



Being Your Own Advocate in a Medical Setting

This toolkit offers tips on how individual warriors and caregivers can advocate for themselves and their loved ones during an emergency department (ED) visit or hospital admission.

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Before Admission

Be informed

- **Find a primary care provider and hematologist.** You can start looking for one by asking a local SCD community-based organization (CBO) for a suggestion. You can search the [Sick Cells Advocacy Map](#) to find a CBO in your state. Having a relationship with a primary care provider will help you when you are admitted.
- **Ask your hematologist to create an individualized pain plan** for you that can be added to your medical record.
- **Put together your health history** like comorbidities, previous health issues and diagnoses. Make a list of all your medications and have a summary ready to hand over to hospital staff. An easy way of doing this is making sure you have access to and are signed up for your hospital's patient portal, for example MyChart (requires internet access or data plans).
- **Ask your trusted care provider for a travel letter**, which outlines your recent care, including appointments, prescriptions, and any important information about your medical condition. If you find yourself at a new hospital or clinic, the travel letter can help new providers get in touch with past or current providers.
- **Be respectful, but firm, in communicating** very specifically what is going on with you and what key information the hospital staff should know.
- **Know what services are offered at your hospital.** Do they have social workers, financial assistance workers, or translators that would be helpful for you? These are advocates who can help you, especially when you are in a situation where you feel unable to advocate for yourself. Each person needs to hear the whole story; don't assume information is being communicated from one to the other.
- **Help your providers correctly diagnose and treat your SCD** by providing them with the [ASH Clinical Practice Guidelines on SCD](#)

Overcome stigma & bias

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- **Make yourself known.** One of the ways to fight against stigma, racism, and implicit bias is to get involved with the hospital and make yourself known. Many hospitals or clinics have a community advisory board or committees that you can apply to join. Additionally, you recommend to speak to the diversity & inclusion board, or advocate for the hospital to mandate anti-racist curriculum for their staff.
- **Know the system.** Stigma and racism have been shown to negatively affect access to care, treatment, and outcomes of individuals with SCD. Even if most physicians may not be explicitly racist, they operate in an inherently racist system. In addition, we know that unconscious prejudices and implicit bias can affect the way patients are treated. Basically, there are many layers and levels to this issue which make it challenging to overcome. Understanding the system can help you know how to best advocate for yourself and for others.

- **Recognize and understand any personal bias you might have** toward hospitals, care providers, or clinical settings. While bias may be due to how you have been treated in the past, it is important to continue to keep an open mind; you never know when you will come across someone who will really listen to you and understand you.
- **Take action if you are feeling dismissed or not listened to.** Don't be shy about saying directly, "I don't think that you are hearing my concerns."
- **Ask to speak to a patient advocate if you are unsatisfied with the care you are receiving.** The advocate can come in to help and will talk to the provider to bridge the gap.
- **Trust your instincts and get the care you deserve.** If an interaction with anyone on your medical care team leaves you feeling uneasy, trust your instincts and get the care you deserve elsewhere. You can also file a formal complaint or ask for a patient feedback form. It is best to make sure the hospital receives the feedback form before you leave, but you can file a formal complaint once you are home and rested.

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Document your experience

- **It is important to document your experience** to refer back to. Keep a small journal with you to record important information or details about your care during and after medical events. Or, you may prefer to download a notepad app or record a summary with a voice memo app on your cell phone.
- **It may help to include the names of medical providers** and specific **data points** like length of wait time, time to first dose, etc. It is equally as important to mention any doctors or other care team staff who left a good impression on you as it is to mention those who provided subpar treatment.
- **Provide feedback or reviews of your doctors** using [Healthgrades](https://www.healthgrades.com) or similar websites with information on hospitals and medical providers.
- If you have a patient safety concern, **you can report it to the [Joint Commission](https://www.jointcommission.org/).** The Joint Commission on Accreditation of Healthcare Organizations is an official organization that seeks to improve medical care by reviewing the quality of hospitals and medical providers.
- **You can also write directly to the head of the hospital** or other key administrator. Sometimes those who are not involved in the day-to-day activities of the hospital will be more ready to take action. It is important to keep your letter based on the facts of your visit and why you are reaching out.
- During your follow-up, **it is important to remember that hospitals are businesses.** Sometimes you will have to **speak their "language"** in order to get the help that you need and deserve. This may mean learning some phrases or words that will get their attention or help them understand why they should invest in your concern.
 - **Research terms** like "hematologist" and "oncologist" so you can be familiar with types of doctors who often work with SCD warriors
 - **You can often request a bedside shift change** so nurses exchange information in front of you. This way, you can make sure your voice is heard when your care is transitioned to someone new.
 - **Make sure those involved in your care are all in-network.** Even if you go to a hospital that is in-network for your insurance, it is still possible individuals on your care team are not.

Contributors



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