

Janaki's Story

On living with Sickle Cell Disease



My parents were so happy when I was born. I am told that I was a smiling relaxed baby who loved watching the people around me.



When I was 5, my eyes and skin turned yellow - my parents were scared it was jaundice.

At the health center (10 kms away by cycle!), the doctor asked my parents some more questions.

My history included -

- recurring infections,
- delayed growth,
- tiredness,
- and swelling in my hands and feet

"Your daughter has sickle cell disease (SCD)."

The doctor informed my parents to be very careful about infections, ensuring I drink a lot of water and get rest whenever I need it.

Some questions my parents asked at this time were:

- *What is SCD? Is it common?*
- *How do we best take care of a child with SCD?*
- *Could we have done something to prevent this from happening?*
- *What will Janki's life look like as she grows up?*

In some years, I started going to school. I liked some parts and not the others.



- *The uniform*
- *Maths classes*
- *Lunch time*
- *My best friend*
- *Getting tired*
- *Not being able to play*
- *Missing out on school due to feeling unwell*

When I turned 14, I started experiencing even more pain. My chest and joints would hurt so much that even going to the toilet was a nightmare. There was a very sharp pain in my body. Every month, I started missing school for 3-4 days - then one year, all my friends moved to a new class while I had to repeat.

Once, during exam, I was in so much pain that I could not complete my paper. I only wish I got another chance to write it when I feel stronger. My classmates said I was infectious and stopped eating with me. I felt so alone.



Then Lata Ma'am joined the school. She immediately noticed my pain, understood my circumstances, and spoke to me. She told me about SCD, how she has been living with it for 30 years, and gave me tips on managing my pain. I had so many questions -



- *Why am I always sick?*
- *Are there other people who are going through the same thing?*
- *Will I have to keep going to the doctor?*
- *Will I ever be able to work? Will I be able to play?*

With her support, she guided me with resources on SCD. She also guided me to Mittaninn didi, who spoke to my classmates and me about SCD. That is when we learned that SCD is very common in our community, we even organised an assembly in school to talk about this, and nudged people to get screenings (boys included!) so they could get the care they needed.

In between all of this, I had to visit the health centre at least monthly to get my medicines. Sometimes, when my doctor wasn't around, it was hard to explain to the new ones how much pain I was in. When my medicine was not available due to a shortage, I worried about managing everyday life and kept wondering when it would be restocked.

With Lata ma'am's help and guidance, I enrolled for a diploma in computers after finishing school. This was a careful choice, keeping in mind my family's financial needs, my love for computers, and my need for less movement. It was so exciting since the internet connected me to the world while staying at home!

Seeing the men and women around me who continue to do physical labour - inside and outside the house - while having SCD continues to break my heart. I started working with a local NGO to raise awareness, support early screenings, and provide information on SCD. In the process, I found and built a community of my own.



Savita, 23, was abandoned by her husband after they both learned that she had SCD when she got pregnant. Now she has to work to take care of her daughter and cannot afford to go to the health center regularly.

Mahesh, 35, lost his job due to recurring fever, infections, and pain. He tried getting a disability certificate to get some government support, but faced a lot of hurdles and eventually had to give up.

Turns out, even my grandmother (Sugam) has SCD. She developed AVN (avascular necrosis) soon after she turned 50. She needs hip surgery, which we can't afford. My NGO is helping me fundraise, though I wish the government could support us at this time.

As for me, I started my own social media channel to ensure that even more people learn about SCD, to share about my journey, and to connect with many sickle cell warriors across the world.



I met Nigam (he also has SCD apart from being a fantastic cook) during one of my trainings on government support available to people with SCD. We became friends and then started liking each other. Questions we often ask are -

- *How can the government support people with SCD better?*
- *Do we want to have children if there is a high chance that our child may also have SCD?*
- *What are some things we need to be aware of as we grow old together?*

We haven't decided anything yet, but if we do choose to have children - we want it in a world where the appropriate care is available. So till then, we focus on building a world where people with SCD are seen, supported, and taken care of.

Can you estimate what these numbers look like for me?

- # doctor visits each year
- # average spending on health per year
- # time needed to rest, heal, and seek treatment
- # dreams that had to be let go
- # opportunities missed at school, work, and career
- # friendships lost
- # money that could be spent on other things

Learn More



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