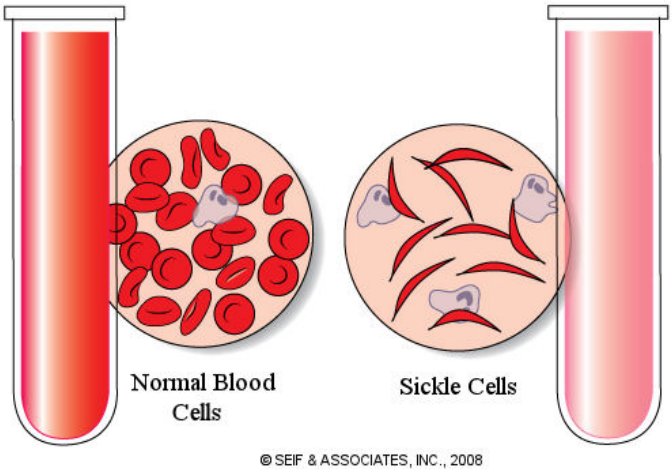
Sickle Cell Anemia

Sickle cell anemia needs regular medical care by your caregiver and awareness by you when to seek medical care. Pain is a common problem in children with sickle cell disease. This usually starts at less than 1 year of age. Pain can occur nearly anywhere in the body, but most commonly happens in the extremities, back, chest, or belly (*abdomen*). Pain episodes can start suddenly or may follow an illness. These attacks can appear as decreased activity, loss of appetite, change in behavior, or simply complaints of pain.



DIAGNOSIS

- Specialized blood and gene testing can help make this diagnosis early in the disease. Blood tests may then be done to watch blood levels.
- Specialized brain scans are done when there are problems in the brain during a crisis.
- Lung testing may be done later in the disease.

HOME CARE INSTRUCTIONS

- **Maintain good hydration.** Increase your child's fluid intake in hot weather and during exercise.
- **Avoid smoking around your child.** Smoking lowers the oxygen in the blood and can cause sickling.
- **Control pain.** Only give your child over-the-counter or prescription medicines for pain, discomfort, or fever as directed by their caregiver. **Do not give aspirin to children because of the association with Reye's syndrome.**
- **Keep regular health care checks** to keep a proper red blood cell (*hemoglobin*) level. A moderate anemia level protects against sickling crises.
- Your child should receive all the same immunizations and care as the people around them.
- **Moms should breastfeed** their babies if possible. Use formulas with iron added if breastfeeding is not possible. Additional iron should not be given unless there is a lack of it. People with SCD build up iron faster than normal. Give folic acid and additional vitamins as directed.
- If your child has been prescribed antibiotics or other medications to prevent problems, give them as directed.
- **Summer camps** are available for children with SCD. They may help young people deal with their disease. The camps introduce them to other children with the same problem.
- Young people with SCD may become frustrated or angry at their disease. This can cause rebellion and refusal to follow medical care. Help groups or counseling may help with these problems.
- **Make sure your child wears a medical alert bracelet**. When traveling, keep your medical information, caregiver's names, and the medications your child takes with you at all times.

SEEK IMMEDIATE MEDICAL CARE IF:

- Your child feels dizzy or faint.
- Your child develops a new onset of abdominal pain, especially on the left side near the stomach area.
- Your child develops a persistent, often uncomfortable and painful penile erection. This is called priapism. Always check young boys for this. It is often embarrassing for them and they may not bring it to your attention. **This is a medical emergency** and needs immediate treatment. If this is not treated it will lead to impotence.
- Your child develops numbness in or has a hard time moving their arms and legs.
- Your child has a hard time with speech.
- Your child develops an oral temperature above 101° F (38.3° C) or has other signs of infection (chills, lethargy, irritability, poor eating, vomiting). The younger the child, the more you should be concerned.

- With fevers, do not give medications to lower the fever right away. This could cover up a problem which is developing. Notify your caregiver.
- Your child develops pain which is not helped with medicine.
- Your child develops shortness of breath, or is coughing up pus-like or bloody sputum.
- Your child develops any problems that are new and are causing you to worry.

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