



NATIONWIDE CHILDREN'S
When your child needs a hospital, everything matters.

Helping Hand™

Health Education for Patients and Families

Sickle Cell Disease and Pain

Pain is a common problem for children with sickle cell disease (SCD). Sickled cells have a hard time moving through small blood vessels. They can pile up and clog the vessels, keeping oxygen from getting to certain parts of the body (Picture 1). This causes pain.

Signs and Symptoms

Sickle cell pain and symptoms are different for each child. Your child may be able to recognize their own sickle cell pain. This may be different than other types of pain your child may have. Possible symptoms of a sickle cell disease pain episode are:

- Something hurts
- Behavior changes
- Appetite changes
- Does not use leg, arm, or body part that hurts
- Fussy and hard to comfort
- Swollen, painful area(s) on the body
- Less active than usual, doesn't want to play

What to Do at Home

Most pain can be managed at home by following the directions on the yellow section of the Sickle Cell Action Plan. **Never use ice to treat pain. This will make the pain worse.** You can help ease your child's pain by:

- Applying a warm, moist towel or a heating pad on the area in pain.
- Having them drink fluids like water and juice. Amount is in your Sickle Cell Action Plan.
- Massaging the painful area.
- Getting extra rest by going to bed early or taking a nap.

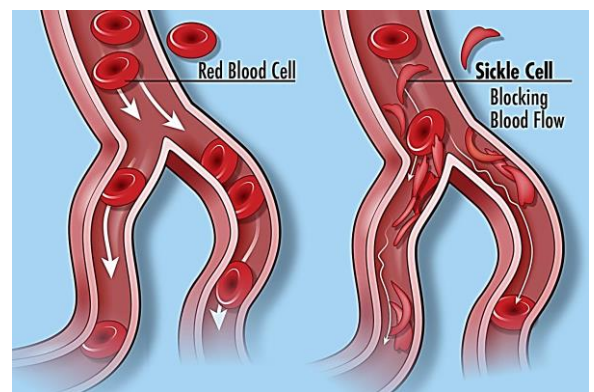


Image source: National Human Genome Research Institute

Picture 1 The shape of sickled cells blocks blood flow.

- Focusing on things other than the pain, such as video games, music, or a television show. You can also do deep breathing with your child to help them relax.
- Giving pain medicines as directed by their doctor or health care provider. Take your child's temperature before giving pain medications to make sure they do not have a fever.

Any time your child stays home from school because of pain, please call the sickle cell nurses. They will note this in your child's chart. If your child needs to miss school or you need to miss work, the nurses can give you a school or work excuse.

How to Prevent Pain

There are daily habits and medicines that can help prevent or reduce sickle cell pain.

- Getting enough sleep
- Eating a healthy diet
- Drinking enough water
- Following the green section of your Sickle Cell Action Plan
- Daily physical activity
- Psychosocial support
- Taking the prescribed medicines. These may include hydroxyurea, Endari[®], voxelotor (Oxybryta[®]), or crizanlizumab (Adakveo[®])

Some SCD patients may benefit from other treatments like blood transfusions or pain clinic.

When to Call the Doctor

Call the sickle cell team if you know your child needs to be seen. This prepares doctors and health care providers so they can better care for your child. Call the doctor or health care provider if your child has any of the following:

- Pain that is too intense to manage at home
- Stiff neck, severe headache, or dizziness
- Refuses to eat, drink, or take medicine
- Pain that has not gone away after 2 days of treatment at home
- Chest or back pain with a constant cough or trouble breathing
- Severe stomach pain or swelling with pale skin or being more sleepy than usual

If your child gets sick, call the sickle cell nurses at (614) 722-8914 Monday through Friday from 8 a.m. to 4:30 p.m. If they are not available, call the Sickle Cell Clinic at (614) 722-3250. For evenings, weekends, and holidays, call (614) 722-2000. Ask for the hematologist on call.

When to Call 911

Call 911 for emergency help if your child:

- Is breathing slowly or stops breathing
- Cannot wake after a nap.
- Is unresponsive and cannot talk to you.
- Has sudden weakness, loss of feeling, or cannot move a body part.