

Sickle Cell Disorders

Supporting Pupils with Medical Conditions in Hertfordshire Schools.

Insert School Logo

Designed to support Schools in the implementation of the Department of Education (September 2014) Guidance on Supporting pupils with medical conditions.

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Glossary of Terms

Schools – this guidance uses the word schools to mean all state, free and academy schools in Hertfordshire that have chosen to use this guidance. This term also applies to nurseries and early years settings.

Public Health Nursing staff– individuals employed by Hertfordshire Community NHS Trust working in School Nursing Teams and Health Visiting. Staff include School Nurses, Health Visitors and Community Staff Nurses and Nursery Nurses.

Introduction

This policy is intended to ensure that appropriate processes are in place to fully support and safeguard pupils at our school who have Sickle Cell Disorders. It has been prepared with reference to information available from Young People with Sickle Cell Disorders, HCT Children's Sickle Cell Nurse Phil Daly and the [Department of Education \(2014\) guidance](#).

Persons operating under this guideline are as follows:

- Hertfordshire Community NHS Trust (HCT) staff
- Doctors
- Teachers
- School/nursery support staff
- Parents/carers
- Children /young people with a sickle cell disorder

Communication with Parents

When a pupil who has a Sickle Cell disorder joins our school, a meeting will be arranged with the parents (and pupil where appropriate) to:

- Discuss the pupil's medical needs.
- Discuss if and how the pupil's Sickle Cell disorder and medication affect his or her ability to concentrate and learn, and how the pupil can be supported with this.
- Discuss any potential barriers to the pupil taking part in all activities and school life, including day and residential trips, and how these barriers can be overcome.
- Advise parents and the pupil of the school's Sickle Cell Disorder policy.
- Discuss with parents and the pupil the arrangements for ensuring that all relevant staff are trained and other pupils are Sickle Cell aware.
- Ensure that both medical prescription and parental consent are in place for staff to administer any necessary medication.
- Initiate the completion of an Individual Healthcare Plan, including symptoms, possible triggers, preventive procedures before and after an acute attack and medicines to be administered.
- Discuss how the school, parents and pupil can best share information about the pupil's progress in school and any changes to his or her Sickle Cell condition and medication.

A record of what was discussed and agreed at this meeting will be kept by the school.

After the initial meeting, the school will continue to share information with the pupil's parents and to involve the parents in any decision making process. Where appropriate the pupil will also be involved in this process. The children's specialist sickle cell nurse will attend the meeting, please contact on 07887995059 to arrange.

With Health Professionals

Our school recognises that information held by the school may be extremely useful to the pupil's healthcare team. Where appropriate, and with the parents' permission, our school will share this information, either via the parents or directly with the pupil's healthcare team. Our school will also encourage information sharing between health and education, for example changes in medication.

With School staff

All appropriate staff, including teachers and office staff will be told which children in the school have Sickle Cell disorders, and what type of disorder they have. All staff (teaching and support) who are responsible for a child with a Sickle Cell disorder will receive basic Sickle Cell awareness training, including what to do if a child has an acute attack. New staff will be given this information as part of their induction. Supply staff who will be responsible for a child with a Sickle Cell disorder will be given information about Sickle Cell disorders, including what to do if a child has an acute attack, before they begin working in the school.

At the beginning of the academic year, a meeting will be arranged to discuss the pupil's support needs. At this meeting all attendees will be given a copy of the pupils Individual Health Plan.

One named member of staff will take responsibility for sharing any changes to the pupil's Individual Healthcare Plan with appropriate members of staff.

With the pupils who have a Sickle Cell disorder

The school will give voice to the views of pupils with Sickle Cell disorders, for example regarding feeling safe, respect from other pupils, teasing and bullying, what should happen during and following an acute episode, adjustments to support them in learning, adjustments to enable full participation in school life and raising Sickle Cell disorder awareness in school.

School Life

An Inclusive, Safe Environment

Pupils with Sickle Cell will not be isolated or stigmatised and will be allowed to take a full part in the school curriculum and school life, including activities and school trips (day and residential). Parents and staff will discuss any special requirements prior to such events. The pupil's safety should be considered in all such activities and a risk assessment produced when needed. Staff will consider the adjustments necessary to enable the pupil to participate fully in school life and to reach their full potential. This might include changes to timetables, exam timings and coursework deadlines. These adjustments will be recorded and shared with other appropriate members of staff.

Raised Awareness

The School will ensure that awareness of Sickle Cell is raised across the whole school community. Particular attention but with parental permission information will be given to the pupil's peer group so that they know what to expect.

Mentor / Buddy

The school will offer support by providing a mentor or buddy for the pupil if wanted.

Education

All pupils who have Sickle Cell disorder will have an Individual Education Plan. The pupil's teachers will keep records detailing the pupil's achievement, behaviour, memory, concentration and energy levels.

For Primary School Children

The pupil's teacher will review his or her progress termly. If any problems are identified the teacher will meet with the SENCO and the Sickle Cell Specialist Nurse, to discuss and agree strategies for supporting the pupil.

For Secondary School Students

Once a term the pupil's teachers will review the pupil's progress in their subject, and inform the form tutor if the child is not achieving to their full potential or is experiencing problems with concentration etc. If any problems are identified the form tutor will meet with the pupil's teachers / the SENCO / the Sickle Cell Specialist Nurse, to discuss and agree strategies for supporting the pupil.

Any changes or problems identified, as well as strategies for supporting the pupil, will be discussed with the pupil's parents and, when appropriate, with the pupil. With parental permission any problems/issues with learning should be discussed with the specialist sickle cell nurse. If appropriate the pupil may undergo an assessment by an educational psychologist. Any changes to the pupil's Individual Education Plan will be shared with the appropriate members of staff.

Medical Needs

The pupil's Individual Healthcare Plan will be kept in the (**Inset where these are kept**) The pupil's form teacher will be responsible for reviewing the plan at least once a term and will advise other appropriate staff of any changes.

All staff (including support staff) will be trained in first aid. The first aid procedure will be prominently displayed in all classrooms.

The pupil's Individual Healthcare Plan will include the names and contact details of the staff trained to administer medication. There will be a trained member of staff available at all times to deliver emergency medication. We will ensure that enough staff are trained and available, so that even if the person who usually administers emergency medication is unexpectedly absent, there will still be a trained member of staff available to administer the emergency medication. A record of staff trained in administering emergency medication will be kept with the Individual Healthcare Plan.

A medical room with a bed will be kept available, so that if needed, the pupil will be able to rest following an acute event, in a safe supervised place.

Individual Healthcare Plan

Name of school/setting

Child's name

Group/class/form

Date of birth

Child's address

Medical diagnosis or condition

Date

Review date

Family Contact Information

Name

Phone no. (work)

(home)

(mobile)

Name

Relationship to child

Phone no. (work)

(home)

(mobile)

Clinic/Hospital Contact

Name

Specialist Nurse Phone no.

07887995059

G.P.

Name

Phone no.

Who is responsible for providing support in school

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Sickle Cell Disorders have 3 main symptoms; Anaemia, Increased risk of infections and Painful Crisis.

In Sickle Cell Disorders the red cells become sickle or crescent shaped. These sickled cells can clump together and become trapped within the blood vessels, interrupting normal blood flow and oxygen delivery, causing a sickle cell crisis. This can lead to severe pain. The pain can be to any part of the body.

All staff need to be aware of the following preventative measures

- *Any complaints of pain must be taken seriously and early intervention is essential.*
- *Unrestricted access to drinking water during class time. Age appropriate reminders.*
- *Unlimited access to the toilet, including during class time.*
- *Permission to stay indoors in cold/damp weather if requested. In addition recognising the need to keep warm in classrooms e.g. not sitting in draughts, need for extra clothing etc.*
- *Listening to the child and not forcing them to undertake exercise if they say they are tired or in pain. Allowing them to rest when they need to. Some children will be unable to do outdoor physical exercise lessons in winter months.*
- *Extra time may be needed for exams as stress can cause a painful crisis.*

Management of Pain in School

- Sickle cell pain can last minutes, hours, days or weeks, it can range in severity and may require hospital admission if severe.
- Give the child a drink, if possible in cold weather a hot drink
- Reassure child and find somewhere warm and comfortable to sit/relax, in addition try and keep the child's mind occupied distracting them from the pain, some children may prefer to stay in the lesson.
- Inform the parent
- Administer Calpol/paracetamol and /or Ibuprofen – the parent should bring these medicines to the school. Pain relief should take effect within 30 minutes.

Daily Care Requirements:

Daily care requirements: (e.g. before sport/lunchtime)

- Encourage child to have a drink before/during and after sport if needed.
- Swimming; children are advised not to become too cold. This may happen when swimming in unheated pools or by delays in drying off afterwards. In particular ensure that the hair is dried. The views of the parents and the young person about inclusion/exclusion in swimming must be listened to. Transport to and from the swimming pool may be required.
- Provision to stay indoors in cold or damp weather.

Learning and educational needs

All staff need to be aware of strokes and silent strokes and the effect on academic performance.

A stroke is a sudden and severe complication of sickle cell anaemia and sickle beta zero thalassaemia, the type of sickle cell disorder dictates the risk.

A stroke happens when a blood vessel is blocked. This slows down or stops the flow of blood and oxygen into the brain, causing part of the brain to die. When this happens, a part of the brain is damaged and does not work as well. If a child is having a stroke this is a medical emergency and urgent medical treatment is required. Children are screened on an annual basis using a special test called a trans Doppler scan to assess the risk of stroke in that child.

Signs of Stroke

- Change in behaviour – appearing unusually quiet, confused or disorientated.
- Becoming drowsy and/or unable to speak in sentences.
- Weakness of one or both sides of the body / Inability to walk /lack of co-ordination/ unexpectedly falling over/ more clumsy than normal.
- Convulsions / loss of consciousness

Silent Strokes occur in 1 in 5 children with sickle cell anaemia. Silent Strokes happen when a small area of the brain is damaged. Sometimes the only symptom is a change in behaviour/ concentration / memory / processing speed / academic attainment so it is important that you alert the parents and specialist nurse if this happens so that the cause can be investigated and help arranged.

Missed Schooling

- Planned support for missed lessons due to hospital appointments or illness need to be arranged.
- It is of benefit if the school can arrange for additional work to be given to the family during periods of illness.
- Tiredness may mean pupils need extra time to complete class / homework and exams.

Sensitivity to stature and effect of jaundice (yellow eyes) may make the child/adolescent feel different to peers. A lot of children with this illness need a lot of emotional support to share knowledge of their illness with their peers.

Arrangements for School Visits / Trips etc.

Extra consideration needs to take place when planning :

- Ensure child has enough water for duration of trip.
- Extra trips to toilets need to be considered.
- Assessment of amount of walking and if child will have opportunity to rest if required.
- Request for pain medication for trip.
- If the trip is overnight or longer, a letter from the specialist nurse or hospital consultant should be requested. The specialist nurse should be contacted for advice particularly for travel abroad.
- It should be mentioned that due to the inability to concentrate urine a lot of these children suffer from night time enuresis (bedwetting)

Other information

If parvovirus (slap cheek) is in the child's classroom, please inform the parents and specialist nurse if advice is needed. A complication of this virus is that it can cause the body to stop making new red blood cells for a short time and for the red blood cells to become trapped in the spleen . This can cause the haemoglobin to fall to very low levels, requiring urgent treatment. A blood transfusion is usually necessary if this happens. The child can still attend school if this virus is in the classroom but everyone needs to observe the child for signs of severe anaemia e.g. pallor, lethargic or signs of extreme tiredness.

When to seek medical assistance.

- Sudden **severe** onset of pain occurring in any part of the body (caused by sickled blood cells blocking small blood vessels)
- Severe pain or sudden swelling in the abdomen (due to enlargement of the spleen)
- Severe headache, dizziness or stiff neck.
- High temperature, any temperature above 38 inform mother as medical assessment will be required.
- Very pale in colour especially the palms of the hands & lips.
- Painful or difficult breathing

Signs of Stroke

- Change in behaviour – appearing unusually quiet, confused or disorientated.
 - Becoming drowsy and/or unable to speak in sentences.
 - Weakness of one or both sides of the body / Inability to walk /lack of co-ordination/ unexpectedly falling over/ more clumsy than normal.
 - Convulsions / loss of consciousness
- **If there is any cause for concern, Dial 999 ambulance service stating pupil has a sickle cell disorder. Parent/carer should be contacted at the same time.**

Who is responsible in an emergency (*state if different for off-site activities*)

Plan developed with

Staff training needed/undertaken – who, what, when

Form copied to

Parental Agreement for setting to Administer Medicine

The school/setting will not give your child medicine unless you complete and sign this form, and the school or setting has a policy that the staff can administer medicine.

Date for review to be initiated by	
Name of school/setting	
Name of child	
Date of birth	
Group/class/form	
Medical condition or illness	

Medicine

Name/type of medicine <i>(as described on the container)</i>	
Expiry date	
Dosage and method	
Timing	
Special precautions/other instructions	
Are there any side effects that the school/setting needs to know about?	
Self-administration – y/n	
Procedures to take in an emergency	

NB: Medicines must be in the original container as dispensed by the pharmacy

Contact Details

Name	
Daytime telephone no.	
Relationship to child	
Address	
I understand that I must deliver the medicine personally to	[agreed member of staff]

The above information is, to the best of my knowledge, accurate at the time of writing and I give consent to school/setting staff administering medicine in accordance with the school/setting policy. I will inform the school/setting immediately, in writing, if there is any change in dosage or frequency of the medication or if the medicine is stopped.

Signature(s) _____ Date _____

Record of Medicine Administered to an Individual Child

Name of school/setting	
Name of child	
Date medicine provided by parent	
Group/class/form	
Quantity received	
Name and strength of medicine	
Expiry date	
Quantity returned	
Dose and frequency of medicine	

Staff signature _____

Signature of parent _____

Date			
Time given			
Dose given			
Name of member of staff			
Staff initials			

Date			
Time given			
Dose given			
Name of member of staff			
Staff initials			

Record of Medicine Administered to an Individual Child (Continued)

Date			
Time given			
Dose given			
Name of member of staff			
Staff initials			

Date			
Time given			
Dose given			
Name of member of staff			
Staff initials			

Date			
Time given			
Dose given			
Name of member of staff			
Staff initials			

Date			
Time given			
Dose given			
Name of member of staff			
Staff initials			

Staff Training Record – Administration of Medicines

Name of school/setting	
Name	
Type of training received	
Date of training completed	
Training provided by	
Profession and title	

I confirm that [name of member of staff] has received the training detailed above and is competent to carry out any necessary treatment. I recommend that the training is updated [name of member of staff].

Trainer's signature _____

Date _____

I confirm that I have received the training detailed above.

Staff signature _____

Date _____

Suggested review date _____

Contacting Emergency Services

Request an ambulance - dial 999, ask for an ambulance and be ready with the information below.

Speak clearly and slowly and be ready to repeat information if asked.

- Telephone number
- Your Name
- Your Location as follows [insert school/setting address]
- State what the postcode is – please note that postcodes for satellite navigation may differ from the postal code
- Provide the exact location of the patient within the school setting
- Provide the name of the child and a brief description of their symptoms. Please ensure that you inform them that the child has a sickle cell disorder.
- Inform Ambulance Control of the best entrance to use and state that the crew will be met and taken to the patient
- Put a completed copy of this form by the phone

Model Letter: Inviting Parents to Contribute to Individual Healthcare Plan Development

Dear Parent

DEVELOPING AN INDIVIDUAL HEALTHCARE PLAN FOR YOUR CHILD

Thank you for informing us of your child's medical condition. I enclose a copy of the school's policy for supporting pupils at school with medical conditions for your information.

A central requirement of the policy is for an individual healthcare plan to be prepared, setting out what support the each pupil needs and how this will be provided. Individual healthcare plans are developed in partnership between the school, parents, pupils, and the relevant healthcare professional who can advise on your child's case. The aim is to ensure that we know how to support your child effectively and to provide clarity about what needs to be done, when and by whom. Although individual healthcare plans are likely to be helpful in the majority of cases, it is possible that not all children will require one. We will need to make judgements about how your child's medical condition impacts on their ability to participate fully in school life, and the level of detail within plans will depend on the complexity of their condition and the degree of support needed.

A meeting to start the process of developing your child's individual health care plan has been scheduled for xx/xx/xx. I hope that this is convenient for you and would be grateful if you could confirm whether you are able to attend. The meeting will involve [the following people]. Please let us know if you would like us to invite another medical practitioner, healthcare professional or specialist and provide any other evidence you would like us to consider at the meeting as soon as possible.

If you are unable to attend, it would be helpful if you could complete the attached individual healthcare plan template and return it, together with any relevant evidence, for consideration at the meeting. I [or another member of staff involved in plan development or pupil support] would be happy for you contact me [them] by email or to speak by phone if this would be helpful.

Yours sincerely

Resources and useful links:

- NHS Sickle Cell and Thalassaemia Screening Programme:
<http://www.sct.screening.nhs.uk/>
- Sickle Cell Education: <http://www.dmu.ac.uk/research/research-faculties-and-institutes/health-and-life-sciences/sickle-cell-education/sickle-cell-education.aspx>
- Sickle Cell support: <http://www.sicklecellsociety.org>
- Sickle Cell and Thalassaemia A Guide to School Policy by the Sickle Cell Society
:<http://sicklecellsociety.org/wp-content/uploads/2015/01/Dyson-School-policy-sickle-cell.pdf>
- Herts Sickle Cell service: <https://www.hct.nhs.uk/our-services/children-s-sickle-cell-specialist-service/>