Sickle Cell & School: Bridging the Gap
Between education & health care for children with sickle cell disease
Handbook

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Significant portions of this handbook were reproduced from:


The Virginia Sickle Cell Awareness Program: Virginia Department of Health, Richmond, Virginia, 2006
### Contact Information

For more information or if you need to contact your provider, please use the appropriate phone number below.

<table>
<thead>
<tr>
<th>Hospital</th>
<th>Operating Hours</th>
<th>Phone Number(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Boston Medical Center</strong></td>
<td>Monday – Friday: 9am – 5pm</td>
<td>617-414-5725 (Administrator)</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Emergencies, Evenings, and Weekends:</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td>617-414-5000 to reach on-call doctor</td>
</tr>
<tr>
<td></td>
<td></td>
<td>617 638-5795 to page a doctor or social worker</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Philippa Sprinz, MD: ID# 2587</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Amy Sobota, MD: ID# 3253</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Maria Champigny, LICSW: ID# 5143</td>
</tr>
<tr>
<td><strong>Children’s Hospital Boston</strong></td>
<td>Monday – Friday: 8:30am – 5pm</td>
<td>617 355-8246</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Emergencies, Evenings, and Weekends:</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td>617 355-6369 and ask for the hematologist “on call” to be paged</td>
</tr>
<tr>
<td><strong>Massachusetts General Hospital</strong></td>
<td>Monday – Friday: 9am – 5pm</td>
<td>617 726-2737</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Emergencies, Evenings, and Weekends:</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td>617 726-2737 and ask for the pediatric hematologist/oncologist “on call” to be paged</td>
</tr>
<tr>
<td><strong>Tufts Medical Center</strong></td>
<td>Monday – Friday: 8:30am – 5pm</td>
<td>617 636-5535</td>
</tr>
<tr>
<td>Floating Hospital for Children</td>
<td></td>
<td><strong>Emergencies, Evenings, and Weekends:</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td>617 636-5114 and ask for the pediatric hematologist/oncologist “on call” to be paged</td>
</tr>
</tbody>
</table>
Sickle Cell Disease

A RESOURCE GUIDE FOR PATIENTS, FAMILIES, AND PROVIDERS.
Sickle Cell Disease
A resource guide for patients and families

Introduction
Children and families living with sickle cell disease often have many questions. This guide was created as a resource to help answer some of those questions and give families the knowledge they need to live and thrive with sickle cell disease.

What is Sickle Cell Disease?
Sickle cell disease is an inherited blood condition that affects red blood cells. In people with sickle cell disease, red blood cells, which carry oxygen throughout the body, are shaped like sickles or crescent moons rather than being round and donut-shaped. The sickle-shaped cells can prevent the blood from flowing properly in the body. Most of the medical problems related to sickle cell disease occur due to poor blood flow.

A child will have sickle cell disease if he or she inherits two sickle cell genes – one from each parent. Sickle cell disease is believed to have originated from West and Central Africa. In the United States, it is most commonly found in African-Americans. It can also affect those whose origins are from the Middle and sometimes Far East as well as Southern Europe and the Caribbean. There are approximately 80,000 people living with sickle cell disease in the US. Each year about 2000 children are born with sickle cell disease in this country.

Sickle cell disease can affect many different organ systems in the body. When sickle-shaped red blood cells get stuck inside smaller blood vessels, this can lead to severe pain at times. Important organs like the brain, heart, and kidneys, which need a constant blood supply to work properly, can be damaged by sickle cells.

There is currently no standard cure for sickle cell disease. By receiving special medical care, people with sickle cell disease can lead long, healthy lives.
Medical Issues
Sickle cell disease can lead to many medical issues that may vary depending on a child’s age and condition. The information that follows addresses some of these medical complications and steps you can take to ensure safe and proper care for your child.

If you or your child notice that he/she is experiencing the following medical conditions, please contact your doctor:

- **Fever** (a temperature greater than 100.5°F for a child under one year of age or greater than 101.5°F for children older than one year of age)
- **Pain** (either sickle cell disease pain or other pain) that has not responded to home pain medicines or is different in nature from usual
- **Any new breathing problem**: cough, wheezing, shortness of breath, tightness of the chest or chest pain
- **For a baby**, unexplained fussiness, change in feeding, and/or vomiting
- **In the abdomen**: An increase in spleen size
- **In the skin**: An increase in paleness of the skin
- **For movements**: Any change in strength, ability to use arms or legs, abnormal uncontrolled movements (seizures) or change on consciousness, even if very short lasting
- **Vomiting or diarrhea**
- **Priapism**: An erection of the penis that persists more than a few minutes or is painful

Remember that people with sickle cell disease may become sick very quickly. Never hesitate to call your doctor if you have any concerns about a possible complication of your child’s sickle cell disease.

**Fever**
Fever may be caused by a viral illness, a bacterial illness, dehydration or other conditions. Children with sickle cell disease take penicillin from birth to age 5 to try to reduce the risk of infection. Taking penicillin, however, does not guarantee to protect your child from a bacterial infection. Children also receive vaccinations against a group of infections known as pneumococcal infections. These are known as Pneumovax® and Prevnar®. These also help to reduce the risk of infection but are not guaranteed to prevent your child from being sick and getting a fever.

You must make sure that you always have a thermometer to take your child’s temperature. If your child has a fever, your doctor may recommend a hospital stay for about 48 hours to determine if the infection needs ongoing antibiotic treatment.

**If your child has a fever, call your child’s doctor right away. Do not give Tylenol, do not wait to see if the temperature comes down, and do not only call if the fever persists. These will waste valuable time.**

**Pain**
If your child experiences pain that does not get better with Tylenol® or other pain medicines that you have at home, you need to be in touch with your child’s doctor. The best treatment for your child may be admission into the hospital, or the pain may be addressed through the emergency room or in an outpatient setting. You must help the doctor determine if the pain can be made better with one or two pain treatments in the ER or clinic, or if your child should be admitted for pain management. If your child has a fever along with pain, call your doctor before giving any Tylenol or Motrin.

**If your child has pain that is different than usual or does not respond to the pain medicines you have at home, call your child’s doctor for advice.**

Remember to have your child’s doctor to refill pain medicines before they run out. Tylenol with codeine can be “called in” for a refill. Morphine, Dilaudid®, Methadone or other similar narcotics cannot be “called in.”
**Chest Problems**
Sometimes sickle-cell related problems in the chest may make your child very sick very quickly. If your child develops any new chest problems, such as coughing, wheezing, tightness of the chest, shortness of breath or chest pain, please call to the doctor right away. Your child may need a chest X-ray or to be admitted to the hospital to receive antibiotics and medical care while the chest problem resolves. Do not try to treat new chest problems at home on your own.

*If your child has any new chest problems, call your doctor for advice right away.*

**Increase in Spleen Size**
Younger people with sickle cell disease may sometimes develop an enlarged spleen, which is when this organ on the upper left side of the body becomes full of blood. This is called **splenic sequestration**. Your doctor should show you where your child’s spleen sits, how to feel for it, how to recognize if it is enlarged, and when to seek medical attention. If you suspect your child’s spleen is enlarged, you should check and see if you can feel it. If you think you can feel it you must call your doctor right away. Even if you cannot feel an enlarged spleen, if your child is fussy or irritable and you don’t know why, please call your doctor.

**Increase in Skin Paleness**
Children with sickle cell disease can occasionally become very anemic due to either splenic sequestration or a **parvovirus infection (aplastic crisis)**, which is an infection that causes the bone marrow to stop producing red blood cells.

Sometimes it is difficult to recognize anemia in the skin. If your child looks pale or is more tired than usual, is experiencing headaches, dizziness or shortness of breath, or is fussy and irritable or shows signs of an enlarged spleen, call your child’s doctor immediately as a significant anemia may be present.

*If your child is pale or has signs and symptoms of anemia, call your doctor right away.*

**Neurological Changes**
Children with sickle cell disease have an increased risk of problems with the blood vessels of their head. Because sickle cells can get stuck in the vessels of the brain, people with sickle cell disease are at an increased risk of having a **stroke**, or a transient ischemic event (a short-lasting brain event.) Your doctor needs to know about such an event immediately to take care of your child quickly. If your child experiences any weakness of arms or legs, altered consciousness, difficulty in speaking or thinking, or any seizure-like activity (abnormal, uncontrolled movements), you must call your child’s doctor immediately. If your child has lasting altered consciousness, do not take the time to call your doctor, but dial 911 or the emergency number for your area and have your child taken to hospital, where your doctor can then help.

If your child has any neurological changes, including weakness, altered consciousness, difficulty speaking or thinking, or seizures, call your doctor or 911 or the emergency number for your area immediately.
**Vomiting or Diarrhea**

Children with sickle cell disease may become dehydrated if they experience vomiting or diarrhea. The sickle cells may “sickle” more if there is less fluid in the blood vessels.

It is important for good health for individuals with sickle cell disease to drink plenty. Vomiting and diarrhea lead to loss of body fluid. If your child does experience any vomiting or diarrhea and can take fluid by mouth, clear liquids such as water, Gatorade®, Powerade®, punch, iced or hot clear tea, or similar liquids are better than a milk-based product at this time. If your child experiences vomiting or diarrhea, call your child’s doctor for advice. Your child may need to be admitted to hospital for intravenous fluid.

*If your child experiences vomiting or diarrhea, call the doctor for advice.*

**Sustained or Painful Erection of the Penis**

This is called priapism and is another complication of sickle cell disease. It is important that boys with sickle cell disease know that this is something not normal that they can experience because they have sickle cell disease.

If a boy does have a painful or protracted erection of the penis, please be sure to contact the doctor. Sometime just pain medicines and fluid will help resolve this problem. Other times, however, a blood transfusion or surgery is necessary. If this problem is not addressed quickly, and particularly if the problem recurs, it is possible that impotence would be the eventual outcome.

*If your son experiences a painful or long last erection of the penis, call the doctor right away for advice on how to resolve this.*
<table>
<thead>
<tr>
<th>ORGAN/TISSUE INVOLVED</th>
<th>PROBLEMS CAUSED</th>
</tr>
</thead>
</table>
| KIDNEY               | • Inability to control urination  
|                      | • Hematuria (blood in the urine)  
|                      | • Unconcentrated urine  
|                      | • Frequent urination  
|                      | • Kidney disease  
| SPLEEN               | • Splenic sequestration (pooling of blood in the spleen)  
|                      | • Scared spleen becomes non-functional by age two contributing to increased risk for serious infections  
|                      | • Abdominal pain  
| LUNGS                | • Pneumonia  
|                      | • Acute Chest Syndrome (sickling in the chest)  
| BONES                | • Infection  
|                      | • Aseptic necrosis (breakdown of the bone)  
| BRAIN                | • Stroke  
|                      | • Headache  
| SKIN                 | • Slow healing leg ulcers  
| PENIS                | • Priapism (painful unwanted erection)  
| EYES                 | • Sickle cell retinopathy (changes in the blood vessels in the eye)  
| LIVER                | • Enlarged liver  
|                      | • Gallstones  
|                      | • Jaundice (yellowing of eyes and skin)  

* Not all these complications occur in every child with SCD. You need to know, however, that they can happen. Ask parents about their child’s history regarding complications.
Table 2: Physical Complications: Warning Signs

<table>
<thead>
<tr>
<th>SIGNS</th>
<th>SYMPTOMS</th>
</tr>
</thead>
<tbody>
<tr>
<td>FEVER</td>
<td>• 101 degrees or higher</td>
</tr>
<tr>
<td>PALLOR</td>
<td>• Noticeable change in complexion, lips,</td>
</tr>
<tr>
<td></td>
<td>fingernails</td>
</tr>
<tr>
<td>BREATHING</td>
<td>• Dyspnea (difficulty breathing)</td>
</tr>
<tr>
<td></td>
<td>• Tachypnea (fast rate of breathing)</td>
</tr>
<tr>
<td></td>
<td>• Stertorous breathing (labored breathing)</td>
</tr>
<tr>
<td>HEADACHE</td>
<td>• Sudden or constant</td>
</tr>
<tr>
<td></td>
<td>• Dizziness</td>
</tr>
<tr>
<td>HEARTBEAT</td>
<td>• Tachycardia (rapid heartbeat)</td>
</tr>
<tr>
<td></td>
<td>• Pounding</td>
</tr>
<tr>
<td>PAIN</td>
<td>• Head</td>
</tr>
<tr>
<td></td>
<td>• Chest</td>
</tr>
<tr>
<td></td>
<td>• Joints</td>
</tr>
<tr>
<td></td>
<td>• Abdomen (abdominal distention)</td>
</tr>
<tr>
<td></td>
<td>• Penis (prolonged erection)</td>
</tr>
<tr>
<td>SWELLING</td>
<td>• Hands</td>
</tr>
<tr>
<td></td>
<td>• Feet</td>
</tr>
<tr>
<td></td>
<td>• Joints (with redness)</td>
</tr>
<tr>
<td>MUSCULAR WEAKNESS</td>
<td>• Either side of the body</td>
</tr>
</tbody>
</table>

• Contact the child’s family if you notice any of these signs and symptoms.
Any change from what you feel is normal for the child should be reported to the family.
When Your Child is in Pain

Pain can be a life-long challenge for those living with sickle cell disease. In addition to medical intervention, there are a number of non-medical approaches that may help your child better cope with pain.

To best help your child when he/she experiences pain, you should take responsibility for managing the pain. You should be alert to when your child starts having pain and, at that time ask him/her to rest, to stay warm, to take a warm shower or use a heating pad. You should give Tylenol® or Motrin® as your doctor will have advised. It is often helpful if your child drinks clear liquids at the time of a painful crisis. If the pain does not settle with Tylenol® or Motrin® and you have stronger medicines at home, use the medicines as your child’s doctor has prescribed. If your child’s pain continues even after you have given your child the prescribed pain medicines, call your child’s doctor. It may be that your child’s pain would be best managed in the hospital.

While you are trying to resolve your child’s pain, you may want to try one or more of the following techniques. Some of these you may be able to provide yourself. Others you will need to ask your doctor about.

Acupuncture is based on the belief that life forces move through the body in specific paths. These paths are called meridians. With acupuncture, a needle is put into the meridian that runs to the area where your child is having pain. This needle blocks the meridian, which stops or decreases the pain.

Aromatherapy is a way of using good smells to help your child relax and decrease pain. Candles, massage oil, scented bubble baths, and even baking cookies are all ways that smells are used. Scientists are learning that good smells may change your child’s mood and help him relax. It may also help your child’s brain make special chemicals like endorphins, which can help decrease pain.

Breathing exercises are another physical way to help your child’s body relax. Teaching the body to relax helps lessen pain. You should teach your child to breathe in and out very slowly. A fun way to practice breathing slowly is to blow soap bubbles or a party blower. Your child will know he is doing great when he gets large bubbles or the blower makes long noises.

Control often helps children have less pain when they need to have medical procedures. If they understand what is going to happen and are allowed to help, they may experience less pain. For example, let your child choose the finger that will be poked for a blood sample. Or, let him put on the bandage. Also, caregivers may explain treatments and procedures using a doll to help decrease the fear of the unknown.

Distraction teaches children to focus their attention on something other than pain. Watching TV, playing board and video games, or telling stories may relax you and your child. This can help keep your child from thinking about the pain. Take a “fun bag” with these kinds of toys when your child goes for treatments or procedures.

Guided imagery teaches your child to put pictures in his/her mind to help make the pain less intense. With guided imagery, your child learns how to change the way her body senses and responds to pain. Ask your child to imagine floating in the clouds, or remembering a favorite place, or imagine doing a favorite activity. Ask your child to tell you what she feels when floating, if she can see things all around, and so on.

Heat can help decrease pain. Some types of pain improve best using heat. A warm bath may help calm your child and let his muscles relax. A heating pad held against the area of pain may help to reduce the pain.
Music increases blood flow to the brain and helps your child take in more air. It does not matter whether you and your child listen to it, sing, hum, or play an instrument. Scientists are learning that music increases energy and helps change your child’s mood. Music also may cause your child’s brain to make special chemicals like endorphins.

Relaxation and biofeedback teach your child’s body to respond in a different way to the stress of being in pain. Normally, when pain starts, the body responds with tense muscles, a faster heartbeat, and higher blood pressure. Your child’s breathing also becomes faster and shallower. These responses can make the pain worse. Relaxation helps make the pain less by changing these responses. Caregivers may use a biofeedback machine so that you and your child know right away when your child’s body is relaxed.

Massage is often used to help a child become more relaxed. You or other family members can gently massage your child’s back, shoulders, and neck. Massage may work even better if you help your child use guided imagery, breathing exercises, or music.

Being in a quiet place may make it easier for your child to deal with the pain. Avoiding bright lights or loud noisy places may help you control your child’s pain.

Self-hypnosis is a way for older children to change their level of awareness. This means that by focusing their attention, children can move away from their pain by making themselves open to suggestions like ignoring the pain or seeing the pain in a positive way.

Hypnosis can give long-lasting relief of pain without affecting a child’s normal activities. Self-hypnosis gives your child better control of his or her body. Your child may feel less hopeless and helpless because he or she is doing something to decrease the pain.

Please remember that your child may react to how you are feeling. If you are upset or nervous, your child may become upset or nervous. This can increase your child’s pain. Relaxation exercises can work to help you become calm. If you can be calm and relaxed, your child may become calm and less fearful, which will help decrease his or her pain.
Emotional Issues

Helping Your Child Cope
A chronic illness like sickle cell disease can create many challenges for children and their families. As a parent or caregiver you may be asking:

- What does my child know about sickle cell disease?
- How does my child feel about the treatment?
- How can I support my child?

Children of different ages understand and react differently to sickle cell disease and its treatment. Your child’s personality, normal coping style, support system, treatment plan, as well as age or developmental level will affect how your child copes with sickle cell disease.

When children are faced with stress their normal behaviors may change. They often become more dependent on adults or may act younger than their age (baby talk, wetting pants after being potty trained, sucking his/her thumb or holding a favorite toy or blanket.). Your child may not know how to handle the many feelings that have been caused by the sickle cell disease diagnosis.

You are a very important part of your child’s life for many different reasons. You know what your child has experienced in the past and how your child usually handles stress. You can help the health care team understand your child. You and the health care team can work together to find new ways to help your child cope with sickle cell disease and treatment.

In the following section, we look at common ways children of different ages respond to stress and sickle cell disease. The section also discusses specific suggestions for how to help children in each age group cope.

Preschooler (3-5 years)

Preschoolers are also trying to do things on their own. They take pride in being able to do things for themselves (“I can do it!”). Preschoolers are learning more words to express what they think and feel. However, they often use their play to tell you these same things. They can see the hospital and treatment as punishment for something they did wrong. Also, they often become confused by adult words and make up reasons for the things that happen.

Tips for supporting your preschooler when he/she is ill or hospitalized:
- Tell your child what will happen a little before the treatment using simple words, pictures, or books
- Explain terms that your child may not understand (ex: thinking a “CAT” Scan has
- Let your child play with doctor kits and safe medical supplies such as a blood pressure cuff
- Allow your preschooler to make choices whenever you can (ex: apple juice or orange juice?); however, do not offer choices when choices do not exist
- Praise your child for doing things independently such as dressing, brushing teeth, and eating
- Maintain your routines as much as possible as a child responds best to predictability
- Use play to help your child to show feelings
- Maintain discipline strategies as much as possible as before diagnosis
School Age (6-12 years)

School age children take pride in being able to do most things by themselves. They enjoy school because it helps them learn and master new things. Their friends are becoming more important. School age children are able to think in terms of cause and effect and have a better sense of time. They have more words to describe their bodies, thoughts, and feelings. School age children can also understand more of how their bodies work; however, they still may have a hard time with and be confused by medical words.

Tips for supporting your school-age child when he/she is ill or hospitalized:

- Allow your school-age child to make choices whenever you can, but do not offer choices when no choices exist.
- Let your child practice things that are new and scary.
- Let your child go to school or do school work and activities.
- Maintain the same routines and discipline for the whole family.
- Have your school-aged child write letters, e-mail or call friends.
- Let friends visit when your child feels well enough.
- Use simple works, pictures, or books to tell your child what will happen.
- Let your child play with safe medical supplies like a blood pressure cuff.

Teens (13-18 years)

Teens are beginning to see themselves as individuals in the world. They are striving to be independent from the adults around them. As teens strive to think and act for themselves, their peers become even more important. Teens want to be like their friends and are concerned with how they are viewed by others. Illness and treatment cause teens to be different when they are trying so hard to be the same. Teens are able to see not only cause and effect, but also can see things from many points of view.

Tips for supporting your teen when he/she is ill or hospitalized:

- Let your teen be active in social and school activities.
- Involve your teen in the treatment plan by including him or her when talking to the team about the plan.
- Allow your teen to do things that makes him/her feel good about him/herself.
- Respect that teens made need to do some things by themselves, when possible.
- Offer your teen private time.
- Encourage time with peers and allow friends to visit or call in the hospital or home.
- Answer questions openly and honestly.
- Help your teen to plan for the future.
- Encourage your teen to keep doing normal things like school.
- Give your teen safe ways to express feelings, especially anger, such as physical activity, talking, or writing.
- Assure your teen that all feelings are normal, such as guilt, fear, or sadness.
Impact of Sickle Cell Disease on Siblings
Brothers and sisters of a child with sickle cell disease may have many different feelings and responses. Often they have needs similar to their sick brother or sister. They may feel upset, scared, and unsure of what the future holds.

While siblings may feel sad and worried about their sick brother or sister, they may also feel some resentment or anger. Mom and dad are spending all of their time with or talking about the sick child. Friends and family send gifts and money. Children, especially young ones, may feel jealous. Siblings may also feel sad and cry easily. Often siblings have problems of their own, such as depression, trouble sleeping, physical complaints or problems in school.

How to help siblings

The following suggestions may be useful in helping your other children cope with their brother’s or sister’s illness:

- Try to spend time alone with your other children, doing things that are of interest to them.
- Let your other children know they are still loved and important to you.
- Talk with your other children about the diagnosis, treatment, and effect on their brother or sister. What you tell them will depend on their ages and ability to understand. Assure them that sickle cell disease is not contagious and they are not responsible for their brother or sister getting sickle cell disease.
- Take your other children with you to the hospital to help them feel involved in the care and treatments of your sick child. Taking them to the hospital or clinic may help to decrease their fears and help to keep a feeling of closeness with their brother or sister.
- Ask a friend or relative to stay in your home, rather than send your children elsewhere when the ill child is hospitalized.
- Allow your children to help with chores at home to help them feel needed and help you too.
- Talk with your children’s teachers. Teachers can be supportive of your children and let you know about any school-related problems.
- Ask for help from a member of the health care team, such as the child life specialist, social worker, psychologist, or child psychiatrist.
Transition to Adulthood

Transitions are a common part of life but can be difficult at times. Many children diagnosed with sickle cell disease have to be seen by their pediatric providers very often throughout their childhood. Therefore they become accustomed to the way they receive their healthcare and are comfortable with and trusting of their providers. At eighteen years old, adulthood is setting in along with various responsibilities. At this time, high school is coming to an end and a new chapter begins with college on the horizon. Correlating with the change in education; health insurance, finances and other needs all become factors that one has to deal with.

*In 2002 several medical organizations developed a consensus statement on the health care transition of young adults with special health care needs. The goal of this statement was to ensure that physicians who provide care to children and youth with special health care needs (CYSHCN) understand the transition process, are able to facilitate the process, and recognize when transition of care is appropriate (American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP), & American College of Physicians-American Society of Internal Medicine (ACP-ASIM), 2002).

The statement is comprised of 6 main components. They are:

1. There is a designated health care professional (HCP) to support CYSHCN as they transition.
2. Health care providers (HCPs) provide appropriate transition services.
3. Clients have an updated, portable medical summary.
4. By the age of fourteen the client and client’s family have assisted in the formation of a written health care transition plan.
5. The same primary and preventive care guidelines are applied to all young adults.
6. CYSHCN have access to affordable and continuous health insurance that incorporates coordination of care and planning for the transition process (AAP, AAFP, & ACP-ASIM, 2002).

*The above information is taken from Joseph Telfair’s statement on Global & Theoretical Transisitons Issues.

For more information on the Transition Program at Boston Medical Center, please contact the Division of Pediatric Hematology/Oncology at 617 414-5725.

The Transition Clinic currently runs monthly in the Moakley Center (3rd floor) of Boston Medical Center. This clinic currently serves patients with sickle cell disease who are between the ages of 18 and 22. The providers at this clinic include pediatric and adult hematologists, and pediatric and adult social workers.
Food and Nutrition

Meeting your Fluid Needs with Sickle Cell Disease

Drinking enough fluids is an important part of helping to keep pain away. Based on your age, weight and individual condition, your fluid needs will vary. The list below is a good place to start, but you check with your doctor to make sure you are getting enough to drink.

Fluid Goals:

<table>
<thead>
<tr>
<th>Age</th>
<th>Weight</th>
<th>Ounces</th>
<th>Cups/bottles</th>
</tr>
</thead>
<tbody>
<tr>
<td>6-12 months</td>
<td>17-23 pounds</td>
<td>50</td>
<td>6</td>
</tr>
<tr>
<td>1-2 years</td>
<td>23-28 pounds</td>
<td>54</td>
<td>7</td>
</tr>
<tr>
<td>3-4 years</td>
<td>30-40 pounds</td>
<td>62</td>
<td>8</td>
</tr>
<tr>
<td>5-6 years</td>
<td>40-50 pounds</td>
<td>75</td>
<td>9</td>
</tr>
<tr>
<td>7-10 years</td>
<td>50-75 pounds</td>
<td>82</td>
<td>10</td>
</tr>
<tr>
<td>11-13 years</td>
<td>75-100 pounds</td>
<td>95</td>
<td>12</td>
</tr>
<tr>
<td>14 years and over</td>
<td>Over 100 pounds</td>
<td>105</td>
<td>Over 13</td>
</tr>
</tbody>
</table>

Tips for meeting your fluid needs:
- Carry a water bottle with you at all times
- Start your day by drinking a glass of water and remember to drink every 2 hours, at least, to meet your daily needs
- Drink liquids after you eat and between meals to prevent filling your stomach with fluids, which may make it difficult to eat
- Add extra fluid when you have pain and with exercise

What fluids should I drink?
There are many different choices when it comes to fluids. In general, it is best to choose fluids that are non-caffeinated, see list below for suggestions. It is also important to avoid sugary drinks that do not offer our bodies the nutrition that it needs to stay healthy.

Choose more:  
Water, spring or tap  
Flavored waters, sparkling waters  
Milk  
100% fruit juice*  

Limit:  
Caffeinated sodas  
Coffee  
Tea  
Kool aid, fruit drinks  

* Be careful not to drink too much 100% fruit juice as it may fill you up, making it difficult to eat a balanced diet
### Eating to be Well with Sickle Cell Disease

With Sickle Cell Disease it is especially important to eat a **balanced diet** to make sure that we give our body the energy, fiber and vitamins and minerals that it needs to keep us healthy.

### What is a balanced diet?

A balanced diet is a diet that includes foods from all of the five major food groups and oils. Each of the different food groups provides our bodies with important nutrients. Avoiding any one food group places individuals at risk for less than optimal nutrition. The following includes examples of the different food groups:

<table>
<thead>
<tr>
<th>Food Groups</th>
<th>Examples of foods and what they give our bodies:</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Grains</strong></td>
<td>Whole grain breads, rice, pastas, cereals and crackers – <em>aim to make at least half of the grains that you eat “whole” grains</em></td>
</tr>
<tr>
<td></td>
<td><em>Fiber – helps to reduce blood cholesterol and keeps our bowels moving</em></td>
</tr>
<tr>
<td></td>
<td><em>Folate – (in fortified grains)- helps our body make new red blood cells</em></td>
</tr>
<tr>
<td></td>
<td><em>B-vitamins – helps our body to use the energy from foods that we eat</em></td>
</tr>
<tr>
<td></td>
<td><em>Magnesium – important for healthy bones</em></td>
</tr>
<tr>
<td></td>
<td><em>Selenium – important for healthy immune system</em></td>
</tr>
<tr>
<td><strong>Vegetables</strong></td>
<td>Spinach, carrots, broccoli, tomato, green beans, salad – <em>aim for orange and dark green leafy vegetables</em></td>
</tr>
<tr>
<td></td>
<td><em>Fiber – Tip: keep the skin on veggies and fruits for extra fiber</em></td>
</tr>
<tr>
<td></td>
<td><em>Folate – Tip: choose leafy greens</em></td>
</tr>
<tr>
<td></td>
<td><em>Vitamin A – helps to keep eyes and skin healthy and helps to protect against infections</em></td>
</tr>
<tr>
<td></td>
<td><em>Vitamin C – helps heal wounds and keeps teeth and gums healthy</em></td>
</tr>
<tr>
<td></td>
<td><em>Potassium – may help maintain healthy blood pressure</em></td>
</tr>
<tr>
<td><strong>Fruits</strong></td>
<td>Oranges, bananas, apples, grapes, melon, berries, kiwi, peach, plums   <strong>*</strong></td>
</tr>
<tr>
<td></td>
<td>*Provide similar vitamins, minerals and fiber as vegetables, see above.</td>
</tr>
<tr>
<td></td>
<td><em>Note: individual fruits and vegetables provide different amounts of vitamins, minerals and fiber so it is important to eat a variety of different fruits and vegetables daily to maximize your benefits.</em></td>
</tr>
<tr>
<td><strong>Milk</strong></td>
<td>Low fat milk, yogurt and cheese</td>
</tr>
<tr>
<td></td>
<td><em>Calcium and Vitamin D – for strong, healthy bones</em></td>
</tr>
<tr>
<td></td>
<td><em>Potassium – especially in milk and yogurt</em></td>
</tr>
<tr>
<td><strong>Meats &amp; Beans</strong></td>
<td>Lean chicken, pork, fish and beef, nuts, seeds, peas and beans</td>
</tr>
<tr>
<td></td>
<td><em>Protein and zinc – for energy and growth</em></td>
</tr>
<tr>
<td></td>
<td><em>Iron – helps to carry oxygen in our blood</em></td>
</tr>
<tr>
<td></td>
<td><em>Omega 3 fatty acids – in certain fish, nuts and seeds – help to reduce inflammation and decrease risk of chronic diseases, like heart disease</em></td>
</tr>
<tr>
<td><strong>Oils</strong></td>
<td>Liquid vegetable oils like olive, canola, corn oil; nuts</td>
</tr>
<tr>
<td></td>
<td><em>Vitamin E – works as an antioxidant to help to prevent disease</em></td>
</tr>
<tr>
<td></td>
<td><em>Omega 3 fatty acids – in flax, canola, soybean and walnut oils, and walnuts, flaxseeds and pumpkin seeds</em></td>
</tr>
</tbody>
</table>
Additional Support & Resources

A diagnosis of sickle cell disease may be overwhelming and extremely stressful at times. The ways people respond to the diagnosis and treatment vary, and many social, emotional, and spiritual concerns may arise. A pediatric hematology social worker is available to provide individual and family counseling that will assist you and your child to help deal with concerns in the following areas:

- Your child’s feelings about him/herself
- Reactions to the illness
- School issues
- Financial and insurance concerns
- Providing electric and gas company documentation of medical necessity
- Application for a disabled parking permit

Sickle Cell Resource List

There are many resources available to help you and your family to manage life with sickle cell disease.

The Community Sickle Cell Support Group
Telephone: (617) 427-4100

Greater Boston Sickle Cell Disease Association
Telephone: (617) 427-4100
1542 Tremont Street, Roxbury, MA 02120

Massachusetts Department of Public Health - Genetics Program
Telephone: (617) 534-5121

Boston Center of Excellence in Sickle Cell Disease
Telephone: (617) 534-5727

Sickle Cell Disease Association of America
Website: www.sicklecelldisease.org
The Sickle Cell Disease Association of America provides the latest information on the treatment of sickle cell disease as well as research and news about the disease.

Sickle Cell Information Center
Website: www.SCInfo.org
The mission of this site is to provide sickle patient and professional education, news, research updates, and worldwide sickle cell resources.

American Red Cross
Website: www.newenglandblood.org
Telephone: 1-800-GIVE-LIFE (1-800-448-3543)

Department of Public Health Community Support and Care Coordination Programs for Children with Special Health Care Needs
Telephone: (800) 882-1435

New England Newborn Screening Program
University of Massachusetts Medical School
305 South Street
Jamaica Plain, MA 02130
Telephone: (617) 983-6300

Financial Assistance

Mass Health
Telephone: 1-800-841-2900 (for general information)/1-800-332-5545 (to apply for assistance)
Website: www.hcfa.gov/medicaid/medicaid.htm

Also know as Medicaid, this is a program of comprehensive medical coverage for low and moderate income residents of Massachusetts. Many kinds of coverage are available. Some programs include prescription drug coverage, as well as transportation assistance to medical appointments.

If you are eligible for Mass Health benefits, you most likely are eligible for the following services (please check with your primary care doctor or social worker):

Prescription for Public Transportation (PT-1 form)
Telephone: 1-800-841-2900
Provides free door-to-door transportation for your child to medical appointments. The application should be completed by your child’s physician. Ask your physician or social worker how to obtain an application

WIC
Telephone: 1-800-942-1007
This program supports low income woman and children up to age five years by providing foods to supplement nutritional needs.

Education

Massachusetts Department of Education (DOE)
(781) 338-3000
Federation for Children with Special Needs
1135 Tremont Street, Suite 420
Boston, MA 02102
Telephone: (617)-572-2094/1-800 331-0688
Website: www.fcsn.org
The Federation for Children with Special Needs provides information, support and assistance to parents of children with disabilities, their professional partners, and their communities.

Mass. Association of Special Education Parent Advisory Councils (MASSPAC)
617-962-4558
P.O. Box 167
Sharon, MA 02067

Special Kids Special Help – Boston Medical Center
Web based resource for parents with children with special needs.
Website: www.specialkidsspecialhelp.org

Sickle Cell Disease: Information for School Personnel
Website: www.state.nj.us/health/fhs/sicklecell
This information is designed for school personnel and explains many issues related to sickle cell disease. This is an excellent site to pass on to teachers who may want to know more about a student's condition, and it's helpful for sickle cell patients and families as well.

Camps for Children/Teens with Sickle Cell Disease

The Hole in the Wall Gang Camp
Telephone: (860) 429-3444
Website: www.holeinthewallgang.org
Located in Ashford, Connecticut, this camp offers free sessions for children age 7 to 15. Special sessions are available for specific illnesses.

Camp Sunshine
Telephone: (207)655-32800
Website: www.campsunshine.org
Located in Casco, Maine. Offers free sessions for families. Special sessions available for specific illnesses.

Legal Aid

Patient Advocate Foundation
Website: www.patientadvocate.org
Telephone: 1-800-532-5274
Provides education and legal counseling on managed care, insurance, and financial issues for Sickle Cell patients.

Disability Law Center
(800) 872-9992
11 Beacon Street, Suite 925(800) 872-9992
Boston, MA 02108

Massachusetts Advocacy Center
(617) 357-8431
100 Boylston Street, Suite 200
Boston, MA 02116

Parent Professional Advocacy League (PAL)
(617) 227-2925
15 Court Street, Suite 1060
Boston, MA 02108
www.ppal.net

Volunteer Lawyers Project
(617) 423-0648
(VLP of the Boston Bar Association)
29 Temple Place, 3rd Floor
Boston, MA 02111

Government Agencies

Massachusetts Department of Mental Health
(800) 221-0053
25 Staniford Street
Boston, MA 02114

Massachusetts Department of Public Health
(617) 624-6000
250 Washington Street
Boston, MA 02108

Massachusetts Department of Social Services
(617) 748-2000
24 Farnsworth Street
Boston, MA 02108

U.S. Office for Civil Rights
(617) 223-9662
FAX (617) 223-9669
U.S. Department of Education
J.W. McCormack P.O.C.H., Room 707
Boston, MA 02109
(for section 504 and ADA complaints)
Know Your Child's Rights

IEPS, 504s & Special Education Process
Education & Sickle Cell

When children with sickle cell disease reach school age, they may face special challenges due to their illness and lack of understanding of the disease by those in the school setting. There are special laws in place to ensure your child overcomes any barriers to receiving an appropriate education.

Your Child's Legal Rights

There are four major laws that relate to children with special needs and education. These laws are about the accommodations, the instruction, and the services your child may receive in school.

IDEA: INDIVIDUALS WITH DISABILITIES EDUCATION ACT

IDEA, the federal special education law, provides services to students with disabilities when their disability (or disabilities) affects the student's educational progress. This a federal law that guarantees each child with a disability receives a free and appropriate public education.

Part B of IDEA makes sure that eligible students with disabilities ages 3-21 receive a free and appropriate public education. IDEA makes sure that supports and services are provided for your child in the least restrictive environment.

The LRE (Least Restrictive Environment) is a term that means that a child should be educated in the same classroom and school as he or she would be educated in if he or she did not have disabilities.

A child is removed from the general classroom setting only if he or she is not able to succeed there with special services. If your child cannot attend his or her neighborhood school, he or she may go to another public school where there are more special services. If needed, your child may need to attend a separate public or private school. If your child cannot attend school at all for medical reasons, then your school system must provide education services either at home or in the hospital.

Part C of IDEA makes sure that children age 0-3 who have, or are at risk for having, a disability or developmental delay are provided with special services to help care for these needs. These are infants and toddlers who develop differently or at a slower rate than most other children. These services are called Early Intervention (EI).
MASSACHUSETTS SPECIAL EDUCATION LAW AND REGULATIONS

Formerly known as Chapter 766, this is the state special education law in Massachusetts. This law requires public school systems to provide a free and appropriate education for all eligible children with disabilities from the ages of 3-21.

Special education should be provided in the least restrictive environment possible. The Massachusetts special education law is related to IDEA, the federal special education law.

Not all children with special healthcare needs are entitled to or require special education. An evaluation process must take place to determine if a child is eligible.

A child is eligible for special education if:

- The child’s disability falls into one of the Massachusetts disability categories and
- The child is not making effective progress in school because of his or her disability.

If the school’s educational team (including the parent as a member) decides that your child’s disability affects the way he or she learns, then the school must work with you and other members of an evaluation team to develop an Individualized Education Program (IEP).

THE AMERICANS WITH DISABILITIES ACT (ADA) and SECTION 504 OF THE REHABILITATION ACT OF 1973

These federal laws protect the rights of people with disabilities from discrimination. The ADA and Section 504 laws make sure that plans are made to address your child’s special health needs in any program that uses federal funds. This means your child will receive special services to care for his or her needs in any public child care center and school. For example, if your child uses a wheelchair, plans are made to make sure that the school is wheelchair accessible. If your child takes medications during school hours, plans are made for a school nurse to give medications.

This information is provided in part by the Division of Perinatal, Early Childhood, and Special Health Needs within the Massachusetts Department of Public Health and mass.gov.

http://www.specialkidsspecialhelp.org/PlanYourChildsEducation.aspx
Individualized Health Care Plan

Every child with special healthcare needs in school should have an Individualized Health Care Plan (IHCP). An IHCP helps to make sure your child receives the health services he or she needs during the school day. There is no law that says your child has a right to an IHCP. If your child has a specific health problem, you should ask for an IHCP.

People who may help create your child’s IHCP include:

- You
- Your child (when appropriate)
- The school nurse
- Other members of the school staff
- Healthcare providers
- Staff from community support services (when needed)
- The MASSTART vendor in your area (when appropriate)

Contact your child’s school nurse first. Schedule a meeting with the nurse to develop the plan. It is very helpful to involve your child’s primary care provider (PCP). He or she can give the school nurse all the necessary medical information and specific doctor’s orders for your child. If your child is eligible for special education, ask your child’s school nurse to work together with the Special Education Administrator to make sure that services are coordinated.

Your child’s IHCP should include:
- The health services your child should receive at school
- When, where, and how the health services will be provided
- Who will provide the health services
- Information about your child’s transportation needs, including any special needs when taking field trips
- An Emergency Response Plan that lists possible emergencies and what to do. This plan should be discussed with all school staff and the local Emergency Medical Services (EMS) providers.
- A copy of the Emergency Information Form for Children with Special Health Needs

The IHCP should be reviewed and updated whenever your child’s medical condition changes. It is very important that you notify the school nurse immediately when changes happen. The IHCP should be kept in your child’s school record. If your child receives special education, ask to have the IHCP attached to your child’s Individualized Education Plan (IEP). That way the people who provide healthcare services and the people who provide education services can coordinate care for your child. We recommend having your child’s school staff conduct an emergency drill to make sure that the plan works.

This information is provided in part by the Division of Perinatal, Early Childhood, and Special Health Needs within the Massachusetts Department of Public Health and mass.gov. http://www.specialkidsspecialhelp.org/PlanYourChildsEducation.aspx
504 Plan

A 504 Plan helps a child with special healthcare needs to fully participate in school. Usually, a 504 Plan is used by a general education student who is not eligible for special education services. A 504 Plan lists accommodations related to the child’s disability and required by the child so that he or she may participate in the general classroom setting and educational programs.

504 Plan may include:
- Extra set of textbooks
- Access to tutors when hospitalized
- Classroom liaison to communicate missed or catch-up work
- Hall passes to visit the restroom
- Water bottles in the classroom
- Ability to wear coats when necessary
- Elevator access
- Modified or limited participation in gym
- Plans to make a school wheelchair accessible
- Your child’s assistive technology needs during the school day
- Permission for your child to type assignments instead of writing them by hand
- Permission for your child to hand in assignments late due to illness or a hospital stay

Your child may be eligible for accommodations under a 504 Plan if he or she has a physical or mental health disability that limits one or more major life functions. A 504 Plan is supported by the federal civil rights law, Section 504 of the Rehabilitation Act of 1973. A 504 Plan is to be provided in programs that receive federal funds, such as public schools.

Each school is required to have a Section 504 Coordinator. Developing any plan requires working together as a team. Work with your child’s school nurse, primary care provider (PCP), and the Section 504 Coordinator to create a 504 Plan.

In developing a 504 plan, the process should include:
- A school evaluation
- A letter from your child’s PCP describing the disability, related problems, and needed medications and/or treatments
- Identification of the accommodations to be provided – physical and instructional
- Your child’s Individualized Health Care Plan (IHCP)
- A copy of the Emergency Information Form for Children with Special Health Needs

If you are having trouble creating a 504 Plan or getting appropriate accommodations for your child, contact the US Department of Education’s Office for Civil Rights at 617-223-9662.

This information is provided in part by the Division of Perinatal, Early Childhood, and Special Health Needs within the Massachusetts Department of Public Health and mass.gov.
http://www.specialkidsspecialhelp.org/PlanYourChildsEducation.aspx
Individualized Education Program (IEP)

According to state and federal special education laws, all children who have been found eligible for special education must have an Individualized Education Program (IEP). The IEP is a written plan that describes exactly what special educational services and accommodations your child will receive. It must be reviewed every year.

Your child’s IEP is developed by a team of people at the school and includes the parent as part of the IEP Team.

The IEP should include:
- A report on how your child is doing in school.
- A list of your child’s strengths and areas to improve.
- A vision statement – your and your child’s hopes and goals.
- Measurable educational goals for your child and a plan for achieving those goals.
- Specially designed teaching and/or services your child needs to help reach those goals. The expected start and end dates for these services should be included (such as speech, occupational, and physical therapies, in-school private duty nursing, assistive technology, and other services to be provided at school).
- The amount of time during the school day your child will spend in regular and/or special education activities.
- Beginning at age 14, a description of special instruction that will help your child transition from school to adult life activities when ready.

After the IEP is developed, the IEP Team decides on the placement for your child that is most able to provide the services identified in the IEP. This placement decision should be the least restrictive environment possible. Throughout the school year, you are entitled to receive regular progress reports to tell you if your child is making progress towards his or her IEP goals.

IEPs (Individualized Education Program) and 504 plans are binding, legal, written documents that are centered on your child’s specific needs in order to create a successful educational experience. If your child has frequent absences from school, ask your child’s guidance counselor in school or your child’s social worker in the clinic how to set up a meeting for your child to be evaluated for individual plans/arrangements to optimize his/her school experience.
Advocating For Your Child

If your child has significant medical needs, the education plan may be just one of many concerns. Here are steps that can help you address health and safety needs in school:

1. Contact the school’s principal, special education director, and school nurse three to six months before your child is scheduled to enter the school. Schedule a meeting to introduce yourself and discuss your child’s needs.
2. Provide the school nurse with healthcare information about your child, including a copy of your Emergency Information Form for Children with Special Health Needs.
3. Work with your child’s primary care provider (PCP), specialist, and/or school nurse to develop a list of everything your child needs on a daily basis to go to school.
4. Contact your child’s physician or MASSTART (Massachusetts Technology Assistance Resource Team) for help developing your child’s Individualized Health Care Plan (IHCP) and Emergency Response Plan. MASSTART is a free program that provides consultation services for children with special health needs who are in school. It helps children who use medical technology (like a feeding tube, oxygen, ventilator, etc.) to safely attend school.
5. Request a meeting between you, your child’s PCP, and the school nurse. The school nurse will probably be your child’s healthcare coordinator at school. This meeting will provide an opportunity to develop an Individualized Health Care Plan (IHCP) for your child. An IHCP explains all of your child’s daily needs, lists the staff that will be working with your child, and reviews possible health problems and solutions.
6. If your child is receiving special education, request that your child’s Individualized Health Care Plan (IHCP) be attached to the Individualized Education Program (IEP).
7. Contact your child’s teacher and/or evaluation team leader if your child must be away from school due to illness, including hospitalization. He or she will help plan for your child’s education during this time.
8. If your child is hospitalized, send a copy of the discharge summary to the school nurse. Also, tell the nurse if your child’s health needs change.

When going to a meeting at your child’s school, think about bringing someone with you to provide support. If possible, bring a family member, friend, or advocate.

This information is provided in part by the Division of Perinatal, Early Childhood, and Special Health Needs within the Massachusetts Department of Public Health and mass.gov. http://www.specialkidsspecialhelp.org/PlanYourChildsEducation.aspx

You may wish to distribute the information below to staff at your child’s school to help them better understand your child’s sickle cell disease.
For the most part, children with sickle cell disease should be able to actively participate in the regular school setting. There are, however, some ways to make participation in day-to-day activities less likely to trigger complications of the disease. It is important to keep in mind that for children with sickle cell disease, any severe or untreated complication can be life threatening. If you observe any sign or symptom that concerns you, you shouldn't hesitate to get the child into the care of medical professionals or evaluated at a hospital or treatment center.

Socialization and Peer Support

While many children are well adapted emotionally to handle the stresses produced by their illness, others are not. Some children enter school from an environment in which they have been overprotected as a result of their illness. Their behaviors may be characterized by over dependency, a sense of helplessness, excessive and unpredictable levels of frustration and a reluctance to try new tasks. By creating opportunities for independence and accomplishment, and emphasizing progress, the teacher can foster the child’s coping abilities and increase self-esteem.

Interventions

- Choose the child for classroom jobs
- Assign leadership roles to the child in classroom activities and projects
- Encourage participation in extracurricular activity in which the child should excel

Nutrition and Diet

There is no special diet for children with sickle cell disease, however recent research shows that children with sickle cell need about 20 percent more calories than other children to fuel their production of red blood cells. Not getting enough calories may lead to delays in growth and maturation.

Constipation is an unfortunate side effect of some of the pain medications these children take. Fiber is critical, whole grains and fruits will help prevent or treat constipation. Children with sickle cell disease need extra folic acid in order to produce red blood cells more quickly. These can be found in foods such as grains, fruits, and leafy green vegetables.
Physical Activity

Children should take an active part in any physical activity that interests them. Let them set their own pace. The student should not be required to participate in physical education activities that involve strenuous exercises and long distance running. The student should not be required to participate in the Presidential Physical Fitness Testing.

Interventions

• Emphasize the child's assets and strengths; give positive reinforcements with praise and attention
• Assess hobbies and pastimes to encourage socialization and to avoid boredom
• Assist the child to retain roles and tasks as much as possible within existing limitations

Absenteeism

Absenteeism may be the largest obstacle to school success for some children with sickle cell disease. Children may be absent a lot due to clinic visits, pain crises or other health problems. Make classwork and homework assignments available to the parents to prevent the student from falling behind. If the child is in the hospital, communicate with the hospital's teachers and give them the classwork. If necessary, help the parent arrange tutoring for your student. Absenteeism may also contribute to social isolation and disturbances in peer relationships.

In-service Education Sessions for Classmates

Classmates may begin to wonder, question and worry about their missing classmate. A class in-service can be very beneficial in helping teachers, staff and classmates learn about sickle cell disease. Educational in-services help to eliminate rumors and offer ideas on how to be a supportive friend. An educational consultant or member of the medical team that is serving the child, a parent, or the child himself can provide these programs. Please contact your health care team for more information.

Learning Problems

Learning problems can affect how well children do at school and in their social lives. Children with sickle cell disease are more prone to silent brain infarctions that can result in cognitive deficits. If a teacher notices a change in a child's school performance parents should be informed.

Depression

Depression is no stranger to those coping with chronic disease and unpredictable episodes of pain. The young adult with sickle cell disease may experience particular feelings of fear and anxiety or be depressed by the prospect of being ill for the rest of his life or having a potentially fatal disease. Depression may affect an adolescent's ability to manage his disease and personal life.
Interventions

- Provide avenues for the student to express feelings
- Assist the student to understand his or her own way of coping
- Give positive reinforcement for efforts to cope
- Maintain hope and share it with the student

Vocational Counseling

Children with this disease should set their educational and career goals in accordance with their ambitions and innate abilities. Guidance is especially important. Military careers and jobs requiring heavy manual labor are not options for persons with sickle cell disease. With proper vocational and professional counseling, an exciting and rewarding career can be realized. Role models are important and can demonstrate to the young adult that there are people with physical limitations who have succeeded.

Stay Informed

The teacher is a direct observer of daily behavior, activities and functions of a child in the classroom. The best thing you can do is to be informed about sickle cell disease and then create a plan to help a child stay involved, free of complications and engaged in learning. Children with this disease are just like other children in many respects, but they do face particular challenges because of their life-long disease. You can play an important role in offering them the chance to lead relatively normal and productive lives.

Interventions

- Awareness. Learn more about sickle cell disease. A comprehensive Web site, filled with valuable information on sickle cell can be found at www.scinfo.org
- Partnership. Facilitate a family conference to assess both the family and the student’s adjustment to illness and school pressure.
- Psychosocial support. Involve the school social worker or counselor in your plan to understand the psychosocial aspects of living with a chronic disease
Intro to the Medical Legal Partnership | Boston

- MLP | Boston is a unique partnership between lawyers and physicians that seeks to help families address problems accessing basic needs such as income supports, education, housing, utilities, and personal safety

MLP | Boston Services

- Training medical providers and social workers to identify unmet legal needs
- Case consultation for providers
- Weekly legal clinics for families
  - Referral by PCP at Boston Medical Center or Community Health Centers
  - Legal evaluation, advice, assistance, representation
- Systemic advocacy

Common Education Issues

- Evaluation and services for special needs
- Discipline
- Medical/reasonable accommodation

Your Child’s Educational Rights

- Right to attend school regardless of homelessness or immigrant status
- Right to be safe at school
- Right to a comprehensive evaluation for suspected disabilities that interfere with learning
- Right to a free and appropriate public education
- Right to participate fully in school despite disability or chronic illness

Education Tips

- Communicate with teachers and school staff, including school nurses and guidance counselors
- Ask and advise school staff about your child’s strengths and weaknesses and how they relate to her performance or participation in school
- If your child is having trouble at school, ask school staff for an evaluation
- Document your observations, concerns and requests

Right to Evaluation for Suspected Disabilities that Impact Learning

- Contact teacher
  - Explain concerns and ask teacher to share her concerns and suggestions
- Contact school special education department
  - If child continues to have difficulty at school, parent /guardian should refer child for a special education evaluation
- Consult with pediatrician
  - Consider referral to development pediatric specialist
Who is Eligible for Special Ed Services?
- Ages 3-22 (prior to 3 = Early Intervention)
- Diagnosed Disability

The IEP Process
- To begin the process, a written referral is made to the child’s school, requesting a Special Education Evaluation
- The school will then send parent a consent form
- Once parent signs and returns the consent form, the school must begin the evaluation process
- Within thirty school days of receiving the signed consent form, the school must complete the evaluation process
- Within forty-five school days of receiving the signed consent form, the school must hold a Team meeting to discuss the evaluations—the Team includes the child’s teachers, parents, evaluators, and other professionals who may work closely with that child
- The Team, after determining if the child is eligible for special education, is responsible for writing and developing an Individualized Education Program (IEP), which will document the special education services the school must then provide
- A parent has thirty days to sign—either reject, accept, or partially accept—and return the IEP

Right to a Free and Appropriate Public Education
- Right to specially designed instruction and related services to help a child learn the regular education curriculum.
- Right to be included in classroom, and not to be disciplined more than 10 times without reevaluation of the appropriateness of the school placement.
- Parent/guardian can request re-evaluation and team meeting at any time.

Right to Participate Fully in School Despite Disability or Chronic Illness
- A child with a physical or mental condition that limits one or more major life activities (caring for oneself, walking, seeing, hearing, breathing, learning) may benefit from a 504 or reasonable accommodation plan.

Examples of Reasonable Accommodations
- What will enable your child to participate fully in school?
  - Increased access to drinking water
  - Moderate temperatures
  - Increased access to bathroom
  - Pre-arranged breaks
  - Extra testing time to avoid stress
  - Avoiding overexertion
  - Elevator key; access to lounge
  - Home /hospital tutoring when absent for medical reasons

Parent Tips
- Request an evaluation if your child is struggling in school
- Make sure school staff has information about your child’s medical history and needs.
- Provide the school with a physician’s letter explaining the child’s conditions and needs
- Check in periodically with school staff
- Make sure child’s school has a 504 plan in place if your child requires a substantial support
Sickle Cell & School: Bridging the Gap
Between Education and Healthcare for Children with Sickle Cell Disease

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A very special thank you to Haemonetics® for their ongoing support and recognition for the importance of assisting children with a chronic illness and valuing their education.