

SICKLE CELL DISORDERS
**"THE SCHOOL CHILD WITH SICKLE
CELL DISORDER"**

SCHOOL WORK

SPORTS

SCHOOL JOURNEYS

MEDICAL EMERGENCIES

**IMPACT OF CONDITION ON THE
SCHOOL CURRICULUM**

KEY NOTES FOR PARENTS AND PROFESSIONALS

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The booklet ‘**Sickle Cell Disorders - Not Another Lazy Child**’ is provided as a practical guide for professionals involved in the education of children who have a sickle cell disorder. Children with this inherited disorder have a health condition that need to be managed sensitively and effectively within the context of an education environment. The booklet provides a brief overview of some of the common problems that children may experience at school. Several remedial actions are offered, but sensible care planning with parents, medical, nursing and education staff provide the best possible solution for the effective management of school children with a sickle cell disorder. The keynotes for **secondary health prevention** or the booklet in its entirety may be a useful source of information for parents.

CONTENT

INTRODUCTION

1. SICKLE CELL DISORDERS – A Brief Description
2. SCHOOL CHILD WITH SICKLE CELL DISORDERS
3. SCHOOL WORK
 - A. SPORTS
 - B. SCHOOL JOURNEYS
 - C. MEDICAL EMERGENCIES
 - D. PSYCHOLOGICAL AND SOCIAL FACTORS
4. KEY NOTES FOR PARENTS AND PROFESSIONALS
5. SUMMARY
6. APPENDIX – notes that can be used for Biology Lesson
7. CONTACT LIST FOR SICKLE CELL CENTRES
8. REFERENCE

Sickle Cell Disorder

INTRODUCTION

A sickle cell disorder is an inherited blood condition that affects the haemoglobin of the red blood cells. Haemoglobin is a special substance that colours the blood red and is responsible for carrying oxygen around the body. People with a sickle cell disorder have an unusual haemoglobin type that is inherited from both parents. This unusual haemoglobin causes the red blood cells to change shape under certain circumstances. This is known as "sickling" and sickled blood cells can obstruct the blood circulation causing a sickling crisis that is extremely painful. Often the severity of these painful episodes is best managed in hospital by strong pain relief and other medical treatment.

The sickling and unsickling of the red blood cells causes early destruction of the cells that results in anaemia. People with sickle cell disease often appear lethargic and are susceptible to infections.

Pain, anaemia and recurrent infections are the common symptoms of a sickle cell disorder.

Sickle cell disorder may have a disruptive influence on the educational needs of the school child. This has implications for teachers, for the parents and also for the child with this condition.

Teachers may be presented with two common dilemmas: -

- a) Not knowing if a child they are worried about is affected by a sickle cell disorder &
- b) Knowing that the child is affected by a sickle cell disorder but worried about the impact of the illness on the child's education.

There have been cases where the teacher is concerned that a member of her class is affected by a sickle cell disorder. The child seems "lazy" and appears generally uninterested in schoolwork and sporting activities. When encouraged to participate, the child is easily tired and misses many days from school due to illness.

This is perhaps due to the fact that the child's condition was not diagnosed, if the child came from an area where screening and follow up diagnostic testing was not available at birth. However, in some instances parents have not provided the school with this information because they might not consider this as important (especially if the child has been very well). Additionally the fears and stigmas that are associated

with sickle cell disorders, even today, are still felt strongly in the community. Parents may therefore withhold this information from the teachers for these reasons and not due to parental irresponsibility.

Specially trained professionals, such as sickle cell and thalassaemia counsellors are able to advise and assist in these matters by counselling parents on the importance of their 'genetic' disclosure, if they are aware of the disorder, or by arranging for the child to have a blood test. This of course must be pre-empted by earlier discussions between the teachers and parents and parents' consent must be obtained prior to blood testing.

There is no general rule for the management of children with a sickle cell disorder in schools as the condition is quite variable. Although some children have repeated crises others are hardly ill. Teachers to a large extent have to rely on their own judgement in responding to the needs of the child balanced against the needs of the entire class.

For the child affected by a sickle cell disorder the impact of the condition on his /her education can be far reaching. The child is physically disadvantaged and as a consequence of this is more likely to rely on educational achievements for future career prospects. The time scale for obtaining qualifications may vary according to the number of days missed from school due to ill health.

As there is no cure for this condition much emphasis is therefore placed on the prevention of repeated sickling crises. The child's haematologist or general practitioner would have prescribed daily antibiotics to reduce the risk of infections and daily folic acid to minimise the problems of anaemia. These together will do much to reduce the episodes of painful sickling crises precipitated by anaemia and infections, but other practical measures are also important.

The following section is a summary of practical measures that may provide useful information for the management of children with sickle a cell disorder in schools.

CLASS WORK

Sickle cell disorders do not affect mental intelligence and therefore the child should be expected to cope with class work.

READING

All children with sickle cell disease should have routine eye testing from the age of 10 years. If a child has difficulty reading, visual problems must first be excluded before other options are considered.

REMEDIAL EDUCATION

Where children have missed a significant amount of time from school due to ill health, remedial education should be considered. Parents should be encouraged to assist children at home with work that is relevant to the school's curriculum. This is particularly important when the school does not provide homework routinely. Children admitted to hospital may not be well enough to be discharged home, but may feel able to undertake light schoolwork on the ward and this should be encouraged.

SPORTS

Many children with a sickle cell disorder are keen on sporting activities but should not be pushed beyond their limitations, as they are likely to start sickling. A fundamental problem is that affected children may not be able to balance their enthusiasm for sports against the limitations of their illness. These children may be quite adept at sporting activities, but may find that the pain of a sickling crisis accompanies participation. The emotional and psychological implications are significant as feelings of frustrations may often overwhelm these children.

Children affected with this illness will inevitably recognise their own abilities. For example a boy taking part in a **football** match may want to sit down before half time and substitution should be made if he indicates that he is tired. Although teachers may be reluctant to rule out participation in any one sport, cross country running is very taxing physically for children with sickle cell disease and children may be admitted to hospital in pain at the end of these races. These long distance runs should be avoided.

Swimming is an enjoyable sport for many children but precautions must be taken that children are dried well once out of the pool. Afro-Caribbean and African children often have the type of hair that will not dry in a few minutes and teachers must take this on board. Children with sickle cell disease should be encouraged to wear swimming caps and it is sensible to get the children out of the water several minutes before the end of the swimming lesson, as this would provide some extra time for children to dry off properly. If there is a warm area available the child should be allowed to wait in this area for classmates before making the journey home or back to school. Extra time for drying off and warming up is important for reducing the risk of sickling after a swim.

Gym exercises are a common feature of many schools' sporting activities. Some children are more prone than others to have joint sickling and this problem may become more pronounced with certain types of gym exercises. If children complain

of pain with certain exercises it is advisable that these exercises are pursued more gently or changed to a different type of exercise or discontinued altogether.

The exertion from **climbing** could also cause sickling on a hiking trip. Children who feel able to continue should be allowed to do so at a slower pace. Where there is significant altitude change children may also experience breathlessness but this is more likely to be due to exhaustion than to a reduction of oxygen in the air.

Often the concern arises that children will use their illness to "get out of" participating in sporting activities. This presents a dilemma for many teachers but a child's complaint of pain should in general be accepted. Teachers do know "their children" i.e. their attitudes and personalities, and are often experienced at judging whether or not excuses are plausible.

Children with sickle cell disease above all want to be "normal" and very much want to be the same as their peers. For those who use their illness as an excuse to opt out of sports or other areas of the schools curriculum, other factors, primarily social and emotional must be considered.

If children are not able to participate in games physically they should be encouraged to take part in other ways. Children excused from swimming could for example be responsible for looking after the locker keys or the stop watch; the child that is not able to take part in athletics could assist the teacher with keeping the roster for the races; the child not able to play cricket could participate by keeping scores and this also applies for other school activities as for example a child finding the school play exhausting, could be responsible for the lighting or the props. This list cannot be exhaustive as teachers have developed or will develop their own strategies for dealing with children.

SCHOOL JOURNEYS

School journeys are an exciting time for children and for those with sickle cell disease extra preparation and planning may be required. It is not necessary to exclude the child from any trip away with the school but the impact on health should be considered when trips are planned.

LOCATION

The choice of location is of course determined by desirability, costs, and relevance to the curriculum but where medical facilities are poor or inaccessible the choice of location may be unsuitable for a child with sickle cell disease.

TYPE OF HOLIDAY

The type of holiday may affect the child's health. A skiing trip for example could cause a crisis as altitude and cold weather do affect the circulation; a trip to a rural tropical area could increase the risk of sickling from an infection and an action packed adventure could cause sickling from over exertion.

FOOD AND DRINK

During a trip abroad particular care should be taken with drinking water. If indicated boiled or bottled water should be used. Children should be careful also with the eating of convenience foods. The risk from salmonella is very high for children with sickle cell disease and this infection could be fatal. A special diet is not necessary, but should be well balanced, nutritious and include a high intake of fluids.

SENSIBLE CLOTHING

Even on a warm day a child with sickle cell disease may feel cold. Parents should be advised to pack clothing that is suitable for the child's needs, taking care not to rely entirely on their own judgement of the weather as this could be misleading.

When other children are wearing t-shirts only, the children with sickle cell disease will require a light cardigan as well; when other children are wearing sandals only, the child with sickle cell disease will require light socks as well.

MEDICAL PREPARATION

It is advisable that haematologists or general practitioners are consulted prior to holiday departure. A few children may need to have blood transfusions before travelling and all children in general should have sufficient antibiotics and folic acid to cover the holiday period. Certain countries may have vaccination requirements and children with sickle cell disease, who are travelling to these countries, are strongly advised to have these vaccines.

Sufficient analgesia may also be prescribed for the time on holiday. The haematologist or general practitioner may at their discretion, provide a letter for hospital in the event of an emergency, but haemoglobin cards are readily available for all children with sickle cell disease and should be taken on holiday. These cards provide written confirmation of the child's diagnosis and are useful particularly in emergencies.

MEDICAL EMERGENCIES

Not all painful sickling crises are medical emergencies. Other complications of sickle cell disorders such as an aplastic crisis can require emergency intervention.

When experiencing a painful crisis, if the child is able to cope, is uncomfortable but not distressed, is able to drink fluids and is communicable there maybe time for the parent or guardian to collect the child from school. The sudden onset of acute pain accompanied with much distress would indicate a major painful crisis, requiring prompt medical treatment. The appearance of shock or any such dramatic symptom should be treated in hospital immediately.

In some hospitals children with the disorder, are admitted directly to the wards when they are unwell. This is familiar territory and children do not have to cope with the impersonal environment of the casualty department.

It is advisable that the school contact the ward to inform the ward staff of the child's illness prior to admission, as the nurse in charge is then able to make preparation for the child's arrival.

Parents should inform teachers of the child's treatment centre as children may be admitted directly to a ward or via the hospitals casualty department. It is advisable that the school staff is familiar with the local policy for admitting children with a sickle cell disorder to hospital.

PSYCHOLOGICAL & SOCIAL FACTORS

The knowledge that a child affected by sickle cell disease is often a shock for parents, no matter how well prepared the parents may have felt. The initial hurdle of accepting the diagnosis is often quite difficult and parents may experience the initial emotion of denial. Other common emotions include anger, fear and even grief. There sometime is an overwhelming sense of frustration, the blame of self and also of partners and feelings of inadequacies are not uncommon. For the majority of parents these are transient emotions but others never "come to terms" with the fact that their offspring is affected by sickle cell disease.

Often environmental and social factors are major influences on the parent(s) ability to cope and these have far reaching implications affecting the child in all aspects of his/her development.

Parents with little or no support, living in unsuitable accommodation would perhaps find it more difficult to cope with an affected child more so than those parents who are well supported and are not experiencing hardship.

It is very much recognised that the clinical manifestations of the illness are often the end products of adverse social, psychological and environmental factors and the school child is not immune to these.

If the child's environment is inadequately heated he/she will have more sickling problems. If parents, due to financial difficulty, are not able to provide a good diet and suitable clothing the child is prone to those sickling crises precipitated by

infections. The child constantly exposed to negative emotions at home is unlikely to have a positive self-image and is more likely to be admitted to hospital (even when not in a crisis) because he/she feels unable to accept and cope with the condition.

The effect of sickle cell disease on the school child is not only physical as psychological and social factors have major influences also on the child's health.

PROFESSIONAL ROLE AND RESPONSIBILITY

Screening for school children is not provided routinely for children in schools but parents can be advised of how and where they can access screening. This is an important aspect of **primary health prevention** and parents may approach their GPs as the first point of contact to request a blood test for themselves or their children.

Health education programmes in schools is another aspect of **primary health prevention** to increase awareness on haemoglobin disorders. Children that are aware of the risk for haemoglobin disorders are able to make informed decisions with regard to forming relationships in later years.

Health education for parents of children with a sickle cell disorder is an important element of **secondary health prevention**. Although the child is affected much can be done in the form of health education to educate parents on the management of the child with the condition. With proper education and support, parents will be more confident of their ability to care for the child and are more likely to use the medical services appropriately.

SUMMARY

A possible cure for sickle cell disease is a bone marrow transplant from a suitable donor, but this is not an option for many children. Therefore much emphasis is placed on the prevention of repeated sickling crises, as this is crucial in disease management.

The child's haematologist or general practitioner would have prescribed daily antibiotics to reduce the risk of infections and daily folic acid to minimise the problem of anaemia. These together will do much to reduce the episodes of painful sickling crises precipitated by anaemia and infections, but other practical measures as described in the booklet are also important.

HELPFUL HINTS FOR CONSTRUCTING A BIOLOGY LESSON

1. Sickle cell disease in general does not affect intelligence.
2. Children that have experienced strokes may have a degree of impaired mental function.
3. Delays in learning are usually attributed to the disruption caused by frequent admission to hospital.
4. Poor learning outcomes will impact on future employment especially as careers that are physically demanding is not possible for many people with sickle cell disease.
5. Where children have missed a significant amount of time from school due to ill health, the need for remedial and other educational support should be explored.
6. Children admitted to hospital may not be well enough to be discharged home but may feel able to undertake light schoolwork in hospital. Where possible this should be encouraged.
7. Supporting children to undertake school work whilst in hospital is beneficial for children in keeping up with the school curriculum, provides a form of occupational therapy and can be used to distract children from their symptoms or treatment during admissions.
8. It is recommended that all children with sickle cell disease have a routine eye test from the age of 10 years, as sickle retinopathy is a complication of sickle cell disease.
9. If children have difficulty reading, visual problems should initially be excluded prior to other assessments.
10. Preventing sickling crises is an important aspect of keeping children well and it is important that the factors precipitating crises are known by parents, staff members and eventually by the child.
11. Many children are able to participate fully in the schools curriculum and can take part in various sporting activities.

12. It is important that children are not made to feel different to their peers as this can have an adverse psychological impact in the long term.
13. Activities that predispose sickling crises should be limited or discouraged altogether. These may include hiking, cross country running or athletic sprinting events.
14. Children experiencing pain during an activity should discontinue the activity immediately. The pain brought on by the activity can subside once these activities are stopped. The pain will get worse if the activity continues as more and more cells sickle.
15. Sudden changes in the atmospheric temperature or children getting soaked in the rain can cause a sickling crisis.
16. The majority of crises do not usually require medical intervention. Prompt action in keeping children warm, increasing fluid intake, getting the children to rest and giving a light pain relief may be enough to stop the crises.
17. If the pain stops and children are not unduly distressed, there is usually sufficient time for the parents or guardians to collect children from school.
18. Prolonged pain and pain that is increasing in severity despite taking prompt action indicates that medical intervention is necessary.
19. Any signs of collapse should be treated as a medical emergency.
20. The contact details of the hospital treating children with sickle cell disease should be clearly recorded where appropriate professionals could easily access this information.
21. The admission procedure of hospitals treating children with sickle cell disease should be clearly recorded as this will save valuable time in the event that a child needs to be admitted.

Health promotion and health education activities can be delivered through collaborative working between general teachers, the personal social and health education (PSHE) teachers and school nurses. Health promotion on the haemoglobin disorders can enter the schools curriculum through different formats. The information content for a biology lesson or a sex education lesson is illustrated.

Content of a biology lesson

- How the blood circulation works.
- The constituents of blood.
- Why the blood is coloured red.
- Explain the purpose of haemoglobin.
- How haemoglobin is inherited.
- Why haemoglobin is different in people from different parts of the world.
- Why the sickle and thalassaemia haemoglobin has some benefit for people that carry these.
- Why sickle cell disease happen.
- Why thalassaemia disease happen.
- The problems that these conditions cause.
- How these illnesses can be prevented.
- How and where people can be tested to find out if they carry sickle cell or thalassaemia.

Content of a sex education lesson

- What genes are and how they are inherited.
- What haemoglobin is and how haemoglobin is inherited.
- Why it is important for people to know their haemoglobin type.
- How babies inherit the normal haemoglobin, the carrier status or a haemoglobin disease.
- What is sickle cell disease and how could this be prevented.
- What is thalassaemia disease and how can this be prevented.
- How and where can people get tested.

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Readers provided:

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This list summarises information that school nurses and teachers may find helpful for management of children with sickle cell disease.