WORLD SICKLE CELL DAY

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REDUCING THE BURDEN OF SICKLE CELL DISEASE

SCD CAREGIVER/PARENT EDUCATION

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Burden of SCD Care

- Physical
- Psychological
- Schooling
- Family
- Community

SCD Carers

- Parents
- Other family members
- Teachers
- Friends-parent groups, patient groups, professional groups, community based organizations, advocates, religious groups etc

Components of care

- Physical
- Mental
- School health
- Environment
- Sports and exarcise

Parents/caregiver focus

- Education about the disease
- Education about inheritance
- Education about the signs and symptoms
- Education about pain
- Home management of pain
- Daily medications
- When to go to the hospital
- Hospital admissions
- Blood transfusions
- Chronic organ complications
- Transition to adult care

Sources of information/education for carers

- Health workers
- Radio/TV/
- Social media
- School
- Community organizations
- Religious organizations
- Internet

Main features of SCD

- Anaemia-pallor, fatigue,
- Vasoocclusion crisis-most common bone pain
  - Triggers for bone pain
    - Infection
    - Dehydration
    - Stress/fatigue
    - Exposure to cold and very hot varying temperatures

What to do if the child is unwell

- Check temperature.
- Ask for pain and do a pain assessment
- Check for breathing
- Palpate for spleen in younger children

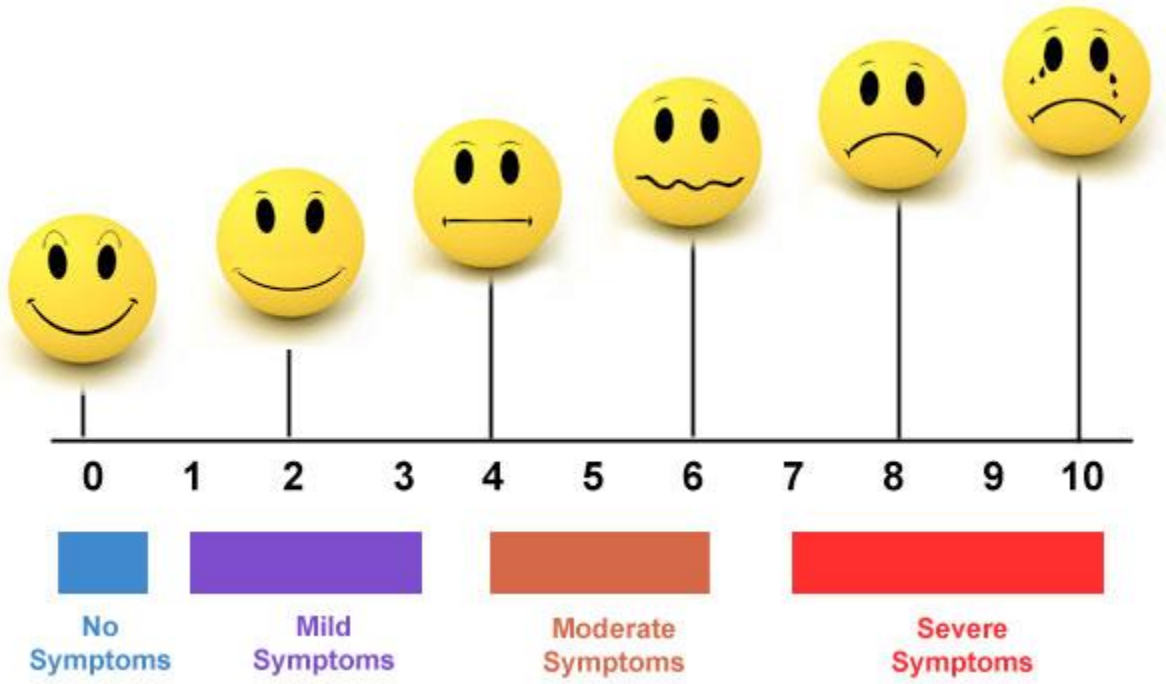
What to do..

- Parents and patients should be taught how to read a thermometer. It is very important to provide these for parents or patients that do not have them available. Inexpensive digital thermometers are now available that are accurate and easy to use. The patient and parent need specific guidelines on how and when to seek immediate medical attention when a fever develops or signs of infection appear.
- Parents of small children with big spleens should be taught to feel the spleen and instructed to do this on a regular basis and at any time that the infant appears ill.

Pain Assessment

- Doing a pain assessment
- 1. Ask your child about their level of pain on a scale of 0 to 10, with 0 being no pain and 10 being “the worst pain ever”. Ask where the pain is located.
- 2. If the pain is less than 7/10, give them pain medication as prescribed by their doctor.
- 3. If the pain is limited to one or two areas, you can apply a warm pack to the site of pain. Do not use ice packs.
- Children (5 to 8 years of age) Ask your child: "If 0 is no pain and 10 is the worst pain you can imagine, what are you feeling now?"
- Older children (8 years of age and older) Ask your child: "If 0 is no pain and 10 is the worst pain you can imagine, what are you feeling right now?"

Pain Assessment



Pain management

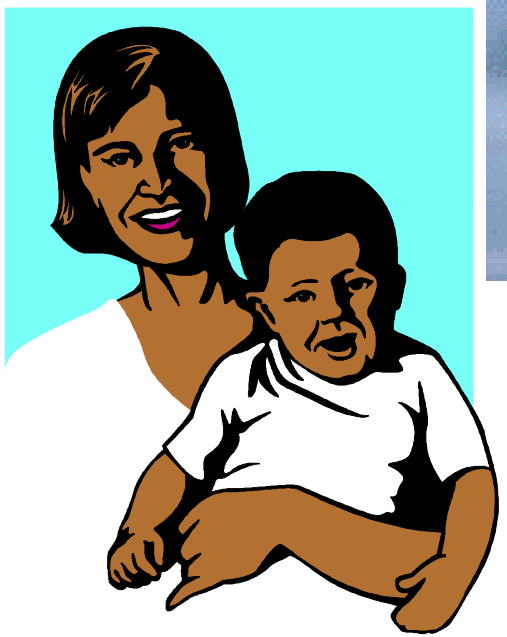
- Give your child plenty of fluids. Do not give cold fluids.
- 2. Gently massage the area.
- 3. Apply warmth to the area.

- Tips for using heat
  - Use disposable, instant hot packs. Be sure to follow the instructions on the package.
  - Use warm blankets from the dryer.
  - Use warm baths
  - Apply heat in 20 minutes intervals – 20 minutes with heat, 20 minutes without.
  - Do not leave babies and young children unattended with heat.
  - Use heat with children 3 years of age and older. If the area becomes painful or uncomfortable or if a local skin reaction develops, remove heat immediately

Pain management

- Psychological/behavioural
  - Have your child practise deep breathing.
  - Encourage your child to do relaxation exercises.
  - Use distractions (movies or music).
  - Use imagery – have your child imagine a favourite place or memory

Healthy Living



Healthy living..

- Those with sickle cell disease should be evaluated periodically by clinicians skilled in sickle cell care. This is to establish a normal baseline for the patient, identify impending problems, to update immunizations and maintain nutrition support, and to provide patient and parent education and support.
- Prevention of infection is one of the major methods of preventing death in sickle cell disease. Penicillin should be started from 3 months

Prevention..

- Prevention of triggers to crisis is key to enjoying healthy life in SCD
- The things that cause the red cells to sickle are: dehydration, fever, low oxygen, stress, cold exposure, and slow blood flow.
- Preventive care tries to prevent these known causes of red cell sickling.
- Situations of too hot or too cold should be avoided by dressing in warm clothing on cool days and with loose clothing on hot days. Getting upset
- Becoming over heated or exhausted from too much physical activity
- Drinking alcohol or using drugs like cocaine

Prevention..

- Fluid-drink liberally
- Keep thermometer at home to check temperature. Seek for health advice at T >38
- Eat healthy food
- Rest well and not overdo things
- Routine medications: penicillin, folic acid, anti malarials and (hydroxyurea)
- Periodic follow up at specialist clinics
- Keep tab on vaccinations –NPI and others

Prevention..

- Individual immunization schedules will need to be developed based on the child's past immunization record, reactions to vaccination, presence of febrile illness, and local school requirements.
- The parent should be provided a permanent record of immunizations that also records the hemoglobin diagnosis, allergies, medication, other medical problems, and the phone number of the primary care provider.
- Parents should always present this during follow-up care.

Transfusions

- At times, blood transfusions may be needed to prevent or treat complications such as stroke, sequestration, priapism, and severe anemia.
- Transfusions are also needed in acute chest syndrome and in aplastic anemia when the bone marrow factory shuts down.
- Blood transfusions over time can load the body with too much iron. This may need to removed by a special medication.
- Caregivers need to know their child's blood group

Support

- Support from family members, is important.
- Sickle cell patients need to be encouraged to attend school, seek out careers that will not interfere with their sickle cell disease and plan for a long life.
- Family love and support can help ease the painful episode and keep the patient looking ahead to a career and a family of their own.
- Support groups assist individuals, families, health institutions,

provides platform for community education, sensitization, screening, care etc

Other Considerations

- Psychological complications
- Analgesics and addiction
- Transfusion Therapy in Sickle Cell Disease/Iron chelation
- Hydroxyurea Therapy in Sickle Cell Disease
- Transition to adult care
- Hematopoietic Stem Cell transplant : Limited availability of transplant experts and centers, Requirement of a matched donor, Cost and Outcome

Conclusion

Education is key to reducing burden of SCD both in terms of number of children born with SCD as well as morbidity and mortality.

Education is the key theme of the ARISE Project

ARISE

African Research And Innovative Initiative For Sickle Cell Education

This presentation reflects only the author(s)'s view and the EU Research Executive Agency (REA) is not responsible for any use that may be made of the information it contains.

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