

# Sickle Cell Disease

## An overview for school professionals

**Sickle Cell Disease** is a blood disorder that causes red blood cells to assume a sickle shape, leading to blockages in the blood vessels and bones.

### What are some common symptoms of sickle cell disease?

- Fatigue
- Chest pain
- Cold hands or feet
- Dizziness
- Hand-foot syndrome (swelling and pain in the backs of hands and feet, moving into the fingers and toes)
- Headache
- Pale skin
- Shortness of breath
- Sudden pain throughout the body (due to clumps of red blood cells flowing through the body)

### What type of support plan is appropriate for a student with sickle cell disease?

Students with sickle cell should have a 504 or equivalent healthcare plan. The diagnosis of sickle cell gives reasonable cause to bypass the SST process, which will allow you to provide immediate accommodations to the student. All teachers who provide instruction for the student should be made aware of these accommodations. Most children with sickle cell disease have normal learning capabilities; however, the symptoms and side effects of sickle cell disease can profoundly impact a child's educational outcomes. It is also possible that during their school career, a child may experience cognitive changes as a result of their disease. Consequently, it is possible that a student with sickle cell disease may require the support of an IEP.

### What academic accommodations are necessary for a student with sickle cell disease?

**ATTENDANCE:** Students with sickle cell are capable of attending school regularly; however, they may intermittently miss school due to illness and/or hospitalizations.

- intermittent hospital/homebound instruction may be necessary due to frequent medical appointments (i.e. chronic transfusions) or illness
- hospital-homebound attendance requirements for absences due to medical appointments and illness
- suspension of attendance requirements for absences due to medical appointments and illness, including allowances for student to participate in extra-curricular programs and events without penalty due to absences.
- partial-day attendance, as necessary

**ASSIGNMENTS:** It is important for teachers and parents to ensure that students receive assignments in a timely manner so they do not fall further behind.

- a system for providing advance assignments to the parent or student for absences due to planned medical appointments
- a system for providing make-up assignments in a timely manner when patient is unexpectedly absent due to illness or hospitalization

- modified assignments: shorten assignments to emphasize mastery and to limit repetition
- extra time to make up missed assignments
- teacher-provided copies of class notes missed during absences

**TESTING:** Please discuss the expectations for standardized testing with the student and family. Testing accommodations should be considered. Students may need to reschedule test dates or participate in make-up testing if they are admitted to the hospital or ill on the day of testing. In an effort to keep them on track for graduation/grade promotion, please explain to the family the implications of taking or not taking these tests.

**MEDICAL: SEND TO DOCTOR IF FEVER IS PRESENT.** A fever can indicate a life-threatening infection. If the child has a temperature of 101.1°F once, he or she needs prompt medical evaluation with a doctor for blood cultures and intravenous antibiotics. It is important to notify the family if this occurs.

**NUTRITION AND HYDRATION:** Good fluid intake, such as water or sports drinks, is extremely important for children with sickle cell disease to prevent complications.

- Make sure that the child has fluids readily available at *all times in class* (a water bottle at the desk is usually recommended).
- Adequate hydration is especially important during physical education. It's important to avoid dehydration, which can cause a pain crisis.

**RESTROOM:** Children with sickle cell disease may need to go to the bathroom more often because they need high fluid intake and because their kidneys do not work well. Please allow the child to have *free access* to the bathroom during school.

**FATIGUE:** A child with sickle cell disease may fatigue easily, and activities that lead to exhaustion can trigger sickle cell pain crises.

- Please make sure the child paces himself/herself and avoids exhaustion.
- Please allow for brief rest periods or slower activity as needed, since the child may have decreased endurance because of anemia.
- It is helpful to allow the child to have a rolling backpack to prevent the additional fatigue associated with carrying heavy books.
- Allow the child to have a second set of books kept at home. A second set of books provides the additional benefit of access to materials in case of sudden onset illness or hospitalization.
- Additional time to navigate the hall in between classes may be necessary; allow student to leave class early or enter next class late (please provide a pass to show school personnel)
- When possible, considerations should be made to create a daily schedule that decreases the need to walk very far between classes.

**AVOID EXPOSURE TO TEMPERATURE EXTREMES:** Temperature extremes can trigger sickle cell pain crises.

- It is important to avoid staying wet after exposure to water/swimming. The child should be dried promptly and should put on dry clothes.
- In cool or cold weather, the child needs to have dry, warm clothing.
- During outside exercise, the child should avoid becoming cold from sweaty or inappropriate clothing.
- If the outside temperature is cold, make sure the child wears a hat, gloves, and warm base layer.
- In hot weather, the child may need frequent breaks from activity to avoid dehydration.

- In the event of extreme weather conditions, it may be more appropriate for the child to stay inside and participate in an alternate activity.
- Please refrain from seating children with sickle cell near or under an air-conditioning/heating unit in the classroom.
- If the student rides a school bus, they should not be made to wait outside in extreme temperatures, either cold or hot.
- When outside temperatures are extreme, the student should ride a school bus with air conditioning and/or heating.

The list of accommodations above is not meant to be exhaustive; each student's unique needs will dictate the appropriate accommodations to be listed in his/her 504 plan.