



ADVOCACY IN THE EMERGENCY ROOM

Many individuals living with sickle cell disease (SCD) face severe symptoms that require immediate treatment.

These **FOUR STEPS** can help sickle cell warriors and caregivers advocate **BEFORE, DURING, & AFTER** an ER visit:





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STEPS FOR WARRIOR ADVOCATES

BEFORE
THE ER VISIT...

STEP 1: PREPARE FOR AN EMERGENCY



✓ GATHER YOUR SUPPORTERS

Talk with **family and trusted friends** about your crisis plan and their role to support you in the ER.

✓ RESEARCH YOUR LOCAL ER

Contact your local hospital to learn about their **sickle cell protocols or services** offered to SCD warriors in the emergency room.

✓ MAKE A PLAN WITH YOUR HEALTH PROVIDER

Talk with your hematologist to create an individualized pain plan and ask them **what they can do to support you in the ER.**

Ask your health provider if they can **call ahead to your ER** to help with your triage.

Here are **resources** for you to share with your local hospital:

1 CLINICAL GUIDELINES

Guidelines are developed by experts and give doctors recommendations for how to care for SCD pain:

- [NHLBI Evidence-Based Management of Sickle Cell Disease: Expert Panel Report, 2014](#)
- [ASH Guidelines for SCD: Management of Acute and Chronic Pain, 2020](#)

2 POINT-OF-CARE TOOL

This "bedside information" tool can provide concise, summarized medical information to ER nurses and doctors:

[ACEP Managing Sickle Cell Disease in the ED Point-of-care Tool](#)

3 EDUCATIONAL VIDEOS

Brief video-based education for health professionals to understand SCD pain and improve negative provider attitudes:

- [Understanding Sickle Cell Patients' Pain in the ER](#)
- [CRISIS: Experiences of People with Sickle Cell Disease](#)



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STEPS FOR WARRIOR ADVOCATES

DURING
THE ER VISIT...

STEP 2: GET THROUGH TOUGH TIMES



Supporters can reduce stress in many ways such as a **massage** or **reading**.

STEP 3: SOUND THE ALARM

✓ **SPEAK UP**
Take **action** if you are feeling dismissed by ED staff. Be as specific as you can and ask the nurse or doctor **how your concern can be addressed**.

✓ **TALK WITH A MANAGER**
Know the **chain of command in your ER**. Then, **request to speak** with a nurse supervisor, and patient rights advocate.

✓ **DOCUMENT YOUR EXPERIENCE**
Warriors and supporters can **collect specific information** like length of wait time, time to first dose, names of staff you speak with, and your concern.

✓ **MANAGE STRONG EMOTIONS**
Consider going to the ER before the pain is severe. It is often difficult to speak when in pain. **Having a supporter with you at the hospital** can help you communicate your needs.

✓ **STICK TO THE FACTS**
You or your supporter should give as much information as you can to the ER staff. Have a copy of your **pain management plan**, including the names and dosage of what medicine has worked best.

✓ **STAY CALM**
There are many ways to stay calm during a medical emergency. **Breathing exercises, listening to music, meditation, or video games** can help you stay calm and act as a distraction.



Based on clinical recommendations, pain medication should be given within **60 minutes of your arrival**.

Create a **pain plan** to ensure that you receive the **best medication route, dose, and dosing intervals**.

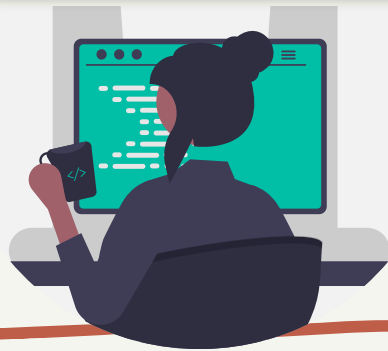


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STEPS FOR WARRIOR ADVOCATES

AFTER
RECOVERY...

STEP 4: WORK WITH YOUR ALLIES



Some people to consider contacting:

- Head of the ER department
- The hospital leadership team
- The hospital's patient advocate
- The Joint Commission

✓ TALK WITH YOUR CARE TEAM

Talk with your hematologist about **any negative experiences and possible solutions** for future ER visits.

✓ SUBMIT YOUR FEEDBACK

Complete any satisfaction forms or questionnaires. A **thank you letter** also can help build relationships with hospital staff. If necessary, you can **file a formal complaint**. Be specific and detailed about your experience.

✓ EDUCATE YOUR LOCAL HOSPITAL STAFF

Follow up with your hospital and offer education about SCD. You can offer to share your SCD story at a lunch and learn, seminar, in-service, etc.

✓ ENGAGE OTHER ALLIES

Share your story with advocacy organizations, insurance company, quality & safety boards, policy makers, and racial equity committees.

LEARN MORE ABOUT ADVOCACY & ERs:

- Join the **Sick Cells Ambassador Program:** sickcells.org/ambassador-program/
- Find a local advocacy organizations using the **State Advocacy Map:** sickcells.org/advocacy-tools/
- Join the **Emergency Department Sickle Cell Care Coalition (EDSC3):** www.acep.org/by-medical-focus/hematology/sickle-cell/

