Understanding Your Child with Sickle Cell

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Your Child's Role in Sickle Cell Care

As your child gets older, it's important that he or she play an active role in meeting their health care needs. They should depend on you less and less as time goes by.

Learning About the Disease

One of the best things you can do to help your child be more independent about their health is to teach them about sickle cell and help them to understand what's happening inside their bodies. Here are some websites that focus just on teaching kids and teens about sickle cell:

- KidsHealth
- St. Jude
- SickleCellKids

Primary School Children Can Do These Things:

- Learn the danger signs of when it is important to call a doctor and tell you when they happen
- Take their medicine (you will still need to make sure how much they take)
- Speak up at doctor visits by asking questions and giving answers about themselves
- Drink fluids regularly, even when they might not be thirsty
- Take breaks and rest when they feel tired
- Learn to manage mild pain by relaxing, staying busy, drinking fluids, and maybe taking Tylenol or using "home remedies."

Teens Can Do These Things Too:

- Be able to call the doctor if they have a danger sign and tell you about their concerns
- Take their own medicine and tell you how much they are taking
- Take their own temperature
- See the doctor while you wait in the waiting room
- Manage mild pain by themselves
- Go to a teen support group
- Talk to a genetic counselor
- Keep you informed about what they are doing and how they are feeling

Babies and Toddlers with Sickle Cell

Your Infant

For the first months of your baby’s life, he is protected from the disease. Most babies don’t have sickle cell complications until they are two or three months old. This will give you some time to get to know your baby and deal with your own feelings. After the first few months, your baby may begin to have problems from sickle cell disease. The first signs of the disease may be hard for you. You may realize that there is little you can do to prevent pain or certain infections. A baby has few ways to let you know if something doesn’t feel right. He may cry, be fussy, eat less or be less active. Give him as much comfort as you can. When your baby isn’t feeling well, your touch and soothing voice can make a big difference. If your baby is in the hospital, your presence can make him feel better.

Your Toddler

Toddlers are learning fast. Because they are curious and active they can get into dangerous places. They need opportunities for walking, running and climbing. This is a time to make sure your home is safe to prevent accidents. Children at this age must be watched at all times. Like other parents, you may become tired of caring for the active toddler. Most toddlers do not have words to express how they are feeling. Because of this they may be happy one moment and grumpy the next. Try to be patient with this behavior. Providing the same time daily for eating, playing and sleeping can be helpful. At this age, your child may be very afraid of being away from you. Most toddlers feel this way, but it is important for them to spend time with other people. As your child becomes more comfortable with others, it will be easier for you to leave him with someone else. Your toddler needs to feel secure in your love. Play with him, comfort him, include him in family activities and let him learn things on his own.

Young Children with Sickle Cell

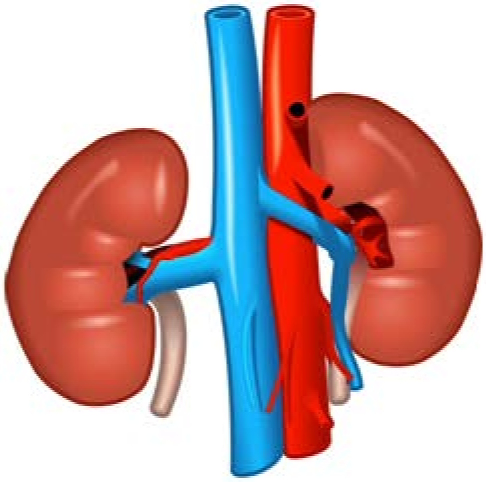
Your 2-4 Year

Older children from the ages of two to four want to be independent. They say “no” and want to do things themselves. Let your child begin to make decisions for himself. Even in the hospital, he can choose his own meals or TV programs or walk to the playroom when he feels better. At home, he can help you remember when to take his medicine and remind you to give him drinks. Use your judgment about things he can try for himself and avoid doing most things for him. Even though your child is more independent, he still needs you. Comfort him, respond to his fears, answer his questions and help him learn more about his world.

Kidney Problems: Bed-wetting

The kidney has just the right conditions—low oxygen, high salt concentration, and high acid concentration—to cause red cells to sickle. The kidney is the main filter of the blood, saving or releasing water, salts, and waste products. If early damage impairs the kidney’s ability to retain water it can let too much go, even when the body is dehydrated.

When the kidney releases too much water, children may wet the bed at night and may need frequent bathroom breaks. This is important to discuss with teachers and caregivers. To help control the bed-wetting problem, use an alarm that sounds when dampness is detected. These are available at most drug stores. Encourage your child to stop drinking fluids one hour before going to bed.



Your 4-6 Year Old

Here are some key things to know about this age group:

- Between the ages of four and six, children use imagination to understand their world, including their disease. For example, a child may believe that the pain is a punishment for something she did. Or she may believe he caught sickle cell disease from something she ate. Pay attention to what your child may be saying about her illness. Clear up any wrong ideas. Don't worry if you have to go over the same ideas more than once.

- Let your child ask any questions she may have about sickle cell disease. Answer these questions clearly, in words that suit your child's age. You may want to use stories, stuffed animals or puppets to help you explain what will happen to her.

- Even though your child is talking, she may not be able to tell you what she is feeling. Watch your child's play to get helpful information. Also, look for patterns in how your child acts when she feels sick or in pain so you can know how to help him. For example, she may want to stay in bed in the morning because she "feels funny" when she has pneumonia. You will need to always check for a fever and get a thermometer, then call the doctor if she does have a fever. She may act listless and want to be left alone when she is in pain.

- This is also the age to start teaching your child how to take care of herself. For example, you can explain "You need to drink 6 cups of water today". If possible, she can pour her own drinks or get her own cup.

- Because your child has sickle cell disease, you may feel she should be treated differently than other children (special treats, toys, attention, less discipline). This is not really best for the child, however. Children with sickle cell disease need to feel that they are the same as other children. If your child has brothers and sisters, they should all have the same rules to follow and your expectations for their behavior should be the same. If there is a household chore that causes her trouble because of her sickle cell, switch her to another job that she able to do.

Easing Pain at Home

Your child may have pain at times from sickle cell disease. Usually, the pain is mild enough to treat at home. Infants and toddlers may show pain by crying, refusing to walk, or pointing to the areas that hurt. Try different ways to ease pain to see which ones help the most. Here are some ideas:

1. More fluids - Extra fluids can help keep the sickle cells from clogging up small blood vessels. Since this is a major cause of pain, extra fluids can do a lot to ease the pain. Give your child up to double the amount of fluids she usually drinks.

2. Quiet play - Cutting back on physical activity can be helpful. Complete bed rest may not be needed, just less active play. Find things for your child to do quietly inside for a while. See if quiet play will help her feel better.

3. Warm baths - Let your child soak in a warm bath for a while. When it cools off, you can add more hot water or she can get out. Sometimes it feels good to do mild exercises in the warm water.

4. Heating pad or warm, moist towels - Apply either one of these to the painful area. If you use a heating pad, set the dial to medium heat. If you use warm towels, change them when they cool off. Wet them with warm water, and then wring them out. You can apply these as often as it helps.

5. Massage Gently - massage the painful area with warm baby oil or lotion to relax tense muscles and increase blood flow. You can massage the arms, legs, back and neck areas easily.

6. Distractions - Your child will feel less pain if she is involved in something she enjoys. Some children like to be alone when they feel pain. If she likes to be busy, keep her busy with games, stories and other fun things. Read her books, talk to her or let her watch movies or TV.

7. Relaxation - Relaxation is a skill that can be learned. You can teach your child different breathing exercises and ways to relax their body.

Pain that could be serious Call your doctor right away if your child has any of these symptoms:

1. Chest pain or shortness of breath
2. Abdominal pain

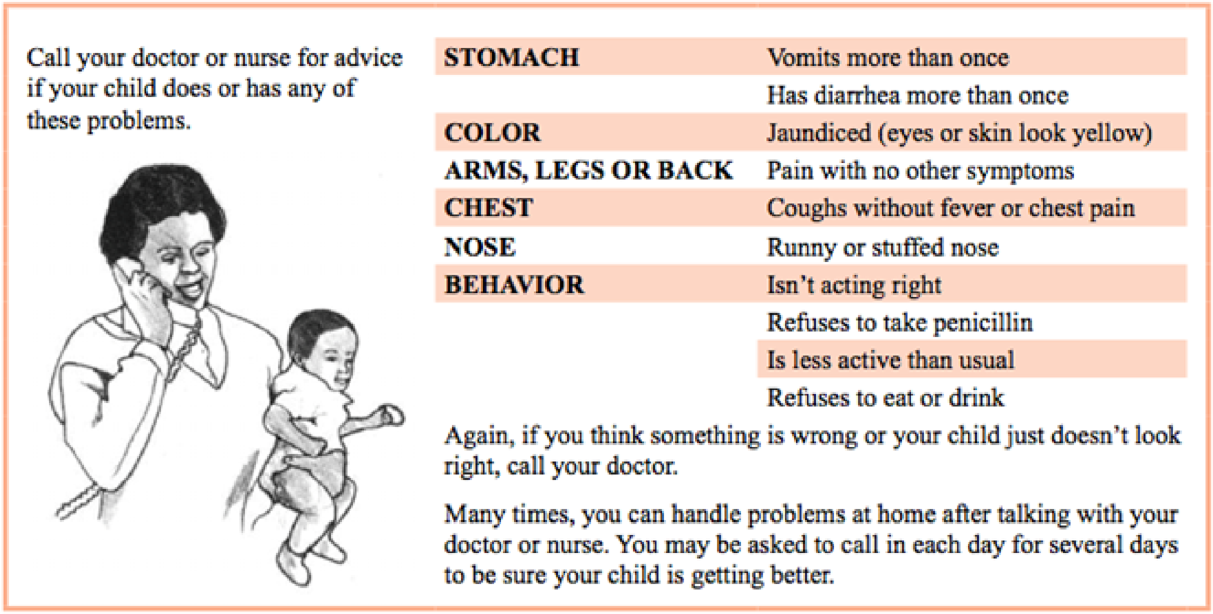
3. Pain along with fever or swelling and redness
4. Pain which isn't relieved by home treatment
5. Severe headache

Ask your doctor for suggestions so that you can learn more ways to help your child feel better.

Danger Signs and When to Call for Advice

Unfortunately pain is a normal part of sickle cell disease and can usually be managed outside of the doctor's office, but there are certain symptoms you need to monitor.

Here are the signs when you should call your doctor to get more info:



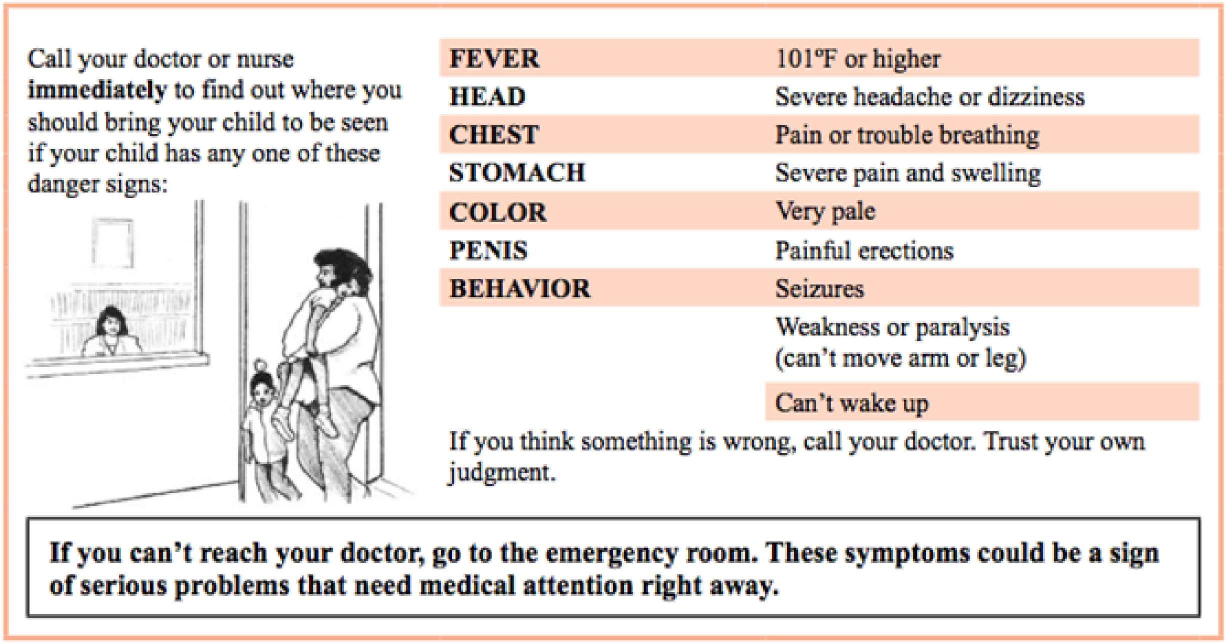
Call your doctor or nurse for advice if your child does or has any of these problems.

STOMACH	Vomits more than once
	Has diarrhea more than once
COLOR	Jaundiced (eyes or skin look yellow)
ARMS, LEGS OR BACK	Pain with no other symptoms
CHEST	Coughs without fever or chest pain
NOSE	Runny or stuffed nose
BEHAVIOR	Isn't acting right
	Refuses to take penicillin
	Is less active than usual
	Refuses to eat or drink

Again, if you think something is wrong or your child just doesn't look right, call your doctor.

Many times, you can handle problems at home after talking with your doctor or nurse. You may be asked to call in each day for several days to be sure your child is getting better.

Here are the danger signs of when you should seek help right away:



Call your doctor or nurse **immediately** to find out where you should bring your child to be seen if your child has any one of these danger signs:

FEVER	101°F or higher
HEAD	Severe headache or dizziness
CHEST	Pain or trouble breathing
STOMACH	Severe pain and swelling
COLOR	Very pale
PENIS	Painful erections
BEHAVIOR	Seizures
	Weakness or paralysis (can't move arm or leg)
	Can't wake up

If you think something is wrong, call your doctor. Trust your own judgment.

If you can't reach your doctor, go to the emergency room. These symptoms could be a sign of serious problems that need medical attention right away.

School Success

At the start of a new school year, go to school and meet your child's teacher and school nurse. Bring your child with you. Let your child ask any questions that she may have and help her feel at ease. Tell the teacher about sickle cell disease and give her things to read so she can learn about the disease. The teacher needs to know that your child will come to school even when she has minor aches and pains. She should be sent home only if she has a fever or severe pair or if she needs to see a doctor. Explain your child's special needs. She needs to:

- Get water regularly, especially when she is thirsty.
- Go to the bathroom as soon as she feels the need.
- Make up school work if she has to miss school
- Rest or slow down if she is tired or sore. For example, during gym class, she may only be able to run 2 laps, not 6.
- Get medicine if she needs it.
- Avoid extremes of cold or heat.

Check to see that her teacher gives your child what she needs. Some teachers may protect your child too much while others may ignore her. Talk to the teacher about these things if you are concerned. If you ever need help or support, talk to your doctor, nurse or social worker.

Your child has the right to get an education that meets her needs. There is a law, which says that the school has to give it to her. This law (PL94-142) means that the school must provide help if your child needs it. If your child is not doing well in school, talk with her teachers. If she has a learning problem, she should get special help so she can learn better. Ask the school counselor for an "individualized educational plan (IEP)."

Your child can also get accommodations through Individuals with Disabilities Education Improvement Act (IDEA 2004) or with an Individualized Health Plan (504 Plan or IHP). Your child can get written approval for different accommodations including:

- Permission to carry a water bottle throughout the day
- Bathroom and clinic passes when needed
- Extended time for quizzes and assignments
- Permission to take rest breaks in gym

Children and Self Esteem

Children with sickle cell disease may sometimes have low self-esteem. There are many things you can do as a parent to help your child feel better:

- Pay attention to more than his problems.
- Notice his skills, his strengths, his interests and his style.
- Praise him when he does well. You can't give too much praise. Children thrive when they are told that they are special. They feel good when someone sees something they've done well.
- Listen to what he has to say. Ask him questions. Show him that you care about what he thinks and feels.
- Help him get involved in things besides his illness. He can try some of these things to see if he wants to do them:

    - o Playing music
    - o Being with friends
    - o Learning the computer
    - o Drawing or working with clay
    - o Playing chess or other board games
    - o Acting in a play or reading books
    - o Non-contact martial arts

Be careful not to push your child to compete where he can't succeed. If he can't run very long without getting sore or tired, don't force him to play fast sports. Help him to find at least one thing he does well and enjoys.

When your child starts school, he may begin to notice that he is different from other children. When he becomes aware of having "a disease," he may feel afraid or angry. Make sure your child knows that he didn't get the disease because he was "bad”. Your child needs to accept the fact that he has sickle cell disease and make the most of his life. Tell him that except for his disease, he is just like other children. Help him learn what he can and cannot do so he can gain more control.

We all like to feel that we belong. Your child may be afraid that he won't fit in because sickle cell disease makes him different. He may think that others will make fun of him or treat him "special." Some children feel good about telling their friends about sickle cell disease. Others don't want anyone to know. It is good for children to tell at least one close friend about their disease. If no one knows, it is more likely that they will feel ashamed of their secret. When friends know, they can support your child when he needs it.

Setting Limits For Your Teen

As the parent, you are still in charge. You have a right to know what your teen is doing and who your teen is with. It is your job to decide how much freedom to allow. Limits can cover many issues, like curfew, homework, chores and use of the car. The rules should be fair and make sense. Discuss them with your teen. Better yet, see if you and your teen can set the limits together. Make sure the limits are clear to both of you. Rules should be consistent – all the adults in the home should agree on them. If the rules are broken, you should respond as you would with any child. The disease is not an excuse for breaking rules. Your teen needs to be held responsible for his actions.

Sickle Cell Disease and Risk

Like other teens, young people with sickle cell disease sometimes take risks. Teens with sickle cell disease may have a stronger need to prove that they fit in. Drugs and alcohol, sex and fast driving are all things that some teens do to prove themselves. They may also be depressed and want to escape from their pain. This can lead them to take risks that can be hurtful to themselves and others. Some of these risks may carry extra danger for your teen with sickle cell disease:

- Sex without condoms can bring a greater risk of getting a sexually transmitted disease (STD).
- Getting pregnant can be more of a problem for your teen.
- Alcohol can increase sickling because it dehydrates the body.
- Smoking cigarettes or marijuana can damage the lungs and increase sickling.

If your teen is taking risks that could be harmful, you need to get involved. Your teen needs proper and fair discipline if he is hurting others. He also needs your guidance and attention. Listen to your teen. Ask why he is taking risks and listen to his answers. If your teen doesn't stop or can't stop taking these risks, he needs help. Taking risks that put him and others in danger can be a sign of a deeper problem.

You may need outside support and help. Most people are not taught how to be parents, let alone parents of teens. It is OK for you to be confused about how to handle your teen. It is OK to get help. Reach out to your doctor or social worker who can get you connected to resources that could help.

Sex and Teens

Like all teens, teens with sickle cell disease face challenges with sex. As they reach puberty, their bodies go through many changes. They begin to have strong sexual feelings. All teens have choices to make which will have a major impact on their lives.

Here are some of the questions, which teens need to answer for themselves:

- How will they respond to their sexual feelings?
- When will they have sex?
- With whom?
- Will they wait to have sex until they are married?
- Do they want to have children?
- If they have sex but don't want children now, what kind of birth control will they use?
- How will they protect themselves from the AIDS virus?
- What about other STDs (sexually transmitted diseases) like chlamydia or genital warts?

These are not easy questions. Teens need to give these questions a lot of thought and make good choices for themselves and their future families. Teens with sickle cell disease may have concerns about maturing late. Boys may wonder whether they can have sex if they have not reached puberty or if they have a problem with priapism (prolonged erection). Boys and girls may worry about whether they will be able to have children. Because sickle cell is a genetic disease, they also need to think about whether they know the hemoglobin type of their partner and understand the risk of having a child with sickle cell disease. Remind them that getting pregnant or having sex are not good ways to prove that they are OK.

You don't have complete control over what your teen does about sex, but you can talk to her. You can give her the facts and help her make sense of all that she has heard. You can share your feelings and values so that she knows where you stand. You can listen to her feelings and thoughts and help her decide what is best for her. Don't wait until your child becomes a teen to start talking about sex.

Don't assume your teen knows it all even if she acts like she does. Research shows that teens that know the least about sex are more likely to have sex sooner. More often than not, it is what teens don't know about sex that can hurt them.

Great job!!

You’re another step closer to finishing the CHECK Sickle Cell Online Program. Hopefully you now know more about understanding your child with Sickle Cell.

Now you can move on to the next topic, which talks about HealthCare Tips.