REALHEALTH™

One Year Out of the Hospital

February 18, 2015 By Cyntra Scott

This February makes one whole year that I have stayed out of the hospital. This isn't because I haven't been hurting, but that I managed to deal with the pain without an overnight stay in the oh-too-familiar hospital.

I do know that many people without sickle cell disease (SCD) live year after year without a hospital admission. (The majority of people with SCD are often in the hospital for periods of time throughout their lives.) But, for me, during my 42 years avoiding the need to be hospitalized is an anomaly. For most people with sickle cell, living with this disease usually means you will get more acquainted with your local hospital than anyone would want.

As a frequent patient, it's not long before you learn the good, bad, and the ugly about a hospital stay. But before I begin, let me preface this blog post by thanking the many doctors, nurses, healthcare professionals and hospital staff who have taken excellent care of me throughout countless hospital stays. As in any industry, there are individuals who represent their field well. They perform their jobs with integrity, excellence, consideration and to the best of their ability. Then there are the few who do not. These individuals don't perform their jobs well, or, even worse, are disrespectful, uncaring and simply do not belong in healthcare.

Fortunately, for kids with sickle cell who stay in the hospital, the treatment is often great and they are surrounded by caring, concerned health professionals. Unfortunately, when you transition from childhood to adulthood, the treatment you receive for sickle cell and the way you are perceived often changes for the worse. Sickle cell patients have expressed that while in the hospital (already suffering through an agonizing pain crisis) they have been made to feel like a burden, a bother, an annoyance and a nuisance. This is something I have experienced myself, and I believe this injustice must be brought to the attention of the medical community.

There are some in health care who stereotype sickle cell patients as "drug seekers." But research shows that the sickle cell patient population has the same miniscule number of addiction-related patients, under 2 percent, which is the same for other disease-afflicted populations.

The reality is that as a person in the midst of an excruciating sickle cell crisis all you want is some type of relief from the pain. When you think about the pain sickle cell sufferers undergo, it's clear why we are so focused on receiving the therapeutic dose of ordered pain medication on time. In addition, there are no other main treatments (aside from pain medication) to select from to relieve our unrelenting and continuous pain.

The Basics of a Sickle Cell Pain Crisis Hospital Experience

A SCD crisis can last from about two days to two weeks. When a sickle cell patient is in crisis and is admitted through the ER, the main focus of care consists of the following treatments, 1) Hydration, running an IV line to administer IV fluids; 2) Administering oxygen, connecting the patient to oxygen through nasal tubing; 3) Providing pain medication, prescribed narcotics that work best for the individual patient. 4) Ordering other medications, the doctor might order medication for nausea and for itching.

In addition, many ER’s will order a chest X-ray to rule out pneumonia. The ER will also collect blood to run a panel of blood tests which include a CBC (Complete Blood Count). Also, often you will be asked to give a urine sample.

After a couple of hours in the ER, the doctor will check to see if you are improving and can be released to handle the crisis at home, or he or she will recommend that you be admitted.

You’ve Been Admitted for a Hospital Stay

Once you are admitted you will be transported to your room on a hospital floor. The nurse will come in to evaluate you. The medication orders will now be assigned to the hospital doctor on duty, or your private doctor if he or she has been contacted. When having a sickle cell crisis, this period can be very trying because coordinating the most effective medication to help control the pain can take hours.

Maybe your doctor might order a PCA Pump for you to have. A PCA Pump is a Patient Controlled Analgesia machine that is connected to your IV and set according to the doctor’s orders to dispense a specific amount of medication over a specific time period. You are given a controller to press when you feel you need more pain medication. The primary purpose is to allow the patient to have more control over his or her need for more or less pain medication throughout the hospital stay. Be sure to ask that the dosages be adjusted until the PCA Pump is set to adequately control your pain.

I find that having the television on is a welcome distraction even though, with the severe pain I am in, I’m not actually focused on the shows. Be prepared to pay for the television service in many hospitals. Usually, the fee for television service is between $6 to $10 per day. This cost can be billed to a credit card, paid with a debit card or cash, the transaction handled through a hospital attendant, or, sometimes, it can be billed to your home telephone number.

When you have issues or concerns with nurses or any situation while in the hospital ask for your patient advocate. Most hospitals have these individuals on staff. Their main purpose is to advocate for and help the patient with a range of issues concerning a hospital stay. The patient advocate listens to your concerns, follows up on addressing your complaints, finds solutions to any problems you express, explains hospital policies, connects you with community services and, in general, helps to make your overall stay go as smoothly as possible.

Also, the presence of family and friends while you are in the hospital can be immensely helpful. Aside from their assistance and the uplifting spirit that visitors bring, the hospital staff often seems

more responsive when they know that others are vigilant about the type of care you are receiving. That said, ask your family to check on you. If they cannot come in person, then have them call the nurses' station periodically and talk to your nurse.
In addition, keep a record of your care. I know that this isn't easy, but it can be very helpful to keep a journal when you're in the hospital. Write down the names of your care providers, concerns and issues (as well as kudos) you had while in their care. When you are better and back home, write a letter about your experience to the hospital's administrators. If more of us do this, little by little, hospitals will take notice.

Although hospitals vary in their protocols and level of care they all have advantages and disadvantages with how they conduct care management of patients who are enduring a sickle cell crisis. Across the country, hospitals continue to try to improve their protocols for the handling of patients in a sickle cell crisis.

Still, there's much more effort needed to improve sickle cell crisis management when patients arrive in the ER and get admitted onto the hospital floor. As patients, we have to speak up when we're in the hospital. But we must also get involved with our local hospitals' SCD protocols when we are not in crisis and able to focus on addressing our concerns.

Be Well! Be Wonderful! Be You!
