

Not all pain is a sickle cell pain episode.

What is a Sickle Cell Pain Episode?

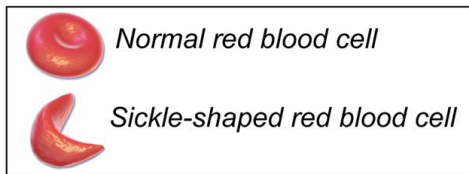
This is bone pain that you feel

You may feel the bone pain in your arms, legs, joints, back, or chest.

- This pain can come on suddenly.
- It can be mild or severe.
- It can last for hours or days.

Shape of Sickle Cells

Sickle cell disease changes the shape of the red blood cells.



Normal red blood cells: Disc shaped and *flexible*.

Sickle red blood cells: Curved and *rigid*.

Sickle cells look similar to an old farming tool called a "sickle" which is how the disease got its name.

What Causes a Pain Episode?

Sickled cells can clump together in a blood vessel. This blockage will decrease the blood flow and oxygen delivery to a particular area of tissues in the body's organs and bones.

- Cells in this area *immediately* begin to react to the decrease in oxygen.
- Nerve cells cannot tolerate even the slightest decrease of oxygen.



Nerve cells immediately send signals to the brain.

These signals are translated by the brain and felt as pain.

Without Oxygen Tissues Are Damaged

Nerve tissues and body tissues become increasingly inflamed and will quickly become damaged.

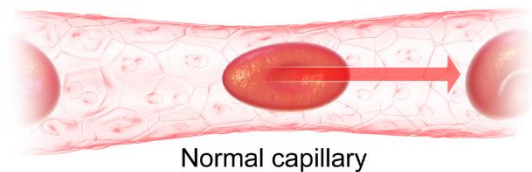
The length of this pain can last until the tissues begin to heal and the nerves calm down.

Chronic Pain: If the nerves do not calm down, some people can experience longer pain.

Sickled cells do not flow easily

Can clump inside blood vessels

Sickled blood cells do not flow easily through the blood vessels and can clump forming a blockage.



Normal capillary



Sickle Cell Disease

Goal of Pain Treatment

*Increased function and comfort
Not necessarily to be pain-free*

It is important to learn good coping skills and to have a positive outlook. It is also important to discuss the following options with your primary hematologist:

- Pain plan for home
- When to go to the hospital
- Therapy referrals: clinical therapy, massage, yoga

There are many ways to ease pain without medicine

<p>Drink Fluids Lots of fluids</p>	<p>Drink plenty of fluids even if you are not thirsty.</p> <ul style="list-style-type: none"> • Staying hydrated can help you head off an attack. • Water is best. Non-sugar liquids also ok. • Limit sodas: <i>Avoid sodas or juice. They can cause dehydration.</i>
<p>Reduce Stress</p>	<p>Find a quiet place to relax, rest, and be comfortable.</p> <ul style="list-style-type: none"> • Begin slow deep breathing. • Relaxation apps on phone such as <i>breath2relax</i>. • <i>Guided imagery to think happy relaxing thoughts.</i>
<p>Keep Busy Shift focus from pain</p>	<p>Find activities that hold your attention.</p> <ul style="list-style-type: none"> • Play video, board, or card games. • Visit friends. • Watch TV or movies. • Play music. • Work on hobbies.
<p>Use heat on painful area As prescribed by your doctor</p>	<p><i>Do not use ice. Ice can trigger a vaso-occlusive reaction.</i></p> <ul style="list-style-type: none"> • Heat increases blood flow. • Use warm baths or towels. • Elevate area if possible. • Gently massage area.

For Milder Pain or Pain Just Starting First check your temperature

Fever is a temperature of 101 degrees or higher

Normal is a temperature under 99 degrees

<p>My temperature is normal Under 99 degrees</p>	<p>Begin with primary pain medicines: acetaminophen (Tylenol) and ibuprofen (Advil, Motrin).</p>
<p>My temperature is higher than normal 99 to 100.9 degrees ... <u>But not at 101°</u></p>	<p><i>Do not take acetaminophen or ibuprofen.</i></p> <ul style="list-style-type: none"> • Check temperature at least every 2 hours. • It's important to see if your temperature will go back down or if it will get higher. • There are many causes of <i>non-infectious</i> fever. • These causes usually do not lead to a fever of 101.
<p>My temperature is 101 degrees or higher. Get Help Immediately</p>	<p><i>Do not take acetaminophen or ibuprofen.</i></p> <p>Possible Infection: You will need a blood test to see if bacteria is growing in the blood.</p> <p>Antibiotic: You will need a dose of IV antibiotic such as Rocephin.</p>

Begin with primary pain medicines: acetaminophen and ibuprofen

Studies show taking acetaminophen and ibuprofen around the clock
(either *together every 6 hours* **or** *by alternating each medicine every 3 hours*)
Can provide effective pain control for some pain with fewer side effects.

For More Severe Pain

Your doctor may prescribe opioids such as hydrocodone or oxycodone

Pain medicines can cause serious or even “Life-Threatening” side effects.

Know the side effects and when to call your doctor.

Common side effects	When to call doctor
<ul style="list-style-type: none">• Nausea, vomiting	<ul style="list-style-type: none">• Dizzy, confused
<ul style="list-style-type: none">• Constipation	<ul style="list-style-type: none">• Slurred speech
<ul style="list-style-type: none">• Itching	<ul style="list-style-type: none">• Stumbles when walking
<ul style="list-style-type: none">• Dry mouth	<ul style="list-style-type: none">• Sleepy, hard to wake up

Call 911 if your child

- Has trouble breathing
- Cannot stay awake
- Cannot talk normally

Alternate opioid medicine with a primary medicine

<p>Start schedule for taking opioid medicine with primary medicine</p> <p>Remember to check your temperature before taking acetaminophen or ibuprofen</p>	<p>It takes approximately 60 minutes to feel full pain relief and it will last about 3 to 4 hours.</p> <p>Alternating your prescription opioid with either acetaminophen or ibuprofen every 3 hours can provide effective pain control for sickle cell episodes.</p>
<p>Hydrocodone</p> <p>Do not alternate with acetaminophen</p>	<p>Hydrocodone contains acetaminophen. You can only alternate with ibuprofen.</p>

Pain Uncontrolled at Home

Call your doctor or go to the ER. You may need stronger medicines and IV fluids.

Calling Your Doctor

During the Day

Call the office
682-885-4007

After Hours

Call Hospital Operator
682-885-4000

Ask operator to page H/O Doctor on call

These instructions are only general guidelines. Your health care providers may give you special instructions.
If you have any questions or concerns, please call your health care providers.