Fact Sheet

Sickle Cell

What Is Sickle Cell?

Sickle cell disease is an inherited blood disorder where a person produces an abnormal form of hemoglobin, which is the protein that carries oxygen in red blood cells. Normal red blood cells are round and flexible and move through blood vessels easily. Sickle cell red blood cells are stiff and shaped like a sickle, allowing them to stick together and block blood vessels. A person with sickle cell anemia produces mostly the abnormal form of hemoglobin. Individuals vary in their clinical severity of illness, but possible complications include significant anemia, painful crises, acute chest syndrome, and strokes. Persons with sickle cell disease are also at increased risk of infection, gallstones, and kidney damage.

How Can Sickle Cell Affect Youth at School?

While anemia is persistent, many of the complications of sickle cell can occur suddenly.

Anemia: A low blood count can cause decreased exercise ability and general fatigue, affecting a youth's ability to concentrate.

Pain: This is the most common complication of sickle cell. Triggers of painful episodes include fever, illness, stress, exposure to extreme temperatures, or physical exhaustion. Pain episodes may last days to weeks. Pain is a distraction to good concentration in school. Painful episodes, hospitalizations, and frequent doctor visits may cause children to miss school more often than their peers.

Chest syndrome: Youth with sickle cell may have a sudden lung problem with fever, cough, significant shortness of breath, and a drop in oxygen level. If a child develops chest pain or difficulty breathing, this requires immediate medical evaluation.

Stroke: Youth with sickle cell may have a blockage in the blood vessels of the brain, causing damage to that part of the brain, called a stroke. Symptoms of

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stroke include sudden or persistent headache; difficulty with speech, memory, or balance; weakness; or changes in vision.

Priapism: A complication in boys with sickle cell is priapism, which is a painful, sustained erection. This occurs due to sickling in the blood vessels of the penis, unrelated to sexual excitement. Priapism may require hospitalization for treatment.

How Do We Work with Youth with Sickle Cell at School?

Youth with sickle cell anemia should have an individualized health plan and an emergency plan. Teachers and nurses should remain in contact with the student's parents about problems and health concerns at school. Accommodations for a student with sickle cell may include the following:

Permission to carry a water bottle during the day and to allow bathroom passes when needed. Dehydration may trigger pain. Youth with sickle cell may have a need for frequent urination due to changes in the kidney.

Access to medications. Within the health plan, medication use should be well-defined for specific symptoms. Questions beyond the usual definitions should lead to use of an emergency plan. Youth with chronic pain may require regular medications.

The student may be excused from long-distance running or other strenuous exercise, but should still participate in fitness programs. Strenuous exercise, overheating, or dehydration may trigger a painful crisis.

Exemptions from outdoor activities when the temperature is >90° or <40°. Extremes of temperatures may trigger a painful crisis.

Individualized plan for completing assignments. Students with sickle cell may miss school often due to pain, hospitalization, or illness. Home-bound instruction may be considered in the case of a prolonged absence.

Identification of a teacher or other adult at school with whom the youth feels comfortable. Treatment for some urgent complications, such as priapism, may be delayed if youth are embarrassed to talk with an adult at school. ♦