

# Psychosocial Impact of Sickle Cell Disease



# Isolation:



Children in particular feel very alone in dealing with this disease. When I ask them “do you know anyone else who has sickle cell?” Nine times out of ten, the answer is “No.”

Do you tell any of your friends you have SCD? Answer: “No.” We attempt to link children and families with support groups:

- MSCDA
- Programs with the Holistic Life Foundation
- Summer Camp

## Dealing with pain and medical complications:



While there are some things we know have the potential to bring on a sickle cell crisis, they are often unforeseen and unpredictable. For some patients (and their families) there is a chronic, underlying feeling of anxiety that they could become sick without warning. Crises can be extremely painful with some children requiring very strong pain medication and/or hospitalization.

We provide support and education for children and families and refer them for individual counseling or chronic pain management through the Kennedy Krieger institute

•<https://www.kennedykrieger.org/patient-care/centers-and-programs/pain-rehabilitation-clinic-outpatient>




For some children, the only option to adequately treat the disease is to have monthly blood transfusions which take several hours to complete, causing disruption to school and work. We often offer to interface with school and parents' employers to help them understand chronic, intermittent absences.

Adult/young adult patients have experienced difficulty keeping jobs as a result of missing work due to sickle cell crises – we work with employers and assist with FMLA paperwork



Offer a full compliment of services to patients and families, assisting them with life issues which effect the quality of their lives:

- Financial help
- Transportation assistance
- School education & coordination
- Employment/career guidance
- Mental health services



# Practical Plans, Real-World Accommodations, and Support That Works

IT'S A TEAM EFFORT!!

# Care-Coordination Checklist (Quick Reference)

- Before school year / at enrollment:
  - Obtain medical summary from family/provider and signed consent to share info
  - Establish IHP and Emergency Action Plan; file in nurse's office
  - Determine need for 504 plan or IEP referral; start paperwork if indicated
- Ongoing communication:
  - Set preferred contact methods for family and providers; schedule regular check-ins
  - Notify teachers of planned absences for treatments; arrange make-up work
  - Log health visits, medications given, and absences in student record
- For scheduled treatments (e.g., monthly transfusions):
  - School/family agree on notification timeline and transportation plan
  - Plan for late arrival/early dismissal and prearranged make-up assignments
- Crisis response:
  - Activate Emergency Action Plan for severe pain/respiratory distress or altered mental status
  - Notify family immediately; document actions and follow-up plan
- Community resources:
  - Maintain list of local clinics, pain management programs, support groups and counselors to refer families

# Practical Academic & Classroom Accommodations

- Attendance & grading
  - Excuse illness-related absences; flexible deadlines and make-up plans
  - Allow remote participation or recorded lessons when feasible
  - Provide catch-up tutoring or modified assignments after prolonged absences
- Testing & classroom time
  - Extended time for tests and assignments
  - Option for breaks during exams; separate quiet testing space if needed
  - Reduce consecutive class periods or allow rest periods during the day
- Physical activity & environment
  - Modify PE participation (alternate activities, avoid extremes of temperature)
  - Permit water bottle and frequent restroom use; allow rest in nurse's office
  - Avoid forced outdoor activities in cold/rain without alternatives
- Cognitive supports
  - Check for attention or processing issues; refer for classroom accommodations or neurocognitive testing if concerned
  - Provide written instructions and visual aids; allow extra processing time
- Social & extracurricular participation
  - Support gradual re-entry to activities after hospitalization; consider buddy system
  - Allow excused absences from extracurriculars for treatment without penalty

# Emotional Support Strategies — School-Based

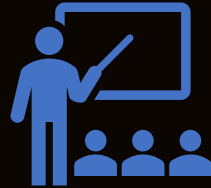


## Proactive supports

Routine check-ins with school counselor or nurse during school year

Classroom education (age-appropriate) about chronic illness to reduce stigma

Link student to peer support groups, mentoring, or camps listed by clinicians



## During/after crisis or hospitalization

Debrief with counselor and teachers on return: academic catch-up, social reintegration

Screen for anxiety/depression and refer for mental-health services if needed



## Ongoing resilience building

Teach coping skills: relaxation, pacing activity, problem-solving

Encourage participation in adapted extracurriculars to maintain social ties

# Roles & Responsibilities — Student, Family, School

## Student

- Know/describe condition (age-appropriate) and report symptoms early
- Follow agreed self-care and medication plan; use accommodations

## Family

- Provide medical documentation, consent to share info, notify school of appointments
- Collaborate on 504/IHP and communicate treatment schedule

## School health staff (nurse)

- Create/maintain IHP & Emergency Action Plan; implement med/pain orders
- Communicate with family, teachers; document visits/absences

## Teachers & Admin

- Implement classroom accommodations, modify PE, excuse absences, support inclusion

# IHP vs. 504 PLAN

**IHP (Individualized Health Plan):** A school nursing/health plan that outlines how the student's **medical needs will be managed during the school day**. It focuses on *health and safety*: baseline information, symptom monitoring, nursing interventions, medication/treatment orders, emergency steps (often paired with an EAP), and **who to notify/when**. It's typically developed/maintained by the **school nurse** with input from the family and medical provider.

**504 Plan (Section 504):** A **civil rights/education plan** that provides **academic and school-access accommodations** so a student with a disability has **equal access** to education. It focuses on *removing barriers to participation and learning*: attendance flexibility, make-up work, testing adjustments, PE modifications, access to water/restroom/rest breaks, and other supports across settings. It's developed by the **school-based 504 team** (often including admin, teachers, nurse, and family).

When in  
Doubt,  
Please Reach  
Out!!!

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