

Protecting Patients with Sickle Cell Disease

Ensuring Access and Accommodations in an Educational Setting

Children and youth with Sickle Cell Disease face unique challenges in public and post-secondary school settings.

Educational establishments are often not familiar with Sickle Cell or the educational impact of the disease.

The law requires schools and post-secondary programs to provide accommodations so children and youth have the same opportunities as their non-disabled peers.

Elementary School, Middle School, High School

The Law

The Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act of 1973 require schools to provide educational accommodations. The specific accommodations are based on the particular needs of the child.

Accessing Accommodations

The "504" Meeting: The school is required to identify children with all disabilities, including Sickle Cell Disease.

The best practice is for the parent/guardian to advise the school of the diagnosis. The school should schedule a 504 meeting to develop requisite accommodations.

Meeting participants make up the "504 Team" and should include the parent/guardian, school nursing staff, school "504 Coordinator," school administrators, classroom teacher, etc.

The team reviews medical documentation and requisite accommodations, which are based on the needs of the individual child. The "504 Plan" is the memorialization of these accommodations.

Role of the Medical Provider

School systems have limited experience with Sickle Cell disease and with the educational impact of the diagnosis.

The medical provide plays a key role in

- educating the school about the disease
- providing insight as to how symptoms may impact the child's schooling and school attendance.
- providing the school with medical protocol to understand hospital visits and circumstances when patients cannot attend school

504 vs. Special Education

Children with learning challenges are identified under federal special education law (IDEA – Individuals with Disabilities Education Act).

Necessary services and supports are developed by the child's school by a Planning and Placement Team (PPT) and are listed as "PPT Recommendations." If a child with Sickle Cell disease needs special education services, the "504 Accommodations" are part of those PPT Recommendations.

Sample Accommodations for Students with Sickle Cell Disease

504 Accommodations in elementary school, middle school and high school are based on the individual needs of the child.

Sample accommodations for your patient:

- Unlimited access to school nurse
- Access to extra fluids
- Unlimited access to bathroom
- Extra set of books
- Door to door transportation
- Modified recess
- Emergency Plan for Fire Drill or Other School Emergencies
- Approved absences from school
- Academic support for missed school work
- Accommodations for test taking
- Access to assisted technology
- Modified school day
- Modified physical activity
- Extended year programming

See information about how the law applies to Post-Secondary Schools and Programs on reverse.



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Post-Secondary Schools and Programs

The Law

The Americans with Disabilities Act (ADA) requires that accommodation must be provided to students with Sickle Cell Disease in a post-secondary setting.

Start Planning Process in High School

Discussions regarding necessary accommodations for students entering post-secondary programs should begin in high school.

Accessing Accommodations

In a post-secondary setting, the burden is on the student and his/her family to access accommodations.

Each post-secondary program should have a staff person or department that assists with accommodations. The student and family should schedule a meeting to discuss accommodations before the start of the academic session. The public school "504 Plan" will have useful information for post-secondary accommodations.

Role of the Medical Provider

The post-secondary program will require medical documentation of the diagnosis. Medical information should be submitted before the start of school.

Important to Note:
Post-secondary programs are not required to have special education programs or to modify their academic requirements.

Sample Accommodations for Students with Sickle Cell Disease

Post-secondary programs are required to make accommodations for all aspects of a student's school experience including class attendance, housing, transportation, medical access, etc.

Sample accommodations for post-secondary students with Sickle Cell Disease may include:

Academics

- Recording classes
- Remote attendance (Skype, etc.)
- Assistance with note taking
- Assisted technology
- Tutor
- Extended time for test taking
- Online classes

Housing and Access

- Housing with accommodations (proximity to classroom building, dining hall, etc.)
- Transportation on campus
- Priority parking

Medical

- Emergency Plan
- Access to medical services
- Transportation to physician and hospital

Center for Children's Advocacy
Medical-Legal Partnership Project
cca-ct.org/mlpp

Attorney Bonnie Roswig 860-545-8581
broswig@cca-ct.org

Attorney Jay Sicklick 860-570-5327
jsicklick@cca-ct.org

Attorney Alice Rosenthal 203-688-0113
arosenthal@cca-ct.org

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