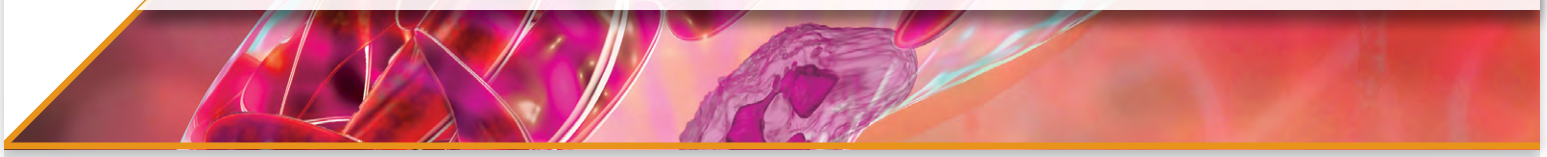
Novel Interventions for Preventing/Reducing Pain Crisis in Sickle Cell Disease



PAIN PLAN TOOLKIT FOR CLINICIANS AND SCD PATIENTS

Until a universal cure for sickle cell disease (SCD) can be found, patients and healthcare providers need to work together to develop a pain management plan for at home and when acute care is needed. This tool has been designed for individuals with SCD to document their current SCD care pain and share with their healthcare providers to facilitate development of an individualized pain plan in an acute care setting as well as for everyday life.

Provided by AXIS Medical Education

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SCD HISTORY

Which of these are you currently taking for your SCD? (*Check all that apply*)

- ☐ Regular, monthly blood transfusions
- ☐ Hydroxyurea
- ☐ L-Glutamine
- ☐ Voxelotor
- ☐ Crizanlizumab
- ☐ Unsure
- ☐ Other: _____

Have you ever had a stem cell transplant? *(Check one)*

- ☐ Yes
- ☐ No

Description of typical pain crisis: _____

_____

_____

_____

Do you have other medical problems? (*Check all that apply*)

- ☐ Diabetes
- ☐ High blood pressure
- ☐ Heart failure
- ☐ Avascular necrosis (bone breakdown due to sickle cell disease)
- ☐ Hearing problems
- ☐ Vision problems or difficulty seeing
- ☐ Other: _____

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CURRENT PAIN MANAGEMENT

Please check any of the words/phrases below that describe your **CURRENT** pain characteristics:

Sensory Pain:

- ☐ Pins
- ☐ Needles
- ☐ Squeezing
- ☐ Stabbing
- ☐ Other _____

Emotions:

- ☐ Annoyed
- ☐ Wanting to scream
- ☐ Wanting to cry
- ☐ Feeling distraught
- ☐ Other _____

Timing:

- ☐ Slow
- ☐ On/off
- ☐ Continuous
- ☐ Fast/abrupt
- ☐ Other _____

What triggers your pain crisis? (*Check all that apply)*

- ☐ Exposure to cold temperatures
- ☐ Exposure to hot temperatures
- ☐ Increased physical activity
- ☐ Decreased physical activity
- ☐ Psychological factors (eg, stress, anxiety, depression)
- ☐ Lack of fluid intake
- ☐ Other: _____

Do you have chronic everyday pain? *(Check one)*

- ☐ Yes
- ☐ No

How often do you experience SCD-related pain?

- ☐ Daily
- ☐ Weekly; times per week _____
- ☐ Monthly; times per month _____
- ☐ Other: _____

If you have daily pain, rate your daily pain severity *(Circle below; on a scale of 1 to 10)*

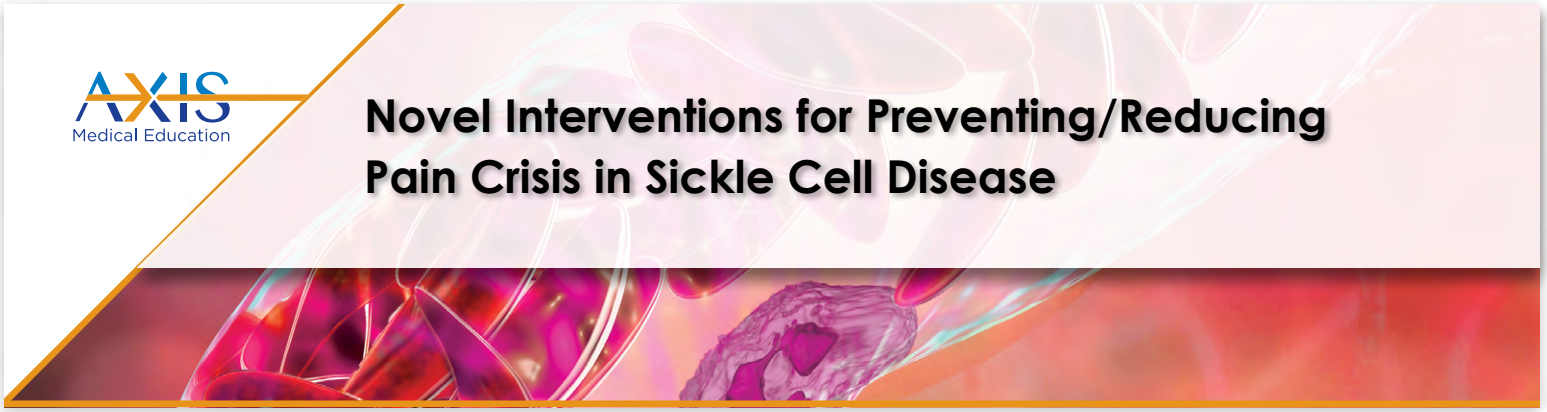
No pain 1 2 3 4 5 6 7 8 9 10 *Worst pain*

Where have you **HISTORICALLY** experienced SCD-related pain? _____

_____

_____

_____



CURRENT PAIN MANAGEMENT (CONTINUED)

Have you had any of these problems with your pain crisis? *(Check all that apply)*

- ☐ Acute chest syndrome/pneumonia/lung infection
- ☐ Kidney failure
- ☐ Stroke or difficulty walking/talking

Have you needed to be in the intensive care unit (ICU)? *(Check one)*

- ☐ Yes
- ☐ No

What has been used to help your pain in the past 2 years? What works best?

- At home: _____
- In the emergency department: _____
- While in the hospital: _____

How many times in the last year have you visited the emergency department for SCD pain? _____

_____

TRANSFUSION

What is your normal/baseline hemoglobin? _____

When should you be transfused? _____

Is it hard to match your blood? Do you have allo-antibodies? *(Check one)*

- ☐ Yes
- ☐ No

Do we need to call your sickle cell doctor before you receive blood? *(Check one)*

- ☐ Yes
- ☐ No

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INDIVIDUALIZED ACUTE CARE PLAN

When to seek care (call your physician or go to the emergency department)

- Breathing is difficult, shortness of breath
- Fever, temperature is >102°F
- Neurologic changes (difficulty walking or talking)
- Pain is different than usual for your sickle cell disease
- Chest pain

Example of home pain regimen:

- Ibuprofen 600 mg every 8 hours
- Cyclobenzaprine 10 mg every 12 hours
- If pain is severe or persistent, add oxycodone 10 mg every 3-4 hours
- Hydration and rest are KEY

Nonpharmacologic Strategies for Sickle Cell Pain Management

Psychological Strategies	Behavior Strategies	Physical Strategies
Distraction (TV, music, phone)	Deep breathing	Hydration
Imagery	Relaxation exercise	Heat (warm blanket, heat packs)
Education/teaching	Self-hypnosis	Massage
Hypnotherapy	Biofeedback	Physical therapy
Psychotherapy	Behavioral modification	Transcutaneous electrical nerve stimulation (TENS)
		Acupuncture/acupressure
		Blood transfusions

https://www.uspharmacist.com/article/sickle-cell-disease-pain-management

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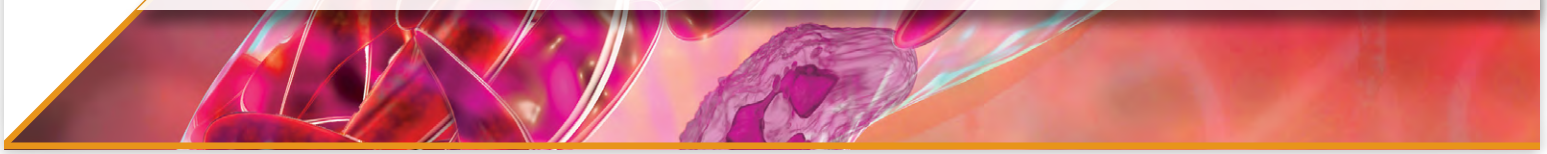

EMERGENCY DEPARTMENT

If you are experiencing a pain crisis, please use this section of the toolkit to provide additional information to your emergency department healthcare team to assist in promptly implementing a pain management strategy.

Emergency Department Checklist:

- ☐ Bring your current pain management plan with you or ask the nurse to look it up in your electronic medical record upon arrival at the emergency department
- ☐ Bring your regular doctor's contact information and provide this to your emergency department healthcare team
- ☐ Bring a list of all of your current medications including dose and frequency
- ☐ Tell the emergency department staff immediately that you have sickle cell disease and share the information you have completed in this pain crisis toolkit

Caregivers/Contact Information

	Name	Phone Number
Hematologist/Sickle cell doctor		
Physician		
Nurse		
Social Worker		
Caregiver/Family member		
Caregiver/Family member		

Current Medications

Name of Medication (Including prescription and over-the-counter medications)	**Dose** (eg, milligrams)	**Frequency** (How many times daily)	**When did you last take this medication?**