Managing & Supporting children with Sickle Cell Disease in School

Jacqui Bowyer
Community Nurse Specialist

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Aim of session

- Prevention of sickle cell crisis
- Managing child with Sickle Cell Disease in school
- Practical measures to support the child
- Covid 19 recovery plan
- Patient experiences- video/call

Sickle Cell Crisis contributing factors

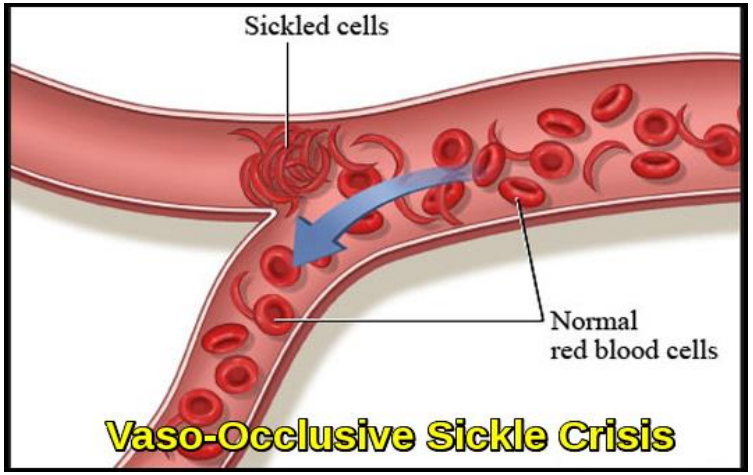
H – Hypoxia

A- Acidosis

D- Dehydration

I- Infection

T-Temperature changes
+Stress, increased physiological demand,
eg: pregnancy, sports training.



Hydration-Water

Young people with SCD need to be well hydrated to reduce the likelihood of becoming ill

Good practice:

- Supply of fresh drinking water available
- Allow to drink throughout the day- aim for 2-3 litres
- Have water bottle on the table
- Ensure water fountains are working and highest state of cleanliness- pupil is not deterred from using it and risk of infection kept to a minimum

Using the Toilet

People with SCD cannot concentrate urine easily. They produce large quantities of dilute urine and need to go to the toilet more often

Good practice:

- Do not restrict toilet breaks
- Consider use of toilet pass- laminated card to excuse the pupil
- Enuresis ("wetting") common complaint of SCD- boys often up to teenage years
- Avoids embarrassment for the pupil

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Temperature

Weather and temperature are an important factor in preventing a sickle cell crisis. Young people can become ill if they are too hot or cold

Good practice:

- Avoid overheating of classrooms- mobile classrooms: maintain good ventilation/ avoid draughts
- Agree that warmer clothing can be worn indoors within school day- coats/scarf on
- Avoid activities that are outside in cold or damp conditions
- Permit the pupil to remain inside during break/lunchtimes- ensure supervisory staff are aware

Physical exercise

Strenuous exercise involving exertion could precipitate a sickle cell crisis

Good practice:

- Encourage moderate exercise
- Listen to pupil and parent – they will know their exercise tolerance level
- Excuse the pupil if they say that they are tired or in pain
- Permit extra layers of clothing if partaking in outdoor sports
- Consider the weather- exposure to cool wind, cold and wet weather may trigger an episode of illness
- Follow advice from specialist medical teams

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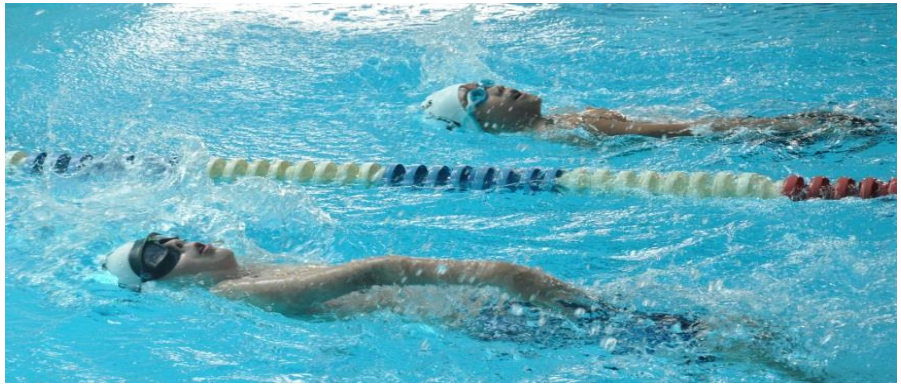
Swimming

Young people with SCD are advised to not become cold. This may happen when swimming in unheated pools or delaying in drying off afterwards

Good practice:

- Listen to parent and pupil about inclusion in swimming activity
- Encourage prompt dressing
- Consider liaising with local leisure centre if not using school pool, that the temperature of the pool is increased to allow pupil to participate
- Consider timing of lesson-end of the day

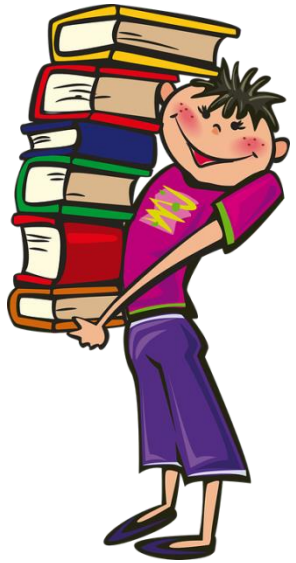


Physical exercise- other points to consider

Good practice:

- Provide easily accessible locker for the pupil to avoid carrying heavy bag or excess books during the day

- Use of lift if available to minimize exercise that may be caused by climbing stairs. Provide lift pass or key



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Managing pain

- **PROMPT RECOGNITION-** crying, quiet, changes in behaviour
- Offer fluids
- Rest
- Medication- Paracetamol & Ibruprofen
- Distraction- reading, quiet toys
- Contact parent
- Know when to seek medical attention

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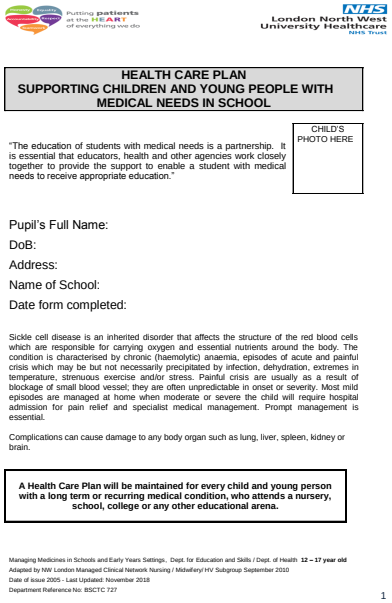
Urgent Medical Attention

- Temperature > 38c
- Pain
- Becomes breathless
- Complaining of pain in chest
- Complaining of severe abdominal pain
- Priapism- prolonged erection of the penis
- Drowsy-unresponsive
- Severe headache
- Has a fit-weakness in one or more limb

CALL 999- CALL PARENTS

Individual HealthCare Plans

- All pupils with a medical condition should have an individual healthcare plan
- Completed by local specialist sickle cell nurse, school nurse and the young person/ parent
- Includes- preventative measure to keep the child well in school, arrangements for pain medication, emergency care, key contacts, key consultant caring for the child, list of all staff that have attended training on SCD
- Reviewed annually
- Training is offered by specialist nurse to schools face to face or virtual



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HEALTH CARE PLAN
SUPPORTING CHILDREN AND YOUNG PEOPLE WITH MEDICAL NEEDS IN SCHOOL

CHILD'S PHOTO HERE

"The education of students with medical needs is a partnership. It is essential that educators, health and other agencies work closely together to provide the support to enable a student with medical needs to receive appropriate education."

Pupil's Full Name:

DoB:

Address:

Name of School:

Date form completed:

Sickle cell disease is an inherited disorder that affects the structure of the red blood cells which are responsible for carrying oxygen and essential nutrients around the body. The condition is characterised by chronic (haemolytic) anaemia, episodes of acute and painful crisis which may be but not necessarily precipitated by infection, dehydration, extremes in temperature, strenuous exercise and/or stress. Painful crisis are usually as a result of blockage of small blood vessel; they are often unpredictable in onset or severity. Most mild episodes are managed at home when moderate or severe the child will require hospital admission for pain relief and specialist medical management. Prompt management is essential.

Complications can cause damage to any body organ such as lung, liver, spleen, kidney or brain.

A Health Care Plan will be maintained for every child and young person with a long term or recurring medical condition, who attends a nursery, school, college or any other educational arena.

Managing Medicines in Schools and Early Years Settings, Dept. for Education and Skills / Dept. of Health **12 – 17 year old**
Adapted by NW London Managed Clinical Network Nursing / Midwifery/ HV Subgroup September 2010
Date of issue 2005 - Last Updated: November 2018
Department Reference No: BSCTC 727

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School absences (i)

- Pupils can miss weeks of schooling a year- more often short absences 2-3 days at a time
- Pupils with SCD do not feel supported by schools
- Minority of pupils have attendance below government levels
- Mislabelling-truancy, important not too

School absences (ii)

Good practice:

- Need strong supportive frameworks on sickle cell disease to reduce school absences
- School work sent home/hospital- online if pupil able to
- Twilight catch-up sessions after school-learning centre that is staffed on a rota for those who have missed a lesson can catch up
- Benefits of this- helps pupil to catch up & detracts attention

Stroke

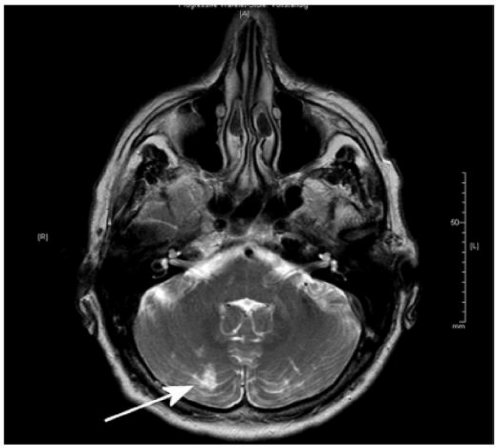
Increased risk of stoke between 2-10yrs

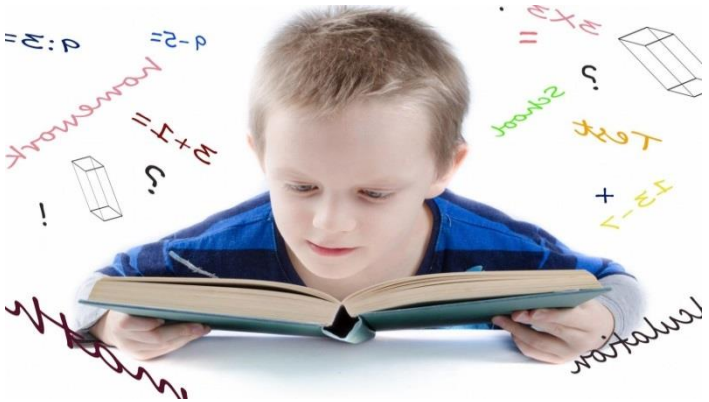
- All children with Hb SS/SBThal 0 are screened for assessing risk
- Apply the **FAST** approach:
- F- Facial weakness: can the person smile or has their mouth/eye drooped?
- A- Arm: can the person raise their arms above shoulder height?
- S- Speech: can the person speak clearly & understand what you say?
- T- Time: to dial emergency 999 ambulance

Silent strokes

- Changes in behaviour/concentration/sudden deterioration in quality of school work

- 1/5 people with Sickle Cell Disease have small area of brain damage which are evident on MRI scanning, a result of impaired blood supply

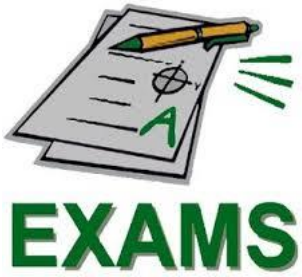




Supporting education & learning

Aim is to ensure that child reaches their full potential and feels supported

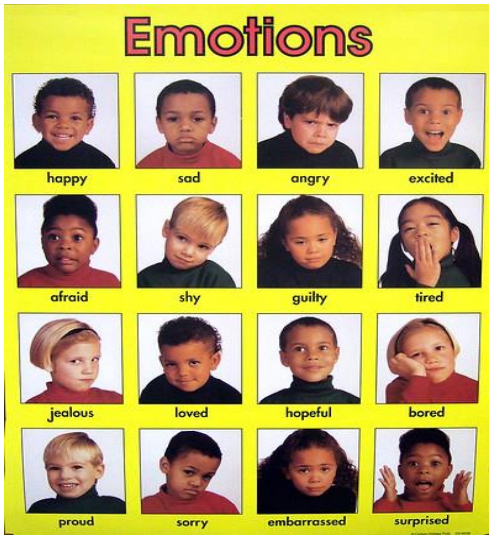
Good practice



- Exams- stress which may result in sickle cell crisis
- Provision for extra time or rest breaks
- Homework- extra time, ensure communication with parent, school planners
- Extra support for those who require it- Education Healthcare Plan (EHCP).

Emotional well-being

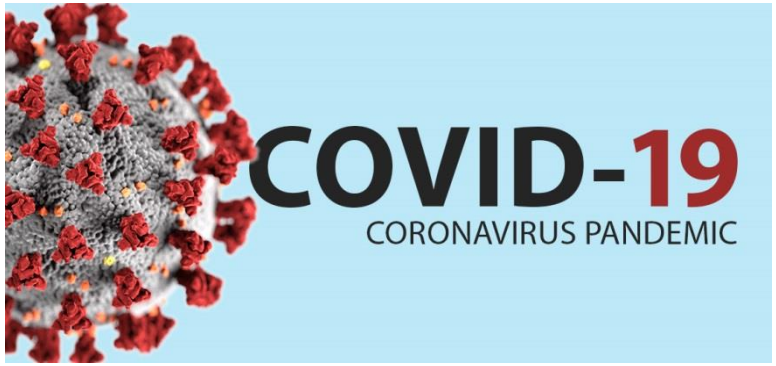
- Important to remember that this child is living with chronic condition, variable day to day
- They themselves may not know much about their condition, except they get pain regularly / taken medicines
- A condition that few if any of their friends have or even know about- culture
- Can affect their mood and mindset



Good practice

- Child has key contact or person in school they can talk to
- Encourage child to tell a few friends about their condition
- Consider school counselling, if indicated and available
- Refer any concerns to specialist healthcare team- Nurse/Dr, Psychologist

COVID 19 Recovery plan



1 August 2020 shielding ended.

General advice

- Keep 2 metres away, if not possible wear face mask- senior schools may be compulsory to wear face masks
- Hand washing
- Children can return to school
- Adults can go to work as long as workplace is COVID secure- risk assessed, work from home if still able to.
- Can go outside to buy food, places to exercise and worship, if open.
- To follow all government recommendations.

Patient experiences

Call-E.T

Video –K.D

Useful Websites

- SCOOTER Open Education Resources for Sickle Cell & Thalassaemia

http://www.sicklecellanaemia.org./

- Research/resources for teachers : My pupil has Sickle Cell Disease, My Friend has Sickle Cell Disease.

http://www.sicklecelleducation.com

- National Health Service Sickle Cell & Thalassaemia Screening Programme

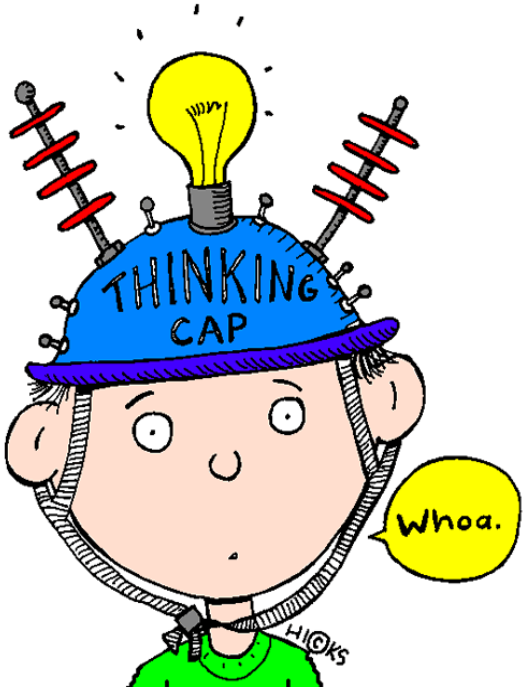
hppt://www.sct.screening.nhs.uk

Downloadable copy of A Parents Guide to Care & Management of your Child with Sickle Cell Disease

- Sickle Cell Society: **www.sicklecellsociety.org**

- UK Thalassaemia Society: **www.ukts.org**

Any questions?



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