

Managing Pain With Sickle Cell Disease

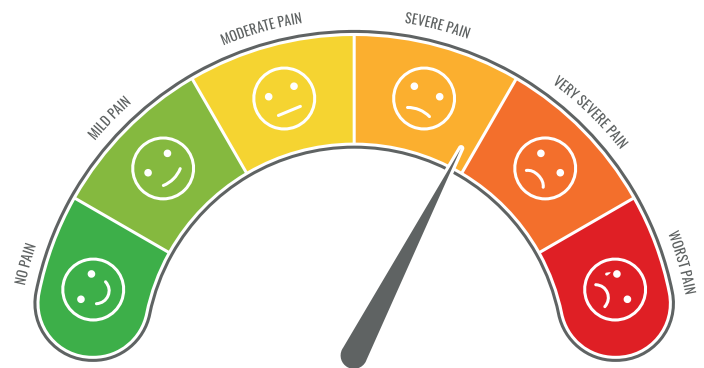
People with sickle cell disease (SCD) may experience pain in different ways. The sickled cells that give the disease its name can lead to pain throughout the body and serious damage to organs, such as the heart and kidneys. If you have SCD, see your healthcare team regularly to help prevent pain, complications, and serious problems. Work with your healthcare team to create a pain management plan that makes sense for you.

Common Types of Pain

- **An acute or severe pain crisis** can happen without warning when sickle cells block blood flow. People describe this pain as sharp, intense, stabbing, or throbbing.
- **Pain from organ damage** may occur when sickled cells affect your heart, kidneys, spleen, or other body parts.
- **Chronic or long-term pain** is also common, but it can be hard to describe. It is usually different from crisis pain or the pain that results from organ damage.
- **Joint problems and pain** may develop if there is sickling that lowers oxygen flow. This can occur in the hip bones and, less commonly, the shoulder joints, knees, and ankles.
- **Priapism** is an unwanted and sometimes prolonged painful erection. This happens when blood flow out of the erect penis is blocked by sickled cells.

Tips to Manage Pain

- Most patients can sense when an acute crisis is just starting. Drink lots of fluids and take a nonsteroidal anti-inflammatory (NSAID) pain medicine, such as ibuprofen. If you have kidney problems, acetaminophen is often preferred.
- If you cannot manage the pain at home, go to a day hospital or outpatient unit or an emergency department to receive additional, stronger medicines and IV fluids. Your healthcare team may prescribe stronger medicines called opioids for severe pain.
- In the event of priapism, seek medical care immediately if symptoms last more than four hours or if it happens more than once within a 24-hour period.
- Keep a copy of your pain management plan (print or electronic) when you seek emergency care.



“If I feel pain within a day or two and don’t do something about it, I’ll be in a full-blown sickle cell crisis.”

That internal barometer has helped Ebow H-Smith, healthcare professional and sickle cell disease advocate, manage pain as an adult.



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sicklecell.nhlbi.nih.gov

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Tips to Manage Pain (*Continued*)

- Other methods for managing pain include physical therapy, acupuncture, using a heating pad, massage, yoga, or guided audiovisual relaxation.
- Talk to your healthcare team about when to [seek emergency care](#).

Prevent Problems Over Your or Your Child's Lifetime

- **Avoid situations that may set off a crisis.** Extreme heat or cold, as well as sudden changes in temperature, are often triggers. When going swimming, ease into the water rather than jumping right in.
- **Do not travel in an aircraft cabin that is unpressurized.**
- **If you experience priapism,** you may be able to relieve your symptoms by doing light exercise, taking a warm bath or shower, emptying your bladder by urinating, drinking more fluids, and taking medicine recommended by your healthcare provider.
- **If your child attends day care, preschool, or school, speak to their teacher about the disease.** Teachers need to know what symptoms to watch for and how to accommodate your child.
- **Ask your healthcare team about medications that may control SCD and help reduce the risk of pain crises.**



Questions to Ask Your Healthcare Team About Treatments

- Which treatments are best for me?
- How is this treatment administered?
- How often do I need this treatment?
- What are the side effects?

With help from your healthcare team, you can create a plan to manage your pain and prevent serious problems. Learn more at sicklecell.nhlbi.nih.gov



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