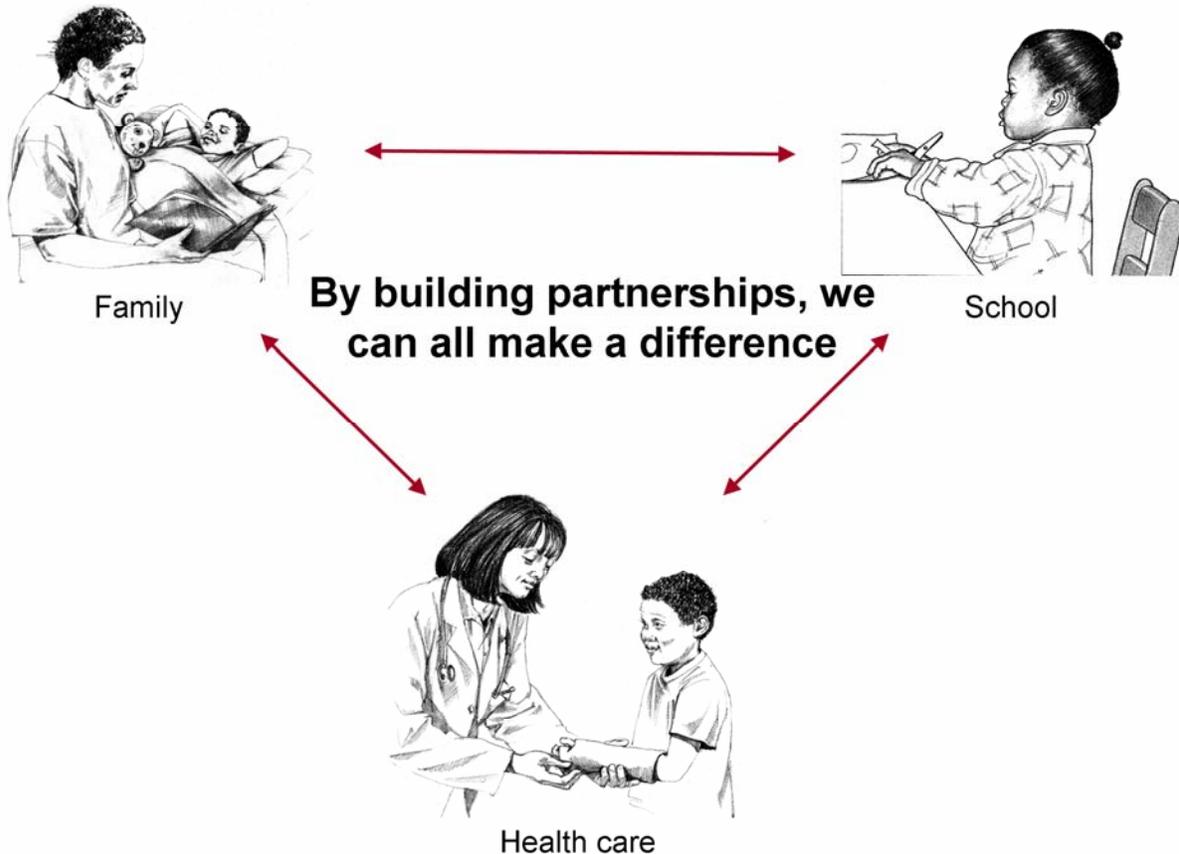


Sickle Cell Disease: Information for parents, teachers, and schools



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<u>Table of Contents</u>	<u>Page</u>
Cover page.....	1
Table of Contents.....	2
Introduction	3
What is sickle cell disease?.....	3
What are the possible physical effects of sickle cell disease and how should schools respond?.....	5
Painful episodes.....	5
Anemia.....	5
Susceptibility to infections.....	5
Stroke.....	6
Gallstones.....	6
Delayed growth and sexual maturity.....	6
Sleep problems.....	7
Bone or joint problems.....	7
What can I do to prevent or minimize the physical effects of sickle cell disease?.....	7
How does stress affect sickle cell disease?.....	8
What can I do if I think the child is exaggerating symptoms of sickle cell disease?.....	8
How are children with sickle cell disease best served in school?.....	8
Do children with sickle cell disease ever qualify for a 504 Plan or under IDEA?.....	9
Why aren't more children with sickle cell disease provided medical and educational accommodations?.....	10
What are some common accommodations to consider?.....	10
Why do children with sickle cell sometimes need homebound instruction?.....	10
What is the connection between sickle cell disease and learning difficulties?.....	11
What do I do if I notice a child with sickle cell having difficulty with learning and attention?.....	11
Do all children with sickle cell disease need to be given an educational evaluation?.....	12
Are children with sickle cell disease at greater risk for adjustment difficulties?.....	12
What can I do to provide emotional support for a child with sickle cell disease?.....	12
What can I do to ensure that I don't over-protect the child?.....	13
What are the shared responsibilities between parents and teachers?.....	14

Introduction

At least 15% of all school children in regular classrooms today have some type of chronic health condition. It is important that parents and teachers are not only knowledgeable about chronic health conditions, but are also aware of how these conditions can impact learning and school adjustment. Communication and collaboration among medical care providers, parents, and school staff is essential for meeting the unique medical and educational needs of children with chronic health conditions.

A good education is more important than ever for children with sickle cell disease. In the early 1970's the median life span of people with sickle cell disease in the United States was approximately 17 years. Health-related quality of life was often low, and disability levels were high. Due primarily to improvements in medical care, by the mid 1990's the median life span of people with sickle cell disease had increased to over 50 years of age. Many adults now are living with sickle cell disease and have adequate physical functioning to work and live fuller lives. With this improvement in health care there is a much greater need to focus on education and career preparation that will lead to more productive and independent lives as adults.

The purpose of this guide is to provide information that will be useful for educators and parents in developing a medical and educational plan for children with sickle cell disease. This information covers a lot of different topics, including basic information about sickle cell (i.e., etiology), physical effects of the disease, and its effect on school functioning. However, the most challenging mission is for the school, medical staff, and family members to work together to incorporate their knowledge of the disease with their knowledge of the unique qualities and strengths of the child to develop a plan that will work.

Questions and Answers

I. What is sickle cell disease?

Definition

Sickle cell disease is a genetically inherited blood disorder that causes red blood cells to become sticky and sickle shaped. Normal red blood cells are round like donuts and move through small blood tubes in the body (arteries and veins) to deliver oxygen. Sickle red blood cells, take on a curved blade shape and become hard and sticky. These hard, pointed red cells clog the flow and break apart as they go through the small blood tubes and can result in pain, damage, and a low red blood count, or anemia.

Sickle cell disease is not a contagious disease. If both parents of a child carry the sickle cell trait, there is a one in four chance that their child will have sickle cell disease. There are three common types of sickle cell disease in the United States. These include Hemoglobin SS (or sickle cell anemia), Hemoglobin SC, and Hemoglobin sickle beta-thalassemia. Each of these types of sickle cell disease can cause pain episodes and complications, but some are more common than others. The gene that causes sickle cell disease developed in parts of the world where malaria was a serious problem, including Africa, parts of the Mediterranean, the Middle East, India, and Southeast Asia. In the United States sickle cell disease is most commonly found in African-Americans whose ancestors came from certain parts of Africa. Sickle cell disease is also found in persons of many other nationalities, including Arabs, Africans, Greeks,

Italians, Latin Americans, and individuals from India. People of all races or ethnicities can have sickle cell disease.

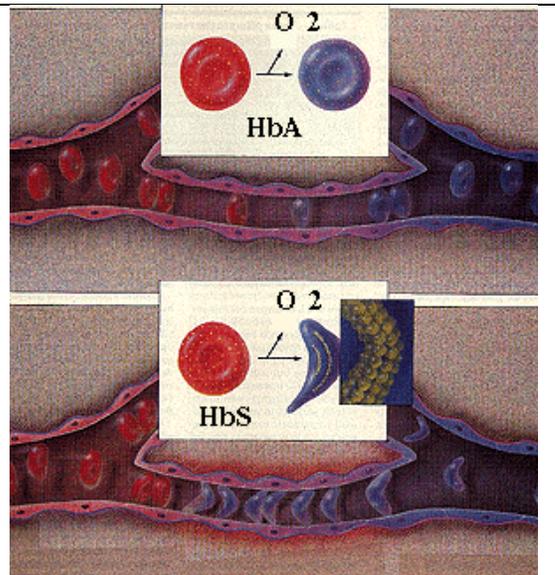
Prevalence

Approximately 1 in 12 African-Americans carry the sickle cell trait and approximately 1 in 400 African-Americans have sickle cell disease. Although the overall prevalence rate is not high, sickle cell disease is more common in the U.S. than diseases such as cystic fibrosis, phenylketonuria (PKU), hemophilia, and childhood leukemia.

Sickle Cell Trait vs. Sickle Cell Disease

Some people only carry the sickle cell trait, but do not have the disease. Trait carriers have only one copy of the sickle cell gene, are more resistant to malaria than the general population, and rarely have serious health problems related to the trait. If a child received two copies of the sickle cell gene from their parents they have sickle cell disease, and can develop a variety of medical problems. Sickle cell disease varies in severity with some individuals having infrequent and mild health problems, whereas others may have frequent and life-threatening health problems. This means you cannot always predict what sickle cell disease is like based on having known one or two individuals with the condition. The cause of most of the health problems is that the oxygen carrying parts of the blood (hemoglobin) change as they are moving through the blood stream. The blood cells become rigid and take on a sickle-like shape; they become poor at delivering oxygen; they become sticky and the cells may clump together; also, the spleen may misidentify and destroy the red blood cells, creating anemia. The blockage of blood vessels can lead to painful episodes, organ damage, and other physical problems. Children are often at a higher risk for developing infections. Some of these infections are life threatening if not detected and treated early.

Figure 1. Hemoglobin type S (HbS) responds differently than typical hemoglobin (HbA) to the normal loss of oxygen as the cell moves through the bloodstream. HbS-type hemoglobin becomes rigid, sticky, and sickle-shaped. The "sickled" cells do not deliver oxygen as well, can clump together to create blockages, irritate the lining of blood vessels, and often are destroyed by the spleen. These changes can lead to painful episodes in the area with blockage, tissue or organ damage, and anemia. There are a number of treatments currently that can help reduce the symptoms of sickle cell disease, including oral hydroxyurea (an oral medication), blood transfusions, and bone marrow transplant. These treatments, however, have potential side effects in a small percentage of children. Therefore, these treatments are reserved for children who are having significant and frequent complications from sickle cell disease.



II. What are the possible physical effects of sickle cell disease and how should schools respond?

Painful episodes. Pain episodes are the most common complication of sickle cell disease. The pain is related to a localized blockage of blood vessels, and can occur anywhere in the body. Pain episodes are often preceded by infection, dehydration, or certain chemical imbalances in body fluids. Pain usually has a gradual onset, but grows to a gnawing and sometimes excruciating pain. It can last from hours to many days and may wax and wane over this time.

- **Intervention:** Mild pain episodes may be tolerated at school with the help of pain medication. Other pain episodes will require the child to stay at home or be hospitalized. Historically we have under-treated pain for fear of children becoming addicted to pain medicine. In fact, addiction is quite rare, and pain should be treated in a responsive way rather than encouraging the child to simply tolerate the pain. Physicians will have provided instructions to the parent regarding the sequence of pain medications to try, and when to seek medical treatment for a pain episode. It is important that parents and the school nurse inform teachers of the medical care plan. *We strongly advise schools to allow parents to keep a child at home due to pain without needing a note from a physician.* Going to a physician or emergency room to obtain documentation of a pain episode that can be handled at home, simply for school documentation, is usually a poor practice. This practice places an additional burden on the family and creates unnecessary health care expenses.

Anemia. Most, but not all, children with sickle cell disease have anemia (a lower than normal level of hemoglobin). Some children will fatigue quickly during vigorous physical activity depending on the severity of the anemia. Most children can run, jump, swim, ride bikes, and participate in physical education activities. Children typically know what they can tolerate, although parents will sometimes recognize when an enthusiastic child tends to not realize their limits. Use the child's self-report as a guide, but consult with a parent at the beginning of the year to learn about the child's level of judgment as well.

- **Intervention:** A child with sickle cell disease may need a longer period of time to recover from vigorous activities than peers. If a child is having difficulty with fatigue, consider options for participating in activities that are less strenuous such as being the P.E. teacher's "assistant", "scorekeeper", or "umpire" for part of the class.

Severe anemia. If a child looks particularly pale, shows a low and decreased tolerance for physical activity, and seems "run down", this may be a sign that their anemia has become worse.

- **Intervention:** The school nurse and the parent should be notified. Although rare, sudden worsening of anemia can be a medical emergency.

Susceptibility to infections. Children with sickle cell disease usually have less ability to fight off infections than peers. Fever is the most common sign of infection. A cough or rapid breathing can also be a sign of pneumonia if the lungs are infected. Infection is the leading cause of death in young children with sickle cell disease, and frequently leads to hospitalization.

- **Intervention:** An elevated temperature is an issue for any child in school, but needs particular attention for children with sickle cell disease. Parents should be contacted as soon as possible. A temperature of 101 degrees or greater is of serious concern and

requires that the child be seen by a physician to rule out complications such as pneumonia or sepsis (the leading cause of death in children with sickle cell disease). If the fever is also accompanied with pain in the ribs or sternum this may be a sign of acute chest syndrome, also a serious medical emergency. The bottom line is that teachers and other educators should be more alert for signs of fever in children with sickle cell disease, and have a plan coordinated with the parent and school nurse for what to do if a fever occurs.

Stroke. Approximately one in twenty children with sickle cell disease suffers a stroke, most often between the ages of 3 and 12 years of age. Signs of stroke are severe headaches, marked dizziness, visual changes, acute onset of weakness (not due to pain) in a limb or one side of the face, a sudden inability to produce speech, or a seizure. Not all of these symptoms will happen during a stroke.

- **Intervention:** *Stroke can be a complication of sickle cell disease and is a medical emergency.* If a child reports severe headache or is groggy, a school nurse should evaluate for symptoms of stroke and parents should be notified. It is possible to mistake a stroke for a migraine headache or simple fatigue if one does not consider that something more serious may be happening for a child with sickle cell disease. **If a stroke is suspected, parents should be called immediately and the child should be taken to the hospital.** Children who have had a stroke often have monthly hospital appointments to receive blood transfusions prevent additional strokes. These appointments can take up to an entire day to complete and result in additional missed school time. Teachers can help these children by planning ahead with the child and parent to provide them with the information they missed when away from school and developing a plan for the child to complete as much work as possible during the school absence.

Silent Stroke: We have recently recognized a condition sometimes called "silent stroke". Silent strokes do not have the same clear signs of a stroke. Silent stroke is a serious problem, but is not a medical emergency.

- **Intervention:** *Teachers are in a unique position to identify changes in their students' school performance that might indicate a silent stroke.* If changes in a student's academic performance, attention, or memory are observed, teachers should contact the student's parents so that the physician and neuropsychologist can be notified.

Gallstones. If a child is experiencing nausea, abdominal pain, shoulder pain, or vomiting this can be due to gallstones. The child may also appear jaundiced, which is most evident by seeing that the white parts of the eyes have taken on a yellowed tint. Jaundice, however can be present without gallstones. Sometimes peers will tease a child due to the appearance of their eyes. The jaundice/yellowing is due to the liver producing more bile than the body is getting rid of.

- **Intervention:** Gallstones are a serious medical issue, and sometimes require surgery. If a child reports symptoms of gallstones, a school nurse should evaluate the child and parents should be notified.

Delayed growth and sexual maturity. Some children with sickle cell disease are small for their age in both height and weight. Puberty is, on average, delayed approximately two years compared with most peers. These growth delays sometimes lead to the child being self-conscious about their size or to have a poor body image. Some youths are treated younger

than their age and maturity level by others due to their small stature. Teasing from peers can also be a problem.

- **Intervention:** It's important that teachers be observant to make sure the child is not being teased by his peers. If teasing occurs, the parent and teachers need to develop a plan to address this issue. Additionally, the teacher should offer a variety of ways the child can experience success both academically and socially. Take care to ensure that you and other adults at school or at home interact with the child at their age level.

Sleep problems. Some children with sickle cell disease have enlarged adenoids and tonsils from the disease. When enlarged, these can cause breathing problems at night while the child is trying to sleep (called "sleep apnea"). The child may not be aware of the fact that he or she is waking up frequently during the night to "catch their breath". A child may sleep enough hours during the night, but does not feel rested the next day due to poor quality sleep. Fatigue, daytime sleepiness, and memory/concentration problems can happen as a result.

- **Intervention:** Teachers should report any observation of fatigue, sleepiness and/or memory/concentration to the nurse and/or parents. A sleep study can be requested to determine if the child is experiencing this problem.

Bone or joint problems. Sometimes blood flow blockages will affect bones, particularly in the hip.

- **Intervention:** If a child complains of pain or you observe decreased use of arms or legs, you should notify the nurse/and or parents. Pain medication or surgery is sometimes needed to prevent pain and support the joint.

III. What can I do to prevent or minimize the physical effects of sickle cell disease?

Hydration. Maintaining good hydration is one of the best ways to prevent painful episodes and other complications of sickle cell. It is better to have frequent, small amounts of fluid than trying to force large amounts of fluid at one time. Not all fluids we drink help with hydration. Bottled water, tap water, juice, milk and carbonated soda without caffeine are all hydrating beverages. Common dehydrating beverages are coffee, tea, carbonated soda with caffeine, and alcoholic drinks. Dehydrating beverages should be discouraged because people often mistake these as sources of hydrating fluids; in fact, they can cause a net loss of fluids.

- **Intervention:** It is important that you allow the child to take frequent drinks or to have a bottle of water in class. See page 8 for suggestions on how you can encourage students to maintain good hydration.

Adequate rest. Children with sickle cell disease typically can participate fully in school activities. However, issues that might affect any child in a negative way can have a greater impact on a child with sickle cell disease.

- **Intervention:** Children with sickle cell disease may need more time than peers to recover from vigorous activities, such as recess or physical education class. Therefore, periodic rest may be needed to allow the body to recover. Parents should allow for adequate time for sleep, and teachers should communicate with parents if there are persistent problems with daytime sleepiness (see Sleep Problems above).

Nutrition. Children with sickle cell disease have a higher metabolism and use vitamins and minerals at a higher rate than most peers. This is a natural part of the body compensating for some of the effects of sickle cell disease. Because of this, children with sickle cell disease often need more calories than peers and need higher intakes of certain vitamins and minerals. Nutrition is likely a major factor in growth delays, and may also impact immune functioning.

- **Intervention:** If a child is eating poorly at school, or is found to be eating nonfood items (“pica”), parents should be notified. Pica is sometimes a sign of vitamin or mineral deficiencies.

IV. How does stress affect sickle cell disease?

Stress management. All physical health conditions can be made worse by psychological stress. For example, emotional stress typically weakens our immune system. When stresses are beyond the child’s control (e.g., a pain crisis) the child will need additional support. Some children may benefit from a guidance counselor or psychologist in managing stress and getting emotional support.

- **Intervention:** Teachers can help the child prioritize and manage his or her academic workload. Monitor regularly to be sure that work is challenging but also attainable and realistic. If needed, consider reducing the child’s workload during stressful times, particularly if the child has been ill and has missed several days from school. Also, it’s important to find positive opportunities for socializing with other children. Children who have a lot of medical challenges may not have as many opportunities to play and interact with other children. These recreational activities are very important for developing positive self-esteem and good interpersonal skills, and also reduce stress.

V. What can I do if I think the child is exaggerating symptoms of sickle cell disease?

Occasionally teachers have concerns that a child may be making complaints of symptoms of sickle cell disease to get out of classroom activities. Most symptoms of sickle cell will not be directly observable, and you will only know of them when the child reports the symptoms. It is better to take the child’s self-report as accurate until you have strong reason to believe otherwise. Parents are typically in the best position to gauge whether or not their child is exaggerating pain or trying to use illness as an excuse. If you suspect a child is using medical symptoms as an excuse to get out of classroom activities, talk with the parents and ask for their input, as well as the child’s physician. If the pain is “real”; the child needs medical treatment. If the pain is exaggerated, it could be a behavioral issue that will need to be treated sensitively and may require team collaboration (i.e. parents, educators, psychologist, and health care professionals).

VI. How are children with sickle cell disease best served in school?

Most children with sickle cell disease are best served in the regular class with an individualized health care plan developed by the parents, school nurse and other school staff. This plan includes: a brief description of health care issues, problems, goals, an emergency plan, and any necessary training needed by school staff. The child’s health care plan should be reviewed annually by the school team and parents or as often as necessary.

VII. Do children with sickle cell disease ever qualify for a 504 Plan or under IDEA?

Many children with sickle cell qualify for a 504 Plan. To determine eligibility, the school team looks at how sickle cell disease physically and/or mentally places substantial limits on one or more of the following major life activities: walking, breathing, learning, seeing, performing manual tasks, caring for oneself, hearing, and speaking or working. The child's 504 Plan, along with the Health Care Plan, should be reviewed annually or as often as necessary.

Some children (particularly if the child has had a stroke) may best be served under IDEA, the Individuals with Disabilities Education Act. The most common classification a child with sickle cell disease would fall under is "Other Health Impaired". To be eligible under IDEA, and thus receive special education services, the child's sickle cell disease must be determined to adversely affect his/her educational performance. If the child is eligible for special education, an individualized education program (IEP) is developed that can provide a wide range of special education services depending on the need of the child. For example, a child may need a special education consultant to collaborate with the regular classroom teachers is one type of service. Another service would be a "pull out" program in which the child attends one period a day of resource support. Another type of service would be a child who needs to be educated in a self-contained special education placement. If a health care plan is needed, it can be added to the IEP document.

Differences between a 504 Plan and an IEP

<i>504 Plan</i>	<i>IEP as mandated by IDEA</i>
<ul style="list-style-type: none"> ✓ The purpose is a broad civil rights law that protects the rights of individuals with handicaps in programs and activities that receive Federal financial assistance from the U.S. Department of Education. ✓ 504 protects all school-age children who have or has had a physical or mental impairment which substantially limits a major life activity or is regarded as having a disability by others. ✓ Requires an accommodation plan. ✓ The term "appropriate" for 504 means an education that is comparable to the education provided to students without a disability. ✓ A 504 plan is not remedial (corrective). ✓ 504 does not provide additional funds. 	<ul style="list-style-type: none"> ✓ The purpose is to ensure adequate and appropriate services for children with disabilities. ✓ IDEA protects all school-age children who fall within one or more specific categories of qualifying conditions. ✓ Requires that the IEP be written and followed. ✓ The term "appropriate" for IDEA means a program designed to provide educational benefit. ✓ An IEP plan is remedial (corrective) in nature. ✓ IDEA provides additional funding for eligible students.

VIII. Why aren't more children with sickle cell disease provided medical and educational accommodations?

First, a lot of people are not knowledgeable about sickle cell disease. Second, many people do not understand the seriousness of sickle cell disease and the full range of its effects on a child's academic and social functioning in school. Third, children and families are sometimes hesitant about disclosure for fear that others will tease or label the child in an unfair way. Because of these concerns, families may keep it a private matter; therefore, teachers are unfortunately not informed, resulting in the child not being fully supported at school with appropriate accommodations.

Communication and cooperation between families and schools is essential to ensure success in managing the unique medical and educational needs of the child. We have found it to be rare that a school does not comply. If a parent has met with the school and feels a school is not responsive to the child's needs, more information about sickle cell disease and its effect on school adjustment is provided by PRO-Parents (ph. 1-800-759-4776 or <http://www.proparents.org/>).

IX. What are some common accommodations to consider?

Access to water and/or fluids to maintain hydration. This is an important health factor for individuals with sickle cell disease. Some children become resistant to drinking extra water if they feel this is being forced on them. It is important to work with parents to understand how they encourage the child to take in more fluids. For some children being allowed to use the drinking fountain regularly works. Other children have learned to carry a water bottle with them to maintain hydration. Sometimes children need a specific schedule for taking in fluids that may be overseen by a school nurse (e.g., drinking a certain amount of fluids at a set time during the day in the nurse's office).

Access to the restroom. Maintaining good hydration may mean the child needs to use the restroom more frequently than other children. Children with sickle cell disease sometimes have higher rates of urine production independent of taking in extra fluids. Teachers may need to make some exceptions for the child if there are classroom rules limiting access to the restroom.

Accommodations for physical education / recess activities. Participating in an exercise program is very important for all children including children with sickle cell disease. However, due to fatigue and hydration concerns, it is important to be planful regarding physical education and recess activities. Moderate activity is usually acceptable, but some vigorous activities may not be appropriate for a child with significant anemia. Extreme temperatures (either hot or cold days) may also pose a problem for outdoor activities. Please consult with the child's parent about appropriate activities, or ask the parent to contact the child's hematologist for recommendations on what are appropriate types of exercise.

X. Why do children with sickle cell sometimes need homebound instruction?

Need for homebound services is a decision that a parent should carefully discuss with the child's physician. Sickle cell disease can be very unpredictable. A child may be very healthy one day

or for that matter, for a number of years, and then suddenly have complications requiring the child to miss school for an extended period. These children would be eligible for regular homebound services. Some children experience infrequent absences of only 2-3 days for pain crises or for doctor's appointments (transfusions, etc). Even though it's only a few days, these days add up over a year's time and can greatly affect academic performance.

Therefore, some children's physician and parents decide to request *Intermittent Homebound*, a service that allows a homebound teacher to respond immediately whether it is infrequent, short absences or a longer school absence. Intermittent Homebound can allow a child to receive homebound for frequent, short absences (i.e., monthly transfusions) as well as longer unexpected school absences (i.e., hospitalizations). It's wise to have a plan in place *in advance* so if a medical situation arises there is no wait time. Once homebound begins, it is critical that parents, teachers and the homebound teacher stay in regular contact to ensure that work missed during absences is made up. When children have regular or extended absences from school, teachers may need to consider a reduced workload. By doing so, children are able to continue to learn and practice concepts without becoming overwhelmed by the quantity of work that they may not be well enough to complete. Each school district has a Homebound form that can be sent to the child's physician for authorization. The guidance counselor is usually the contact for these services.

It's important to remember that homebound services are helpful but it is not a substitute for a regular school day. Encouraging the child to attend school is very important.

XI. What is the connection between sickle cell and learning difficulties?

Data collected in South Carolina suggest that approximately 30% of children with sickle cell disease have difficulties with either school achievement (performance levels in academic subject area) or attainment (repeating a grade, needing services to support classroom learning). Some children have attention or other learning problems that appear to be related to stroke or severe anemia or a silent cerebral infarction. Silent cerebral infarction ("silent stroke") is often an unrecognized problem. Approximately one-fourth of children with sickle cell disease may have small brain injuries resulting from a silent stroke. Since these small injuries do not lead to the visible signs of stroke, like a seizure or weakness in a limb, the injury goes unrecognized. Children with these "silent strokes" often have difficulties with focusing and sustaining attention, keeping organized, and sometimes have mild delays in vocabulary development compared with peers. Other school difficulties can be caused by anemia, which results in fatigue, and also limits a child's ability to focus and pay attention in a classroom setting.

XII. What do I do if I notice a child with sickle cell having difficulty with learning and attention?

It is important for teachers to recognize that poor attention or classroom performance may be due to the effects of sickle cell disease rather than an issue of the child's motivation or desire to do well in school. Neurocognitive testing can be helpful to determine if the child has a cognitive disorder related to sickle cell disease, and can help with suggestions as to how best to accommodate a weakness or modify instructional approaches. The Children's Cancer and Blood

Disorders Center at Palmetto-Health Richland, in cooperation with the USC Department of Pediatrics, can arrange for neurocognitive testing, if this seems important based on the child's classroom behavior. Have the child's parent contact our psychology services at 803-434-3621 if this service is of interest.

XIII. Do all children with sickle cell disease need to be given an educational evaluation?

There are many reasons why a child with sickle cell disease might have difficulty learning at school, including stroke, prolonged school absences or attentional and learning differences. While educational evaluations of all children with sickle cell disease might not be necessary, a child who is demonstrating poor academic performance or a decline in their academic performance should be referred for an educational evaluation as soon as possible. A change in academic performance or lower than expected academic performance could be indicative of a "silent stroke". By obtaining an evaluation of the child's abilities as soon as possible, any necessary changes to their medical care or educational placement can be made promptly, thus avoiding a worsened medical or educational situation.

XIV. Are children with sickle cell disease at greater risk for adjustment difficulties?

Each child with sickle cell and his family is unique in how they adapt to having a chronic health condition. Many children with chronic health conditions are very resilient and manage challenges extremely well. Others can feel overwhelmed with the multiple challenges they face. Research indicates that children with sickle cell disease are at a higher risk for adjustment difficulties than their peers without sickle cell. Therefore it is very important for teachers and parents to monitor the child for any signs of difficulty with self-concept, sadness, anxiety, or other adjustment difficulties. Sometimes, children with a chronic health condition may have difficulties with peers oftentimes because the classmates are not educated about the disease. For example peers can become jealous of the "special favors" a child with sickle cell receives because of their medical condition (e.g., water fountain privileges). Other, peers can tease a child about his having "yellow eyes" that sometimes occur if the child has jaundice as part of their sickle cell disease. These difficulties can be avoided with education and a supportive environment for differences.

XV. What can I do to provide emotional support for a child with sickle cell disease?

School is a time when children want to "fit in" and be like other children. Being "different" can be difficult unless the teacher and parents ensure a safe learning environment where children respect and understand differences. Teachers and parents can be strong advocates to educate others about the disease and the complex issues the child faces. Educating both other teachers and the child's classmates is important. Of course, it's important to make sure to obtain permission from the child and also the parents before sharing information, either formally or informally.

Many teachers have also successfully implemented age-appropriate health education units on sickle cell disease to address these issues. Nurses from the Children's Rehabilitative Services clinics in South Carolina or from Palmetto-Health Richland Hospital have sometimes been able

to help teachers in planning or delivering a health unit on sickle cell disease so that other children may better appreciate the health issues involved. Be certain to discuss with the child's parent and obtain permission from the child before letting other children in the class know the child has sickle cell disease. Having the child participate can be beneficial in promoting self confidence and self-advocacy.

XVI. What can I do to ensure that I don't over-protect the child?

It's important that children with chronic health conditions don't become overly dependent on adults. Because of their illness, adults need to be mindful that they don't foster this dependency of "sick person attitude" that can result in the child being reluctant to try new tasks, or be prone to self-pity, or have a poor self-concept. Setting expectations that are challenging but attainable are important followed with encouragement and concrete praise for reaching goals. Even praising the child when they attempt activities on their own is important. Modeling positive thinking by demonstrating the belief that a positive attitude and optimistic thoughts can result in a positive outcomes is another useful technique. The child may need to learn how to talk themselves through tasks to control their frustration level. Assigning the child to roles of importance can also help the child's sense of self-esteem and capability (helper or leadership role). Extracurricular activities can also be very helpful, particularly if chosen with some thought about the child's likelihood of success.

XVII. What are the shared responsibilities between parents and teachers?

What parents need to do...

- EACH YEAR, Notify your child's teacher and the school that your child has sickle cell disease.
- Provide the teacher or a guidance counselor with information about the specific issues or needs for your child. This should include what the school should do if an acute medical problem happens during the school day.
- Request a school meeting for a 504 Plan or Individual Educational Plan (IEP) if your child needs accommodations related to sickle cell disease.
- Obtain appropriate letters or documents (e.g., letter from the doctor) to help school staff provide any accommodations that may be needed.
- Arrange to pick up or otherwise get schoolwork that your child misses due to health-related absences. Even modest amounts of work completed at home or at the hospital during illness can make your child's return to school easier.
- Keep an open line of communication with your child's teacher, either through occasional notes, phone contacts, or conferences.

What teachers and school staff need to do...

- Listen carefully to parents to understand the specific health issues of the child.
- Consult with your school's nurse and the child's family at the beginning of the school year so that the school team understands what the plan will be if any acute medical problems arise.
- Maintain confidentiality about the chronic health condition with both adults and children.
- Develop a 504 plan or IEP if there are accommodations needed. This is the best way to insure that the child's needs are met consistently across different classes.
- Consider how to make any accommodations needed as much a part of the routine. Children do not like being singled out from the class because of their health condition.
- Be prepared to provide schoolwork and/or homework to a parent in case the child misses school. For planned absences (e.g. routine medical appointments) have the homework ready in advance of the absence.
- Keep an open line of communication with the child's family, either through occasional notes, phone contacts, or conferences.

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A program from the University of South Carolina to support children with sickle cell disease and their families

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