

SICKLE CELL DISEASE

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 do not carry oxygen well to the brain, organs and muscles; therefore, students with SCD have chronic anemia (low blood oxygen), causing poor stamina, slowed growth, and (in about 60 percent) problems with attention and learning.

There is very wide individual variation 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; others never have serious problems, and 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.

Sickled cells can stick to each other and to blood vessel walls:

- Restricting blood flow and making clots,
- Causing chronic pain as well as episodes of sudden, severe pain,
- Causing tissue damage in the brain, lungs, spleen, joints or other body parts.

About one-third of students have small strokes (blocked brain vessels) which can affect learning, memory, attention and executive function. About one-half have lung problems, including asthma, further limiting oxygen and affecting growth, stamina, alertness, and learning. Many need pain medication that can interfere with alertness during the school day.

Sickled cells lower a student's resistance to infectious illnesses; they can take longer to recover from illness and so may miss more school days. Frequent school absences may interfere with academic progress.

For some students, self-esteem, mood, or social relationships are affected by frequent pain, illness and hospitalization. The severity of the physical health problems is not closely related to students' social and emotional adjustment.

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What you need to know about your student with SCD

Health Issues	Implications for School	School Strategies and Supports
Anemia	<ul style="list-style-type: none">• Decreased stamina, strength and slowed growth• Problems with executive function and learning	<ul style="list-style-type: none">• Accommodations in physical education and sports• Classroom accommodations to meet attention and learning difficulties

Health Issues	Implications for School	School Strategies and Supports
Infection	<ul style="list-style-type: none"> • Fever can signal a life-threatening blood infection • Illness prevention important; immunizations important • Longer, more frequent absences interfere with academic progress 	<ul style="list-style-type: none"> • Nursing care plan that addresses care for fever • Antiseptics (gel/foam) in classroom; seasonal flu shots encouraged • School-to-home communication about missed work; home-bound or distance learning options

Health Issues	Implications for School	School Strategies and Supports
Stroke	<ul style="list-style-type: none"> • "Silent stroke" causes problems with processing speed and tempo, attention, and working memory • "Overt stroke" causes more severe problems with language, visual processing, attention, memory, or processing speed and tempo 	<ul style="list-style-type: none"> • Modifications and accommodations for individual student • Training for staff about warning signs of overt stroke
Urination	<ul style="list-style-type: none"> • More frequent use of restroom due to differences in kidney function • Special toileting needs (pull-ups in school) or toileting accidents in school 	<ul style="list-style-type: none"> • Unrestricted restroom access, private restroom access if needed • Anti-bullying plan if necessary

Health Issues	Implications for School	School Strategies and Supports
Fluids	<ul style="list-style-type: none"> • Need high fluid intake 	<ul style="list-style-type: none"> • Unrestricted access to water (e.g., water bottle at desk or in class)
Exercise	<ul style="list-style-type: none"> • Needed; usually no specific restrictions on physical activities; stamina and strength limited for some • Fluid intake especially important when active; heat exhaustion can cause serious health problems 	<ul style="list-style-type: none"> • Stop any physical activity if student is short of breath, fatigued, or in pain. Never urge student to “play through the pain” • Good hydration prior to recess, sports, and PE

Health Issues	Implications for School	School Strategies and Supports
Temperature	<ul style="list-style-type: none"> • Prolonged exposure to extreme heat or cold or sudden changes in temperature can trigger severe pain 	<ul style="list-style-type: none"> • Transportation that does not require student to wait outdoors for long periods in extreme cold or hot weather • Clothing appropriate for the weather • Swimming if water is 80 degrees or warmer, and student dries off immediately upon exiting the pool

Health Issues	Implications for School	School Strategies and Supports
Lung Function	<ul style="list-style-type: none"> • Asthma, sleep apnea, and lung disease are common; lung problems worsen anemia, pain, and stroke risk 	<ul style="list-style-type: none"> • Nursing care plan to monitor and manage asthma • Monitor and refer if often drowsy in class

Health Issues	Implications for School	School Strategies and Supports
Pain	<ul style="list-style-type: none"> • Distraction, decreased alertness, poor concentration or memory problems in class • Absences and missed work • Frequent medical appointments, brief hospitalizations and (more rarely) prolonged hospitalizations 	<ul style="list-style-type: none"> • Nursing care plan that addresses pain • Second set of textbooks for home; shortened or waived assignments • School-to-home communication • Home-bound or distance learning options; modified test dates and assignment deadlines • Plan to waive, review, or make up missed work when able

RESOURCES

Jennifer Leigh Hill (1999) *Meeting the Needs of Students with Special Physical and Health Care Needs* ISBN-0-13-262601-2
Teacher reference on health conditions, incidence and prevalence, characteristics, associated problems, diagnosis and treatment, and educational implications and teaching tips.

Platt, Allan F., Eckman, James, & HSU, Lewis. (2010). *Hope and Destiny: The New Hilton Guide to Sickle Cell Disease & Sickle Cell Trait for Patients and Parents*. AL: Hilton Publishing. ISBN-13: 978-0984144709. Describes the different types of sickle cell disease, symptoms, and most current treatments.

Silverstein, A., Silverstein, V, & Silverstein Nunn, L. (2006). *The Sickle Cell Anemia Update*. NJ: Enslow Publishers. ISBN #: 0766024792.

Sickle Cell Disease Association of America: National Organization addressing issues related to sickle cell disease.
Phone: 800-421-8453

<http://www.sicklecelldisease.org>

Sickle Cell Information Center: Sickle cell patient and professional news, information, research updates and worldwide sickle cell resources.

<http://www.Scinfo.org>

Sickle Cell Disease Association of Minnesota: Local resources for family support and advocacy.

<http://www.scdam.org>

Sickle Cell Kids: An Interactive website for children.

<http://www.sicklecellkids.org>

American Sickle Cell Anemia Association: Wide range of services to individuals and families with sickle cell anemia, sickle cell trait, or variants of the disease.

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