

Long road to recovery after complications of sickle cell disease

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I've known people with sickle cell disease who are in and out of the hospital and I never had those issues. As a child growing up in the Islands, every time I went down into the sea they would literally have to carry me home because of pain. A doctor told me I had sickle cell trait, and I always went with that.

I came home 10 months ago and haven't been able to get out of the house.

I remember going into emergency 18 months ago because I noticed my eyeballs were yellow. Everything else I have no memory of until 2 months later. I was in the hospital for 6 months, then rehab for 2.5 months. I was shocked when the doctors said, "You don't have the trait. You have sickle cell disease." When I came out of ICU all my joints hurt and I had limited mobility in my arms. Rehab helped to a certain extent, but I still need a walker because my joints hurt, especially the hip area.

I came home 10 months ago and haven't been able to get out of the house because of my immobility. I live on the upper floor of a duplex and can't do the stairs. My family takes care of the stuff I need. I can't raise my leg high enough to go into the bathtub so the local community services centre (CLSC) helps me with that. At some point there will be a hip replacement, but they have to make sure there's absolutely no infection within my system. In hospital they suspected there was an infection somewhere, but they couldn't find it. What they were looking for finally came out in the left leg where I have had a draining abscess for 6 months. So I'm on antibiotics. Where the pain is concerned, I'm better than 3 months ago. Much better.

For the most part I have a positive outlook. I'm not going to tell you there aren't times when it doesn't get to me. I'm a person who used to go to the gym 4 and 5 times a week. I was very active. And now here I am ...

I haven't seen the sickle cell specialist yet because I haven't been able to get out of the house. The CLSC nurse is here 3 times a week. It's the same nurse every time, which is good. If a doctor wants a blood test, the nurse takes it and sends it to the hospital. I talk to the doctor on the phone. The last time it was a Zoom call

because they wanted to see the abscess. Zoom calls are better than nothing.

It would be nice to go into hospital, but I know the situation. I'm hoping things slowly get better. The key at this point is being able to get out of the house. — Sonia James

As told to Andreas Laupacis MD MSc
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Consent has been given for this perspective to be shared.

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