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My sickle cell disease really affected me when I was 25, right after I had my daughter.

After I had her, I was going to the hospital quite often in crisis. But the crisis wouldn't come on until I was sleeping — usually about five o'clock in the morning.

When it was really bad, I would call an ambulance. Sometimes, I'd have to pack up my infant daughter and take her with me. Her car seat would be in the ambulance right next to me. She'd be on my stretcher. While they were treating me, she would be at the foot of my bed in the emergency room until someone could come and get her.

I have guilt — this issue where I don't want to disturb anybody. I thought it was just me. But in the community of people with sickle cell, I found out I'm not the only one who doesn't want to bother friends

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or family. I came to realize I can always count on my dad. Even now, though I'm older, I will still ask my dad to take me to the hospital.

My relationship with the emergency room is that there is no relationship. Even though I go to the same emergency department several times a year, there is no one to call to let them know that I'm coming in with a crisis. I'd much rather be home than at a hospital, so I try to rest and use oral narcotics at home to avoid going in. If I have to go, by the time I get there, I'm in severe pain. People are usually not that sympathetic to my situation. It is often hours before I am taken to the back to get anything — fluids, warm blankets, oxygen, narcotics administered intravenously. By then, I can barely function; I can't talk. I don't know if people realize how much pain I am in by the time I make it there. I'm usually silent, but I'll have tears running down my face.

When it takes too long to tackle the pain, it feels like it sets in my bones. But when it gets taken care of right away, I can sometimes avoid being admitted.

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I have a fear of being ignored and not being attended to in a timely manner. That's part of why I avoid going to the hospital altogether. The hospital is my last resort.