

Module 3: How to Deal with Pain

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Painful Periods

Pain is really common for people with sickle cell disease. Pain happens when blood does not flow normally. The red blood cells can “sickle” (change their shape) or stick to the sides of the blood vessels, and blood vessels get narrow (constrict) to trap the red blood cells in small blood vessels in the body. The area where the blood cells get trapped does not get enough oxygen and this causes you to feel pain.

Pain can happen at any time of the day or night. It may last a few hours, few days or even a few weeks. The pain can range from mild to severe and is different in each person. Sickle cell pain can be anywhere in the body, but the most common sites are the arms, legs, back and stomach. Some pain can be treated at home or during the day at school, but sometimes the pain becomes severe enough to need hospitalization.



Common Causes of Sickle Cell Pain

Although you cannot always control the pain that happens with sickle cell, there are certain situations that will definitely make your pain worse. Here are some common conditions that could cause or trigger a painful episode:

- Dehydration (not drinking enough water!)
- Exposure to extreme hot or cold temperatures
- “Over-doing it” or going beyond your energy limits
- An infection
- Stress can increase the feeling of pain in your body
- Breathing problems
- Doing anything at high altitudes
- Staying too long in an unheated swimming pool
- Shivering (if wet or cold) can also make your pain worse
- Menstrual periods



Medicines for Pain

There are many different pain medications. You will find that certain medications may work better for your pain. You should know these basic facts about different pain meds:

- Acetaminophen (Tylenol). You can buy it at a pharmacy. It can reduce fever. Talk to your doctor about how much you should take. An adult should never take more than 4000 mg of acetaminophen (eight 500 mg pills) in a 24-hour period because too much acetaminophen can cause serious liver problems. Some medications (Tylenol#3, Percocet, Vicodin, Norco) combine acetaminophen with another drug.
- Ibuprofen (trade names Motrin, Advil) or naproxen (trade name Aleve). You can buy it at a pharmacy. These are types of medicine called a nonsteroidal anti-inflammatory drug (NSAID). They can reduce fever. Side effects include upset stomach and ulcers. Do not take if you have ulcer, bleeding, or kidney problems.
- Opiate medicine (also called narcotics). There are many different opiate medications including codeine, hydrocodone, tramadol, oxycodone, morphine, and hydromorphone. You need a prescription for these drugs, and refills are tightly controlled. Side effects: constipation, itching, nausea, drowsiness/impaired thinking. When you start taking an opiate for new pain, you should also take a medicine to prevent constipation (like Miralax). If you take opiates on a regular basis you will develop tolerance, which is not the same as addiction.

Learning to Relax

Relaxation techniques can help when pain hits you. Relaxation is a skill that can be learned. Like any other skill, it takes practice to learn to relax. Pick times that are quiet and free of distractions to practice. Before you go to bed is often a good, quiet time.

1. Think of a calm and happy place -- an empty beach, a bright blue sky with clouds, or a mountain sunset. Think of details in this place--sounds you enjoy, things you like to touch, taste, and smell.
2. Deep breathing. Deep breathing is one of the simplest and best ways to relax. As you inhale, think about fresh air coming slowly into your chest, out to your fingers and down to your toes. As you breathe out, imagine that any tension that may have been stored in your arms, neck or shoulders is moving from your body and out into space.

[Click here](#) to see a video that guides you through some deep breathing exercises.

3. Muscle exercises. Get in a comfortable position in a relaxing place. Tighten the different muscles in your body and then relax them, allowing them to go limp. Start with making a fist and then releasing your fingers. Slowly move on to your arms, shoulders, neck, face muscles, toes, legs, and stomach.

You can watch a video that guides you through muscle exercises by [clicking here](#). Stress can trigger pain and make existing pain even worse. Learn how to manage your stress. Figure out what works for you.

Dealing with Stress

Being prepared and in control of your condition will help you feel less stress. Follow these six tips to prevent and manage stress.

1. Plan your time —Think ahead about how you are going to use your time.
Write a to-do list and decide which tasks are the most important.
Be realistic about how long each task will take.
2. Relax with deep breathing —Take part in deep breathing activities or yoga classes.
3. Relax your muscles — Try stretching or taking a hot shower to help you relax.
Stress causes tension in your muscles.
4. Get moving —Plan physical activity to help prevent and manage stress.
It also can help relax your muscles and improve your mood.
Before you start, be sure to discuss any new exercise routine with your doctor.
 - Be sure to exercise for at least 10 minutes at a time.
 - Do strengthening activities (like sit-ups or lifting weights) at least 2 days a week.
5. Share your feelings with friends and family —Tell your friends and family if you are feeling stressed. They might be able to help.
6. Get help if you need it —Find help if your stress doesn't go away or keeps getting worse.



Danger Signs: When to Call the Doctor

It's important to be aware when you should get extra help. If your pain ever is out of the ordinary or you have a fever above 101.4 F, you should call your doctor. You should also be aware if you have any of these other symptoms that may be signs of more serious concerns. Call your doctor if you are also experiencing any of these:

- Fever above 101.4 F
- Chest pain
- Severe pain in the belly
- No relief after trying "home remedies"
- Sudden weakness or tingling of an arm, leg or the whole body
- A difference in the way one side of the face or one eye moves compared to the other side
- Seizures (shaking that can't be stopped)
- Speech trouble
- Sudden, strong headache
- Coughing
- Rapid breathing
- Shortness of breath
- Difficulty breathing or "grunting"
- Dehydration – very dark urine or no urine output
- Priapism and unable to urinate for over 30 minutes

Where to Find More Information

If you want to read more about any of the topics in this module, here are the websites where the information is from:

[Click here](#) to visit the Sickle Cell Transition Education Project at Children's National Health System.



To learn more details about Sickle Cell in general, [click here](#) to visit Kidshealth.

Great job!!

You're another step closer to finishing the CHECK Sickle Cell Online Program.
Hopefully you now know more about ideas to help you deal with pain.

Now you can move on to the next topic, which talks about problems you might have with sickle cell.

