



Creating an Ecosystem of Care

For people with Sickle Cell Disease



Sama

Last year, when I was rushed to the health center due to severe chest pain, it was very helpful to have kept all my documents and records in one place.



If you have SCD, it is important to be your own health advocate. You can do this by -

- Knowing that you have a right to health; to care & treatment; to marriage, education, and employment; and to any affirmative support you need to fulfill your dreams. You have this right regardless of your gender, caste, socio-economic status, religion, ability, or anything else
- Identify spaces of care that work for you -
 - a kind healthcare provider/ mitanin
 - the nearest health center to get medicines
- Find & build a support system for yourself - people who can be there for you physically, emotionally, mentally, and financially, when you need it



I know you're not lazy. I understand that you're tired because you have Sickle Cell Disease. How can I help you?

If you know someone living with Sickle Cell Disease, here is what you can do -

- Learn more about SCD, common symptoms, and break your own stereotypes/ myths/ and beliefs about SCD
- Be there for your friends - offer support and care, offer to take up tasks, and always ask how you can help
- Actively work on de-stigmatising SCD - interrupt when you hear or witness people operating with misinformation or bias

We've introduced indoor play activities and listening circles so that students with disabilities are able to have fun and connect with their peers.

As leaders of education spaces, you can -

- Actively include play activities that are accessible and enjoyable for people with SCD
- Offer extra classes where needed
- Conduct awareness sessions on SCD to create a supportive environment for the students



We actively engage employees with chronic health issues in designing and implementing our HR policies.

At the workplace, you can-

- Design policies for people with chronic health conditions ensuring flexible work hours, work-from-home policies, and flexibility around leaves
- Ensure non-discriminatory and supportive hiring for people with chronic health issues

When the couple came to me for pre-natal tests, that is when we discovered that the husband has SCD. It was a difficult conversation. They had to come back multiple times to understand the course of treatment for the husband and to make an informed decision on whether they want to go ahead with the pregnancy.

As health care providers, you can -

- Believe people with SCD when they self-report symptoms - do not underestimate pain
- Ensure a steady supply of medicines, blood, platelets, and beds for people in need
- Develop a standardised protocol for people in crisis
- Build cognizant of your own biases - especially towards caste, gender, socio-economic status, geography, and age of patients
- Ensure informed counseling around marriage and reproductive choice is available for people with SCD
- Ensure that mental health care in the form of psychological and psychiatric support is available



In our community, we have a group of volunteers who step in to support people living with SCD - be it in doing the housework or taking them to the health centre. We don't want any of our members to feel alone in the face of so much pain.

As a community leader and member, you can -

- Address stigma and prejudice against people with SCD through community awareness building
- Be mindful of gender differences and how gender norms affect people with SCD - especially norms around marriage, having children, and ability
- Provide community support and care for people with SCD who often feel lonely, alienated, and may be in psychological distress
- Support people with SCD in accessing health, education, and employment
- Proactively involve people living with SCD in decisions that will affect them

Many of the suggestions mentioned so far depend on your goodwill and sense of responsibility. To ensure that this care is available to people with SCD across the country as a right, we need to advocate for policy-level changes - be it in creating more effective policies or in implementing existing policies more strongly, such as -

- Assigning dedicated sickle cell centres in high-prevalence districts offering standardised services, treatment, mental health care, and marriage and reproductive counselling. Ensure access to prenatal testing, abortion services, and care for children born with SCD
- Ensuring that screenings are accompanied by precise information & counselling, followed by referral to the appropriate health facility for treatment and care
- Social protection under the Rights of People with Disabilities Act, 2016, through reservations in jobs, schools, training institutes, and colleges; streamlining the process of getting the certificate with a focus on the ability of the person to function rather than only diagnosis
- Building and ensuring accountability and grievance redressal mechanisms
- Ensuring mental health care, counselling, and psychological/ psychiatric support are available & accessible for people living with SCD.

Principles of Care to Keep in Mind

One must ground the approach to SCD care in intersectional feminism, disability justice, and a rights-based approach. This means -

- Recognising that health inequities are not accidental — they are structurally created by caste, class, gender, religion, geography, and ability.
- Every person has the right to make informed decisions about their own body and care — without fear, coercion, or judgment and with honest and transparent information
- Disability justice means real access — to care and resources, not just paperwork.
- Quality healthcare is a right — for everyone, regardless of caste, gender, religion or region.

Learn More



Sama

Sama – Resource Group for Women and Health
<https://samawomenshealth.in>
 B-167, Ground Floor, Amar Colony
 Lajpat Nagar IV, New Delhi – 110024
 Phone: 011-26692730, 011-40666255
sama.womenshealth@gmail.com