

Living Well *with* Sickle Cell Disease Action Plan

Sickle Cell Disease (SCD) is a lifelong genetic condition that affects a protein in red blood cells. It can result in a lack of oxygen to vital organs, which can lead to pain. If you are living with SCD, use the chart below to track how you are feeling and for tips you can use to help manage your pain level.



How are my symptoms today?

How am I feeling?

Pain is controlled

- Can do all normal activities.
- Able to sleep through the night.
- No need for high-dose narcotic.

Pain is affecting daily activities

- Can do some, but not all, normal activities.
- Body hurts.
- Body movements are slower than usual.
- A need for more pain medicine.

Pain is at a crisis level

- Can't do most normal activities.
- Can't sleep.
- Pain is getting really bad.
- Over-the-counter and narcotic pain medicines aren't working.

Things to do

- Drink plenty of non-carbonated, low sugar fluids.
- Avoid very hot or cold temperatures.
- Check for fever.
- Take prescribed medicines such as vitamins, hydroxyurea, over-the-counter pain medicine, low-dose narcotics if needed, and antibiotics.

- Rest.
- Take pain medicine when needed. Your doctor may ask you to increase the dose or take them more often.
- Drink a lot of non-carbonated, low sugar fluids.
- Check if fever is going up.
- Use warm packs on places that hurt.
- Move to a comfortable, warm area.
- Do relaxation techniques.
- Begin to figure out personal pain triggers. Is there something that is making the pain worse at this time?

- Keep taking pain medicine as directed by the doctor.
- Call the Hematologist/Oncologist.
- Call a nearby urgent care center or Emergency Department.
- Children with temperatures over 101 should go to the Emergency Department.
- Parents should bring any recent hospital records to all medical visits.
- If ordered by the doctor, parents may apply a numbing cream to places that will be used for IV sites.
- Parents may bring things to help soothe children while in the hospital such as a stuffed animal, book, game, or toy.

Pain

Pain: 1 to 3 out of 10

Pain: 4 to 7 out of 10

Pain: 8 to 10 out of 10



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1

2

3

4

5

6

7

8

9

10

No Pain

Mild Pain

Moderate Pain

Severe Pain

Very Severe Pain

Worst Possible Pain