Sickle Cell and School: A Guide to School Policy and Best Practices

A comprehensive guide to complications, special considerations and planning for a student living with sickle cell in the school environment

Created by: The Parent-to-Parent Initiative
powered by
the Sickle Cell Community Consortium

Adapted from the original document by Simon Dyson entitled, “Sickle Cell and Thalassaemia: Education,Health and Care, A Guide to School Policy” 2016.

HOW TO USE THIS DOCUMENT

Invite the family, student, school team and clinic representative to annual meeting to complete these forms.

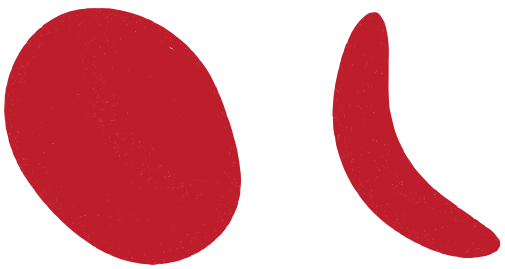
Look to the parent/guardian and student for guidance when confused or unsure about any part of this document. They know a great deal about this since they live with it everyday!

Give a copy of this COMPLETED document to every person in your school that will work with the student. This includes transportation and extracurricluar activies as well!

Review this document every semester or more frequently as needed. If your student is hospitalized, update the health plan based on doctor’s recommendations.

What is Sickle Cell Disease?

Sickle cell disease (SCD) is a collective name for a series of serious inherited chronic conditions that can affect all systems of the body. It is one of the most common genetic conditions in the world, but is considered a rare disease her in the US. Sickle cell disease is associated with episodes of severe pain called sickle cell painful crises. People with sickle cell disease have a type of hemoglobin (called hemoglobin S (HbS) or sickle hemoglobin) which differs from normal adult hemoglobin (hemoglobin A or HbA). This can cause red blood cells to change shape and become blocked in the blood vessels, causing acute pain. Many systems of the body can be affected meaning that different key organs can be damaged and many different symptoms can occur in many different parts of the body. The main types of sickle cell disorder are sickle cell anemia, hemoglobin SC disease and sickle beta- thalassaemia.



Healthy Red Blood Cell

Sickled Red Blood Cell

The Family's Role

The family is the center of all care for the young person living with sickle cell. They are the only people present for every clinic visit, every pain crisis, every hospital admission. Although they will most likely not have a medical degree, they are a wealth of information regarding sickle cell and how it affects their child. It is vitally important to not just include them at the table, but seek them out for information when you are concerned or confused about something related to this illness.

The School's Role

Sickle cell is not a benign illness and requires life long medical care. Students will have complications that will inevitably show up at school or affect their attendance. It is very important that all school staff that interact with the student not only understand the severity of the illness, but feel confident in how to handle possible complications. Although your student has a chronic illness, it is also your role to help them feel safe, normal, and loved. They are more than SCD and want to be treated just like everyone else whnever possible.

The Hospital's Role

The hematology clinic guides all of the care the student receives. They need to be connected and looped in to your meetings that are related to sickle cell and it's effects on the student. Often times clinics have a representative that will provide a training or inservice for staff and students if requested. Ask for a social worker or nurse case manager to see if this education is provided!

SICKLE CELL COMPLICATIONS AT A GLANCE

Hang this page up for quick reference

SWIMMING

Students with SCD need to swim in a heated pool between 88-92 degrees if possible. Be careful with weather shifts when getting out of the pool/ocean/lake. Added warm towels, lotion, and prompt changing can help. Have student take breaks every 30 minutes or so and drink water during breaks.

FEVERS

Fevers of 101 or higher are considered life threatening in a person living with Sickle Cell. Parents/ Guardians should be contacted immeditealy and no fever medication should be administered. Continue through the emergency contact list before calling an ambulance if no person can take student to the ER.

SPLEEN

Any pain on the left side below the rib cage should be taken very seriously in a student with SCD that still has their spleen. Blood can become trapped in the spleen and can become fatal if not checked by a doctor quickly. Call the parent if left side abdomen pain is presented.

BATHROOM BREAKS

Students with SCD require more frequent bathroom breaks because of their kidneys. A student must have unrestricted access to the bathroom at all times. Note this in their 504/IEP as required by law. If the student is able, you may set up a bathroom schedule every 1-2 hours to help them empty their bladder regularly.

PAIN

The pain associated with SCD is caused by blockages in the blood vessels. Pain can be chronic or acute. Over time, damage occurs in bones and organs from repeated blockages. Listen to students when they state they are in pain. Follow the pain management protocol without judgment. Pain higher than a 6 may require hospital intervention.

STROKES

Strokes can be fatal and require immediate 911 attention if suspected. Signs to look for- One side of the /face is drooping, the student has garbled speech, they have weakness on one side of the body. This is a life threatening emergency. Call 911 and the parent/guardian immediately.

FATIGUE

Students with SCD tire quickly due to a constant state of anemia and lower amounts of oxygen in their body. Pay attention for fatigue on the playground, during PE, and at sports practices. Students need frequent breaks, increased water intake, and may have to sit out if they are too tired. Listen to the student, they know their body.

HYDRATION

Students with SCD require more water than the average person. A filled water bottle must be with the student at all times- yes, even during testing and around computers. Take necessary precautions to prevent spills as needed. Students need to be encouraged to drink water constantly as dehydration can cause pain.

WEATHER

Students with SCD do not handle extreme weather (cold or hot) and weather shifts well. Depending on your region, the doctor will have specific weather restictions. Write them Here:

SWIMMING

Children living with sickle cell can enjoy swimming and water fun, but it is important to take precautions.
1) *HYDRATE* It is strongly advised that a student always have bottles of water and drink more during hot sizzling summer months or activities. This is also true during swimming, even if they don't act thirsty.
2) *WATER TEMPERATURE* The temperature of the pool water should be warm. The student should not enter the water if it is cold because the sudden change in body temperature can result to a pain crisis.
3) *SHORTER TIMES* Generally, the best practice to maintain a good water experience is to avoid staying in the water for more than around 30 – 40 minutes, unless warm & active. It may then be extended.
4) *AVOID SHIVERING* As soon as the child gets out of the water he/she needs to get completely dry and dressed as quickly as possible to get warm. If student reports pain, follow pain plan and contact parent.

FEVERS

Children with sickle cell disorder are at increased risk for certain bacterial infections. A fever of 101° Fahrenheit (38° Celsius) or higher, could signal an infection. Parents or the caregiver of the child should be notified of the fever immediately and evaluated by their doctors.

Give no medication to curtail the fever until you speak with the parent or caregiver.

REMEMBER: Fevers of 101 or higher are considered life threatening in a person living with Sickle Cell. Parents/ Guardians should be contacted immeditealy and no fever medication should be administered. Continue through the emergency contact list before calling an ambulance if no person can take student to the ER.

SPLEEN

Young people can suffer from something called a splenic sequestration crisis. The spleen becomes enlarged by trapping the sickle shaped red blood cells. This leads to fewer cells in the general circulation. Early signs include paleness, weakness, an enlarged spleen, and pain in the abdomen. It is important that nursery and pre-school staff are aware of this life-threatening event, as it is more likely in younger children. Older students that have functioning spleens can also have this complication.
REMEMBER: Any pain on the left side below the rib cage should be taken very seriously in a student with SCD that still has their spleen. Blood can become trapped in the spleen and can become fatal if not checked by a doctor quickly. Call the parent if left side abdomen pain is presented.

BATHROOM BREAKS

Sickle Cell affects the kidneys and makes it more difficult for people to concentrate their urine. In addition, students living with SCD require a great deal of fluids to stay hydrated. This combination often leads to a increased need to urinate frequently. It is very important that students have unrestricted access to the bathroom at all times. Younger students may also require prompts every 1-2 hours as needed. Write notes for your student below as discussed by the team:

_____

_____

_____

_____

PAIN

Pain may occur in any part of the body and may be brought on by cold or heat or dehydration. The pain may last a few hours or up to 2 weeks or even longer, and may be so severe that a child needs to be hospitalized. It is important to listen to the young person who will come to know whether the pain is mild or moderate and will pass (where schools can promote school inclusion by permitting rest and re-integration into school later that day) or whether they need to go to hospital.

REMEMBER: he pain associated with SCD is caused by blockages in the blood vessels. Pain can be chronic or acute. Over time, damage occurs in bones and organs from repeated blockages. Listen to students when they state they are in pain. Follow the pain management protocol without judgment. Pain higher than a 5 requires hospital intervention.

STROKES

There are 2 types of strokes to be aware of- minor strokes and major strokes. Minor strokes can often go unnoticed, but do cause cognitive problems that are often the only clue that something is wrong. If you notice a sudden shift in scholastic ability, understanding, cognitive skills, or memory *report this immediately to your team and the parent.* The student's hematologist will recommend different care based on the presence of these types of strokes. Young people living with SCD are at a higher risk of stroke. **Use the FAST acronym for handling a suspected stroke at school-**

FACE is one side drooping? **ARM** Is one arm weaker than the other? **SPEECH** Is their speech garbled? And the most important part of the acronym- **TIME**. If any of these symptoms are present, there is a 72% chance that a stroke is occurring. **Call 911 immediately as they require emergency assistance!**

FATIGUE

The person with SCD may experience severe anemia. The process of hemolysis is a rapid breakdown of red blood cells which depletes the child's energy and ability to physically thrive. Signs would include, yellowing of the whites of eyes, tiredness, lethargy, inability to concentrate, and withdrawal from activites. During this process, This may mean they feel tired, lethargic and unable to concentrate. They may feel tired to the point where they feel they need to of requiring sleep. It is important that teachers do not mistake serious medical symptoms of SCD or laziness or reluctance to participate. Climbing several flights of stairs several times per day to get to and from the classroom is physically demanding for some young people with SCD. Running laps to warm up for physical education would also leaving the young one feeling physically drained. In some cases issuing a personal lift pass may be appropriate.

HYDRATION

Young people with SCD need to be well hydrated to reduce the likelihood of becoming ill. Have a ready supply of fresh drinking water available or allow the student to carry a water bottle with them throughout their school day. Do not restrict drinking water in class. Ensure water fountains are working and kept in the highest state of cleanliness so young people with SCD are not put off using them and risk of infection is kept to a minimum.

REMEMBER: Students with SCD require more water than the average person. A filled water bottle must be with the student at all times- yes, even during testing and around computers. Take necessary precautions to prevent spills as needed. Students need to be encouraged to drink water constantly as dehydration can cause a sickle cell crisis which can lead to future tissue damage.

WEATHER

Young people with SCD may become ill if they are too hot or too cold. Schools should work with the young person to establish agreed warmer clothing for indoor use within school. They should not be made to go outside in cold or rainy or windy weather during breaks. Staff supervising breaks, such as assistants or other teachers, should be instructed not to enforce this. Mobile classrooms can be difficult for students if they are drafty or poorly ventilated. Add additional doctor notes about regional weather restrictions:

_____

_____

_____

_____

SAMPLE INDIVIDUAL HEALTH PLAN TEMPLATE

Full Name:

Date of Birth:

Grade:

Gender:

Condition 1:
Condition 2:
Condition 3:

Date of Plan:
Review Date:

Attach Current Photo

Parent/Guardian Contacts

Contact Name:
Contact Relationship:
Contact Phone Number:

Contact #2 Name:
Contact #2 Relationship:
Contact #2 Phone Number:

Emergency Contacts

Emergency Contact Name:
Contact Phone Number:

On Call Sickle Cell Clinic Contact Name:
Clinic Phone Number:

On Campus Key Person

Name:
Building/Department:
Phone Number:

Primary Care Physician

Contact Name:
Contact Phone Number:

Date of Health and Risk Safety Assessment carried out by school:

Prevention:

Add helpful suggestions and tips below. The following apply to all students with Sickle Cell Disease:

* Student must have unrestricted access to drinking water at all times.
* Student requires unrestricted access to the bathroom, including during class time.
* Student must be kept warm- use of hats, sweater, coat, gloves indoors (if room is cold to them) and outside as needed. (Add regional weather guidelines/restrictions here)
* Student must have the option to sit out during physical or taxing activities and rest if they express fatigue, tiredness, exhaustion or any pain.

AT SCHOOL MEDICATION:

List all medications that may be taken during class time. Include both scheduled and as needed meds. Attach your school required medication forms to this IHP as needed by your district.

PAIN MANAGEMENT

The pain connected to Sickle Cell Disease is actually blocked blood vessels within your body. Pain can vary from mild and annoying to severe and life threatening. It is very important to listen to your student when they report pain. It can be helpful to use the pain scale listed below as a guide. The goal of the school is to find a balance between responding to medical emergencies and not constantly sending the student home for minor pain episodes. Each person living with sickle cell will express their pain in a very personal manner. If your student states that they are in pain, have a plan with administrative and nursing staff (if applicable) for how it will be handled. If you are able to administer pain medication, you can use this scale (or one provided by the SCD clinic to help you gauge the level of pain the student is experiencing.

ALL PAIN CRISES SHOULD BE IMMEDIATELY REPORTED TO THE PARENT/GUARDIAN.

0	2	4	6	8	10
I am not in any pain.	I am in a little pain, but do not need my medication.	I feel if I have my medication, I can be in class.	I feel like I need time out, but may feel better later.	I feel I need to go home.	I feel I need to go to the hospital.

Other student specific issues (include personalized info here- stroke history, priapism for boys, etc.)

Stakeholders in creation of IHP:

Name:	Date:
Parent/Guardian	Date:
School Nurse:	Date:
Sickle Cell Social Worker/Nurse	Date:
Teacher/Administrator:	Date:

Staff that have received a copy of this Individualized Health Plan:

Name & Date:	**Name & Date:**

Extra Space for Notes: