Life as Parent of Child with Sickle Cell

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Things to Know as a Parent with a Child Who Has Sickle Cell

As a parent of a child who has sickle cell, it may seem overwhelming at times to know how to handle your child's condition. This online guide is meant to point out key things you need to know that will help you have more confidence. You will find more detailed information about sickle cell, in the sickle cell section for teens and young adults in a different part of this website. This set of information is divided into 3 modules:

1. Life as a Parent of a Child with Sickle Cell gives general information about your role as a parent of a child who has sickle cell

2. Understanding Your Child with Sickle Cell gives you information about different things to think about depending on your child's age

3. Healthcare Tips gives helpful ideas on how to use the health system in the best way for your child

At any point, if you have questions about any of the information listed in this module, be sure to contact your child's doctor or community healthcare worker (CHW) so you can understand more!

What is Required of Parents?

Parenting is the most rewarding job, but it is also one of the toughest. Bringing up an African-American or other minority youngster can be tougher still. While the opportunities are great for a minority child born today, the child also faces great dangers, from racism in the larger society and from the poverty, drugs, and violence that devastate many minority communities.

No wonder, then, that the parent of a child with a serious, long-term illness like sickle cell disease is often overburdened. Sickle cell disease calls on all the parents' wisdom and love.

There are a lot of things to know, but here are 4 key points to remember:

1. It's very important that you become a student of the disease. This means you must get to know the preventive techniques available and how to get medical help when it is needed. It also means learning to recognize and treat potential problems before they get serious.

2. You must deal with the increased financial and time commitment required to deal with the disease in your child.

3. You must encourage your child's growth and independence without becoming overprotective.

4. If you have more than one child, you must stretch yourself to give enough attention to your healthy children. Otherwise, they are likely to become jealous of the child with sickle cell disease.

This information has been taken from Hope and Destiny, which is a great book you can order that gives you even more information about parenting a child with sickle cell. Click here to find out more.

Support Groups

Health issues for a person can disrupt an entire family's way of life. Parents may feel that their own hold on ordinary life is slipping away. Careers can sink—because, just as your child is likely to experience long and frequent absences from school, you, as parent, may experience long and frequent absences from work to care for your child when he or she becomes ill. An important thing to remember is that you are not alone. There are people around you that can help. Here are some support groups that you can connect with:

University of Illinois Hospital and Health Systems has ongoing support group events where families who have members with sickle cell can connect with others. Visit the website to find out more:
http://hospital.uillinois.edu/Patient_Care_Services/Sickle_Cell/Support_Group.html

The Sickle Cell Disease Association of Illinois is a way for families to connect all around Chicago. Visit their website to find out their events and ways to learn more about sickle cell:
http://www.sicklecelldisease-illinois.org/

Have a Heart for Sickle Cell Youth Development Program is a Chicago-based organization that offers tutoring, mentoring, and support for youth and their families. You can visit their website or Facebook page:
https://www.facebook.com/hhsca and http://hhsca.org/contact/

Take Care of Yourself and Your Other Children

It can be very challenging to deal with a serious illness that affects someone you love. You may find that your life is more stressful in other areas, such as your marriage, your family, your finances and your own personal life. It is important to take good care of yourself so you can take care of your child.

Although you may want to devote your whole life to your child, you can’t. It won’t help her, and it won’t help you. Your needs are also important. Find time for your other children, for your partner and for your friends. Also, make time to do things that you enjoy. A short break, even when your child is sick, can give you a lift. Money can be a major concern for parents of children with chronic diseases.

Talk to your doctor or a social worker about your concerns and how to get more information about health care coverage for your child. Be sure to get help if you need it. Reach out to medical staff, friends, family, clergy, support groups or other parents to help you get through hard times. Sometimes you need more than support. You may need to talk to a social worker or psychologist. Don’t wait too long before you ask for help!

Your Other Children

- Your other children need your attention and care, too. Make time to talk to them and be with them. Try not to miss school or sports events that they are involved in because you are focused on your child with sickle cell disease.

- It can be helpful to teach all of your children about sickle cell disease. If they have questions that you can't answer, let them ask the staff at the sickle cell center. Knowing more about the disease will help them feel included.

- One of the keys to a healthy family is to treat your child with sickle cell disease like her brothers and sisters as much as possible. Try to use the same system of discipline and rewards with all of your children. Special treatment isn't good for any of them.

Patient Perspectives

Sometimes you can feel alone in your experience with caring for your child. It’s important that you remember that you are not alone and there are other parents who understand and relate to your struggle. Here are just a few examples of families who deal with sickle cell:

- Click here to watch Oliver and Hannah share their story about discovering their child has sickle cell disease.

- Click here to hear Isaac’s story of strength

- Click here to see Alexandria and her parents share their experience with possible complications among children with sickle cell.

University of Illinois Hospital and Health Systems has ongoing support group events where families who have members with sickle cell can connect with others. Visit the website to find out more.

The Sickle Cell Disease Association of Illinois is a way for families to connect all around Chicago. Visit their website to find out their events and ways to learn more about sickle cell.

Where to Find More Information

If you want to read more about any of the topics in this module, here are the references where the information is from:

To learn more details about Sickle Cell in general, click here to visit Kidshealth.

The Virginia Department of Health offers several facts sheets and handbooks all about Sickle Cell. Click here to visit their website and explore their resources!

Great job!!

You're one step closer to finishing the CHECK Sickle Cell Online Program. Hopefully you now know more about sickle cell and life as Parent of Child with

Sickle Cell.

Now you can move onto the next topic and learn all about understanding your child with Sickle Cell!