



Believing, Achieving, Serving

SICKLE CELL DISEASE

MANAGEMENT PLAN

ANNUNCIATION OF OUR LORD

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CATHOLIC ELEMENTARY

SCHOOL

September 2015



Believing, Achieving, Serving

SICKLE CELL DISEASE

MANAGEMENT PLAN

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CATHOLIC SECONDARY

SCHOOL

September 2015



## 1. INTRODUCTION

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### 1.1 Definition

Sickle Cell Disease (SCD) is a group of disorders that affect hemoglobin, the molecule in red blood cells that delivers oxygen to cells throughout the body. People with this disorder have atypical hemoglobin molecules called hemoglobin S, which can distort red blood cells into a sickle or crescent shape. SCD is an inherited blood disorder. It is not contagious.<sup>1</sup>

<sup>1</sup> Sickle Cell Disease: A Practical Guide for Teachers. The Hospital for Sick Children, Toronto, 2012.

## 1.2 General Information About Sickle Cell Disease

### 1.2.1 Prevalence

- SCD is one of the most common genetic conditions in the world. The percentage of people who are carriers of the sickle cell gene is as high as 25% in some regions of the world.
- Of all the hemoglobinopathies, SCD affects the largest number of patients approximating 250,000 of the 300,000 to 400,000 children born annually worldwide with various hemoglobinopathies.
- SCD is one of the most common genetic conditions in Canada and affects approximately 5000+ Canadians, 2000 of whom live in Ontario.
- Canadians affected by SCD are both immigrants and Canadian-born with diverse ethnic backgrounds including people from Africa, the Caribbean, the Mediterranean, the Middle East, South America and South Asia.

### 1.2.2 Signs and Symptoms

- Signs and symptoms of SCD usually begin in early childhood. Characteristic features of this disorder include a low number of red blood cells (anemia), repeated infections and periodic episodes of pain. The severity of symptoms varies from person to person. Some people have mild symptoms, while others are frequently hospitalized for more serious complications.
- The signs and symptoms of SCD are caused by the sickling of red blood cells. When red blood cells sickle, they break down prematurely, which can lead to anemia. Anemia can cause shortness of breath, fatigue as well as delayed growth and development in children. The rapid breakdown of red blood cells may also cause yellowing of the eyes and skin, which are signs of jaundice. Painful episodes (vaso-occlusive episodes) can occur when sickled red blood cells, which are stiff and inflexible, get stuck in small blood vessels. These episodes deprive tissues and organs of oxygen - rich blood and can lead to organ damage, especially in the brain, kidneys, lungs and spleen.

- Symptoms of vaso-occlusive episodes depend on where the blood vessels are blocked. If a blood vessel going to the brain is blocked, for example, the child will show symptoms of a stroke, such as weakness on one side of the body. If the blood vessel going to a leg bone is blocked, the child will have pain in the leg.
- The most common symptom of a vaso-occlusive episode is bone pain. Any bone can be affected, including the arms, back, legs and skull. These episodes, commonly called pain crises, are unpredictable. Some children do not feel well prior to the actual onset of pain and can let an adult know. Possible triggers for a pain crisis include:
  - dehydration;
  - exposure to cold or very hot temperatures;
  - infection; and
  - stress/fatigue.

## 2. PROCEDURES

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### 2.1 Role of the Parent/Guardian

- The parent/guardian of the student who has been diagnosed with Sickle Cell Disease is expected to:
  - provide the school Principal/Designate with a letter from the student's physician which outlines the nature of the disease and any interventions and/or accommodations that are required while the student is at school;
  - assist with the development of the Individual Sickle Cell Disease Action Plan (Appendix 2.0);
  - provide up-to-date emergency contact names and telephone numbers;
  - provide an oral thermometer to take student's temperature;
  - provide current photographs of their child;
  - provide a Medic-Alert™ bracelet or equivalent for their child;
  - provide appropriate medication, if student is required to take medication at school.

### 2.2 Role of the School Principal/Designate

#### 2.2.1 Registration

- At the time of the registration of each new student, the school Principal/Designate shall determine if the student has been diagnosed with Sickle Cell Disease and shall record the information in the medical information section on the Personal Screen of the Trillium Student Information Management System.
- At the beginning of every school year, the school Principal/Designate shall update the medical information of each student enrolled in the school to determine if new medical conditions have developed and/or if existing medical conditions have changed.

### 2.2.2 Authorization

- When the school Principal/Designate is informed by the parent/guardian that a student within the school has been diagnosed with Sickle Cell Disease, the School Principal/Designate shall:
  - request the parent/guardian complete a Request and Consent for Sickle Cell Disease Intervention form (Appendix 1.0) and;
  - request the parent/guardian to assist with the development of the Individual Sickle Cell Disease Action Plan.

### 2.2.3 Staff Training

- When the school Principal/Designate is informed by a parent/guardian that a student in the school has been diagnosed with Sickle Cell Disease and the parent/guardian has completed the Request and Consent for Sickle Cell Disease Intervention form, the school Principal/Designate shall:
  - identify the student to all staff members of the school who interact with the student on a regular basis as a student with Sickle Cell Disease;
  - arrange for an education session for staff members on Sickle Cell Disease through the Sickle Cell Disease Clinic at McMaster Children's Hospital;
  - utilize on-line videos about Sickle Cell Disease including –
    - <http://sicklecellanemia.ca/education/video/>
    - <https://www.youtube.com/watch?v=GDOs8fppF-s>
    - <https://www.youtube.com/watch?v=ZI3KJg3jvLc>

#### 2.2.4 Individual Sickle Cell Disease Action Plan

- Upon completion of the staff training the school Principal/Designate shall develop an Individual Sickle Cell Disease Action Plan in consultation with the parent/guardian. This plan will be reviewed on an annual basis.
- The Individual Sickle Cell Disease Action Plan shall contain the following information:
  - student's name and birthdate;
  - a description of the student's medical condition;
  - a current photograph (not a photocopied image) of the student;
  - emergency contact information;
  - emergency procedures;
  - accommodations required to prevent occurrence of emergencies.
- The Individual Sickle Cell Disease Action Plan shall be posted in key locations around the school including the Main Office, the Staff Room and the Resource Room.

### 2.3 **Role of the School Staff**

- All school personnel (i.e. Principal, Vice-Principal(s), Principal Assistant, Principal Intern, Department Heads, Teachers, Educational Assistants, school Secretaries, Lunchroom Supervisors, Occasional Teachers and Occasional Educational Assistants) who are in direct contact with the student diagnosed with Sickle Cell Disease have the responsibility to attend the Sickle Cell Disease Information Session convened by the school Principal/Designate.
- All school personnel shall be able to identify students with Sickle Cell Disease – to be familiar with names and faces.
- All school personnel shall be familiar with the Individual Sickle Cell Disease Action Plan.

## **2.4 Role of the Classroom/Subject Teacher**

- In addition to the duties described in subsection 2.3, Classroom/Subject Teachers are also expected to:
  - meet with the parent/guardian and the school Principal/Designate when the child is first diagnosed to determine the learning accommodations that will be required in the school setting;
  - assist in the development of the Individual Sickle Cell Disease Action Plan;
  - know their role when responding to the occurrence of a seizure ;
  - identify the student with Sickle Cell Disease to Occasional Teachers and Occasional Educational Assistants;
  - inform the parents/guardians in writing (Appendix 8.0) of the students who are to receive an educational session on Sickle Cell Disease prior to the presentation;
  - assist the Sickle Cell Disease Clinic Nurse in the discussion of Sickle Cell Disease with the students;

## **2.5 Role of the School Secretary**

- In addition to the duties described in subsection 2.3, the school Secretary is expected to follow the Emergency 911 Protocol (Appendix 9.0) at the time of an emergency.

## 2.6 Role of Student Services Liaison Staff

- The general role of the Student Services Liaison Staff is to facilitate the provision of appropriate programs and services for students who have been diagnosed with Sickle Cell Disease. The specific aspects of this role include:
  - acting as the single point of contact for the Sickle Cell Disease Clinic at McMaster Children's Hospital when a student attending one of the Board's schools is diagnosed with Sickle Cell Disease;
  - scheduling and assisting in the provision of training about Sickle Cell Disease for staff and students of the school which the diagnosed student attends;
  - assisting the school personnel with the development of the Individual Sickle Cell Disease Action Plan;
  - consulting with school personnel concerning appropriate learning accommodations for students diagnosed with Sickle Cell Disease.

### **3. REVIEW OF SICKLE CELL DISEASE MANAGEMENT PLAN**

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- The Sickle Cell Disease Management Plan will be reviewed in 2018.



## **4. APPENDIX**

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- 1.0 Request and Consent for Sickle Cell Disease Intervention
- 2.0 Individual Sickle Cell Disease Action Plan.
- 3.0 Accommodations for Managing the Effects of Sickle Cell Disease at School.
- 4.0 What to do if a student with Sickle Cell Disease is unwell at school.
- 5.0 Pain Management for Student with Sickle Cell Disease.
- 6.0 Request for Administration of Medication Form.
- 7.0 Individual Student Log of Administered Medication.
- 8.0 Letter Informing Parents/Guardians of Education Session for Students on Sickle Cell Disease
- 9.0 Emergency 9-1-1 Protocol



REQUEST AND CONSENT  
FOR  
SICKLE CELL DISEASE INTERVENTIONS

STUDENT: \_\_\_\_\_ SCHOOL: \_\_\_\_\_

GRADE: \_\_\_\_\_ DATE OF REQUEST: \_\_\_\_/\_\_\_\_/\_\_\_\_  
M D Y

I/We \_\_\_\_\_ / \_\_\_\_\_

the parents/guardians of \_\_\_\_\_  
(Name of Student)

understand that:

- the Principal, Teacher and other school staff are not health professionals and have no more information about the medical condition of my/our child than that which has been provided to them in writing by myself/ourselves or by my/our child's physician. They are not experts in recognizing the symptoms of my/our child's medical condition or in treating it;
- to the extent possible, my/our child has been trained by me/us and by health professionals to recognize her/his need for intervention /medication and to respond to the need by requesting intervention;
- I/We are responsible for ensuring that –
  - all medical updates/changes or emergency information will be provided for the school staff immediately;
  - the teacher will be instructed concerning the incidents related to Sickle Cell Disease about which I/We wish to be informed;
  - an oral thermometer to take my child's temperature will be provided for the school;
  - pain medication prescribed for my/our child by the physician will be provided for the school.

- The specific incidents related to Sickle Cell Disease about which I/We would like to be informed are:

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

In the event of an emergency, I/We authorize the school staff to obtain emergency services and to authorize such emergency treatments as are necessary. I/We agree to assume responsibility for all costs associated with the medical intervention.

I/We give permission to the school staff to post the Individual Sickle Cell Disease Action Plan, with a picture of my/our child, in appropriate locations within the school.

I/We have reviewed and agree to the Sickle Cell Disease Management Plan for my/our child.

Father's Signature: \_\_\_\_\_

Mothers Signature: \_\_\_\_\_

Guardians Signature: \_\_\_\_\_

Date: \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
Month Day Year



INDIVIDUAL SICKLE CELL DISEASE ACTION PLAN

STUDENT: \_\_\_\_\_

TEACHER(S): \_\_\_\_\_

GRADE: \_\_\_\_\_ ROOM: \_\_\_\_\_

PAIN MEDICATION PRESCRIBED: \_\_\_\_\_

STUDENT  
PICTURE 2" x 3"  
PHOTO HEAD  
AND  
SHOULDERS

NAMES OF STAFF WITH FIRST AID TRAINING: \_\_\_\_\_

MEDIC ALERT #: \_\_\_\_\_

PARENT/GUARDIAN TELEPHONE #: \_\_\_\_\_

ALTERNATIVE TELEPHONE #: \_\_\_\_\_

2<sup>ND</sup> ALTERNATIVE TELEPHONE #: \_\_\_\_\_

**EMERGENCY ACTION STEPS**

1. If student not well, take temperature.
2. If temperature in mouth is 37.5° C or below, do pain assessment.
3. If pain assessment is less than 7 out of 10, give prescribed medication.
4. If pain is above 7 out of 10, contact parent/guardian immediately to pick up student.
5. If temperature is 38.0 ° C contact parent/guardian immediately to take student to hospital emergency department.
6. If any of the following occurs, call 9-1-1 immediately:
  - difficulty breathing;
  - difficulty speaking or slurring of speech;
  - fever greater than 39.0 ° C;
  - loss of consciousness;
  - severe headache;
  - unexplained lethargy /sleepiness;
  - vomiting;
  - weakness of limbs.

HEALTHCARE TEAM

• Primary Physician: \_\_\_\_\_ Telephone #: \_\_\_\_\_

• Primary Nurse: \_\_\_\_\_ Telephone #: \_\_\_\_\_

Parent/Guardian Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Principal Signature: \_\_\_\_\_

Date: \_\_\_\_\_



ACCOMMODATIONS FOR MANAGING THE EFFECTS  
OF SICKLE CELL DISEASE

1. Bathroom Privileges

- Children with SCD excrete higher volumes of urine compared with their peers because their kidneys cannot concentrate urine. Bathroom privileges are a must whenever the student needs them.

2. Fluid Requirements

- When a child produces more urine than usual, they must also increase their fluid intake. This is particularly important in SCD, or dehydration can trigger pain crisis.
- Students with SCD should be allowed to have water bottles at their desks so that they will have easy access to water.

3. Missed School Days

- Students with SCD may miss school because of:
  - important hospitalization to treat the severe bone pain associated with SCD;
  - less severe painful bone crises being treated at home; and/or scheduled clinic visits.
- This will result in less instructional time and it has been demonstrated that school attendance is directly related to academic performance.
- A “Buddy System” could be established such that another student in the class would collect handouts and notify the student with SCD of important future deadlines.
- The teacher could post homework assignments and future dates for assignments and tests on the school website.
- When the student is absent for a prolonged period of time, the Principal/Designate should arrange for Home Instruction through the Superintendent or Assistant Superintendent – Special Education Programs and Services.

4. Neurological Problems

- Approximately 1 in 5 children with SCD has so-called “Silent Strokes”. These are small strokes in the frontal area of the brain which usually go undetected unless an MRI is performed. The frontal area of the brain is responsible for executive functioning and this affects a student’s ability to focus, memorize, organize and plan.
- The classroom teacher should consult with the school’s Special Education Resource Teacher about learning accommodations for executive function problems.

5. Special Precautions for Hot Weather

- When exposed to very hot temperatures, such as at a sporting event in the spring, summer or autumn, students with SCD may participate but with frequent rest periods and increased hydration.

6. Special Precautions for Swimming

- Students with SCD may participate in swimming classes. They should, however, limit their time in the pool to 30 minutes. After getting out of the water, the student must dry off and change into dry clothing right away. They should not run around in wet swimsuits as their body temperature will fall, potentially resulting in bone pain.

7. Special Precautions for Winter Activities

- Students with SCD should be allowed to participate in winter activities, but they should be dressed in layers appropriate to the temperature of the day. Areas of increased loss of body heat, such as ears, fingers, head and toes should all be well covered. At temperatures less than -5°C, students with SCD should be excused from participating.



## HAMILTON-WENTWORTH CATHOLIC DISTRICT SCHOOL BOARD

### WHAT TO DO IF A STUDENT WITH SICKLE CELL DISEASE IS UNWELL AT SCHOOL

#### STEP 1 – TEMPERATURE ASSESSMENT

- Have the student sit or lie down in a quiet place.
- Take the student's temperature.
- If the temperature is higher than 38°C in the mouth, telephone parents immediately to take the student to the closest hospital emergency department.
- If the temperature is less than 37.5°C do a pain assessment.

#### STEP 2 – PAIN ASSESSMENT

- Ask the student what level her/his pain is on a scale from 0 to 10, with 0 being no pain and 10 being “the worst pain ever”.
- Ask where the pain is located.
- If the pain is less than 7 out of 10 and the parent/guardian has given the school a supply of pain medication, the student may have a dose given as prescribed.
- If no medication is at school to treat pain or if the pain is greater than 7 out of 10, telephone parent/guardian to pick up the student.
- If the pain is localized to 1 or 2 areas, a warm pack can be applied to the site of pain until the student is picked up by the parent.

**ICE PACKS SHOULD BE AVOIDED**



PAIN MANAGEMENT  
FOR  
STUDENTS WITH SICKLE CELL DISEASE

1. Medications

- Morphine \_\_\_\_\_ mg. Repeat dose every 4 hours
- Acetaminophen \_\_\_\_\_ mg. Repeat dose every 4 hours.
- Ibuprofen \_\_\_\_\_ mg. Repeat dose every 6 hours.
- Docusate \_\_\_\_\_ mL x one dose

2. Physical

- Give student plenty of fluids. NOT COLD.
- Gently massage the area.
- Apply heat to the area.
  - Tips for Using Heat
    - Use disposable instant heat packs. Be sure to follow the instructions on the package.
    - Apply heat in 20 minute intervals.
    - If the area becomes painful, uncomfortable or a local skin reaction develops, remove heat immediately.

3. Psychological / Behavioural

- Deep Breathing.
- Distractions (movies or music).
- Imagery.
- Relaxation Exercises.



HAMILTON-WENTWORTH CATHOLIC DISTRICT SCHOOL BOARD

**AUTHORIZATION FOR ADMINISTRATION OF MEDICATION**

**PART II -To be completed by Parent/Guardian**

(Please type or print)

This is to authorize the administration of the medication(s) prescribed by the attending physician from \_\_\_\_\_ to \_\_\_\_\_ for:  
date date

Student's Name: \_\_\_\_\_

Birthdate: \_\_\_\_\_  
Year Month Day

School: \_\_\_\_\_

I give permission for my child to self-administer the medication prescribed by the attending physician.

Yes \_\_\_ No \_\_\_ Signature of Parent/Guardian: \_\_\_\_\_

I release and agree to indemnify the Hamilton-Wentworth Catholic District School Board and its staff from any liability or damages incurred by any party as a consequence of the administration or lack of administration of medication to my child.

Signature of Parent/Guardian: \_\_\_\_\_

Date: \_\_\_\_\_  
(Year, Month, Day)

**NOTE:**

Parents are requested to PLACE MEDICATION IN INDIVIDUAL CONTAINERS, preferably those in which the medication was supplied from the pharmacist/physician.

The containers should be PROPERLY LABELLED indicating the STUDENT'S NAME AND ADMINISTRATION DIRECTIONS.

The medication will be delivered by parent/guardian, according to an agreed schedule, to the Principal or designated person for safe keeping, unless otherwise determined.

In case of **EMERGENCY**, the contact persons are:

Name \_\_\_\_\_ Telephone \_\_\_\_\_ Relationship \_\_\_\_\_

Name \_\_\_\_\_ Telephone \_\_\_\_\_ Relationship \_\_\_\_\_

**Under The Municipal Freedom of Information and Protection of Privacy Act, 1989, information in forms and documents pertaining to a student registered/enrolled within The Hamilton-Wentworth Catholic District School Board is collected under the legal authority of The Education Act, and its Regulations, and the Ontario Student Record (O.S.R.) Guideline, 2000. This information is being collected to ensure that the educational program which is provided meets your child's needs.**





SCHOOL LETTERHEAD

\_\_\_\_\_, 20\_\_\_\_\_

Dear Parents/Guardians:

This letter is to inform you that one of your child's classmates was recently diagnosed with Sickle Cell Disease, which is a non-contagious disease.

A nurse from McMaster Children's Hospital and the Board's Liasion Staff will be coming to speak with your child's class about Sickle Cell Disease and how it is affecting their classmate. The presentation may include a short video and will provide students with an opportunity to ask questions.

If you have any questions, concerns or comments, please contact your child's teacher.

Sincerely,

\_\_\_\_\_  
Principal

HAMILTON-WENTWORTH CATHOLIC DISTRICT SCHOOL BOARD

**TO BE POSTED BY TELEPHONE**

9-1-1- Protocol Sickle Cell Disease

1. This is \_\_\_\_\_ School.
  
2. We are located at:  
Address: \_\_\_\_\_  
Nearest Major Intersection: \_\_\_\_\_  
Telephone Number: \_\_\_\_\_
  
3. We have a student who is having a Sickle Cell Disease emergency.  
This student:  

<input type="checkbox"/> is having difficulty breathing;	<input type="checkbox"/> has a severe headache;
<input type="checkbox"/> is having difficulty speaking;	<input type="checkbox"/> has unexplained lethargy /sleepiness;
<input type="checkbox"/> is slurring her/his speech;	<input type="checkbox"/> is vomiting;
<input type="checkbox"/> has a fever greater than 39°C;	<input type="checkbox"/> has weakness of limbs.
<input type="checkbox"/> has lost consciousness;	
  
4. The closest entrance for the ambulance is on: \_\_\_\_\_  
Ave./Road/Street
  
5. A staff member will be outside of the school entrance to provide more information.
  
6. Do you need any more information?
  
7. How long will it take you to get here?
  
8. Call parent/guardian/emergency contact.