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WHAT YOUR PATIENT IS THINKING

Help me manage my sickle cell pain

Mary shares her experience of living with sickle cell disease and the importance of empathy

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I received a diagnosis of sickle cell disease when I was around 18 months old. I have since experienced very challenging symptoms and diagnoses, including avascular necrosis, iron overload, and pulmonary embolism. Changes in my body caused by sickle cell have also significantly affected my mobility and my social life.

Experiencing a crisis is awful. The pain is excruciating. It feels like someone armed with knives in their hands and spikes on their feet jumping, stabbing, and stamping to their own rhythm inside a selected part of my body. The knives feel like they are deep within the epicentre of my bones and stabbing outwards, at every angle, in an attempt to escape; creating a piercing radiating pain. When I present to you in crisis, I am in agony. But you can help me through these difficult, traumatic—yet recurring—vulnerable periods in my life.

Empathy is crucial

When I am experiencing a sickle cell crisis, empathy is crucial. Empathy means recognising that I am suffering, listening to me, and engaging me in decisions about my treatment. It can be as simple as reassuring me that resolving my pain is your priority, even if it means we must take some steps back to move forward. I remember an admission to hospital when my pain was so excruciating I was frozen to the bed in a seemingly awkward position. I was trying, but failing, to distract myself with a book. The doctor doing the ward round came in and saw my position, and immediately recognised I was in a lot of pain and that we needed to change strategy.

He shifted the conversation briefly to the book, which helped calm me a bit. He then asked me about myself, what I do, and what I was looking forward to on discharge. We found common ground and spoke about our shared interests. This helped me understand that he truly saw me as a person, and cared about making me better. He suggested going back to a higher dosage of pain relief, which was an apparent step back, but it worked in making me more comfortable.

So much more than my disease

Sickle cell has a huge impact on my life, but I am so much more than a sickle cell patient. There are many components to me that are often lost when I enter a hospital.

My life away from the hospital is beautiful, and I desperately want to get back to that life. Days spent in hospital have wider impacts on my family, career, and social life, and can have adverse consequences for me financially. This is why resolving the sickle cell crisis, as quickly as possible, is my top priority. My plea to doctors is to show empathy, release any negative preconceptions about how people manage pain, and prioritise resolving the pain so that I can get home as soon as it is safe to do so.

What you need to know

- Patients bring their own knowledge, instincts, and experience. Hearing these can help you work together
- Finding shared interests or common ground can help patients relax and cultivate a more trusting relationship
- Patients have whole lives outside their health. Ask them about this to gain greater insight into their plight

Education into practice

- What could you do to help someone navigate the pain they are experiencing?
- How can you ensure you are taking a patient's experience into consideration when managing pain?
- When might you consider asking a patient about their life beyond their health condition?

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