PEDIATRIC SICKLE CELL DISEASE PROGRAM

THE PAULINE ALLEN GILL CENTER
FOR CANCER AND BLOOD DISORDERS

children'shealth®

TABLE OF CONTENTS

SICKLE CELL DISEASE INFORMATION FOR SCHOOL PERSONNEL

This brochure is designed to provide teachers, coaches, school nurses and other school personnel with information about sickle cell disease (SCD). Sickle cell disease is a chronic health condition that may impact a student's school performance. There is a wide variety in the severity of complications with some students experiencing minimal complications, while others may face several episodes of acute illness requiring at-home/at-school treatment, frequent medical appointments and/or hospitalization.

Our goal for everyone with sickle cell disease is to prevent or minimize complications and provide children and their caregivers the knowledge and tools needed to live life fully.

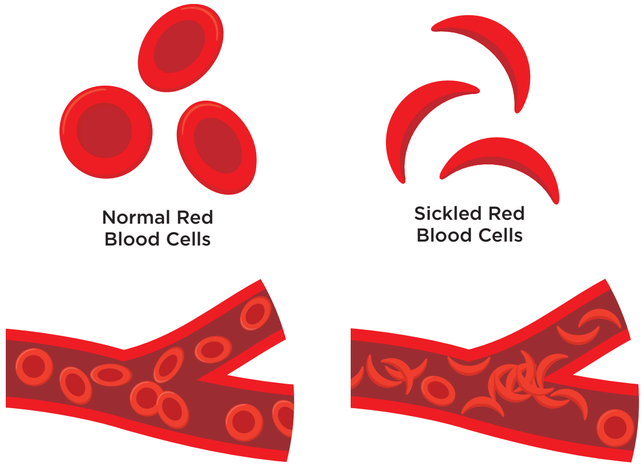
You play an important role in both the student's health and academic success. Knowing the complications and school-related needs of children with SCD allows you to provide the best opportunities and services available to support each individual child. A few simple accommodations during the school day may help to prevent serious complications and allow the child to manage their disease. Knowing what to do when a student under your care becomes ill helps the child with SCD maintain their health and achieve their educational goals.

At Children's Health℠ we believe a team approach between the student, family, school and health care team is essential in helping the student with sickle cell disease thrive. We are here to assist if there are medical or academic concerns regarding a student. Communication between parents and school personnel is a key component in supporting a child with a chronic illness. We ask that you contact the student's parent/guardian first. We are happy to assist once the parent has been notified.

The following information provides tips on what to do for a child with sickle cell disease. Additional links are provided if you would like more information.

WHAT IS SICKLE CELL DISEASE?

Sickle cell disease (SCD) is an inherited blood disorder that affects the hemoglobin in the red blood cells. Normal red blood cells are round, smooth and flexible. This helps them move easily through the bloodstream to deliver oxygen. In sickle cell disease, some of the red blood cells become abnormally shaped and look like a crescent or "sickle." Sickled red blood cells are hard, sticky and rigid, and they easily get stuck in blood vessels, blocking normal blood flow and delivery of oxygen to the body. This can be painful or even cause organ or tissue damage. In addition, the life span of a sickle cell is significantly less than a normal red blood cell (120 days versus six to 14 days). As a result, children with sickle cell disease have chronic anemia.



ADDITIONAL FACTS ABOUT SICKLE CELL DISEASE:

- Sickle cell disease affects about 70,000 people in the United States
- Approximately one out of every 400 African Americans has sickle cell disease
- The disease also affects people of Mediterranean, Middle Eastern, Indian, Caribbean and South American descent
- It is genetically inherited; one gene is passed from each parent
- Many adolescents with SCD experience delayed puberty
- Sickle cell disease is NOT contagious

Goals for Children with Sickle Cell Disease:

- Be treated normally for age
- Maintain academic performance
- Participate in activities to the fullest extent of their abilities
- Manage complications of their disease
- Live a full and productive life!

Common Characteristics of Sickle Cell Disease

Anemia – This means there is a lower number of red blood cells. This results in less oxygen being available in the body as red blood cells carry oxygen to organs and tissues. Symptoms of anemia:

- Being tired
- Decreased endurance
- Weakness
- Pale
- Headache
- Dizziness

Hyposthenuria (Inability to concentrate urine appropriately) **–** This causes the child to urinate more frequently. In addition, to prevent dehydration and a pain episode, the child will need to drink fluids frequently. Allow the child to go to the bathroom and water fountain more frequently than other children. If you are worried that the requests seem excessive, talk with the parents about the child's habits at home.

Jaundice – A yellow color of the skin or eyes is caused by bilirubin, which is a byproduct of the breakdown of red blood cells. This does not mean that there is something seriously wrong or that the child is contagious. They do not need to stay home or be sent home from school. The yellow color may come or go, but some children may always have yellow eyes.

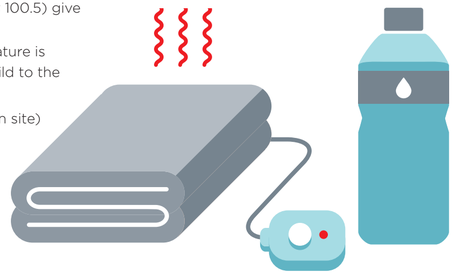
Delayed Growth & Development – Children with sickle cell disease may grow slower or mature later than their peers. They may appear thinner or smaller than others their age. It is important that they be treated in an age-appropriate manner, especially in adolescence when their appearance may be that of a younger child.

COMMON COMPLICATIONS OF SICKLE CELL DISEASE

Fever and Infection – Children with sickle cell disease have an increased risk of infection because their spleen does not work normally. The spleen is an important part of the body's defense against infection and works by removing bacteria from the bloodstream. **Fever, defined as a temperature of 101.5 degrees or higher,** may be the first sign of an infection. Call the student's parents immediately so they can take the child for medical evaluation and treatment. ***Do not give fever-reducing medicines such as acetaminophen or ibuprofen.***

Vaso-occlusive Pain Episode – Episodes of pain are common in children with sickle cell disease. Sickled red blood cells can become trapped inside of blood vessels causing an obstruction in blood flow that can cause pain. This can occur anywhere in the body and can last several hours or even days. Sometimes swelling is seen at the area of pain. Mild episodes of pain should be treated at school. The child will most likely be able to resume school activities within a couple of hours. More severe pain episodes may need to be treated at home or sometimes require hospitalization.

- **Common Triggers of Sickle Cell Pain**
  - Exposure to extreme temperatures (hot or cold)
  - Dehydration (need to encourage fluids to prevent)
  - Over-exertion
  - Infection
  - Stress
  - High altitudes
  - Shivering (if wet or cold)
- **Managing a pain episode at school**
  - Student should be taken to the nurse's office
    - Take the student's temperature, if 101.5 or higher, notify parents so they can take the child to the Emergency Department
      - If the student does not have a fever or if the fever is low-grade (below 100.5) give pain medication per the school's medication authorization form
      - Continue to monitor the temperature before each dose; if the temperature is 101.5 or higher at any point, notify the parents so they can take the child to the Emergency Department
    - Apply heat to the painful area (**DO NOT** use ice/cold on an injury or pain site)
    - Increase fluid intake
    - Allow the student to rest
    - Encourage use of coping skills, such as deep breathing, distraction or guided imagery
- **If the above measures do not work, contact the student's parents to discuss next steps.**



LESS COMMON COMPLICATIONS OF SICKLE CELL DISEASE

Stroke – This is a medical emergency. Sickled cells can block the blood vessels in the brain and keep the brain from getting enough oxygen. If you notice any cognitive changes, no matter how subtle (less attentive than usual or changes in school performance), discuss these concerns with parents ASAP. If you notice any of the following symptoms, call 911 and the parents immediately:

- Inability to move part of the body
- Weakness or numbness in part of the body
- Seizures
- Strange or abnormal behavior
- Sudden blurry vision
- Severe vomiting
- Severe headaches that are not relieved with acetaminophen or ibuprofen
- Slurred speech
- Unsteady gait

Acute Chest Syndrome – This is a medical emergency. Sickle cells can clog blood vessels in the lungs. This may also be caused by pneumonia or lead to pneumonia. If your student experiences any of these symptoms, call the parents immediately:

- Fever >101.5
- Chest pain
- Congestion
- Cough
- Trouble breathing or shortness of breath
- Rapid breathing

Priapism – This is a painful erection that is unwanted and lasts a long time. Sickled cells can cause an obstruction of blood vessels in the penis. The pain crisis should be managed in the way other pain is managed at school with the addition of having the student go to the bathroom at the onset of this type of episode. Notify the parents ***immediately*** when this occurs. If the erection does not go away within three hours, the child will need to go to the Emergency Department for treatment.

Avascular Necrosis (AVN) – This is a bone condition that occurs in joints when sickled red blood cells block the flow of blood to the joints. When the joint does not receive enough blood supply, it can become weak and die. This can lead to persistent pain in the joint. AVN may result in persistent hip, knee or shoulder pain. Students may limp or experience pain when walking up or down stairs. School personnel will need to be aware if the student has AVN, as they may need accommodations.

EVERYDAY NEEDS OF THE STUDENT WITH SICKLE CELL DISEASE

Fluids – Ensure the student has access to plenty of fluids throughout the day. Preventing dehydration is key to decreasing the number of painful episodes the student experiences. Allow the student to have a water bottle with them and especially during any times of physical activity (physical education/recess/sports).

Bathroom Privileges – Allow the student to use the bathroom when needed. Their kidneys do not function as well as those of children without SCD, and they will need to use the bathroom frequently.

Avoid Physical Exhaustion – The child with SCD may participate in most exercise and other activities without restrictions. However, because the child with SCD may tire easily, allow them to self-limit activity and rest as needed. Heavy or long periods of exercise without fluid and rest breaks are not recommended for the child with SCD. Consult with the child's parents if you have questions regarding the appropriateness of an activity.

Avoid Extreme Temperatures – Temperature extremes may trigger a painful episode. In hot weather, your student may need more frequent breaks for rest and water. When it is cold outside, layered clothing, including hats, should be worn outside. Classrooms should be kept at moderate temperatures, as well.

- **Special precautions for water-based activities include:**
  - After 30 minutes in the water, take a 30-minute break out of the water to rest and dry off completely.
  - During the break drink plenty of fluids.
  - When water-based activities are completed, take a warm shower, dry off completely and change into dry clothes.
  - Avoid going from water-based activities into a cold/air-conditioned building.

Monitor for Social Distress or Bullying – Students with sickle cell disease may have physical or cognitive differences than their peers that could make them a target for bullying. The student may also be at risk for self-esteem or body image issues.

Maintain Open Communication with Parents – Talk with the parents regarding questions or concerns you may have about their child. Also, discuss other ways the parents may help to their child succeed in school.

ACCOMMODATIONS FOR CHILDREN WITH SICKLE CELL DISEASE

Section 504 of the *Rehabilitation Act of 1973* is a civil rights law that includes protections against disability discrimination in the school setting. It allows students with medical concerns to receive "accommodations" that will help them succeed in school. Most students with sickle cell disease are eligible for 504 Plan accommodations. They may also qualify for special education under the "Other Health Impaired" category of the Individuals with Disabilities Education Act. This federal education law provides for specialized instruction (Individualized Education Plan (IEP)) when a child has a disability that interferes with academic success.

A few simple accommodations that should be considered for the child with sickle cell disease:

1. Permission to carry a water bottle to drink throughout the day
2. Bathroom and school nurse pass when needed
3. Two sets of books, one for home and one for school
4. Exemption from outdoor activities when the temperature is less than 40 degrees or greater than 90 degrees
5. Exemption from physical education activities that involve strenuous exercises or long-distance running. The student should take water breaks every 10-15 minutes during physical exercise
6. Frequent restroom and water breaks
7. Breaks during physical activity
8. Access to the school nurse or office staff for medical needs, like administering pain medications at school
9. More time on class work, homework or state tests
10. Preferential seating in the classroom
11. Opportunity to make up missed class work or homework
12. If a teacher is not providing make-up work, schedule a parent-teacher conference to address this early
13. A plan to return to school after being away or hospitalized. This plan might include returning to school with a few half days or attending the core classes (math, science or English). Your child can eventually attend a full day of school as soon as he/she begins to feel better

Contact Numbers:

Pediatric Sickle Cell Disease Program
1935 Medical District Drive
Dallas, Texas 75235
Phone: 214-456-6102
Fax: 214-456-8469

School Services
Phone: 214-456-7733

Social Work
Dallas: 214-456-2300
Plano: 469-303-2300

Additional resources:

tea.texas.gov/sites/default/files/Sickle_Cell.pdf

dshs.state.tx.us/newborn/sickle.shtm

cdc.gov/ncbddd/sicklecell/documents/tipsheet_Supporting_Students_with_SCD.pdf

cdc.gov/ncbddd/sicklecell/documents/sickle-cell-coaches.pdf

cdc.gov/ncbddd/sicklecell/documents/sickle-cell-athletes.pdf

cdc.gov/ncbddd/sicklecell/documents/sickle-cell-doctors.pdf

nhlbi.nih.gov/health-topics/sickle-cell-disease

Scan for Children's Health Sickle Cell Page

If you have questions or for more information
call your sickle cell team at 214-456-6102

or visit **childrens.com/sicklecell**

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