Sickle Cell Disease
A Family Handbook

This handbook is for:

This booklet is to help you and your family understand sickle cell disease and manage your child’s care.

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IMPORTANT: PLEASE READ
This handbook is for information only. It is not to take the place of the advice you receive from your healthcare professional. As every patient is different, different treatments are chosen for each patient. Speak to a member of your healthcare team if you have questions or concerns.
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Introduction

Having a child newly diagnosed with sickle cell disease is a stressful time for most families — you are not alone. You probably have many questions on your mind such as:

“How will this illness affect my child’s life now and in the future?”

“What are the symptoms of this disease, what do they mean and what do I do about them?”

“Will my child be able to lead a normal life?”

These are some of the questions that drive many parents to learn more about sickle cell disease so that they can provide the best possible care to their child.

Based on our experience and from what parents have told us, we have designed this handbook so that it is useful, practical and easy to read.

It will provide you with valuable information about sickle cell disease that can help you answer many of the questions you may have and hopefully help you adapt to this stressful situation.
How to Use This Handbook

Many parents feel overwhelmed by the amount of information given to them about sickle cell disease. They worry that they will not be able to remember everything that is being said about their child’s health. This is quite normal. To facilitate your reading and understanding, this handbook is divided into three parts.

**Part 1: What Do I Need To Know Now?**
The first part contains information that will be very useful to you at this point. It includes a list of symptoms to look for, when and who to call for advice and when to get medical attention.

**Part 2: Understanding Sickle Cell Disease**
In the second part, you will find more detailed explanations about sickle cell disease, and how it is passed on.

**Part 3: What More Do I Need To Know?**
The third part of this handbook includes information about possible medical crises and complications that your child may experience due to sickle cell disease.

Keep in mind that not every child with sickle cell disease will experience these difficulties. Most children affected by the illness can lead happy and fulfilled lives.

We encourage you to read this handbook and discuss it with your doctor, nurse or other members of your treating team at the hospital. Do not hesitate to ask any unanswered questions you may have.
Part 1: What Do I Need To Know Now?

The Montreal Children’s Hospital is a first-class pediatric teaching hospital renowned for its expertise in treating sickle cell disease. Our ability to provide excellent family centered care adapted to different cultures makes us unique. The hematology team consists of several healthcare professionals that will work with you to help you and your child manage this new life situation.

Questions or Concerns — How to Get Answers?

The hemotologist is a doctor who specializes in diseases of the blood such as sickle cell disease. When you come to the clinic you will meet many doctors. All of these doctors are there to help you and your child. Besides your regular appointments with the Hematologist, we strongly encourage you to keep taking your child to the pediatrician because you will still need medical care that does not require expertise from a hematologist.

The sickle cell nurse clinician is a helpful person to contact to ask your questions about your child’s health. She will meet with you at diagnosis and offer you information that will be very helpful. Along with the other healthcare team members, she will help you reach a better understanding of your child’s illness, and may also help you manage some of the symptoms. If your child needs to see a doctor, the sickle cell nurse clinician may facilitate your visit to the clinic or to the emergency room depending on your child’s condition.
Part 1: What Do I Need To Know Now?

Social Services
Social workers assist with concrete needs: meals, transportation, financial issues, supportive counseling, school issues, crisis intervention, therapy, compliance issues, and ethical dilemmas. They will assess and evaluate each situation and assist with the appropriate resources. You may find the contact information for social services in the pull-out information sheet called “The Hematology Team.”

The hematology team consists of several healthcare professionals that will work with you to help you and your child manage this new life situation.
Part 1: What Do I Need To Know Now?

When Does My Child Need Medical Care?
Sickle cell disease is a medical condition that can have potential serious consequences if some symptoms are left untreated. Seeking treatment after early recognition of symptoms is very important. Contact us if you are concerned about your child’s health and especially if you observe any of the following:

Contact us or take your child to the emergency room if...

Fever
...your child has a temperature greater than 38.5°C (101°F). The spleen is an organ that filters and removes bacteria from the bloodstream. Because the spleen is affected by the sickle cells at a very young age, infections are more common and can be very serious and even fatal in children with sickle cell disease. A fever must not be ignored. **Report fever to your doctor or nurse immediately. Do not wait.**

Prolonged pain
...your child is feeling pain that is not relieved by rest, increased fluids, Tylenol, Tempra or Advil.
Part 1: What Do I Need To Know Now?

Distended or Enlarged Abdomen
...your child’s belly becomes enlarged and feels hard to the touch. This might mean that the blood cells are getting trapped in the spleen, causing it to enlarge. Your doctor will teach you how to feel your child’s spleen.

Difficulty Breathing
...your child has rapid breathing, shortness of breath, persistent cough, or chest pain.

Painful penile erection
...your child (boy) develops a painful, penile erection that can last a long time (more than 2 hours).
Part 1: What Do I Need To Know Now?

You should also contact us if...

...you notice any of the following symptoms in your child:

- Headache
- Stiff Neck
- Weakness or Numbness of Arms or Legs
- Change in Vision
- Severe Abdominal Pain

If you notice that your child has any of the above symptoms you must see a doctor. Call your hematology team or take your child to the emergency room.
What is Sickle Cell Disease?

Sickle cell disease is an illness that affects the hemoglobin that is contained in your child’s red blood cells. It is often diagnosed during childhood. It is a chronic illness, but different treatments and medications can help in managing some of the symptoms and complications. For a better understanding of the disease, it is important to understand how blood normally flows through our body.
How does blood normally flow through our body?
Blood flows through blood vessels by a complicated system of arteries, veins and capillaries.

- **Arteries** are elastic-like tubes that carry the blood from the heart to the rest of the body (for example, your brain, eyes, liver, and muscles).

- **Veins** carry the blood from the body parts back to the heart.

- **Capillaries** are the tiny elastic-like tubes that connect the arteries to the veins. A capillary is about 1000 times smaller than a vein or an artery.

The **vascular system** is made up of arteries, veins and capillaries.
Part 2: Understanding Sickle Cell Disease

Blood is mostly composed of microscopic cells called red blood cells. Normal red blood cells are disk-shaped, and flexible. Their shape and flexibility allows them to flow freely through the arteries and veins, and ‘squeeze’ through the very narrow passages of the capillaries.

Each red blood cell is filled with small molecules called hemoglobin. An important role of hemoglobin is to transport the oxygen to the different parts of the body. This is important because our body depends on oxygen. Oxygen is like gas for our car — if there is little or no gas in our car; the car will not work properly.

Hemoglobin picks up oxygen and then delivers it to other parts of our body.
Part 2: Understanding Sickle Cell Disease

**How does the blood flow differently when you have sickle cell disease?**

In children with sickle cell disease, many of the red blood cells are “sickle-shaped”. In other words, many of the cells are in the form of a crescent. Furthermore, sickle cells are stiff and less flexible than regular red blood cells. As explained above, normal red blood cells can squeeze through the very narrow capillaries because they are disk-shaped and flexible. Sickle-shaped red blood cells do not pass through so easily. This means that many red blood cells may get stuck in the capillaries creating a blockage.
Part 2: Understanding Sickle Cell Disease

Because the blood flow is decreased by this blockage, your child may experience a variety of symptoms caused by a lack of blood and oxygen to some parts of the body. This is the cause of most “sickle cell crises.” Pain is one of the most common symptoms of a sickle cell crisis. It can range from mild to severe and varies in intensity, location and duration. Many factors can contribute to these events. Some common examples are fever, dehydration, exposure to cold weather, sudden weather changes, and vigorous exercise. However, most often these crises happen without any specific reason. They are unpredictable and can happen slowly or suddenly.
Why do children with sickle cell disease have anemia?

Sickle cells also have a shorter life-span than normal red blood cells. They are destroyed earlier because of their odd shape. For example, the normal red blood cell lives about 120 days while the sickle cell lives for approximately 20 days. The body constantly makes new red blood cells but in this case, it cannot make the cells as fast as they are destroyed. So a child with sickle cell disease is usually anemic, meaning that there is less red blood cells in the body. Fewer red blood cells also mean that there is less hemoglobin.

A blood test measures your child’s hemoglobin levels.

Here are some symptoms of low hemoglobin:

- Your child is more tired
- Your child’s eyes become yellow

If you notice these symptoms, call your Hematology team. A hemoglobin check may be needed

Your child will need to have a blood test to measure the hemoglobin level at each clinic visit. This level will vary from time to time depending on your child’s condition. A lower than usual hemoglobin level might require more frequent medical visits in order to monitor the changes in that level. Sometimes, a blood transfusion may be necessary. To help you keep track of your child’s hemoglobin, we have included a pull-out information sheet called, “Complete Blood Count Log.” Please bring this sheet to your clinic visits, and record your child’s hemoglobin levels.
Part 2: Understanding Sickle Cell Disease

How Did My Child Get Sickle Cell Disease?

Many parents wonder how their child got sickle cell disease. Sickle cell disease is a genetic disorder. It is inherited, which means that your child was born with it. It is not contagious.

How did the sickle cell genes get passed on to my child?

Each child gets two hemoglobin genes, one from the mother and one from the father. Genes are the body’s substances found in each cell that determine everything about us, from the color of our eyes, skin, hair, and also our hemoglobin type. In order to have sickle cell disease, a child needs to inherit one sickle cell hemoglobin gene (HbS) from one parent and one abnormal hemoglobin gene from the other parent.

If a child gets only one sickle cell hemoglobin gene (HbS) from one parent and receives a normal hemoglobin gene (HbA) from the other, the child will have sickle cell trait or be a sickle cell trait carrier. A person with sickle cell trait does not have sickle cell disease but carries the sickle cell gene. People with sickle cell trait usually do not have symptoms of the disease. They may however, pass their sickle cell gene on to their children.

Hemoglobin S Carrier
- Sickle cell trait
- This is not a form of sickle cell disease
What Type of Sickle Cell Disease Does My Child Have?

There are three common types of sickle cell disease:

**Sickle Cell Anemia** *(Hemoglobin SS Disease or HbSS)*
- This is the most common type of sickle cell disease
- Children with sickle cell anemia have almost 100% hemoglobin S in their red blood cells
- They inherit a hemoglobin S gene from each parent

**Sickle-Hemoglobin C Disease** *(Hemoglobin SC Disease or HbSC)*
- Children with sickle-hemoglobin C disease inherit a hemoglobin S gene from one parent and a hemoglobin C gene from the other parent
- Hemoglobin C is another type of abnormal hemoglobin

**Sickle Beta-Thalassemia Disease** *(HbSBThal)*
- Children with sickle beta-thalassemia inherit a hemoglobin S gene from one parent and a beta gene from the other parent
- Beta is another type of abnormal hemoglobin
- Children with sickle beta-thalassemia have mostly hemoglobin S in their red blood cells
Part 2: Understanding Sickle Cell Disease

Because the disease is so **unpredictable**, it is **difficult to know** which children will have more symptoms than others

As indicated above, all three types of sickle cell disease are characterized by the presence of hemoglobin S (HbS) in the red blood cells but the amount will vary from one type to the other. It is HbS that will cause the red blood cells to become rigid, elongated and sickle shaped. The symptoms of the three types are about the same but it is difficult to know which children will have more symptoms than others as the disease is so unpredictable. However, based on the literature and from our experience, children with sickle beta-thalassemia and sickle-hemoglobin C disease may have milder symptoms.
Part 2: Understanding Sickle Cell Disease

Your child’s sickle cell disease type was determined through a blood test. This blood test identifies the different types of hemoglobin and measures the amount (%) of HbS in your child’s red blood cells.

Generally children with sickle cell disease start to experience symptoms during the first year of life, usually after six months of age. Symptoms and complications may be different for each child and may range from mild to severe. It is important to note that there is no single best treatment for all children with sickle cell disease.

Treatment decisions will depend on the child’s condition and on the symptoms.
Part 2: Understanding Sickle Cell Disease

A staff member will help you complete this diagram so you can see how sickle cell disease might occur in your family with each pregnancy.

Please check-off your child’s sickle cell disease type:

☐ Sickle Cell Anemia (HbSS)

☐ Sickle-Hemoglobin C Disease (HbSC)

☐ Sickle Beta-Thalassemia (HbSBThal)
Part 2: Understanding Sickle Cell Disease

Are you planning to have another child?
If you are pregnant or planning on having other children, genetic counseling is available to you at the Montreal Children’s hospital. Genetic counselors are experts in hereditary disorders. They will help you figure out the likelihood of having future children with sickle cell disease. They can also offer you options for family planning and prenatal testing.

Cord blood collection from your future new born baby can also be a very interesting option that may benefit your child with sickle cell disease. We encourage you to discuss these options with your doctor or your nurse. Please let us know if you are pregnant or planning to have other children.

Who gets Sickle Cell Disease?
Sickle cell disease affects millions of people around the world. In the United States, about 300,000 children are born each year with the disease. This makes it one of the most common genetic disorders in the United States. Out of every 375 births of African American parents, one child is born with sickle cell disease. It happens most often to children whose parents are from sub-Saharan Africa, southern India, and the Mediterranean.

Sickle cell disease is one of the most common genetic disorders.

At the Montreal Children’s Hospital, about 10 new children are diagnosed with sickle cell disease each year. We care for approximately 115 children between 0 to 18 years of age with this disease.
Part 3: What More Do I Need To Know?

In the 3rd part of this handbook, we cover the most common symptoms along with some of the potentially serious complications of the illness. Take your time to read this information, and please ask your healthcare providers any questions that you may have.

You will find that a better understanding of the possible health problems that may happen in sickle cell disease will help you be prepared and gain more control of your child’s health.

Most Common Health Concerns

Two of the most common health concerns in children with sickle cell disease are infection and pain. Here is what to look for and what to do if your child experiences these symptoms.
Part 3: What More Do I Need To Know?

Infection

Fever may be a sign of a potential infection. It is a symptom that should be taken seriously in children with sickle cell disease. Fever is common in children and will occur for many reasons. Children with sickle cell disease are at higher risk of getting serious infections because their spleen has been damaged at a very young age (about 4 months) by the sickle cells. As mentioned before, the spleen is the organ of the body that filters and removes bacteria from the blood stream. The damaged spleen of sickle cell children will not filter properly. This may allow bacteria into the blood stream. This potentially serious medical condition is called sepsis and may be very serious and even fatal. If your child’s temperature is greater than 38.5° C or 101° F, contact the hematology team or take your child to the emergency room.

Remember: Do not ignore a fever in a child with sickle cell disease! See the pull-out sheet: “The Hematology Team” for important telephone numbers.

Other potentially serious infections include:
- **Meningitis** (infection in the spinal cord and brain)
- **Pneumonia** (infection in the lungs)
- **Osteomyelitis** (infection in the bones)
Part 3: What More Do I Need To Know?

**Pain**
Pain is another symptom that is common in children with sickle cell disease. During a sickle cell crisis, sickle cells create a blockage in the blood vessels resulting in a decrease of blood flow and oxygen to certain body parts causing pain.

The best way to manage the pain is to treat it as soon as it starts. Please refer to the pull-out sheet on “Pain Management: Prevention and Treatment”. Pain crises may vary in terms of location, intensity, and frequency and can range from mild to severe. Most of them may be treated at home but in some situations, hospitalization may be required. Should your child experience frequent pain episodes, the hematology team, along with pain services, can help you find the best way to manage your child’s pain.

Possible locations of pain during a sickle cell crisis:

Tips for knowing if your child is in pain:
- Crying inconsolably
- Clutching the painful area
- Refusing to use a leg or arm
- Refusing to walk
- Swelling in the painful area
Note: In young children (usually under 2 years), a sickle cell crisis can cause swelling of hands or feet. This is called dactylitis. This condition may last a few days to 1 week and may be accompanied with fever.
Part 3: What More Do I Need To Know?

Other Possible Health Problems
Children with sickle cell disease may experience a variety of health problems that can be potentially serious. Being aware of these conditions, early recognition of the symptoms, along with quick medical intervention, is essential for optimal management of the situation. Here are some of the potential health problems:
• Acute Chest Syndrome
• Stroke
• Enlarged spleen
• Prolonged erection (priapism)
• Aplastic Crisis

Acute chest syndrome
Acute chest syndrome is a serious health problem that needs to be treated immediately. It is a common reason for hospitalization among children with sickle cell disease, and may represent a medical emergency. Acute chest syndrome happens when blood flow is blocked by sickle cells in the lungs. Pneumonia can trigger an acute chest syndrome which may also be associated with a pain crisis. These symptoms can range from very mild to severe and may change quickly.

Here are some of the symptoms associated with acute chest syndrome:
• Chest pain
• Fast breathing, or trouble breathing
• Congested cough
• Fever (Body temperature above 38.5° C or 101° F)
• Abdominal pain

If your child experiences any of these symptoms, you must see a doctor. Call your hematology team or take your child to the emergency room. Do not wait.
Part 3: What More Do I Need To Know?

Stroke
A stroke happens when a part of the brain is deprived of blood supply and oxygen. Children with sickle cell disease are more at risk of having a stroke than other children. A stroke is more likely to happen to children with sickle cell disease between the ages of 2 to 10 years old. It is a sudden and severe complication of the illness that represents a medical emergency.

Here are some of the symptoms associated with a stroke:

- Loss of consciousness (like rapidly falling asleep and falling to the ground)
- Weakness of arms and/or legs
- Difficulty talking or slurred speech
- Unsteady walk
- Complains of changed vision
- Unable to move legs or arms or one side of the body
- Seizures
  - Loud groaning
  - Losing consciousness
  - Body becomes rigid
  - Saliva or foam may drip from the mouth
  - Sweating, tremors, quick movements of arms and legs

If you suspect that your child is having a stroke, call 911. Your child must be brought to the emergency room right away.
Part 3: What More Do I Need To Know?

Your doctor may order a special test for your child that may help detect narrowing in the blood vessels of your child’s brain. This information is critical in helping us possibly prevent a stroke in the future. This test is called a Transcranial Doppler (TCD) Ultrasound. An ultrasound allows your team to view what is happening in the brain as a live video. This is a very important test. Do not miss your appointment for this test. The decision to order such a test will depend on the type of sickle cell disease, age, and clinical evaluation by the doctor. We encourage you to discuss this test with your doctor or nurse. See pull-out sheet on TCD.

Splenic Sequestration (Enlarged Spleen)

Splenic sequestration is a condition that occurs when the blood becomes trapped in the spleen, causing it to become larger than normal. The spleen is an organ that is located on the left side of your child’s abdomen.

As mentioned earlier, the spleen of children with sickle cell disease is damaged by sickle cells from a young age. Red blood cells may become trapped in the spleen because the vessels leading in and out of it have also been damaged. When this happens, the spleen can become very large and easy to feel. This condition is called “splenic sequestration.” Depending on the severity of this condition, your child’s hemoglobin may decrease. Sudden enlargement of the spleen, with a large decrease in hemoglobin level is a serious condition. A blood transfusion may be necessary and it could become an emergency. If the spleen becomes larger over
Part 3: What More Do I Need To Know?

Several weeks, and the blood hemoglobin level is stable, it is not as serious. Nevertheless, any enlargement of the spleen should be closely monitored for any changes.

Here are some of the symptoms associated with enlarged spleen

- Irritability
- Unusual weakness or feeling faint (unusual sleepiness)
- Lips and mucus membranes (inside the mouth) become very pale
- Heart beat is faster than usual
- The abdomen becomes larger in size
- Pain to the left side of the abdomen

If you notice that your child has any of the above symptoms you must see a doctor. Call your hematology team or take your child to the emergency room.
Part 3: What More Do I Need To Know?

Priapism (Prolonged Erection)

Priapism is a serious health problem that may happen to boys living with sickle cell disease. It is characterized by a persistent and unwanted erection of the penis that can last several hours, caused by difficult drainage of the blood out of the penis vessels due to the sickle cells. This condition can be extremely painful and in some instances can lead to impotency. Priapism events may begin during sleep or during everyday activities. Episodes can last for 30 minutes to several hours and may begin in early childhood or at anytime in life. Pain management and blood transfusions may be indicated. If your child reports this condition or if you suspect this condition, talk to your doctor or nurse about it. If this condition occurs and lasts more than 2 hours, you must see a doctor. Call the hematology team or take your child to the emergency room. Do not wait.
Aplastic Crisis

An aplastic crisis happens when the body stops making new red blood cells. This condition is often caused by a virus called Parvo Virus 19. If this happens, your child’s hemoglobin could drop to worrisome levels in a matter of days, worsening the already existing anemia. This condition is usually treated with blood transfusions until the body starts making new red blood cells again.

Here are some symptoms associated with aplastic crisis:

- Full body weakness
- Lethargy (feeling drowsy and sluggish)
- Paleness (For example, ash-like grey color in the lips and tongue. If your child has lighter color skin, the color may look more bluish.)
- Feeling dizzy or fainting
- Headache

If you notice that your child has any of the above symptoms you must see a doctor. Call your hematology team or take your child to the emergency room.
Part 3: What More Do I Need To Know?

How Can I Help My Child Live Better?
Medical care to treat sickle cell disease has improved a lot over the years. This has increased the likelihood that children with such an illness can lead happy lives into adulthood. Parents are also better informed about how to care for their child’s special needs. Here are some guidelines that can help you help your child to live a full and happy life.

Know what symptoms to look for and what to do
Being well informed about sickle cell disease will increase your confidence in caring for your child. Early recognition of symptoms is the key in managing your child’s illness. Your ability to seek medical care quickly when needed will help better manage some of the health problems that can occur. Not all health problems can be prevented, but may be easier to manage if detected and treated early. See pull-out sheet called “Signs and Symptoms: What to look for”.

Part 3: What More Do I Need To Know?

Ensure your child receives all the recommended vaccinations
Adequate vaccination is very important for your child’s health because children with sickle cell disease are more susceptible to infections. Make sure that your child gets all the recommended vaccinations as well as any other vaccines suggested by your hematology team (For example: Hemophilus influenza and Pneumococcal vaccine). Bringing your child’s vaccination book when you come to the clinic will help us keep track of the immunization status. Every member of the family should have a flu vaccine each year.

Encourage a healthy life style
A healthy life-style is important for all children, and especially for those living with sickle cell disease.

The following will help your child stay as healthy as possible:
• Eat a balanced diet (see pull-out sheet: “Foods Rich in Folate”)
• Drink plenty of fluids
• Engage in regular play and activities
• Have time for adequate rest and sleep
• Maintain a normal body temperature by dressing appropriately for the weather

As time goes by, your child will learn to identify what are the things that make him feel good or bad. Parents need to encourage their child to engage in normal childhood activities when possible. Offering your children a healthy lifestyle will help them make better choices for themselves in the future.
Part 3: What More Do I Need To Know?

Bring your child to regular medical visits
Regular medical visits are essential in the management of your child’s health. Seeing your doctor or nurse on a regular basis, even when your child is well, will provide the team with valuable information that will be helpful if complications occur. It also gives you the opportunity to build a strong relationship with your hematology team that is necessary in the successful management of your child’s health. It will also allow you to get involved in your child’s care and be part of the decision-making process.

With each clinic visit, make sure you have the proper prescriptions for the medications that your child will need until his next appointment. If you are unable to attend a visit, we ask you to contact the secretary so she can inform the team and schedule another appointment for you.

Take care of yourself
Caring for a child with sickle cell disease can be challenging for some families. It is easy to focus only on the child and forget about one’s self. It is important for you to take the time to rest as well, in order to stay healthy to best care for your child. Some parents report that a few hours of babysitting allowed them to have time to themselves. Both you and your child may benefit from this.

Some parents find it helpful to notify their employers of occasional absences. Sickle cell disease is unpredictable and when a crisis occurs, you might have to stay with your child.
Part 3: What More Do I Need To Know?

Treatments and medications

**Penicillin** is an antibiotic that has been shown to prevent life-threatening infections in children with sickle cell disease. Your child will be prescribed penicillin, twice a day, everyday, from diagnosis until 5 or 6 years of age. This will offer some protection against infections. Give this medication to your child every day, even when well, and do not stop until your doctor tells you so.

**Folic acid** (folate) is a vitamin that acts as a “building block” in the production of red blood cells. Along with a balanced diet, folic acid, taken as prescribed, will help your child’s body make new red blood cells.

**Hydroxyurea** is another medication that may be recommended for your child. Not every child with sickle cell disease will require Hydroxyurea. To learn more about this medication, speak to your doctor or nurse.

You may find information about these medications in the pull-out sheet called “Recommended Medications.”
Part 3: What More Do I Need To Know?

Services Available to Families

Pain Management Services
Pain management can be a challenge in children with sickle cell disease. The acute and chronic pain teams may be very helpful to us in achieving the best pain management for your child. These pain management specialists will be available to you should you need them.

Genetic Counseling
Genetic counseling may be an option if you are planning to have more children. Counselors can help you to know your chances of having future children with sickle cell disease. They can also provide guidance in regards to family planning and prenatal diagnosis. We encourage you ask your doctor or nurse about genetic counseling.

Child Life Specialists
The child life specialists support the optimum continued development of infants, children and adolescents receiving hospital services by providing educational/recreational programs that reflects normal life experiences and help to minimize psychological trauma. As an integral member of the health care team, the child life specialists provide opportunities for play, for gaining a sense of mastery and control. They also promote learning, self-expression, peer interaction, socialization and family involvement. The child life specialist service contact information can be found in the pull-out sheet called “The Hematology Team.”
Part 3: What More Do I Need To Know?

**Nursing Assistant**
The nursing assistant will see your child at each clinic visit. She will take vital signs, measure the weight and height and may assist in supervising a treatment or giving vaccinations. She works very closely with the nurse clinician and will notify her or the doctor of any changes in your child’s health.

**Clerical staff**
The secretaries will take your calls when you need to reach a member of the team. They can help you by addressing your concerns to the appropriate health care professional. They will also coordinate your appointments to the clinic.