सत्यमव जयते

Government of India

Ministry of Tribal Affairs & Ministry of Health & Family Welfare

Awareness Modules on Sickle Cell Disease

Towards
SICKLE CELL FREE INDIA

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Introduction

Towards Elimination of Sickle Cell Anaemia in India by 2047

The Budget 2023 contained an announcement which reads as **"A Mission to eliminate Sickle Cell Anaemia by 2047 will be launched. It entails awareness creation, universal screening of 7 crore people in the age group of 0-40 years in affected tribal areas, and counselling through collaborative efforts of central ministries and state governments".** The lead Ministry in this regard is the Ministry of Health and Family Welfare (MoHFW) with the supporting Ministry being the Ministry of Tribal Affairs (MoTA). There are other stakeholders identified by the MoHFW in this Mission, including the State Governments.

Constitution of Committee by MoTA:

Following the post budget Webinar on the announcement held on 27.02.2023 and in order to formulate a comprehensive and effective strategy, this Ministry has constituted a Committee to devise guidelines for generating awareness about the disease, its management and prevention of future births with the disease as well as for counseling of patients, care-givers and other stakeholders when an individual is diagnosed with the trait/disease.

Since among communities, there may be certain beliefs, traditional customs, myths, practices related to health and disease, there is need of dedicated efforts to spread scientific awareness about how the disease is transmitted and the manner in which the transmission can be controlled.

These two modules on awareness and counseling are prepared with the aim to provide awareness to the general population as well to the patients, caregivers, school teachers and the health workers. The modules have been prepared in the form of PPT so that it is easier for every one to understand the sickle cell manifestation. In the modules one may find duplication of the messages as these messages have to be conveyed to all the stakeholders. The Awareness module is primarily intended to reach the general public, especially the tribal population, the medical fraternity, the influencers at the local level – the ASHA, the Anganwadi worker, the teacher, the youth, the traditional headmen and healers, the Gram Panchayats and so on. The Counseling module is intended for a smaller target group of those who are directly affected by the disease and are responsible as primary or secondary caregivers such as patients, their parents and other caregivers in the family, school teachers, co-workers and health workers.

The Ministry takes this opportunity to thank the Chairperson and Members of the Committee as well as other experts for having drafted the module within a very short period of intense deliberations. The Ministry also acknowledges the support given by the MoHFW in the vetting, finalization and translation of these documents. It is sincerely hoped that these documents would go a long way in achieving the Mission's objective of elimination of Sickle Cell Anaemia by 2047 in India.

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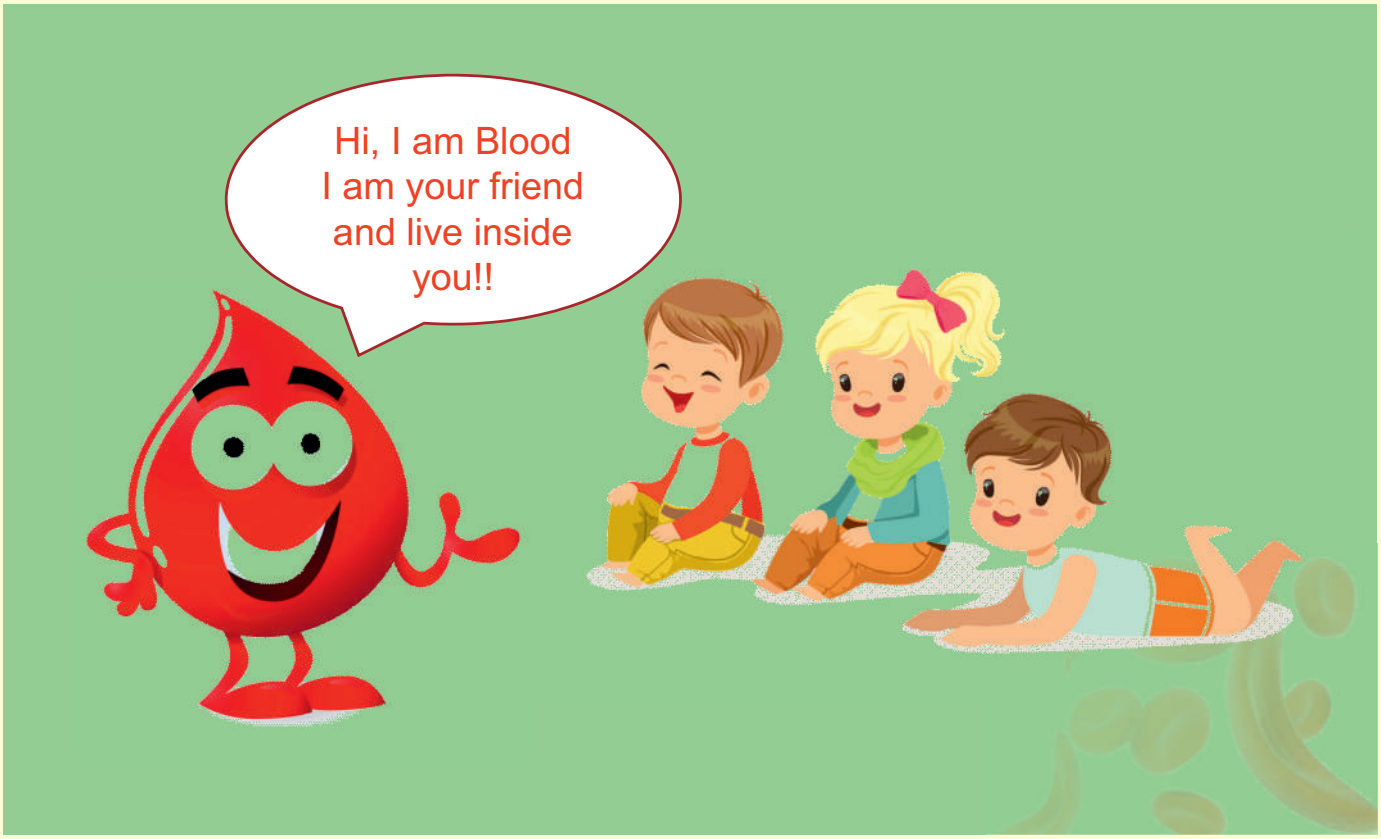
Module Part - I

Awareness Modules for

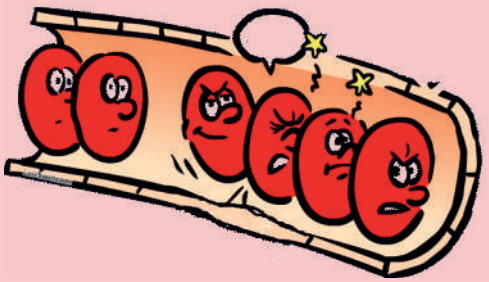
Non-Health Functionaries

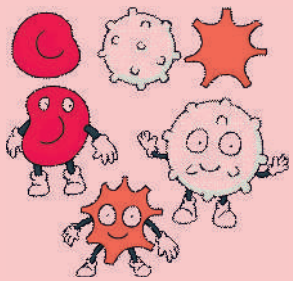


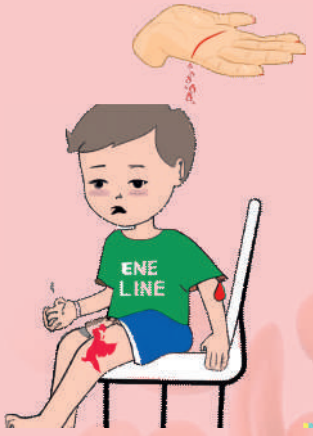
What is Blood ?

Have you ever been injured or got a cut in the skin?

Have you seen red colored fluid flowing from your skin when cut?
This red colored liquid is called “Blood”
The blood is made up of cells that help to carry oxygen and fight infection



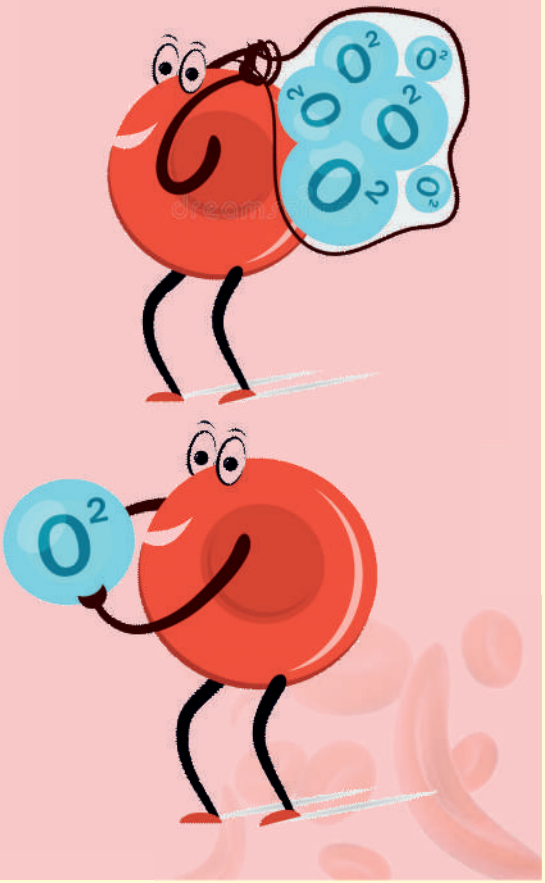




Cells in Blood

Blood contains three types of cells:

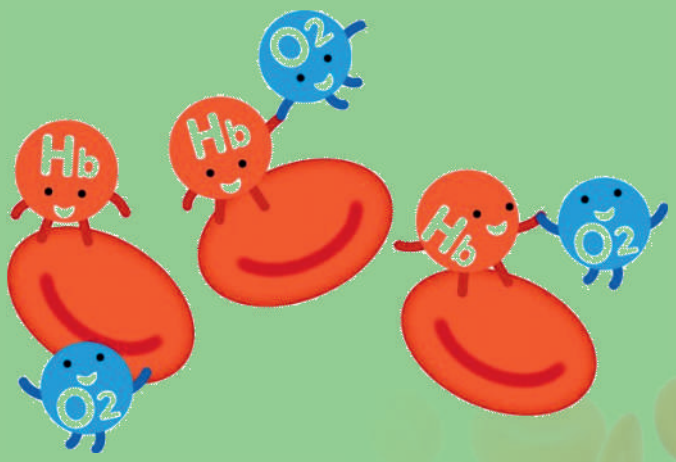
- White blood cells: fight with small enemies like bacteria and virus
- Platelets: Stop bleeding
- Red Blood Cells: Carry oxygen to different parts of your body



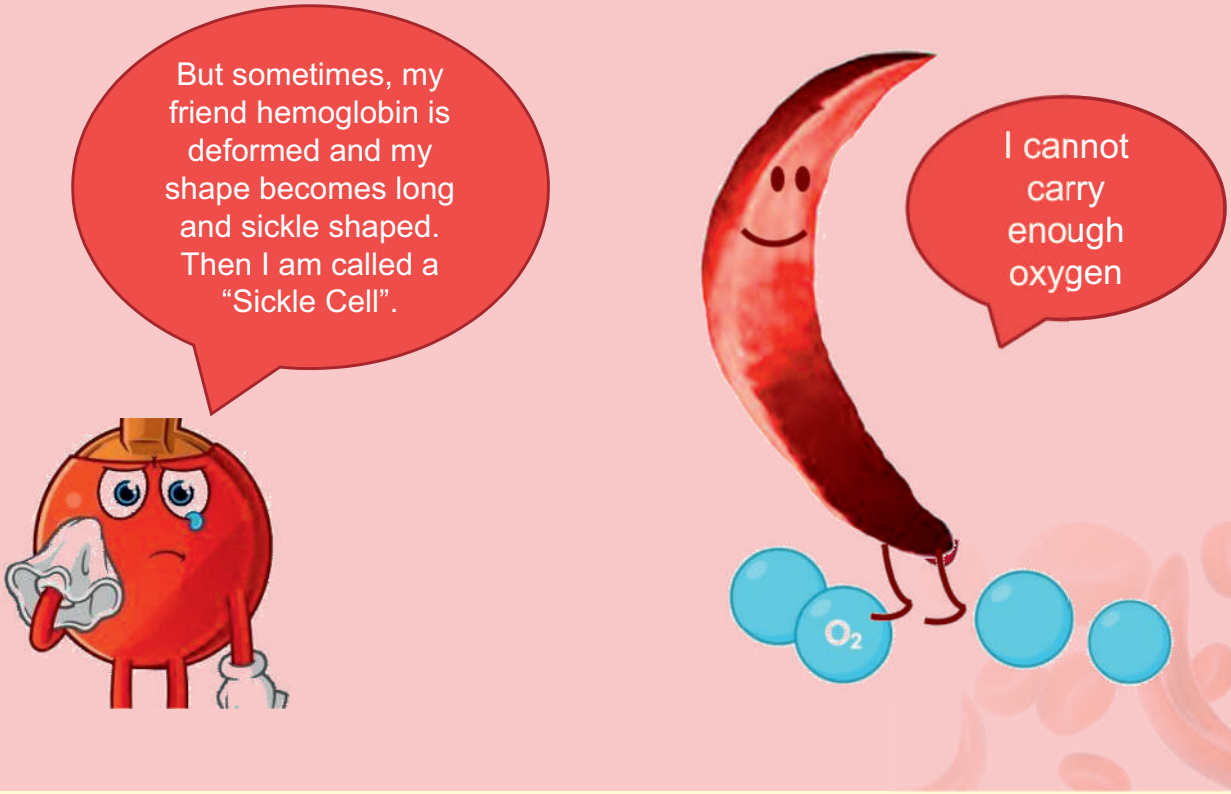
I Am Red Blood Cell

I have many little fellows inside me -- named hemoglobin--which carry oxygen to all parts of the body

Red Blood Cell

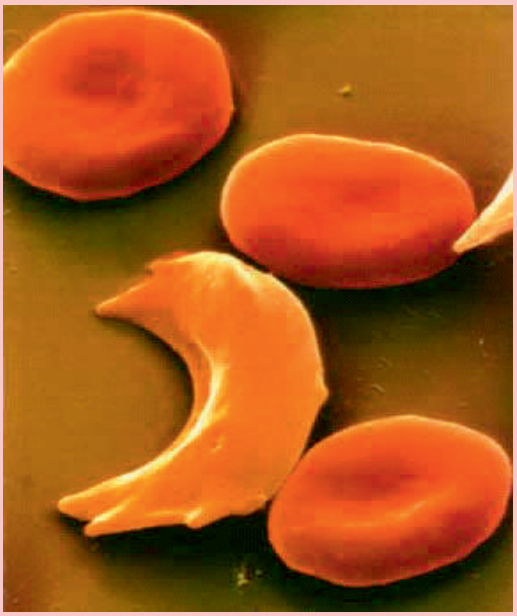


What is Sickle Cell?



Sickle Cell Disease!!!

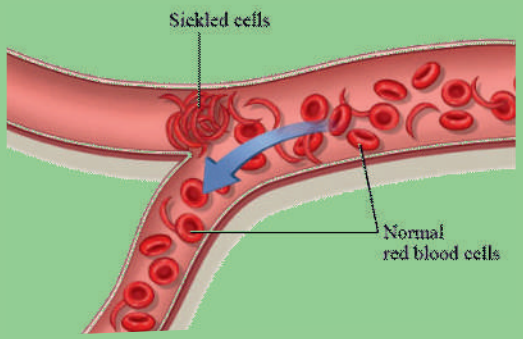
Changes in Red blood cell structure and function



- ✓ Red blood cells in sickle cell disease have cell life of 30 to 40 days instead of usual 120 days.
- ✓ Rate of destruction is high

Italia et al – Sickle Cell Anemia, 2023

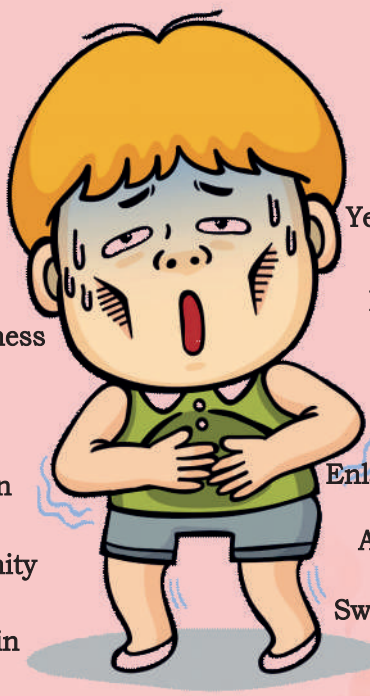
Sickle cell pathophysiology



* Sickle cells are rigid
* The stiffness and abnormal shape reduce their ability to move through smaller capillaries. They also form tangled masses of cells in larger blood vessels.
* Blockage of blood flow produces temporary or permanent organ dysfunction or structural changes

Italia et al – Sickle ell Anaemia, 2023

Symptoms of Sickle cell disease



Anaemia/looking pale

Frequent infections/Illness

Fatigue

Chest pain

Low Immunity

Joint pain

Fever

Yellow colored eye

Breathlessness

Backpain

Enlargement of spleen

Abdominal pain

Swelling

Sickle cell disease can cause several health problems

ANAEMIA: Sickle cells have a shorter life than regular red blood cells, the body cannot make new red blood cells fast enough to replace old ones. With fewer red blood cells, organs and tissues do not get enough oxygen they need for normal functioning.

PAIN: crescent–shaped cells can get stuck in smaller blood vessels. This may block blood and oxygen flow to tissues resulting in pain.

INFECTIONS: Curved and sticky blood cells can clog the spleen and prevent it from doing its job – helping the body kill germs.

ORGAN DAMAGE: Lack of oxygen over many years can lead to tissue and organ damage in any part of the body.

COMPLICATIONS DURING PREGNANCY: A woman with sickle cell disease can have a healthy baby. However, many risks like hypertensive syndromes (such as preeclampsia), blood clot in veins, preterm labor, fetal loss etc. may occur. Both the mother and baby should be closely monitored by a healthcare provider. Care during pregnancy is also very important!

What is the difference between Sickle Cell Trait and Sickle Cell Disease.

Difference between sickle cell disease and sickle cell trait:

SICKLE CELL DISEASE	SICKLE CELL TRAIT
• Two copies of altered hemoglobin gene from parents. • Crescent shaped structure of red blood cells that results in blockage of blood flow to different cells and blood vessels of the body.	• Individuals carry one copy of the altered hemoglobin gene. • Combination of altered hemoglobin and normal hemoglobin result in sickle cell trait.

Being aware of your sickle cell status is very important to improve your health condition and prevent complications

Only screening can identify sickle cell disease and carriers (trait) who may otherwise be healthy and have no symptoms

Should I worry if I am a carrier or have sickle cell disease?

First of all-Don't worry, if you have sickle cell disease or you are sickle cell trait

If you are carrier-	If you have Sickle cell disease-
• You can live normal healthy life. • You should avoid marriage with people having sickle cell trait or sickle cell disease. • You may avoid going to high-altitude places.	• Consult the specialist / Medical officer as advised. • Keep yourself hydrated • Take regular medicines • Consume balanced and healthy diet • Keep yourself safe from extreme environmental conditions and follow a healthy lifestyle • Avoid high altitude places

By taking regular medicine and regular follow-up with doctors, Sickle cell disease patients can avoid many problems.

Why should I know about it?

- Because sickle cell disease / trait is preventable as it is a genetically transmitted disorder

Individuals –
may be carriers or patients.

Who should know about it?

Families and loved ones – who may be involved in caring for someone with sickle cell disease or those having SCT

What should COUPLES with carrier or disease status be aware of ?

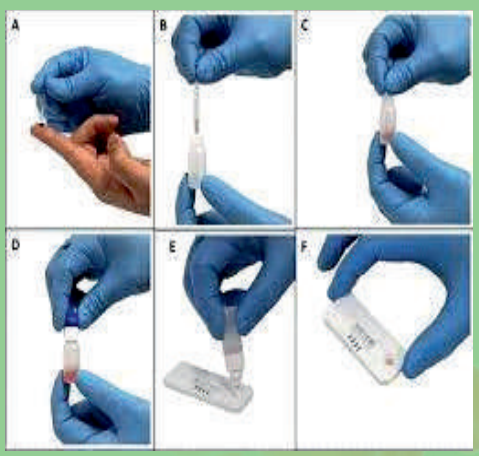
Couples who are carriers of the disease need to be aware of the possibility of passing sickle cell gene to their children

How to Test?

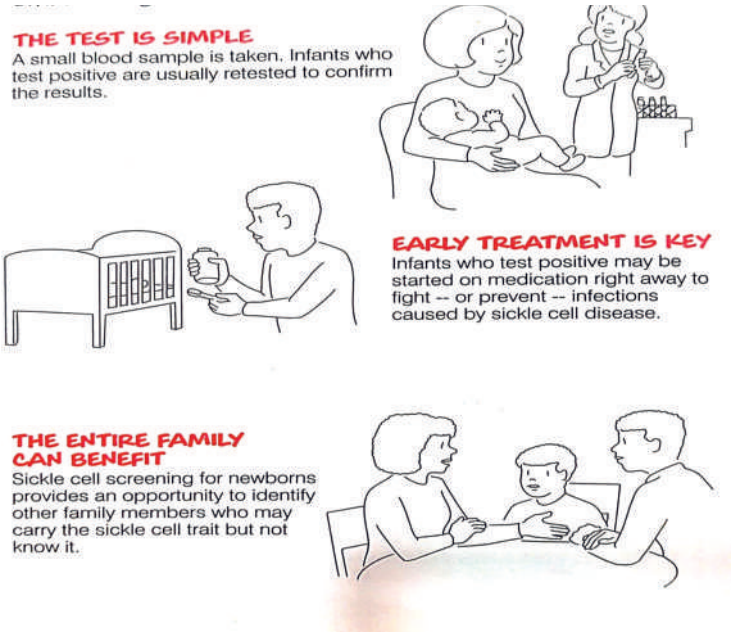
Screening and Diagnosis

A drop of blood will detect sickle cell by available point of care tests; which is also a confirmatory test at AB-HWC and other public health facilities

Special blood test (HPLC, electrophoresis) may be done for evaluating the utility of red cell indices. It is done at higher healthcare facilities



ALL NEWBORNS IN IDENTIFIED DISTRICTS & STATES SHOULD BE TESTED FOR SICKLE CELL DISEASE



Most of the affected states have sickle cell screening programs in place in hospitals where babies are tested at birth.

Sickle cell screening is planned to be conducted among people of age group 0-40 years in 17 states identified for Sickle cell disease elimination

Living a productive life with sickle cell disease

- Sickle cell disease in a child puts economic and emotional stress on the family
- If sickle cell disease is diagnosed on time, medical management can help you lead a productive life

Services available at AB-HWCs

- Prevention Awareness
- Screening through outreach camps and at Health and wellness centers
- Management support
  - o Treatment
  - o Referral support
- Counselling
  - ○ Lifestyle modification
  - ○ Premarital and preconception counselling
- Follow-up
- Rehabilitation (psychosocial and vocational)

Know these facts

- Sickle cell anaemia is more common in tribal areas
- People of any ethnic group can have sickle cell trait or disease. In India, 17 states have high prevalence of sickle cell disease. It's more common in tribal population but non tribals can have it too.
- Sickle cell disease is not contagious
- A person cannot get sickle cell disease through the air, water, skin, etc
- The only way to get is to have it passed on from your parents through genes.
- Sickle cell trait can not develop into sickle cell disease
- Sickle cell trait is not a disease. There is no chance that a sickle cell trait will develop into sickle cell disease.
- Sickle cell disease is not caused by any personal / food habits
- It's by chance that someone has Sickle cell disease- so please get newborns and all others tested in affected areas

Module Part - II

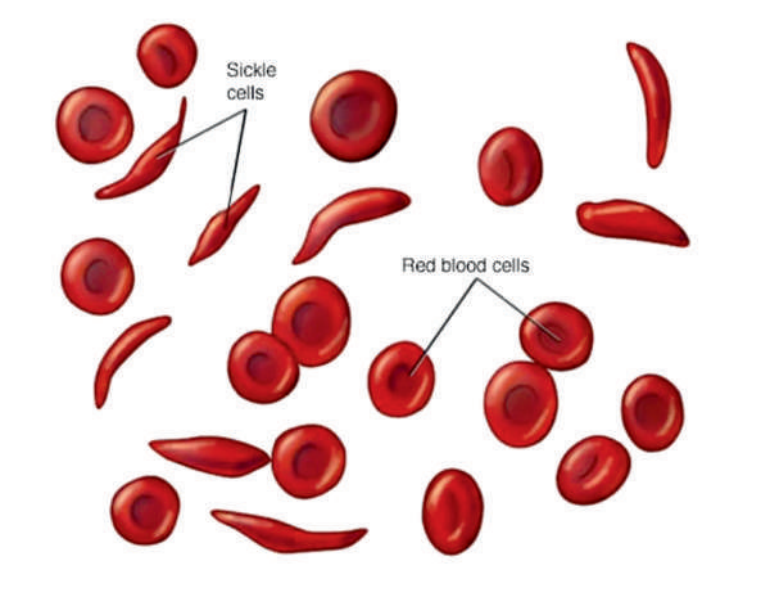
Awareness Modules for Parents

Parent Information Sheet

- Parents should share the information to the school and other places of regular contact about the child having sickle cell disease
- Parents should know that child must be taken for regular check ups to prevent complications
- The child should be taken immediately to healthcare facility / clinic/ hospital if having high fever, breathing problem or pain not getting relieved within 24 hours, or sudden weakness or any other complications

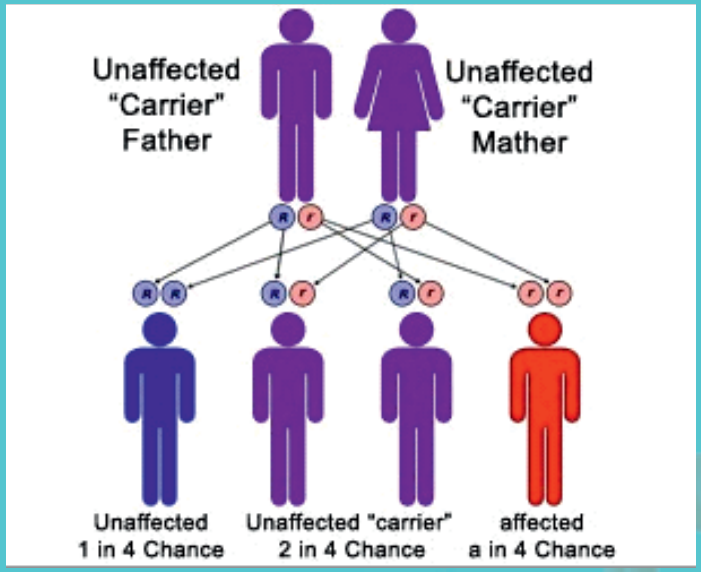
What is sickle cell disease?

- In Sickle cell disease, the hemoglobin molecule inside red blood cells is abnormal.
- The red blood cells carrying sickle-hemoglobin become sticky and deformed (C shaped)
- This can block small blood vessels causing severe pain and organ damage including stroke
- These red cells also get destroyed early resulting in anaemia

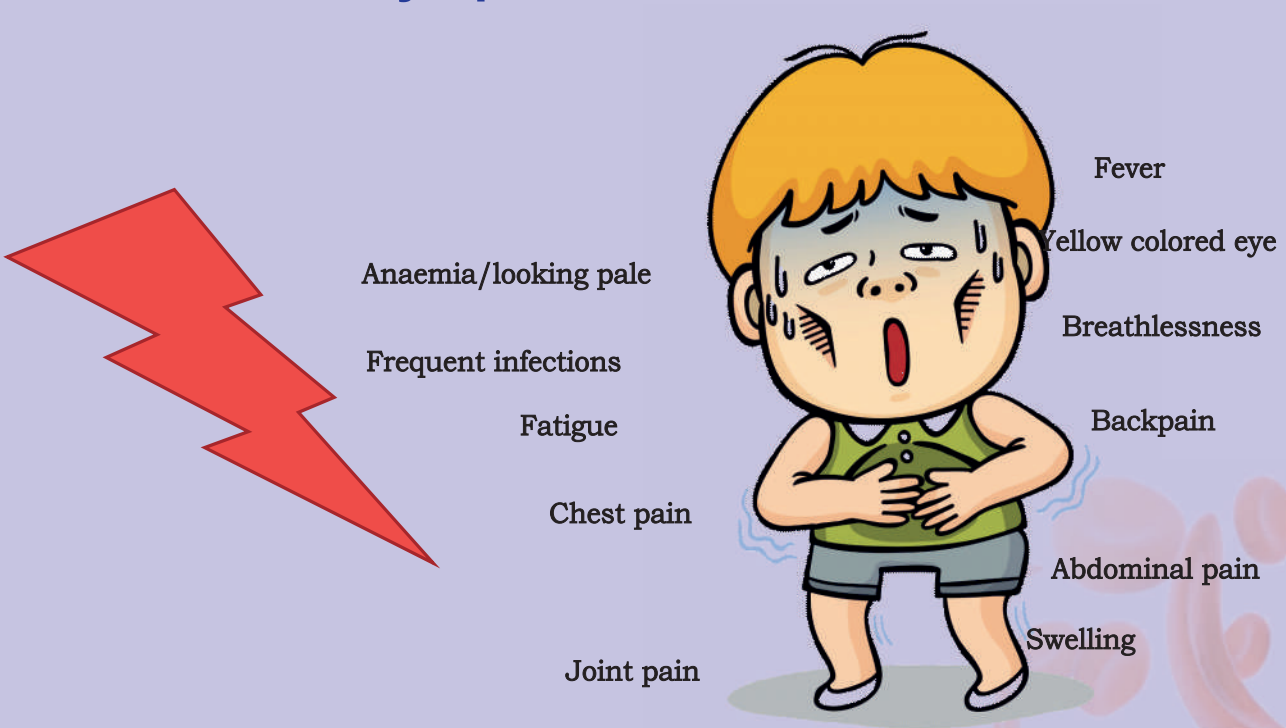


WHAT CAUSES SICKLE CELL DISEASE?

- Sickle cell disease is an inherited condition from parents who have sickle cell trait or disease
- Here hemoglobin is different compared to the normal hemoglobin because of mutation in gene
- Carriers of the disease are usually not symptomatic and can be detected only when screened



What are the symptoms of sickle cell anaemia?



WHAT IS SICKLE CELL CRISIS?

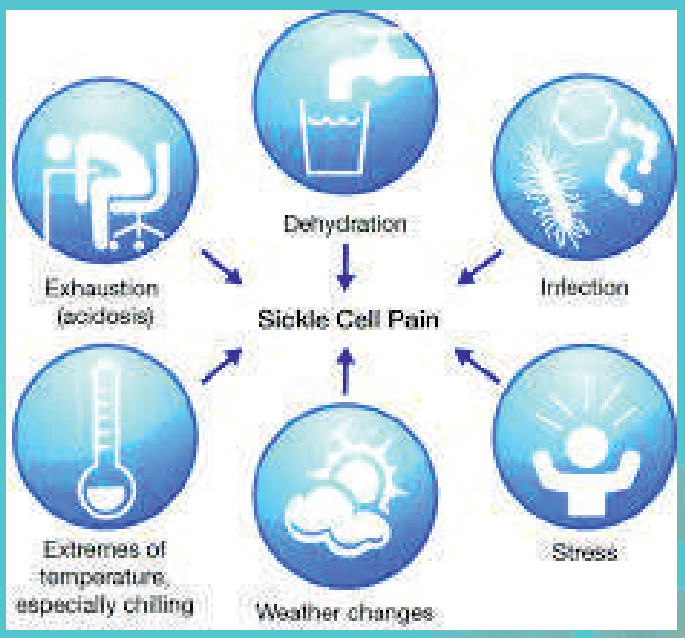
- Many children and adults develop what is called pain crisis
- During this period, they present with acute pain in the back, legs, chest etc.

What triggers pain?

Change of weather, diarrhea, fever, dehydration, infection, stress, exhaustion etc.

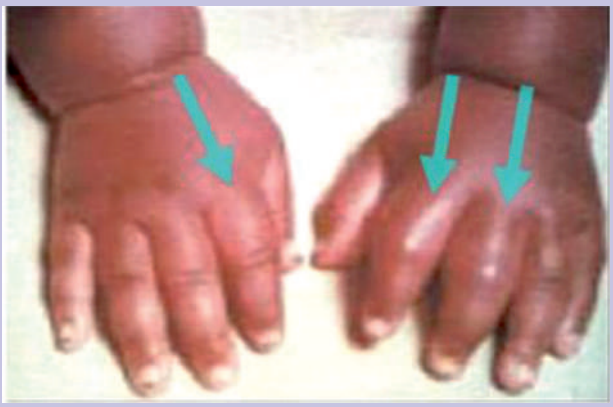
Other symptoms during the pain crisis

Breathlessness, nausea, etc.

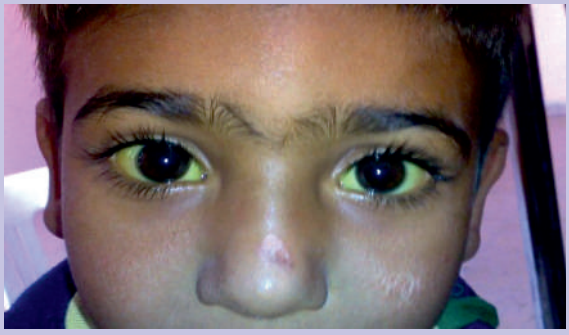


How can you identify sickle cell anaemia crisis?

- **Crisis can present as -**
- **Hand-foot syndrome -** swelling and pain in hands and feet
- **Acute chest syndrome –** cough and difficulty in breathing
- **Eye –** can affect blood vessels in eye and reduce vision
- **Stroke –** can affect blood vessels in brain and cause stroke



Pain crisis Painful swelling of hands and feet



Recurrent episodes of jaundice

Pallor Child's hands look pale

My child has sickle cell disease. What should I do?

- Sickle cell disease is a lifelong condition
- But the good news is that children can be managed well if they are under the care of a doctor
- These children can do well in life, finish their studies, take up a job and get married to a normal person and have kids also.
- So, by focusing on good medical care, we can provide them the 'healthiest life possible'.

How should I take care of my child with Sickle Cell Disease?

- Your child needs additional support and care compared to any other child
- This includes-
  1. Routine follow-up visits with the doctor2.
  2. Pneumococcal vaccination
  3. Consultation at the earliest in an event of crisis or any complication
  4. Possibility for curative treatment may be explored

How should I take care of my child?

- Your child needs additional support and care compared to any other child

- **This includes-**

1. Routine follow-up visits with the doctor
2. Pneumococcal vaccination
3. Consultation at the earliest in an event of crisis or any complication
4. Possibility for curative treatment may be explored

HOW DO WE TREAT SICKLE CELL ANEMIA?

Regular checkups even if there are no symptoms, as advised by your doctor.

Take medicines and vaccinations as advised by the doctor.

- In case of anaemia, if the child is not improving with medicines, blood transfusion may be needed.
- In case of sickle cell crisis, the child is admitted and treated with antibiotics, IV fluids, etc.

WHEN SHOULD I TAKE MY CHILD TO A DOCTOR?

- Your child should be seen by a doctor regularly at least once every 3 months or earlier as advised by the doctor
- If you are on hydroxyurea, visit the health and wellness centre for monthly complete blood checkup and other tests as advised
- Maintain records of the treatment properly in a file, keep all your papers together

TAKE YOUR CHILD TO A HOSPITAL IF HE/SHE HAS

- Repeated fever
- Repeated infections/pneumonia
- Repeated pallor
- Recurrent episodes of jaundice
- Repeated bouts of pain anywhere in the body
- Swelling of hands, feet or joint pain
- Ulcers in legs
- Child not growing well
- Breathlessness
- Enlargement of spleen
- Blood in urine

Consult the nearest medical officer or pediatrician immediately

HOW CAN WE PREVENT COMPLICATIONS IN SICKLE CELL ANEMIA?

1. **Be regular with treatment**

   As caregiver, parents need to make sure the following

   - Keep medical records: Hard copy or digital record by ABHA ID
   - Keep copies of reports, discharge records, diary of events and pain crisis scores
   - Give copies of reports and prescriptions to the doctor during a visit
   - Maintain a digital health record - when possible

2. **Be regular with medications such as folic acid, penicillin, hydroxyurea, etc.**
3. **Show child to doctor regularly as advised even when otherwise healthy**
4. **Educate the patient for self-management**
5. **Be patient and considerate**

MAINTAIN A MEDICAL RECORD FOR YOUR CHILD CONTAINING THE FOLLOWING

- Name
- DOB
- Type of sickle cell disease
- Ongoing medical problems
- Past medical and surgical history
- Transfusion dates
- Medications
- Immunizations received

2. NONMEDICAL CARE TO THE CHILD

As a parent, make sure of the following:

- Encourage child to take a balanced diet
- Prevent dehydration: 6-8 glasses of water is advised per day. Take breaks during exercise in school routine to prevent dehydration. Keep child hydrated during summer/fever, etc.
- Know symptoms and seek timely care for symptoms

3. THINGS TO DO TO REDUCE INFECTIONS

It is important to prevent infections in children with sickle cell disease. Because children with sickle cell disease are prone to infections. The risk of sickle cell crisis increases during infections. As a parent, make sure of the following:

- Maintain good hygiene to prevent infections. Simple measures to reduce the chance of infections are -
  a. Washing hands regularly
  b. Brush teeth twice a day
  c. Food hygiene - avoid food prepared unhygienically
  d. Balanced diet
  e. Vaccinations as per the national immunization schedule
  f. Penicillin prophylaxis to prevent some common infections under the supervision of the doctor

4. MAINTAIN ACTIVE AND HEALTHY LIFESTYLE

- Advise children to exercise regularly
  - It strengthens heart and lungs
  - Improves stamina
  - Reduces pain crisis
- Discuss with your doctor regarding the level of physical activity to be followed by your child
- Children should be encouraged to continue schooling and follow active lifestyle
- Children should be encouraged to participate in sports
  - Avoid strenuous exercise in hot climate
  - Give breaks in between exercises to hydrate themselves
  - Encourage children to use the toilet since they will be drinking more water
  - Breathing exercises, yoga and meditation are helpful

Services available at AB-HWCs under the Sickle Cell Disease Elimination Mission

- Prevention Awareness
- Screening through outreach camps and at Health and wellness centers
- Management support
  - Treatment
  - Referral support
- Counselling
  - Lifestyle modification
  - Premarital and preconception counselling
- Follow-up
- Rehabilitation (psychosocial and vocational)

WHAT IS THE VACCINATION SCHEDULE TO BE FOLLOWED?

NATIONAL IMMUNIZATION SCHEDULE

For Infants		
BCG	At birth or as early as possible till one year of age	0.1ml (0.05ml until 1 month age)
Hepatitis B - Birth dose	At birth or as early as possible within 24 hours	0.5 ml
OPV-0	At birth or as early as possible within the first 15 days	2 drops
OPV 1, 2 & 3	At 6 weeks, 10 weeks & 14 weeks (OPV can be given till 5 years of age)	2 drops
Pentavalent 1, 2 & 3	At 6 weeks, 10 weeks & 14 weeks (can be given till one year of age)	0.5 ml
Rotavirus#	At 6 weeks, 10 weeks & 14 weeks (can be given till one year of age)	5 drops
IPV	Two fractional dose at 6 and 14 weeks of age	0.1 ml
Measles /MR 1st Dose$	9 completed months-12 months. (can be given till 5 years of age)	0.5 ml
JE - 1**	9 completed months-12 months.	0.5 ml
Vitamin A (1st dose)	At 9 completed months with measles-Rubella	1 ml (1 lakh IU)

WHAT IS THE VACCINATION SCHEDULE TO BE FOLLOWED?

For Children	
DPT booster-1	16-24 months
Measles/ MR 2nd dose $	16-24 months
OPV Booster	16-24 months
JE-2	16-24 months
Vitamin A* (2nd to 9th dose)**	16-18 months. Then one dose every 6 months up to the age of 5 years.
DPT Booster-2	5-6 years
TT	10 years & 16 years

Additional vaccines to be administered as per National Programme.

WHEN SHOULD WE TAKE THE CHILD TO A DOCTOR IN AN EMERGENCY?

If the child has any of the following, take him/her to the hospital immediately

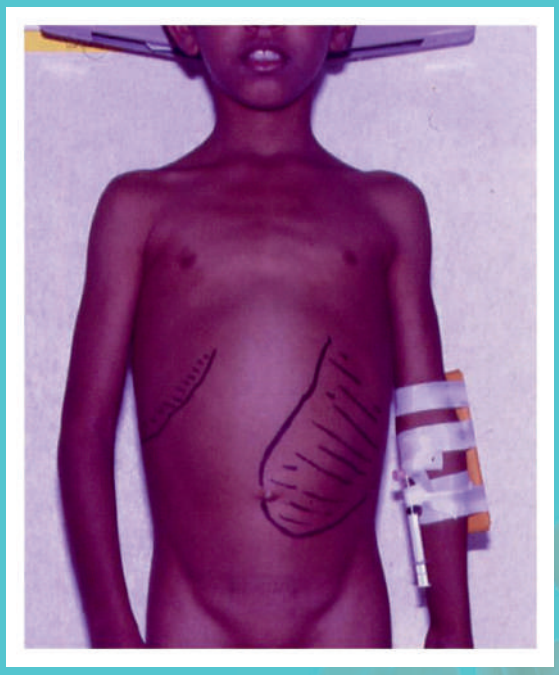
1. Fever more than 101 °F
2. Vomiting or loose stools
3. Difficulty in breathing or chest pain
4. Pain in abdomen
5. Sudden increase in pallor or yellowness of eyes
6. Distention of abdomen
7. Severe headache
8. Sudden weakness of arms/ legs
9. Seizures
10. Sudden increase in size of spleen
11. Unconsciousness or giddiness or confusion

In case of fever/pain

- Fever and pain are EMERGENCIES for a child with sickle cell anemia
- Keep child well hydrated.
- Child needs to be taken to the doctor even if when fever or pain reduces

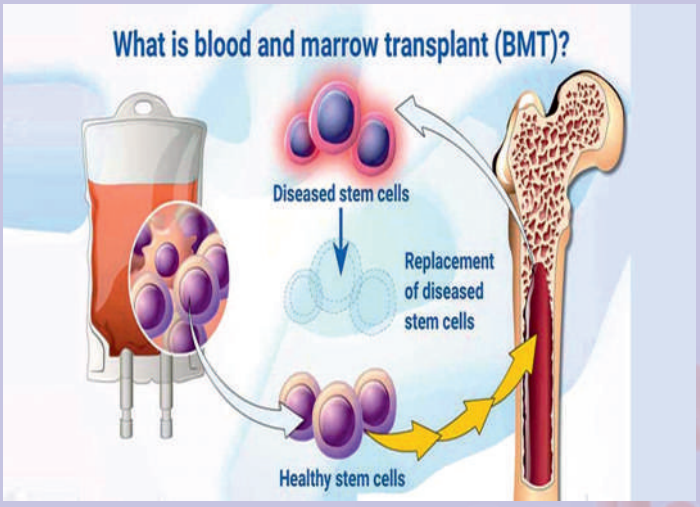
HOW DO WE LOOK FOR INCREASE IN SPLEEN SIZE?

- Any sudden increase in size of abdomen or pain in abdomen, dizziness, pallor, etc., should be considered as an emergency



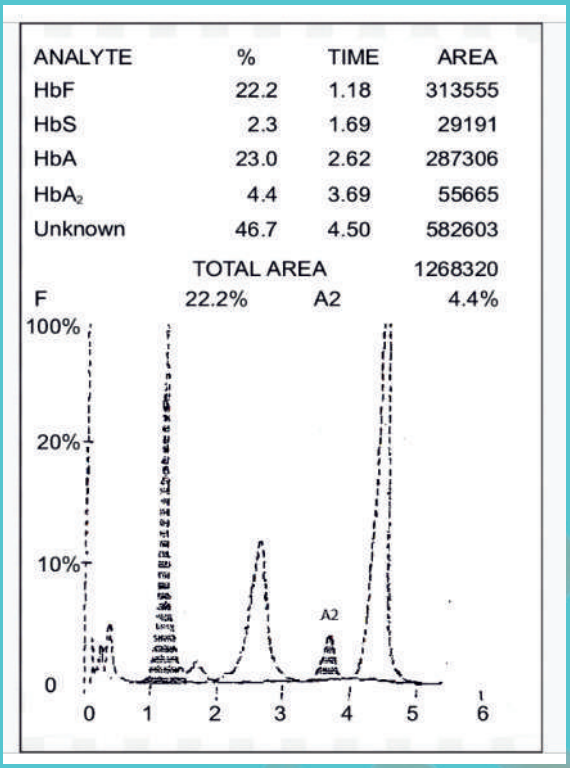
ARE THERE CURATIVE OPTIONS FOR SICKLE CELL ANEMIA?

- Usually, patients are maintained well on regular medicines. They can maintain a good life with medicines and good follow up
- Only few patients with very severe sickle cell anemia need a curative option



CAN WE PREVENT SICKLE CELL DISEASE?

- If both parents are carriers for sickle cell anemia, there is a 25% chance of a child being affected.
- Hence screening of couple before planning a child is very crucial.
- Screening for sickle cell anemia is possible by simple blood tests (point of care tests, CBC, HPLC, Electrophoresis, etc.).



CAN WE PREVENT BIRTH OF CHILD WITH SICKLE CELL DISEASE?

YES

- Get yourselves tested today for sickle cell trait
- Ideally sickle cell status should be known prior to marriage
- If not tested before marriage, all pregnant women should be tested in the first 3 months for both sickle cell anemia and thalassemia which is another hemoglobin disorder that is common in India, using the same tests.
- If a pregnant lady is found to be positive for the sickle cell trait, her spouse should be tested immediately so that the fetus can be tested early in pregnancy.

WHAT SHOULD BE THE WORRY ABOUT SICKLE CELL TRAIT?

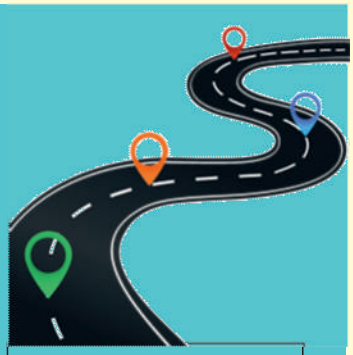
- Usually asymptomatic
- Prevent dehydration during exercise and hot weather.
- Contact doctor for urgent advice:
  1. If traveling to high altitude
  2. If having eye trauma
  3. If noticing blood in urine

WHAT ARE THE GOVERNMENT BENEFITS FOR MY CHILD?

Government of India offers support for:

- Free investigations and treatment
- Free blood transfusions
- Free train/bus travel
- Disability benefits -Benefits in exams, reservation in education

ROAD MAP



Newborn baby

Get newborn screening done

Start medicines advised by doctor

Get vaccinations as advised.

Ensure normal breast feeding and weaning

Care during childhood illnesses

Childhood

Get vaccinations and medicines as advised

Ensure healthy diet

Care during childhood illnesses; recognize emergencies.

Prevent dehydration

Normal schooling and activities

Adults

Encourage active lifestyle

Healthy diet; vitamin D and calcium

Medicines as advised

Get regular checkup for organ damage

Check sickle status of spouse before planning for a family

Senior citizens

Encourage active lifestyle

Medicines as advised

Watch for lifestyle diseases

Encourage young children with sickle to do well in life

Government of India Sickle Cell Anemia Elimination Mission 2047
PARENT INFORMATION SHEET

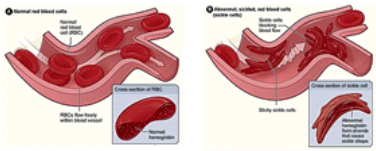
What is sickle cell anaemia?

Sickle cell anaemia is a genetic condition where the haemoglobin molecule inside red blood cells is abnormal.

The red blood cells carrying sickle-haemoglobin are abnormal and they can block small blood vessels causing severe pain, and organ damage including stroke.

These red cells also get destroyed early resulting in anaemia

जनजातीय कार्य मंत्रालय
MINISTRY OF TRIBAL AFFAIRS
GOVERNMENT OF INDIA



Go to a doctor immediately if the child has

- Has repeated fever
- Has repeated infections/pneumonia
- Has repeated anaemia – needs blood transfusions
- Has recurrent episodes of jaundice
- Has repeated bouts of pain anywhere in the body
- Has swelling of hands, feet or joint pain
- Has ulcers in legs
- Is not growing well

Sickle cell disease is an inherited condition

Carriers are not symptomatic and can be detected only when screened
Children born to carriers who have the disease are symptomatic from a young age

They can do well in life, finish their studies, take up a job and get married, have kids and lead the "healthiest life possible" if you can guide them appropriately.

The early signs are swelling of hands and feet, paleness of body, repeated fever, fatigue, repeated infections, poor growth, repeated episodes of jaundice etc.

Many children and adults develop what is called a pain crisis.

During this period, they present to the hospital with pain in the back, legs, chest etc.

What triggers crisis in sickle cell anemia?
Change of weather, diarrhoea, fever, dehydration, infection, stress, exhaustion, high altitude etc trigger crisis

Your child needs additional support and care compared to any other child

Vaccination – all routine vaccines plus special vaccines for sickle cell anemia
Medication – Folic acid, Hydroxy urea, Penicillin
Routine follow-up visits with the doctor
Curative treatment with BMT when needed

For any doubts contact your nearest sickle cell treatment center or scan this QR Code

Module Part - III

Awareness Module for Teachers

TEACHER INFORMATION SHEET

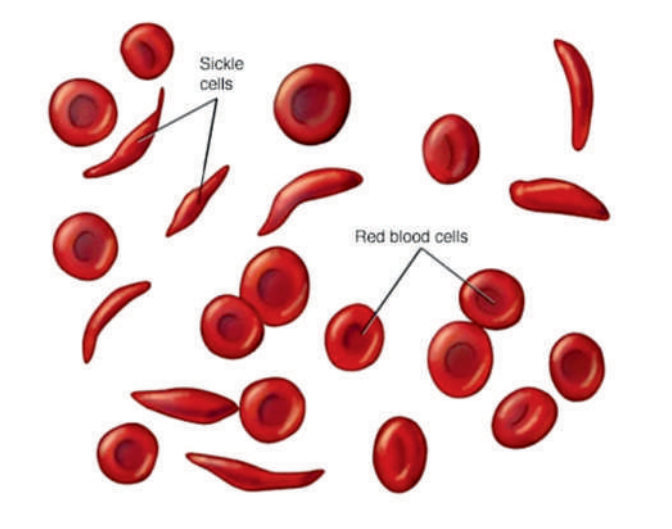
1. Teachers should be aware of children having sickle cell disease.
2. Teachers should know that these children need regular medicines and extra regular fluids. Since they have to drink extra water regularly, they will need to use toilet more frequently.
3. Teachers should know that child must be taken for regular checkups to prevent problems.
4. Urgent visit to healthcare facility/clinic/ hospital if high fever, breathing problem or pain not getting better within 24 hours, or sudden weakness or other concerns.
5. When in doubt –Best option is to consult the doctor- these children are at risk of sudden problems.

WHY ARE WE DISCUSSING ABOUT SICKLE CELL DISEASE?

- The prevalence of sickle cell carrier state is high in the tribal belt of India.
- Hence children born in these states/districts in all schools in these areas should be screened for disease and carrier status

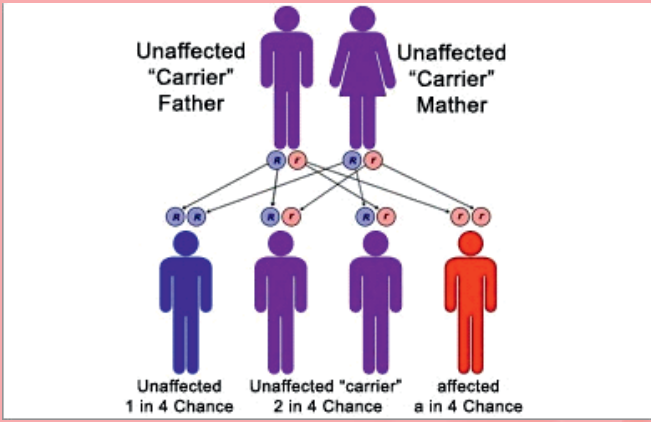
WHAT IS SICKLE CELL DISEASE?

- Sickle cell anemia is a genetic condition where the hemoglobin molecule inside red blood cells is abnormal.
- The red blood cells carrying sickle-hemoglobin become sticky and deformed (C shaped)
- This can block small blood vessels causing severe pain, and organ damage including stroke.
- These red cells also get destroyed early resulting in anaemia



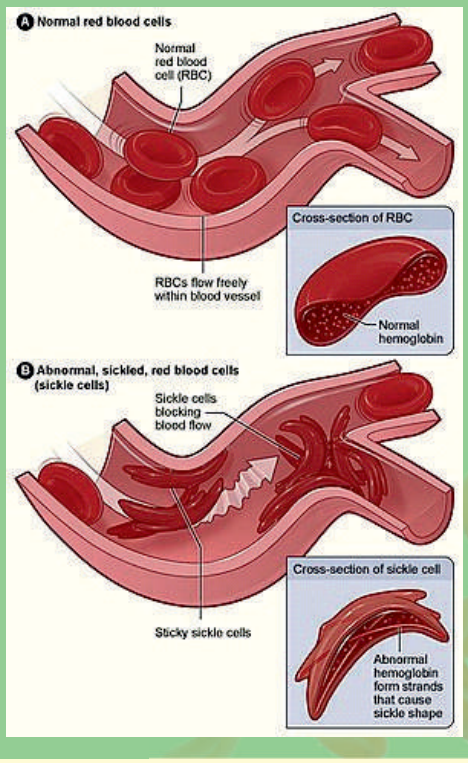
WHAT CAUSES SICKLE CELL DISEASE?

- Sickle cell disease is an inherited condition from parents who have sickle cell trait/ SCD
- Here hemoglobin is different compared to the normal hemoglobin because of mutation in gene
- Carriers of the disease are usually not symptomatic and can be detected only when screened



WHAT ARE THE SYMPTOMS OF SICKLE CELL ANAEMIA?

- Sickle cell anemia patients (HbSS) are symptomatic from early life.
- They present with occlusion of small blood vessels in hands, feet, chest etc
- The early signs are swelling of hands and feet, anemia (paleness of body), repeated fever, fatigue, repeated infections, poor growth, repeated episodes of jaundice etc.



WHAT IS A SICKLE CELL CRISIS?

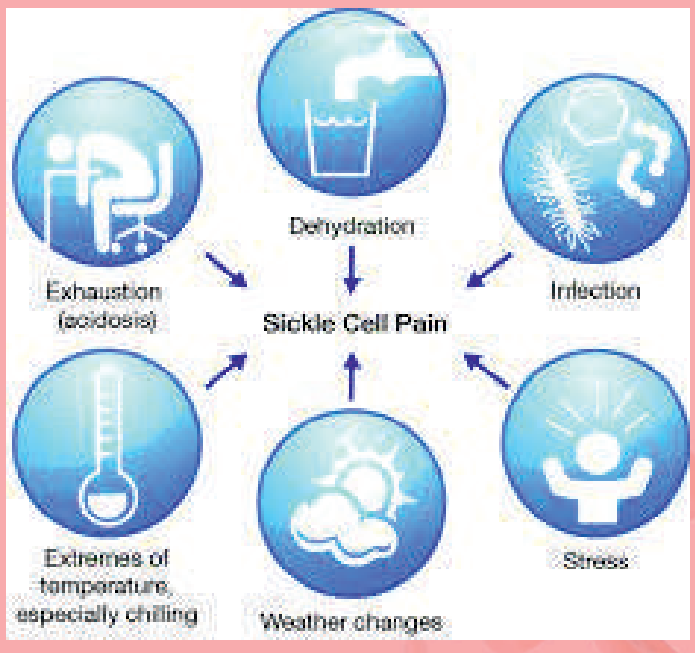
- Many children and adults develop what is called a pain crisis
- During this period, they present with pain in the back, legs, chest etc.

What triggers pain?

Change of weather, diarrhea, fever, dehydration, infection, stress, exhaustion.

Other symptoms during the pain crisis.

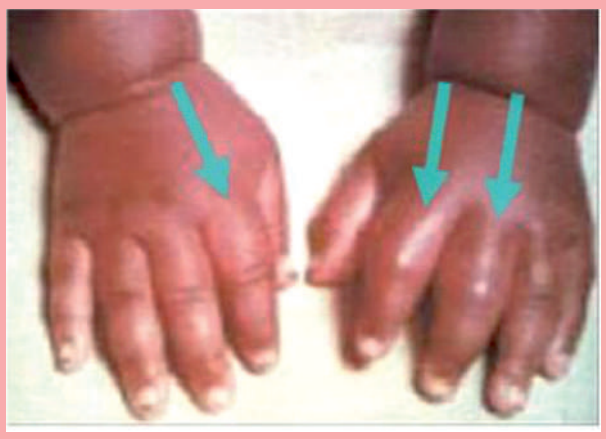
Breathlessness, nausea, etc.



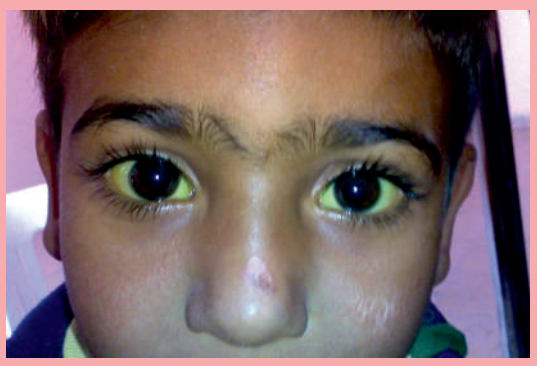
HOW CAN YOU IDENTIFY SICKLE CELL ANAEMIA CRISIS IN CHILDREN?

- **Crisis can present as :**

1. Hand-foot syndrome- swelling and pain of hands and feet
2. Acute chest syndrome – cough, difficulty in breathing
3. Eye – can affect blood vessels in eye and reduce vision
4. Stroke – can affect blood vessels to brain and cause stroke



Pain Crisis
Painful swelling of hands and feet



Recurrent episodes of jaundice

Pallor Child's hands look pale compared to yours

HOW DO WE TREAT SICKLE CELL ANEMIA?

Regular checkups even if there are no symptoms, as advised by the doctor.

Taking medicines and vaccination as advised by doctor. We treat children with sickle cell anaemia with:

- In case of anaemia, if the child is not improving with medicines, blood transfusion may be needed.
- In case of a sickle cell crisis, the child is admitted and treated with antibiotics, IV fluids, etc.

HOW TO TAKE CARE OF A CHILD WITH SICKLE CELL DISEASE?

1. Guide parents and children to maintain a healthy lifestyle.
2. Encourage drinking plenty of water.
3. Maintain hygiene to reduce the chance of infections.
4. Educate them to
   a. Be regular with their medicines.
   b. Avoid triggers like exhaustion, extreme cold, dehydration, high altitude and long-distance travel including long flights.

TAKE THE CHILD TO A HOSPITAL IF HE/SHE HAS

- Repeated fever
- Repeated infections/pneumonia
- Repeated anaemia
- Recurrent episodes of jaundice
- Repeated bouts of pain anywhere in the body
- Swelling of hands, feet or joint pain
- Ulcers in legs
- Child is not growing well
- Blood in urine

Consult the nearest medical officer or pediatrician.

HOW TO SUPPORT PARENTS AND CHILDREN TO PREVENT COMPLICATIONS IN SICKLE CELL ANEMIA?

1. GUIDE THEM TO:

- Be regular with treatment medications
- Maintain a digital health record by ABHA ID
- Keep medical records (reports, discharges, etc.) carefully. Keep a diary of events. Score pain crisis and mention it in diary
- Be regular with showing child to doctor as advised even when otherwise healthy

MAINTAIN A MEDICAL RECORD FOR THE CHILD

- Name
- DOB
- Type of sickle cell disease
- Ongoing medical problems
- Past medical and surgical history
- Transfusion dates
- Medications
- Immunizations received

2. NON-MEDICAL CARE TO THE CHILD

As a teacher, make sure of the following:

a. Encourage child to take a balanced diet.

b. Prevent dehydration: 6-8 glasses of water intake is advised per day. Take breaks during exercise in school routine to prevent dehydration. Keep child hydrated during summer/fever, etc.

c. For children, you should ask your doctor how much water to be taken, usually 1.5 times more than normal for the age child, is advised.

d. Know symptoms and seek timely care for symptoms

3. THINGS TO DO TO REDUCE INFECTIONS

Children with sickle cell disease are prone to infections. The risk of sickle cell crisis increases during infections. hence it is best to prevent infections. As a teacher, make sure of the following:

Maintain good hygiene to prevent infections. Simple measures to reduce the chance of infections are

a. Washing hands regularly

b. Brush teeth twice a day

c. Food hygiene – avoid food prepared unhygienically

d. Balanced diet

e. Vaccinations as per the national immunization schedule

f. Penicillin to prevent some common infections under the supervision of the doctor

g. Pneumococcal vaccination as per medical advice

4. MAINTAIN ACTIVE AND HEALTHY LIFESTYLE

As a teacher, make sure of the following

- Advise children to exercise regularly.
  - It strengthens the heart and lungs
  - Improves stamina
  - Reduces pain crisis
- Children should be encouraged to participate in sports.
  - Avoid strenuous exercise in hot climate.
  - Give breaks in between exercises to hydrate themselves.
  - Encourage children to use the toilet since they will be hydrating more.
  - Breathing exercises, yoga and meditation is helpful.

WHAT IS THE VACCINATION SCHEDULE TO BE FOLLOWED?

NATIONAL IMMUNIZATION SCHEDULE

For Infants		
BCG	At birth or as early as possible till one year of age	0.1ml (0.05ml until 1 month age)
Hepatitis B - Birth dose	At birth or as early as possible within 24 hours	0.5 ml
OPV-0	At birth or as early as possible within the first 15 days	2 drops
OPV 1, 2 & 3	At 6 weeks, 10 weeks & 14 weeks (OPV can be given till 5 years of age)	2 drops
Pentavalent 1, 2 & 3	At 6 weeks, 10 weeks & 14 weeks (can be given till one year of age)	0.5 ml
Rotavirus#	At 6 weeks, 10 weeks & 14 weeks (can be given till one year of age)	5 drops
IPV	Two fractional dose at 6 and 14 weeks of age	0.1 ml
Measles /MR 1st Dose$	9 completed months-12 months. (can be given till 5 years of age)	0.5 ml
JE - 1**	9 completed months-12 months.	0.5 ml
Vitamin A (1st dose)	At 9 completed months with measles-Rubella	1 ml (1 lakh IU)

WHAT IS THE VACCINATION SCHEDULE TO BE FOLLOWED?

For Children	
DPT booster-1	16-24 months
Measles/ MR 2nd dose $	16-24 months
OPV Booster	16-24 months
JE-2	16-24 months
Vitamin A* (2nd to 9th dose)**	16-18 months. Then one dose every 6 months up to the age of 5 years.
DPT Booster-2	5-6 years
TT	10 years & 16 years

Additional vaccines to be administered as per National Programme.

WHEN SHOULD WE TAKE THE CHILD TO A DOCTOR AS AN EMERGENCY?

- Take the child to the hospital immediately, If the child in your care has any of the following :

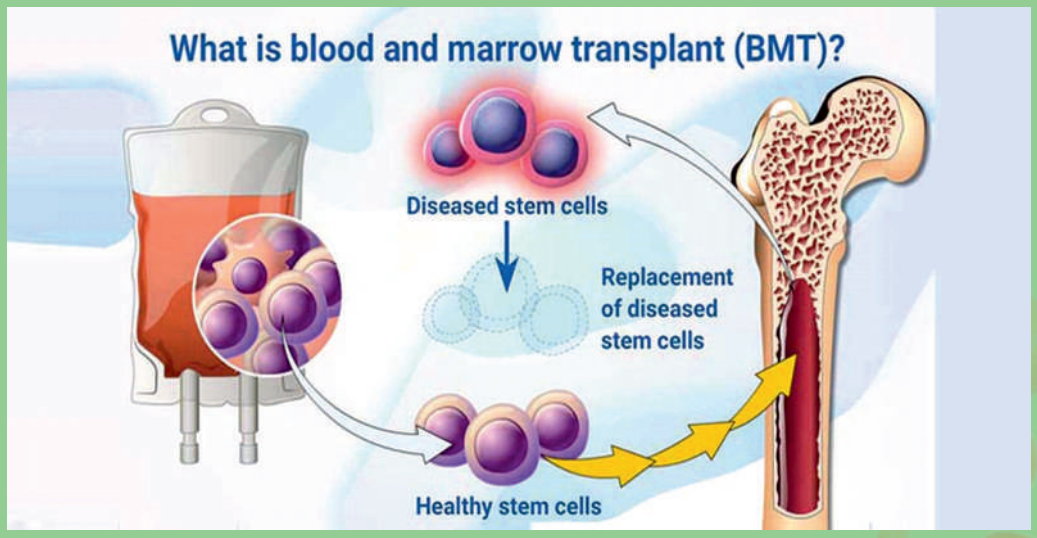
1. Fever more than 1010F
2. Vomiting or loose stools
3. Difficulty in breathing or chest pain
4. Pain in abdomen
5. Sudden increase in pallor or yellowness of eyes
6. Distention of abdomen
7. Severe headache
8. Sudden weakness of arms/ legs
10. Seizures
11. Unconsciousness or giddiness or confusion

IN CASE OF FEVER/PAIN

- Fever and pain are EMERGENCIES for a child with sickle cell anemia
- Keep child well hydrated
- Child needs to be taken to the doctor even when fever or pain reduces

ARE THERE CURATIVE OPTIONS FOR SICKLE CELL ANAEMIA?

- Usually, patients are maintained well on regular medicines. They maintain a good lifestyle while on medicines and with good follow up.
- Only few patients with very severe sickle cell anaemia need a curative option.



WHAT SHOULD BE THE WORRY ABOUT SICKLE CELL TRAIT?

- Usually asymptomatic
- Prevent dehydration during exercise and hot weather
- **Contact the doctor if**
  1. traveling to high altitude
  2. having eye trauma
  3. noticing blood in urine

WHAT ARE THE GOVERNMENT BENEFITS FOR PATIENTS WITH SICKLE CELL ANEMIA?

Government of India offers support for

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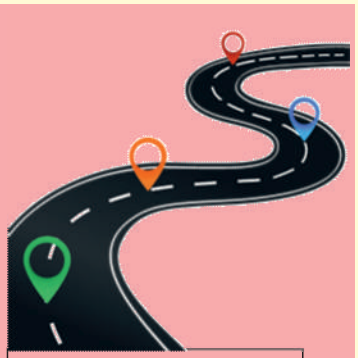
- Free blood transfusions
- Free train travel
- Disability benefits -Benefits in exams, reservation in education.

ROAD MAP



Newborn baby

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TEACHER INFORMATION SHEET

जनजातीय कार्य मंत्रालय
MINISTRY OF TRIBAL AFFAIRS
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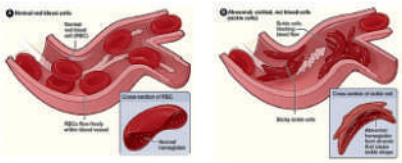

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The red blood cells carrying sickle-haemoglobin are abnormal and they can block small blood vessels causing severe pain, and organ damage including stroke.

These red cells also get destroyed early resulting in anaemia

Sickle cell disease is an inherited condition

Why should teachers know about this?
The prevalence of sickle cell carrier state is high in many states of India.

Hence children born in these states/districts in all schools in these areas should be screened for disease and carrier state

They do well in life, if we can support them through their journey

Children with sickle cell anemia can present with swelling of hands and feet, paleness of body, repeated fever, fatigue, repeated infections, poor growth, repeated episodes of jaundice etc.

Many children and adults develop what is called a pain crisis.
Change of weather, diarrhoea, fever, dehydration, infection, stress, exhaustion, high altitude etc. trigger crisis

Take the child to a doctor immediately if the child has repeated fever, infections/pneumonia, bouts of pain anywhere in the body etc.

Children should be on regular medicines advised by the doctor and should receive special vaccinations also.

They should be seen by a specialist regularly. Keep them well hydrated while in school and during sports

For any doubts contact your nearest sickle cell treatment center or scan this QR Code

सत्यमव जयते

Government of India

Ministry of Tribal Affairs & Ministry of Health & Family Welfare