

Sickle Cell Disease (SCD) Fact Sheet

Sickle cell disease (SCD) is a genetic condition that causes red blood cells to change shape, harden and not function as well as regular red blood cells. The sickled cells can stick to each other and to blood vessel walls, restricting blood flow. Blood clots can form; these clots can cause pain and tissue damage in the brain, lungs and other body parts.

There is great variation in how this disease manifests itself among persons with SCD. Some may have no obvious health or learning issues at all. Others have severely disabling conditions. Some have more severe problems as preschoolers, with few issues in later life. Others do very well until developing more serious problems as adolescents. Still others never have serious problems while some struggle with serious health and learning problems throughout life. Among children with SCD, those who also have asthma, strokes, spleen or liver disease, lead poisoning or other neurologic or medical conditions, are more likely to have significant school difficulties.

Educational Implications

About one-third of students have small strokes (blocked brain vessels). Silent strokes cause problems with processing speed and tempo, attention and working memory. Overt strokes can cause more severe problems with language, visual processing, attention, memory or processing speed and tempo.

About one half of students have lung issues, including asthma, sleep apnea and lung disease, which further limit oxygen and worsen anemia, pain and stroke risk.

Pain can distract, decrease alertness and concentration and affect memory. Many students need pain medication that can interfere with alertness during the school day.

Anemia can decrease stamina and strength, slow growth and affect executive function and learning.

The sickled cells lower a student's resistance to infectious illnesses. Once sick, it will take longer for your student to recover. Frequent school absences often interfere with academic progress.

For some students, self-esteem, mood or social relationships are affected by frequent pain, illness and hospitalization.

Your student will probably have frequent medical appointments causing absences and missed instruction.

- More frequent use of restroom due to differences in kidney function
- Need high-fluid intake
- Exercise needed – usually no specific restrictions on physical activities
- Prolonged exposure to extreme heat or cold or sudden changes in temperature can trigger severe pain

Instructional Strategies

Presentation

- Use books on tape or recorded books to help focus on text.
- Give short and simple directions with examples.

Response

- Use materials or devices to solve or organize responses.
- Use visual and graphic organizers.
- Highlight key words in directions.
- Have your student repeat and explain directions to check for understanding.
- Use templates for written work.
- Use graph paper to keep numbers in proper columns.

Setting

- Have your student sit in front of room.
- Change your student's location to reduce distractions.
- Allow unrestricted restroom access and private restroom access if needed.
- Provide your student with unrestricted access to water (e.g., water bottle at desk or in class); ensure good hydration prior to recess, sports and PE.

Timing and Scheduling

- Allow for multiple or frequent breaks.
- Cue your student to begin working and stay on task.
- Limit reading periods.

- Schedule activities requiring more seat time in the morning and more hands-on and physical activities in the afternoon.
- Schedule tests and difficult classes at times when your student is most alert and able to focus.
- Divide long-term assignments.

Other Strategies

- Maintain school-to-home communication by email or a communication book that goes home every afternoon and comes back every morning.
- Develop an individual health plan (IHP) that addresses pain, fever and illness prevention.

Resources

[National Dissemination Center for Children with Disabilities](http://nichcy.org/)

<http://nichcy.org/>

[Centers for Disease Control and Prevention](http://www.cdc.gov)

<http://www.cdc.gov>

[National Headquarters, Sickle Cell Disease Association of America, Inc.](http://www.sicklecelldisease.org/)

<http://www.sicklecelldisease.org/>

[Mayo Clinic](http://www.mayoclinic.com/health/sickle-cell-anemia/)

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 The Cognitive and Academic Impact of Sickle Cell Disease
 Day, Sara and Chismark, Elisabeth