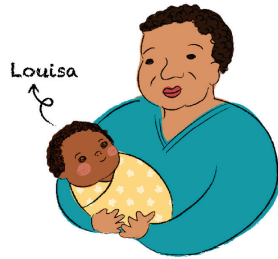




Sickle Cell disease and how it made me an Invisible Warrior

- Louisa's story -



Louisa was born a few months early with **sickle cell disease SS** - the most severe form of sickle cell disease.

This is her life story as a sickle cell warrior...

1



'My mum never heard of sickle cell disease, which is quite funny as it affects black people. But a large number of black people don't know about sickle cell, believe it or not!'

2



'I remember spending most of my childhood in the children's ward, which in my mind was just my second home. My episodes could be for 2-6 weeks, which affected my academic journey and friendships.'

3



'When my teenage years hit, after a childhood of trauma, I rebelled.'

'My whole world changed when I found out I was pregnant at 18 years old. The GP advised me not to continue with the pregnancy, and my mum stopped talking to me out of fear.'

4



'I was concerned that my daughter would inherit my disease. Luckily, my partner tested negative as a carrier of the sickle cell trait.'

'Baby girl Shyla was born with sickle cell trait, healthy and without the disease.'

5



'I had to learn how to be a mum in a hospital environment. My fear of being a single mum came true, and at times had me questioning that I was a bad mum. Friendships broke down over the years, and depression hit me very hard.'

6



'I have always worked since I was 16, as a beauty therapist, but sickle cell made that so hard.'

'I've been politely sacked from most of my jobs - or a suggestion that I should quit.'

7



'Trying to claim disability was so difficult. I was refused all throughout my childhood and teenage years and was only recognised with a disability in my mid-30s, how shocking is that!'

'I'm judged when I say I have a disability. I've been told "You look fine"'

8



'I'm not a frequent visitor to the hospital as I feel being hospitalised added to my depression.'

'I was offered counselling which I realised then how much I needed it! As sickle cell didn't just attack my body but my mind too.'

9



Invisible illnesses exist.

'I hope my insight into my life can show a different light: that although sickle cell is a medical condition, the mental effect is just as challenging, and the two go hand in hand in the way it affects us.'

'Invisible illnesses exist. Be kind'

10

'In memory of my dear friend and sickle cell warrior, Grace Said. You may be gone from my sight but you are never gone from my heart.'

The Invisible Warrior project is a Sickle Cell Disease awareness project from Imperial College London.



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Scan the QR code to watch the video of Louisa's story

