School Services School Guide for Students with Sickle Cell Disease

What is Sickle Cell Disease?

Sickle cell disease is a chronic inherited blood disorder. The majority of people affected are African-American or of African decent. It can also affect persons of Hispanic or Indian ethnicity. Sickle sell disease is caused by an abnormality in hemoglobin, which is contained inside red blood cells. Hemoglobin is responsible for carrying oxygen. The abnormality causes the red blood cells to form a sickle shape in low oxygen areas of the body. The sickle cell is easily destroyed and clogs the blood vessels, which leads to: anemia (low blood) pain in the joints and bones, infection, and stroke along with organ and tissue damage. Children with sickle cell may also be smaller than their peers, become jaundice (have yellowish eyes), fatigue easily, and experience priapism (painful, prolonged erection) There are several types of sickle cell disease.

How can Sickle Cell disease affect school performance?

The most common school concerns for students with Sickle Cell are:

- Frequent absences due to hospitalization for treatment or pain crisis
- Motor, sensory, memory and other learning issues due to stroke
- Focus and attention problems
- Visual spatial concerns

How can school assist students with Sickle Cell? Academic

- Start academic interventions right away if necessary under 504 plan
- If academic concerns arise or if patient has had a stroke that adversely affects them academically proceed with the process for special education
- OT assessment for motor concerns
- Consider any outside testing from the neuropsychologist, to help determine how the patient is learning
- Provide before school or after school tutoring for patient to ask questions on any concepts missed if health permits
- For make up assignments, assign a moderate workload that emphasizes quality versus quantity
- Allow extra time for long projects or reports when needed
- Seat student near teacher if focus or attention problems or present



Academic (cont'd)

- Give student a hard copy of notes to prevent multi tasking if patient has memory issues or visual spatial concerns
- If memory problems are present try the following: teach in a variety of modalities (tactile, auditory, visual), use acronyms or acrostics to remember key words, use rhymes and saying to recall useful information, use timelines to recall sequential information and mapping or webbing to recall information from textbooks or novels
- Create an organization system
- Review abstract concepts daily (i.e. math skills)
- For attention problems allow the student opportunity for movement (i.e. sitting on a bean bag chair and then sitting at the table or allowing this student to take the attendance to the office and refocus)
- Allow extra time to respond orally

Social/ Emotional

- Have a staff in-service for anyone involved with the student
- Assess the student to see if he/she is a candidate for counseling if they become withdrawn, or have difficulty with peers or adults.
- Select a support person for the student to discuss any concerns they may have if issues arise at school

Physical

- Allow students to carry a water bottle
- Allow students bathroom breaks as often as they ask (students with Sickle Cell must hydrate and have difficulty concentrating their urine causing them to use the restroom frequently)
- May participate in PE as tolerated
- Are sensitive to extreme temperatures, give them indoor activities if it is too hot or cold
- Can become fatigue, allow short rest period in the nurse's office if needed

Behavior

- Typically no behavior problems
- Untreated academic issues or social issues may cause behavior problems that communicate "I need help" for these students, if problem arise please assess for appropriate intervention

Remember sickle cell disease can affect students in a variety of ways. You may encounter a student that has sickle cell with no complications or one that has been stricken with several complications. With medication, school and family support children with sickle cell disease are expected to function as their same age peers.

