Glossary

Term	Definition
<b>BLACHIR</b>	Birmingham and Lewisham African Caribbean Health Inequalities Report 2023
<b>BSoL</b>	Birmingham and Solihull
<b>Can you tell its Sickle Cell</b>	NHS campaign to raise awareness of the signs of a Sickle Cell crisis
<b>CYP</b>	Children and Young People
<b>Early Help</b>	Locality teams supporting families across ten areas in Birmingham
<b>Haemoglobin</b>	This substance is in red blood cells which is needed to transport oxygen around the body
<b>Hand Foot Syndrome</b>	A painful swelling of hand and feet in sickle cell caused by a blockage in blood flow
<b>HCP</b>	Health Care Plan
<b>Hb SS</b>	Sickle Cell Anaemia which is most common and serious
<b>Hb SC</b>	Milder form of Sickle Cell
<b>Hb S/BTM</b>	Type of sickle cell that features symptoms of both sickle cell disease and beta-thalassaemia
<b>Iron Chelation</b>	Treatment used to remove excess iron from the body for both Sickle Cell & Thalassaemia
<b>SCaT</b>	Sickle Cell and Thalassaemia
<b>SEND</b>	Children with Special educational needs and disabilities
<b>Specialist Haematology Unit</b>	Based at Birmingham Women's and Children's Hospital. The largest children's Sickle Cell and Thalassaemia Unit in West Midlands