A community of patients, carers and healthcare professionals advocating for the rights of people living with Sickle Cell Disease within Australia

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All brochures created by ASCA are reviewed by adult and paediatric haematologist.

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Australian Sickle Cell Advocacy

Parent's and Caregiver's Guide To Sickle Cell Disease

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WHAT IS SICKLE CELL DISEASE?

- Group of inherited red blood cell (RBC) disorders resulting in structurally abnormal haemoglobin (Hb S).
- Arise when two abnormal haemoglobin genes are inherited from each parents, one of them is a sickle cell gene.
- Signs and symptoms of SCD are mainly caused by the sickling of the RBC's, resulting in abnormally inflexible, adhesive and shortly lived sickle-shaped blood cells.
- Also caused by the activation of white blood cells (WBC) and platelets that eventually leads to complications related to progressive organs damage.
- People with SCD may experience complications including acute pain crisis (vaso-occlusive crisis)

SIGNS AND SYMPTOMS THAT REQUIRE MEDICAL ATTENTION:

- Be alert for signs of fever - students should seek medical attention to evaluate the risk of pneumonia or other bacterial infections as Sickle Cell Disease puts these students at a higher risk.
- Pain episodes - common among children with Sickle Cell disease. They can occur anywhere in the body and severity can vary. Teachers should be responsive to complaints of pain. If pain is light or moderate, schools can allow the student to rest before returning to class. If pain is severe, parents should be contacted and/or student should be taken to the hospital.
- Strokes - Sickle Cell Disease is one of the most common causes of strokes among children. Teachers should look out for signs linked to strokes which include: severe headaches, dizziness, visual changes, sudden onset of weakness in one limb or side of the face, numbness, sudden inability to produce speech and seizures.

TIPS FOR YOU AS PARENTS/CAREGIVERS

- Develop an individualized care plan.
- Set up a meeting to discuss SCD with your child's teacher.
- Inform teachers about a 504 plan or Individualized Education Plan (IEP).
- Maintain open communication with teachers.
- Inform teachers about changes in your child's health.

For more information
https://www.cdc.gov/ncbddd/sicklecell/documents/tipsheet_supporting_students_with_scd.pdf
https://www.cdc.gov/ncbddd/sicklecell/index.html

COMMON QUESTIONS YOU MIGHT BE ASKED BY TEACHERS

Is sickle cell disease contagious?

- No, you cannot catch sickle cell disease like a cold. Sickle cell disease an inherited disorder passed down from a person's parents.

Why is your child out of school so often?

- A person with sickle cell disease needs to be seen by a doctor more frequently than other students, so they may be at a doctor's appointment.

Why do people with sickle cell disease have yellow eyes?

- Sickle cell causes a patient's red blood cells to die more quickly compared to a person who does not have sickle cell disease. Their eyes may become yellow due to a substance that is released when the red blood cells break down.

Why should a student with sickle cell disease be able to keep a water bottle at his or her desk or leave class more frequently for water fountain and restroom breaks?

- Water helps to increase vein size and therefore allows sickle-shaped cells to flow through blood vessels more easily.

Why are children with sickle cell disease smaller or less physically developed than other children?

- In order for any child's body to grow and develop, enough oxygen is required throughout the body. The shape and reduced number of the RBCs of a child with SCD may result in inadequate oxygen supply to all parts of the body, thus limiting their growth.