

Sickle Cell Disease (SCD) A Guide for School Nurses/Educators

Date:

Student Name: _____

Student DOB: _____

Dear school nurse/educator,

The student listed above, has sickle cell disease (SCD), a genetic condition that affects the red blood cells. SCD is not contagious. Although the severity of complications due to SCD vary widely from one person to the next, it almost always has direct impact on educational needs. Sickle cell disease can cause health, learning, and developmental complications, thus directly affecting education. We strongly encourage EVERY child to have a 504 Plan and/or IEP, regardless of their current complications.

Sickle Cell Disease affects education in four major ways:

1. Sickle cells don't carry oxygen well to the brain, organs, and muscles. This can cause fatigue, low stamina, slower growth, and for about 50% of students with SCD, problems with attention/learning. Asthma or other lung disease interferes with oxygen, often increasing complications related to his/her SCD.
2. Sickle cells can stick to each other, which blocks the blood circulation. This causes severe pain and can cause damage to the brain, lungs, joints, eyes, or other body parts.
3. Sickle cells lower the student's ability to fight off infections/illnesses. They can become sicker, take longer to heal, and cause more missed days of school, as compared to other children. Frequent school absences, without a good make-up plan, can interfere with academic progress.
4. For some students, self-esteem, mood, or social participation can be affected by difficulties with frequent pain, illness, fatigue, and other related complications of SCD.

- See next page -

Sickle Cell Disease (SCD)

A Guide for Educators/School Nurses

How can kids with sickle cell disease stay safe and healthy in school?

Medication & Information Releases

Student should have a **Medication Administration consent form** on file and completed and signed by his/her Medical Provider. The student also should have a **"Release of Information" consent form** on file so that the school can communicate with the student's medical and psychosocial team (see contact info above).

Pain

When red blood cells "sickle", or change shape, they are no longer soft and flexible and may get trapped in small blood vessels of the body. Student may experience pain at school. If this occurs the school nurse should be seen, a temperature taken and a parent or guardian called. If there is no fever the nurse should administer pain medication immediately. **DO NOT APPLY ICE** as this can constrict blood vessels and cause increased pain. (See below for school pain plan)

Infection

The spleen does not work properly with most types of sickle cell disease (SCD). If student has a fever is over 101 degrees Fahrenheit the family should be contacted and the family should immediately contact the hematology clinic. **DO NOT give acetaminophen or ibuprofen for a fever.** If the family is unreachable, the 24-hour Hematology Clinic number is (612) 813-5940.

- **COVID-19:**

Families are encouraged to follow state and local guidelines to aid their decision regarding in-person versus distance/home learning. If safety measures can't be implemented or enforced, we recommend/request that schools provide equitable access to high quality education through home-based distance learning.

- SCD remains a high risk condition for severe COVID-19 related infection. Acute chest syndrome (infection in the lungs) is one of the main causes of death in patients with SCD. COVID-19 can be complicated by pneumonia, placing those with SCD at a higher risk of complications and/or death, if they were to contract the virus.
- In light of the COVID-19 pandemic, we recommend the student socially distance and follow the most current recommendations from the Minnesota Department of Health and the Center for Disease Control in regards to safety precautions and restrictions.
- Additionally, further guidance through the **Sickle Cell Disease Association of America (SCDAA)** is available at <https://www.sicklecelldisease.org/files/sites/181/2020/07/SCDAA-MARAC-School-Reopening-Recommendations-MARAC-7-24-2020.pdf>.

Stroke -- warning signs

If student ever suddenly cannot see, speak, keep his/her balance, or move his/her arms & legs normally, call 911, then the parent, then the Clinic. This occurs very rarely among children and youth with SCD, but requires a FAST response.

Kidneys

Sickle cells can damage the kidneys. Consequently, students with SCD cannot concentrate their urine and will need to use the restroom more frequently. Please allow student frequent trips to the restroom.

- See next page -

Sickle Cell Disease (SCD)

A Guide for Educators/School Nurses

Fluids

Extra fluids can keep the sickle cells from clogging small vessels. We encourage students with SCD to drink ONE CUP OF LIQUID per 5 POUNDS OF BODY WEIGHT IN A 24 HOUR DAY. Please allow students the use of a water bottle in the classroom to maintain adequate hydration. (We do not encourage hallway drinking fountains because students do NOT want to miss class or be singled out.)

Exercise

We encourage our sickle cell patients to be active and to fully participate in school activities including physical education and recess. However, student should be allowed to rest if requested and should be well hydrated before and during exercise. Never require him/her to continue exercise if s/he complains of pain, fatigue, or shortness of breath. Modify P.E. expectations/grades for his/her stamina, energy, & endurance, as it relates to their SCD. **It is critical to manage asthma & lung problems carefully.**

Weather

During cold, windy or extremely hot or humid weather appropriate clothing including hat, boots and gloves are important. Please allow student to carry a water bottle and ensure adequate hydration, as dehydration can occur in all weather.

Swimming

Student can swim in an indoor pool if the water temperature is 80 degrees Fahrenheit or above. Sudden chills or temperature changes can trigger sickle cell pain. Student should dry off immediately when leaving the pool and wear a dry robe or towel at all times when out of the water. Student should be allowed to stop swimming on request and should be well hydrated before and during swimming.

Absences

Student may have more planned/unplanned health-related absences than most. Making arrangements to proactively communicate with parents/student about missed classes, assignments or tests increases academic success. For a short absence, arrange time for the student to work with teacher or aide to make up missed information without penalty. If student is absent longer (with Doctor's approval), arrange for someone to bring home assignments & work with him/her at home; shorten or waive assignments, when possible. Extend deadlines. Keep an extra set of books to study at home. Many high school students will need additional support for organizational/study skills. **Please inform us if patient misses > 5 days in a marking period.**

Transportation

If a child lives more than 2 blocks from the school we require a bus pick them up and transport them to school.

- See next page -

Sickle Cell Disease (SCD) A Guide for Educators/School Nurses

Pain Management Plan for School

1. If student is having pain, inform teachers, coaches, playground assistants, etc. All school staff should send the student to the school nurse if he/she complains of pain where student can rest in a quiet spot; relax on his/her own; use relaxation strategies.
2. School nurse should check for a fever. If the child has a fever is over 101 degrees Fahrenheit the family should be contacted and the family should immediately contact the hematology clinic. **DO NOT give acetaminophen or ibuprofen for a fever.**
 - Parent should call the Clinic to help decide if unsure about sending the student to school.
 - If the family is unreachable, the **24-hour Hematology Clinic number is (612) 813-5940.**
3. For sickle cell pain, first, drink a lot of water. **If there is no fever**, school nurse should provide acetaminophen or ibuprofen, warmth (heating pad set on low; hot water), massage and rest. Student should return to class ASAP.
4. Distract him/herself if possible (concentrate hard on work, play, prayer, or breathing).
5. If pain is not controlled after 2 hours, despite oral pain medications, call Hematology Clinic. Again, the student may need to come in to the Clinic or the Emergency Department for treatment. Mild pain medications can also help him/her be more alert, and learn better, when it controls distracting pain.
 - **Note:** Some students take **hydroxyurea** (a medicine that reduces the number and severity of sickle pain crises). Hydroxyurea may improve learning due to better blood circulation; this is not a pain medication and does not interfere with learning.
6. Sometimes the student may need to be hospitalized for pain and/or other SCD related complications. The student should return to school as soon as possible and there should be a plan in place for making up any work that is missed, shortening and waiving some work. Pain and medication may make it impossible for the student to complete work during these absences.
7. Treat minor bumps, bruises, etc. with rest, elevation, analgesics. **Do NOT "ice"** as this can cause vasoconstriction and increased pain.

Who do I contact with questions?

Clinic Nurse/Case Managers:

These expert "front line" nurses will answer questions when you call the clinic and help to decide whether or not the student needs to come to the clinic or emergency department (ED).

Cancer and Blood Disorders Clinic
2530 Chicago Avenue South,
Minneapolis, MN, 55404
Clinic: 612-813-5940
Fax: 612-813-6549

- See next page -

Sickle Cell Disease (SCD) A Guide for Educators/School Nurses

Psychosocial Team:

Helps take care of the student's mental, emotional, behavioral, self-advocacy, and learning needs as he/she grows up; at parents' request, this team also serves as a liaison to the school IEP team. These team members include:

Sickle Cell Patient Health Advocate: ***Rae Blaylark, CHW. 612-813-6399 or Rae.Blaylark@ChildrensMN.org***
Contact Rae for needs related to frequent absences, education plans, sickle cell education, and access to resources related to his/her healthcare needs (i.e. school meds, forms, etc).

Social Worker: ***Keeli Wagner, LICSW. 612-813-7411 or Keeli.Wagner@ChildrensMN.org***
Contact Keeli with concerns about focus, cognitive challenges or attention deficit issues. You may also contact Keeli with concerns related to students' coping with his/her chronic health condition(s) or other mental health needs.

Additional Resources:

- Understanding Sickle Cell Disease:
www.partnersprn.org/assets/public/SchoolNurseSCD
- CDC Tips for Supporting Students with sickle cell disease:
www.cdc.gov/ncbddd/sicklecell/documents/tipsheet_supporting_students_with_scd.pdf
- Sickle Cell Disease Association of America:
www.sicklecelldisease.org

If there are further questions or concerns, please contact our clinic or one of the individuals listed above at (612) 813-5940.

Sickle Cell Team

Children's Minnesota
Cancer and Blood Disorders Program
612-813-5940

Cc: Patient medical record