

What is Sickle cell disease?

Sickle cell disease is generally a severe condition resulting from the inheritance of the abnormal Sickle cell gene from both parents. Where both parents carry the gene, there is 1 in 4 chance of a child having the disease (SS) at each pregnancy, 1 in 4 chance of having a normal one (AA) at each pregnancy, and a 2 in 4 chance of having a carrier (AS) since the Sickle cell gene is carried by 20% of Ugandans. An estimated 6,000,000 Ugandans are at a risk of having a child with Sickle cell disease and 30,000 babies with the disease are born in Uganda each year. Sadly 80% of these babies are dead before their fifth birthday.

Steps to be carried out at home

- Parents must give daily folic acid.
- Parents must give weekly or monthly a malaria preventive drug depending on the health worker's advice, apply mosquito repellents after 6:00pm and always sleep in treated mosquito nets.
- Patients must drink lots of fluids daily: 3 litres at least for children and 5 for adults.
- Oral re-hydration salts should be taken daily but can also be made locally by using one levelled tea spoon of salt plus eight levelled spoons of sugar, add in one litre of drinking water. One can take it as often as possible. Watch out for the colour of children's palms, lips and tongue daily if they change from dark to white/yellow or pale then rush to the hospital.
- Take diluted boiled avocado leaves or fresh beet root once in 3 months for adults and 2 months for babies (discovered by patients and parents), helps in boosting haemoglobin levels.
- In case of high fever the patient should be given paracetamol and rushed to hospital
- Always find out the cause of pain i.e. 24 hrs before the pain what happened?
- Artificial iron e.g. Heamup, Fero B, Heam phote, Ferrous are not recommended unless in cases of iron deficiency.
- If an (SS) person is pregnant, she should attend two (2) clinics; that is Sickle cell and antenatal clinics.
- Patients must eat a balanced diet daily especially fruits and vegetables.

The five problems below can be treated at home within two days

- The patient may have been exposed to a wet or cold environment which triggers a painful crisis.
- Constant stress related factors over a long time.
- Exhaustion
- Dehydration
- Anxiety / Excitement.

First Aid in case of pain at home

1. Take pain killers.
2. Take lots of fluids.
3. Get enough rest.
4. Use a hot water bottle or warm piece of cloth on the affected area.
5. Understand that the pain, even though unbearable, doesn't kill. It is the cause of pain which kills.

Prevention of complications

- a). In case one experiences difficulty in climbing hills or steps, he/she should stop walking long distances on foot and climbing stairs. Try to lose some weight as this may develop into severe disease.
- b). Painful erection should be rushed to hospital within 24 hours. This is an emergency to be managed by experts.
- c). In case of a cut around the ankles, the wound should be treated immediately and seriously to prevent leg ulcers (wounds).
- d). Mothers should feel for the spleen, an organ below the left ribs, daily as they bathe the babies. If it becomes bigger they should see a doctor.
- e) . Regular medical check-ups and follow-ups.
- f). Safeguarding against infectious diseases especially Malaria, Tuberculosis and HIV/AIDS.

Key issues in bringing up Sickle cell children

- They should be given more love and care in the family but also given the same opportunities especially in education. However, they shouldn't be spoilt because the parents will not be available all the time in their lives.
- Over protection sometimes spoils them in adulthood so some freedom should be given after 18 years of age.
- They should be groomed into responsible citizens to avoid stigma and discrimination.
- They need to develop good skills to earn a living for survival.
- The first five years are risky years because in Uganda the average survival age is less than five years.
- The disease is not widely cured but a lot can be done for one to improve on the quality of life.
- Should be able to join the Sickle cell Association of Uganda and take part in the activities.

Always consult a doctor whenever you have a problem.

The information on this page was developed by The Sickle cell Association of Uganda
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