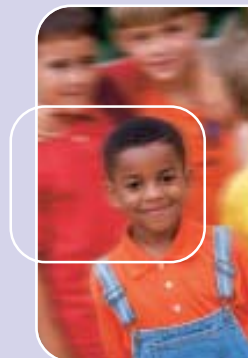


Educator's Guide to Sickle Cell and School



Children's Mercy
HOSPITALS & CLINICS
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Introduction

It is our hope that this book will provide insight and/or information to schools that educate students with sickle cell disease. An important goal of the sickle cell team is to work closely with the student, family, and school to achieve school success. If there are any concerns regarding the student, medically or academically, please contact the student's parent first. We are more than happy to assist once the parent has been notified.



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Understanding Sickle Cell



What is Sickle Cell Disease?

Sickle cell disease is a group of disorders that affects the red blood cells in the body. Normal red blood cells are soft and round (like a donut) and travel through the body without any problems. The main job of red blood cells is to carry oxygen. When exposed to certain triggers, red blood cells affected by sickle cell disease can become hard, sticky and curved in shape (like a banana). Sickled cells are not as soft and flexible so they may get stuck in small blood vessels. If this happens, some parts of the body do not get enough oxygen. Pain or damage may occur.



Other facts about sickle cell disease

- It is genetically inherited, one gene passed from each parent
- It is usually identified at birth (through mandatory newborn screening)
- It affects 1 out of every 400 African-Americans
- The disease also affects people of Mediterranean, Caribbean and Asian descent
- The disease is characterized by chronic anemia, increased susceptibility to infections and painful episodes

Types of Sickle Cell Disease

- Hemoglobin SS Disease
(Sickle Cell Anemia)
- Hemoglobin SC Disease
- Sickle Beta Zero Thalassemia
(Sickle β^0 Thalassemia)
- Sickle Beta Plus Thalassemia
(Sickle β^+ Thalassemia)
- Sickle Hereditary Persistence of Fetal Hemoglobin (S/HPFH)
- Other types

**Sickle cell
affects
1 out of
every 400
African-
Americans**

Sickle Cell Trait

Sickle cell trait is passed on from a child's parents. Children who get one normal hemoglobin gene from one parent and one sickle hemoglobin gene from the other parent will have sickle cell trait. A child born with sickle cell trait will have it all of his life but it will never turn into sickle cell disease. Sickle cell trait is found in one out of every 10-12 African-Americans. It can also be found in people of Mediterranean, Middle Eastern, Indian, Caribbean and South American descent. People with sickle cell trait usually do not have any medical problems. The normal hemoglobin that was passed on by one parent keeps them from having sickle cell disease. **People with sickle cell trait should live normal, healthy lives and have a normal life expectancy.**



Common Characteristics of Sickle Cell Disease

- **Anemia** is a lower number of red blood cells (oxygen carrying cells) in the body. This results in a lower hemoglobin level.
- **Infection** may occur due to the spleen not working properly. Sickled red blood cells get trapped in the spleen causing damage. The spleen normally filters bacteria out of the blood to help reduce infection.
- **Pain** occurs when red blood cells “sickle” (change their shape) and become trapped in small blood vessels in the body. Once trapped, blood cannot flow normally. The area where the blood cells are trapped does not get enough oxygen, therefore pain may occur.
- **Decreased urine concentration** causes frequent trips to the restroom.
- **Delayed growth and development** is common in children with sickle cell disease.



Less Common Complications of Sickle Cell Disease

- **Stroke** occurs when there is decreased oxygen to parts of the brain due to sickle cells blocking blood vessels.
- **Gall stones** happen more often in people with sickle cell disease because sickle red blood cells break down much faster than normal red blood cells. When these break down, they release bilirubin which collects in the gall bladder and can form a sludge or gall stones.
- **Aplastic Crisis** is a sudden drop in the hemoglobin usually caused by a virus called parvovirus or Fifth's Disease.
- **Splenic Sequestration** is an enlargement of the spleen and a sudden drop in the hemoglobin.
- **Avascular Necrosis (AVN)** is a change in the shape of the hip or shoulder bones which can cause pain.
- **Priapism** is a painful, unwanted erection due to trapped sickle cells in the penis. It is treated like a painful episode, with fluids and pain medicines.

Anemia

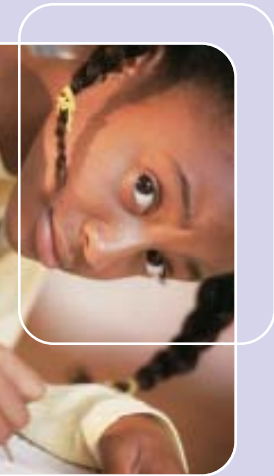
Most children with sickle cell disease will be anemic. This means that the child will have a lower amount of red blood cells in the body and have a lower hemoglobin level. Normal red blood cells (without sickle cell) usually live 120 days. Sickle red blood cells only live 10-20 days. **Being anemic may cause the child to tire more easily and need to rest more frequently.**

Infection

Children with sickle cell disease (especially sickle cell anemia and sickle beta zero thalassemia) are at higher risk of infection than people who do not have sickle cell disease. Infection is the leading cause of death in young children with sickle cell disease. **It is very important for infections to be treated quickly.** Some common infections children with sickle cell disease may get include meningitis (infection of the spinal fluid), pneumonia (infection of the lungs), osteomyelitis (infection of the bone) and sepsis (infection in the blood).



Painful Episodes



One common occurrence in children with sickle cell disease is pain. Pain can happen at any time of the day or night. It may last a few hours, few days or even a few weeks. The pain can range from mild to severe and is different in each child. Sickle cell pain can be anywhere in the body but the most common sites are the arms, legs, back and stomach. **Some pain can be treated at home or during the day at school but sometimes the pain becomes severe enough to need hospitalization.**

Common Triggers of Sickle Cell Pain:

- Exposure to extreme hot or cold temperatures
- Dehydration (extra fluids are needed to prevent dehydration which can cause pain)
- Over-exertion
- Infection
- Stress
- High altitudes
- Shivering (if wet or cold)

Decreased Urine Concentration

Children with sickle cell disease urinate frequently because they are not able to concentrate their urine. Occlusion from sickle cells may cause small amounts of damage to the kidneys, therefore causing the inability to concentrate the urine. **More fluid intake is required to prevent sickling, therefore more restroom breaks are needed.**

Growth and Development

Children with sickle cell disease may be thinner and smaller than other children their age. The child's metabolism is usually increased due to the chronic anemia causing him to burn off more calories and put on less weight. **Children will usually “catch up” in the later teen or early adult years.**

Jaundice/Yellow Eyes

Children with sickle cell disease sometimes have yellowing of the eyes. Red blood cells in the body break down quickly in these children. As this occurs, bilirubin is released causing the white part of the eye to turn yellow. The yellow color may come and go but some children may always have yellow eyes. **This is not a contagious condition or one that requires medical intervention.**

Tips for the Educator



Here's How You Can Help

Tip #1: Collaborate with the student's parent.

- Always include the family in educational planning.
- Call the family with any questions or concerns.
- Help the family advocate for the student's educational success.

Tip #2: Discuss with the parent and student their wishes for disease disclosure.

- Do not assume the student wants other students to know about the disease.
- Always obtain parent/student permission to share information with the student's classmates.

Tip #3: Assist with missed classroom instruction.

- Follow established educational plans.
- Allow additional time to complete missed assignments and exams.
- Coordinate with the family on how they can help the student to catch up.
- Consider asking the school to establish a 504 or IEP plan.

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Here's How You Can Help (cont'd)

Tip #4: Hydration

- Encourage frequent trips to the water fountain.
- Allow a water bottle at the student's desk.

Tip #5: Bathroom privileges

- Provide an open pass to the restroom.
- Remember that students with sickle cell disease cannot concentrate their urine, therefore needing frequent bathroom breaks.

Tip #6: Activities

- Allow the student to participate in all activities, as he/she is able.
- Allow rest during activities as needed.
- Modify activities to include, instead of exclude the student from his/her peers.
- Swimming may cause painful episodes due to cold water. Provide an alternate activity for the student as needed.
- Allow extra fluid intake during times of increased physical activity.



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Here's How You Can Help (cont'd)

Tip #7: Nutrition

- Offer a well-balanced diet (there should be no food restrictions related to sickle cell disease unless instructed by the parent).
- Encourage extra fluid intake, preferably avoiding caffeine-containing drinks, to prevent dehydration.

Tip#8: Transportation

- Assist the parent in establishing bus transportation to and from school if needed.
- It is important for the student not to walk long distances in the cold or heat.

Tip#9: Fostering Self-Esteem

- Encourage the student's strengths and assets.
- Provide positive reinforcements as much as possible.
- Encourage creativity and imagination instead of emphasizing limitations.
- Treat student as normal as possible.

Managing a Student Through Pain

- Encourage fluids.
- Allow rest.
- Escort the student to the school nurse.
- Dispense pain medications as instructed by the parent.
- Apply heating pad or warm pack to painful area.
- Notify the parent of the student's condition.
- Provide emotional support.
- Utilize relaxation or distraction techniques.

Managing a Student Through a Fever

- Notify the parent immediately.
- Monitor temperature.
- Give Tylenol as directed by the parent.
- Encourage extra fluids.

Notify the student's parent immediately for:

- Fever of 101.5 degrees F or greater
- Moderate to severe pain
- Paleness
- Excessive fatigue
- Slurred speech
- Inability to use an arm or leg
- Vision changes
- Shortness of breath

What Can You Do To Help?



What You Can Do as the Teacher



- Help the family maintain a comprehensive assignment notebook with clear instructions.
- Identify when a 504, IEP (other health impaired), and/or homebound instruction is needed.
- Communicate frequently with the family.
- Clearly explain the parent's responsibility to pick up and turn in homework while the student is out.
- Be familiar with sickle cell disease and its characteristics.
- Allow the student to have water breaks and/or a water bottle at his/her desk.
- Provide additional passes to the restroom and school nurse as needed.

**Communicate
frequently with
the family.**

What You Can Do as the Principal

- Encourage staff involvement in learning about sickle cell disease.
- Collaborate with parents and teachers in the development of a 504 or IEP.
- Designate a staff person to monitor the student's 504 or IEP.
- Communicate with the parent your school's willingness to assist in the student's physical health and intellectual development.

504 ACCOMMODATION PLAN

Student: _____ **Student ID Number:** _____ **Date of Birth:** _____
School: _____ **Teacher(s):** _____
Grade: _____
Today's Date: _____

Instructions: Check the accommodations required for the student. Indicate the date(s) the accommodations will be initiated/completed to adapt to the student's area(s) of concern:

evaluate on mastery of subject instead of the number of assignments completed
Date Initiated _____ Date Completed _____

provide/assign a peer note taker
Date Initiated _____ Date Completed _____

provide extra time to complete assignments including time after the quarter
Date Initiated _____ Date Completed _____

provide a second set of books for home
Date Initiated _____ Date Completed _____

modify tests as needed
Date Initiated _____ Date Completed _____

provide weekly assignments in an assignment book
Date Initiated _____ Date Completed _____

allow restroom breaks as needed
Date Initiated _____ Date Completed _____

allow a water bottle at all times
Date Initiated _____ Date Completed _____

allow an open pass to the school nurse for rest and/or medications
Date Initiated _____ Date Completed _____

provide teachers with information regarding student's health problems
Date Initiated _____ Date Completed _____

modify the length of the assignments
Date Initiated _____ Date Completed _____

provide study guides
Date Initiated _____ Date Completed _____

TEAM MEMBERS DEVELOPING THE PLAN

_____	_____
Name/Position	Signature

Review Date(s) _____

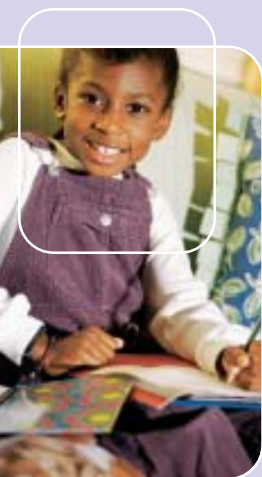
(Sample 504 plan)

What You Can Do as the Guidance Counselor

- Facilitate staff development by hosting an educational session on sickle cell disease.
- Evaluate students with sickle cell disease to determine the need for a 504 or an IEP. Often the parent(s) may not be aware the student qualifies for special education or 504 accommodations. If a teacher comes to you with concerns about a student, assess the student's absences and days spent in the nurse's office.
- If an IEP or 504 evaluation process is requested by the school or the parent(s), coordinate with school representatives to see that this process is timely.
- Designate a staff person to monitor the student's 504 or IEP.
- Provide emotional support to the student with sickle cell. Welcome the student back when there has been a prolonged illness at home or in the hospital.
- Provide educational resources, such as information about summer school, after school sessions and tutoring to assist and enhance the student's learning.

What You Can Do as the School Nurse

- Become educated about sickle cell disease including its characteristics and treatments.
- For every student with sickle cell disease, maintain a plan that includes information on warning signs, complications, “as needed” medications, routine medications, things to do in an urgent situation.
- Communicate with the parent for any questions or concerns.
- Ask the student what he/she usually does at home for treatments or things that work best for him/her.
- Have all necessary paperwork in place to administer medications as needed.
- Monitor response to pain management interventions.



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School Nurse (cont'd)

- Coordinate educational sessions for other school staff members.
- Notify the parent for any painful episodes, fevers of 101.5 degrees F or greater, increased lethargy, increased paleness or any other concerns.
- Provide necessary treatments for painful episodes:
 - Rest
 - Increased fluids
 - Heating pad
 - Pain medications
(as instructed by the parent)
 - Notify parent for further directions

What You Can Do as the Physical Education Instructor/Coach

- Be familiar with sickle cell disease and its characteristics.
- Encourage participation in all activities as tolerated.
- Communicate with the parent about the student's ability to fully participate in activities and note any restrictions.
- Allow the student to rest as needed (children with sickle cell disease may tire more easily than others and prolonged strenuous activity may lead to a painful episode).
- Provide an alternate activity that includes other students when the scheduled activity is too strenuous for the student with sickle cell disease.

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Physical Education Instructor/Coach (cont'd)

- Be supportive if the student is unable to complete the scheduled activity.
- Allow frequent use of the water fountain (children with sickle cell disease may become dehydrated quickly).
- Avoid exposure to extreme temperatures (hot, cold, damp).

Closing

Many students enjoy academics and go on to graduate, attend college, and pursue a career or vocation. Your role as a teacher, mentor, or friend will assist the student in becoming a successful adult. With your support, the information in this booklet will help a student with sickle cell disease succeed.



Can You Pass the Test?

FUN QUIZ

- Sickle cell is a disease that affects the red blood cells.**
 True False
- What are ways you can assist with the student's educational success:**
 - Allow bathroom privileges
 - Communicate with the student's parent
 - Create a notebook with classroom assignments
 - All of the above
- Circle the common characteristic(s) of sickle cell disease:**
 - Mild to moderate pain
 - Contagious disease
 - Anemia
 - Impairs cognitive ability
 - Infection
- Student's with sickle cell disease can graduate and lead normal lives.**
 True False



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