



# 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:





# ADVOCACY IN THE EMERGENCY ROOM

## STEPS FOR WARRIOR ADVOCATES

BEFORE  
THE ER VISIT...

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### 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**.

In case of an emergency, will you be able to meet me at the hospital right away?



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](#)



# ADVOCACY IN THE EMERGENCY ROOM

## 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**.



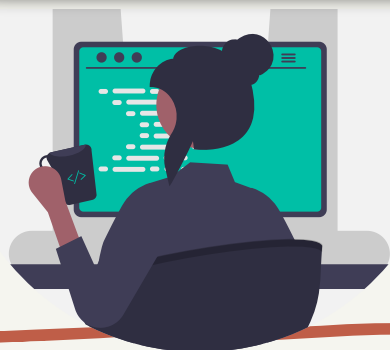
# ADVOCACY IN THE EMERGENCY ROOM

## STEPS FOR WARRIOR ADVOCATES

AFTER  
RECOVERY...

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

