

PATIENT INFORMATION: Pain in Sickle Cell Disease

Pain episodes are a very common complication of sickle cell disease that can often occur during childhood. The Sickle Cell Team at University Hospitals Rainbow Babies & Children's Hospital believes that children have a right to the best level of pain relief that can be safely provided. We take a team approach to pain and anxiety management using both medicine and nonmedicine therapies. We want to work closely with the child and his or her family in order to evaluate pain and treat it effectively.

What causes pain?

Sickled red blood cells stick together and become trapped inside a blood vessel and block blood flow. When blood does not flow to an area, that body part does not receive oxygen and that can cause pain.

Some things that can trigger a pain episode:

- Recent illness or fever
- Extreme temperatures (hot or cold)
- Dehydration
- Stress or fatigue

Sometimes swelling is seen in the area where the child is having pain. In infants, swelling often occurs in the hands and/or feet. This is called "dactylitis." Older children often have pain in the arms, legs, back or stomach, but can have pain anywhere in the body.

How can I care for my child when he or she has pain?

If your child is having pain, you should have him or her drink as much as possible. It is helpful to drink about double the amount of fluid as normal (fluid without caffeine). Examples are water, juice, ice chips, broth, Gatorade, Jell-O® or popsicles.

While your child has pain, you will give pain medicines as instructed by the Sickle Cell Team:

- You will start by giving ibuprofen every six to eight hours or naprosyn every 12 hours while your child is in pain. You will give the dose prescribed by your doctor or nurse practitioner.
- If the pain has not improved after 30 minutes, you can give oxycodone every four to six hours if this has been prescribed for your child.

Other things you can do for pain include giving warm baths, using a warm moist towel or heating pad, rubbing or massaging the area that hurts, help your child to relax by distracting them with quiet games, stories or music.

When should I call the sickle cell clinic?

You should always call the clinic if you have any questions or concerns regarding the care of your child.

Be sure to call if:

- Your child is having vomiting, unable to keep medicines or fluids down
- Your child is having consistent diarrhea (watery stool every one to two hours)
- Your child is experiencing constipation (no stool in two days or abnormal stool for your child)
- Your child's pain continues to increase despite medications

Your child needs to be seen right away by the doctor if:

- He or she has a fever greater than 100.4°F if less than one year old, or greater than 101°F if one year or older
- He or she is experiencing severe headache or dizziness
- He or she is experiencing breathing problems or chest pain
- He or she is experiencing swelling in the abdomen
- He has a painful erection of the penis (called priapism)
- He or she has any seizure or weakness
- He or she is pale, weak or very tired

Key Points

1. Increase fluids to prevent dehydration
2. Use heating pads, massage, relaxation and warm baths tolerated
3. Rest as much as possible
4. Take the following medication:

If pain has not improved or worsened in 30 to 60 minutes, take: _____

If pain is uncontrolled despite pain medications, call the sickle cell team.

Rainbow Sickle Cell Anemia Center

If your child has signs or symptoms of illness, please call 216-844-3345 and follow the prompts.

Angie Fowler Adolescent & Young Adult Cancer Institute at University Hospitals

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