

Understanding Sickle Cell Disease

What is Sickle Cell Anemia: Sickle cell is a life-threatening blood disorder that is characterized by red blood cells that assume an abnormal, rigid sickle shape. Sickled cells can stop or slow blood flow to parts of the body, causing less oxygen to reach different areas, resulting in a pain crisis and other complications.

Sickle Cell Pain Crisis/Complications of Sickle Cell Anemia

A sickle cell crisis can begin suddenly and last for several hours or several days. Complications are: extreme vulnerability to infection, jaundice, deterioration of joints, delayed growth, recurrent severe pain episodes, strokes, blindness, kidney, liver, spleen, gallstones, lungs, bones, joints, skin leg ulcers, priapism (painful unwanted penis erection) concerns, and shortened life expectancy. Although simply staying hydrated (drinking at least one liter a day) can aid in preventing pain crisis and other complications.

Warning Signs of Sickle Cell Pain Crisis/ Complications

Although, students may not portray any outward signs of someone with a serious illness, there are several signs and symptoms that warrant medical attention:

Signs	Symptoms
Fever	101 degrees or higher
Lethargy	Unexplained Tiredness
Pallor	Change in complexion, lips, fingernails
Breathing	Fast, Rapid, Labored, or Difficulty Breathing
Headache	Dizziness; sudden or constant
Heartbeat	Pounding:Tachcardia (rapid heartbeat)
Pain	Head, Chest, Joints, Abdomen (abdominal distention): Penis (prolonged erection)
Swelling	Hands, feet, or Joints (with redness)
Jaundice	Yellowing of the eyes that is greater than normal
Dehydration	Fluid Requirements s for Children with SCD 25 lbs.= 5 cups; 50 lbs.= 8 cups; 75 lbs. and above = 10 or more cups

Signs of a Stroke/Vision Concerns

Sickle cell disease is one of the few conditions that can cause stroke. An uncharacteristic slip in academic importance may be a subtle sign. If a teacher notices any of the following signs and symptoms they should inform the parents immediately:

* Difficulty with memory, using a hand, a leg, or one side of the face due to muscle weakness, balance, with vision or hearing, speaking or understanding what other people are saying, unusual headache, defective or absent language, muscular weakness on one half of the body, sudden loss of or blurred vision, persistent headaches or sudden strong headaches, fainting or dizziness, sudden weakness, numbness, or tingling of an arm, leg or the whole body.

* Minor strokes and other brain problems can happen without any signs or symptoms. These events often cause learning problems and are believed to affect a child's cognitive learning skills.

Vision

Children with sickle cell disease may develop eye problems that can occasionally lead to blindness. The condition manifests slowly and rarely occurs before the age of 10. Children's family should be notified immediately of any vision problems or trauma to the eye.

Pain Management/ Treatment

A mild pain episode may be managed at school with the use of drinking increased fluids (preferably water) and non-narcotic pain medications like ibuprofen or acetaminophen. However, severe pain or any complication untreated can be life threatening. Seeking immediate treatment at a hospital or sickle cell center is expected.

Treatment to relieve mild to moderate pain may include any or all of the following:

- Fluids – water, fruit juice, popsicles, clear broth, jell-o
- Pain medication as directed by the physician
- Moist warm heat applications; **never** apply cold packs as these could increase vessel constriction
- If a child has a fever, phone parents immediately

Modifications for students with sickle cell disease

Under the category of other Health and Impairment or under Section 504 or the Rehabilitation Act, a child with sickle cell disease may qualify for Special Education through the Individuals with Disability Education Act (IDEA). However, if a child does not meet the guidelines for accommodations under these programs the school nurse (RN) can write accommodations under an Individual Health Plan (IHP).

The following represent accommodations that should be considered for a child with SCD. Other accommodations may be considered based on the student's individual needs.

Basic classroom guidelines

Anticipate more missed school days. The students' IEP should include the exclusion of mandatory attendance due to episodes of pain, routine medical treatments, and trips to the hospital. Aside from any materials or extra help that you can offer, if you anticipate or see a child starting to lag behind, request that her parents arrange for a tutor or education consultant at home or at the hospital. Allow for two sets of books, one for home and one for school.

Allow extra water and bathroom breaks. Children with sickle cell disease need to take bathroom breaks more frequently, not only because of increased water intake, but because their kidneys produce more urine, even when they're dehydrated. A restroom pass to use when needed allows the student to leave the classroom without drawing attention from the other students.

Pay attention to temperature control. Becoming overheated or too cold is enough to trigger a pain episode. Keeping the temperature in the classroom comfortable is important, as is reminding the child to wear a jacket outside during cold weather or to take off a layer of clothing if she gets hot. Exempting students from outdoor activities when temperature is less than 40 degrees or greater than 90 degrees is essential. Extreme temperatures can change the blood flow in the body and precipitate a pain episode. Dressing in layered clothing or allowing the student an alternative activity during recess or P.E. class is recommended.

Be aware of the need to rest. Many children will not admit to fatigue or needing a break from sports or gym activities. Participation should be encouraged however; the student should take regular breaks. The student will not be required to participate in physical education activities that involve strenuous exercises and long-distance running. The student should not be required to participate in the Presidential Physical Fitness Testing. Strenuous exercises and long-distance running can often trigger the onset of lactic acidosis leading to sickle cell pain.

Don't assume lesser intelligence. While sickle cell disease can affect many aspects of everyday life, it does not inherently play a role in a child's intelligence. Missed school and the impact of having a lifelong illness, not generally from a learning disability, may affect the academic abilities of a child with sickle cell disease. For this reason, it is especially important to promote continued learning even in the face of absences, and identify learning problems as you would for any other child. In this day and age, children with sickle cell disease can lead long and productive lives, and a good education is key to making this a reality.

Quality vs. Quantity

Student will be assigned a moderate workload with limited assignments requiring quality vs. quantity when absent from school for clinic visits, hospitalizations or complications resulting from the diagnosis of sickle cell disease. Justification: Stress can precipitate a pain episode. The student may feel overwhelmed and worried about missed work and assignments; shortening assignments and allowing modifications will reduce stress and make the task of completing missed assignments feasible. The student should be granted extended time to complete class work tests and quizzes. The student may process information more slowly due to hospitalization, medical treatment schedule, pain medications or stroke. The student will be assigned an intermittent homebound teacher or education consultant to help with assignments when he misses school. Students with sickle cell disease often have frequent absences. Over time this may cause them to become skill deficient in one or more of the core subjects. An intermittent homebound teacher or consultant can work with the student on a routine basis and prevent this from happening.

Utilizing an education consultant/case manger/or school buddy.

Students may have frequent absences that cause them to miss important school events, such as picture day or field trips. Assign the student a case manager or buddy to keep them informed of class activities and school functions.

Be informed.

Other concerns of possible school problems include adjustment difficulties after absences, side effects of pain medications, depression, family conflicts, and fatigue. Those with sickle cell should be treated as normal as possible with awareness that they may have intermittent episodes of pain, infection or fatigue. Have a plan of action with the individual to do what you can to keep them productive and complication free.

Sources:

This document researched and formatted by Trista Saunders B.A., M.E.D., using the following sources:

The Sickle Cell Information Center- <http://scinfo.org/>

Texas Department of State Health Services – <http://www.dshs.state.tx.us/newborn/sickle.shtm>

Sickle Cell Disease Association of America - <http://www.sicklecelldisease.org/>

Sickle Cell Association of Austin - <http://www.sicklecellaustin.org/>

Understanding Sickle Cell Disease: Instructions for Teachers, Laura Jana, M.D., F.A.A.P.