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For more information

For more information on sickle cell disease or Broken Silence visit www.brokensilence.org or contact Broken Silence via e-mail – brokensilence@brokensilence.org

Useful websites

1. http://www.brokensilence.org/
2. http://www.nhs.uk/Conditions/Sickle-cell-anaemia/Pages
3. www.sickle-thal.nwlh.nhs.uk
4. www.theiron les.co.uk

References

1. http://www.brokensilence.org/
2. NHS Direct Online Health Encyclopaedia. Available at: http://www.nhsdirect.nhs.uk/articles/article.aspx?articleId=361&sectionId=983 Accessed: 07 July 2008
3. http://www.nhs.uk/Conditions/Sickle-cell-anaemia/Pages
4. http://www.scyss.org/awareness.html
5. Simon Martin Dyson, Hala Abuateya, Karl Atkin, Lorraine Culley, Sue Elizabeth Dyson and Dave Rowley (2010) Reported school experiences of young people living with sickle cell disorder in England British Educational Research Journal [Research funded by the Economic and Social Research Council, Grant RES-000-23-1486]

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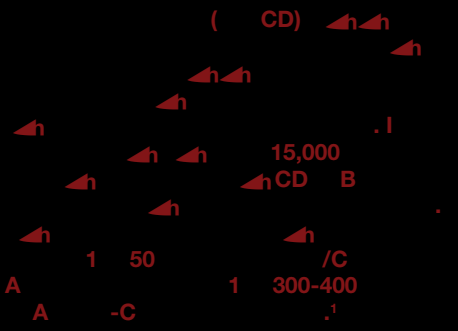

For people without SCD, red blood cells in the body are exible, and therefore easily able to perform the vital function of transporting oxygen from the lungs to the rest of the body[2].

For people with SCD, the haemoglobin in their red blood cells is faulty, causing the shape and texture of the red blood cells to change, forming ‘sickle’ or C-like shapes. This makes it far more dif cult for them to move through small blood vessels. The cells also do not survive as long and are not as plentiful as red blood cells in non-sickle cell sufferers[3].

The sickle cells can get stuck in small blood vessels and stack up, causing blockages and starving organs and tissue of oxygen-carrying blood: this is a sickle cell crisis. Physical symptoms of a sickle cell crisis can vary, from periods of severe pain, to major complications such as stroke, damage to the liver, kidneys, lungs, heart and spleen, or even death[3].

For many SCD sufferers another problem is that because their red blood cells contain sickle haemoglobin, the cells do not last as long as those of someone without the disease, leading to a chronic state of anaemia[2]. This may mean the pupil with SCD becomes tired, nds it dif cult to concentrate, and this may be mistaken for being lazy or inattentive.

People with SCD can suffer from the disease to varying degrees. Some have mild forms of SCD, whilst for others it can be far more severe, leading to the need for regular blood transfusions[2].

Sickle cell disease sufferers can lead CD in Br.

WHAT IS THE PUPIL GOING THROUGH?

- Anaemia – As your pupil's body is not getting all the oxygen it needs, they will often feel tired, weak and out of breath
- Jaundice – Caused by the liver not working properly due to the strain of having to remove broken down sickled cells, one sign of this might be yellow eyes
- Swelling of the hands and feet
- Frequent infections – The sickle cells can also damage the spleen – an organ that helps the body to develop immunity and ght infections. Failure to develop good immunity will increase their risk of getting an infection. From babyhood people with sickle cell disease are given daily antibiotics to reduce the risk of infections

ICKLE CELL C I E

Throughout their lives, sickle cell sufferers can expect to experience sickle cell crises. The severity and frequency of sickle cell crises varies from person to person and can be different each time. Some people experience one or two per year and will be able to control the symptoms using over-the-counter (OTC) or prescribed painkillers, whereas others may require hospital treatment.

:

- Gradually worsening pain in the bones and joints
- Severe pain in the abdomen with rigidity (in exibility) of the muscular wall
- Fever
- Dif culty breathing and a stabbing chest pain on breathing
- Weakness on one side of the body and, if the brain is affected, seizures are possible
- Pain in the upper abdomen from the liver and spleen
- Persistent and painful erections (priapism) in boys/men[2]

A sickle cell crisis can often occur without warning, or due to a number of reasons. Precautions can be taken to reduce the risk and severity of a sickle cell crisis[3]:

- Drinking plenty of water, and remaining hydrated especially in the summer
- Avoiding heavy or strenuous exercise
- Eating healthily
- Avoiding extreme temperatures, particularly the cold and wind and also the heat in summer
- Avoiding stress

If a child is experiencing a mild pain crisis, you can provide them with plenty of uids and allow them to lie down and rest or do whatever makes them feel comfortable; as long as you have had prior agreement from their parents. If necessary, they can be given a mild painkiller and the parents should be informed immediately. Treating mild pain quickly and effectively can prevent it from becoming severe.

If the child is complaining of severe pain or is experiencing the symptoms of a dangerous complication, such as chest pain or problems breathing, they may need hospital treatment. Hospital treatment can involve pain relief, blood transfusions, supplemental oxygen and antibiotics.

The rst signs that someone has had a stroke
are very sudden.f sih /T1_1 1 Tf -22.288 57.025 Td [(The rst signs that someone has had a str)18(oke)]

New research published in the British Educational Research Journal entitled, ‘Reported school experiences of young people living with sickle cell disease in England’ highlights that the lack of awareness of sickle cell disease in some schools is having a serious negative impact on the education of children living with the condition[5]

A survey of 569 young people with sickle cell disease in England has found such pupils miss considerable periods of time from school, typically in short periods of two or three days. One in eight has school absences equating to government-de ned ‘persistent absence’ and students with sickle cell report that they are not helped to catch up after these school absences.[5]

A lack of appreciation of the measures needed to prevent exacerbation of sickle cell symptoms was also apparent in the research:

- Half the children reported not being allowed to use the toilet when needed and not being allowed water in class
- A third reported being made to take unsuitable exercise and being called lazy when tired
- Children surveyed perceived both the physical environment (temperature, school furniture) and the social environment (being upset by teachers or other pupils) as triggers to episodes of their illness

‘Teachers may know that a child has sickle cell but they might not appreciate the full range of factors that can in uence the child. Current frameworks do not appear to be supporting the inclusion of children with sickle cell disease in schools, therefore I am proud to support the Broken Silence initiative in its aims to educate and raise awareness of sickle cell both amongst young people and their teachers.’

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KE CON IDE A ION IF O P PIL HA ICKLE CELL DI EA E

I h h h h h h .

Sickle cell disease is an inherited blood disorder and is NOT contagious.

K :

H D A ION It is important that children with sickle cell disease drink plenty of water in order to remain hydrated. Furthermore, since their kidneys are unable to concentrate urine they need to be permitted to use the toilet more frequently

MONI O E E Cl E Children with sickle cell may be unable to participate in strenuous physical exercise lessons because their cells have dif culty carrying oxygen. Particular attention should be paid when exercising outside during the winter as cold weather may trigger a crisis

M A A M It might be necessary for children with sickle cell to wear warm clothing (even their coat) at all times. Their body temperatures are different to somebody without sickle cell

NDE ANDING The anaemia associated with sickle cell can cause tiredness and apparent lack of concentration; teachers are encouraged to be understanding in these circumstances

AB ENCE Children with sickle cell may miss days at school due to their illness; teachers are encouraged to allocate time to assist the child to catch up with their work as and where necessary

DI C E ION Do not force the child to disclose their sickle cell, provide avenues in order for them to approach you for help anonymously

O K OGE HE Work closely with the child's parents in order to effectively communicate regarding progress and areas for improvement

NIQ E Remember that sickle cell disease is different in each person. Not everybody suffers from sickle cell in the same way. What works for one child might not be the same as the next