



EXCEPTIONAL CARE. WITHOUT EXCEPTION.

# Sickle Cell Disease Transition Guidebook



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Providing Youth Education & Ensuring Continuity of Care!

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*Funded by Inavale Grant*

Your health is our #1 priority. There are new responsibilities and processes on the adult side that young adults must learn and understand when they transition. We are giving you this transition guidebook with the hope that it will help you answer questions about your medical care. It will provide you with information and resources to help you successfully transition into the adult care setting. In this guidebook information will be provided about available medical, clinical, nutritional, and social services that will help prepare you to become an independent adult. We strongly encourage you to make the best use of these resources to help you live a healthy life with Sickle Cell Disease as you grow older.

## **Contact Information**

### **Providers**

Please do not email in an emergency; use the paging operator to reach the on call physician if you have a fever or need urgent assistance.

Philippa Sprinz, MD	<a href="mailto:Philippa.Sprinz@bmc.org">Philippa.Sprinz@bmc.org</a>
Amy Sobota, MD	<a href="mailto:Amy.Sobota@bmc.org">Amy.Sobota@bmc.org</a>
Caitlin Neri, MD	<a href="mailto:Caitlin.Neri@bmc.org">Caitlin.Neri@bmc.org</a>
Lillian McMahon, MD	617-638-5795 Pager 0400
Duyen Ngo, MD	<u>Call</u> 617-638-6428 and ask to speak with Dr. Ngo (during the day)
Laura Dickman, LCSW	<a href="mailto:Laura.Dickman@bmc.org">Laura.Dickman@bmc.org</a>

### **How To Reach a Physician**

	<b>Pediatrics</b>	<b>Adults</b>
Days**	617-414-4841	617-638-6428
Nights & Weekends	617-414-5000 or 617-638-5795 pager 5731	617-638-6428, after hours this becomes an on-call hematology service.

\*This is also the number you should use to schedule, cancel or reschedule an appointment or for prescription refill requests. In addition between the hours of 8:30am-5pm, use this number to reach your nurse, doctor or social worker for non-emergent issues.

\*When paging a Doctor, please make sure your phone is accepting blocked calls.

\*\*Days are typically Monday-Friday from 8:30am-5pm.

### **Clinic Locations as of 2014**

<b>Pediatric Hematology Clinic</b>	<b>Adult Hematology Clinic/Sickle Cell Transition Clinic</b>
Yawkey Building, 5 <sup>th</sup> Floor 850 Harrison Ave, Boston MA 02118 617-414-4841	Moakley Building, 3 <sup>rd</sup> Floor 830 Harrison Ave, Boston, MA 02118 617-638-6428

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## **Common Issues/Questions**

<b>Issues/Questions</b>	<b>Pediatrics</b>	<b>Adults</b>
<b>What do I do if I am in pain?</b>	First, follow your sickle cell care plan. If you need advice then contact your doctor <b>Phone:</b> 617-414-4841 (during the day) <b>Paging:</b> Dial 617-414-5000 and ask for the Pediatric Hematologist on-call. Or, dial 617-638-5795 enter 5731 & then enter your call back number	Call 617-638-6428 (after hours you will reach an on-call service and ask for the hematologist on call)  If your pain is not controlled, report to the Emergency Department.
<b>What do I do if I am low on pain medication?</b>	Call the office at 617-414-4841 and ask to be directed to the nurse. You will need to leave your name and a call back number. This may take up to 2 days to get. Prescriptions for opioid pain medication (such as oxycodone) must be picked up in person! You may need to be seen before a refill can be written.	Call the Hematology/Oncology clinic at 617-638-6428 and request a refill from the triage nurse. It typically takes 24 hours (not including weekends) to get a refill; if you need medication sooner please be sure to say so.
<b>What do I do if I cannot make my appointment?</b>	Call 617-414-4841 and ask to reschedule your appointment.	Call the Hematology/Oncology clinic at 617-638-6428 to reschedule. ** If you miss an appointment and do not reschedule you will not be prescribed pain medication until you are seen by the doctor again.**
<b>Where can I have my general questions answered?</b>	You can email your doctor or write down your questions to bring to your next appointment. Email should only be for non-emergent questions. Philippa Sprinz – <a href="mailto:Philippa.Sprinz@bmc.org">Philippa.Sprinz@bmc.org</a> Amy Sobota – <a href="mailto:Amy.Sobota@bmc.org">Amy.Sobota@bmc.org</a> Caitlin Neri – <a href="mailto:Caitlin.Neri@bmc.org">Caitlin.Neri@bmc.org</a>	Please reach out to Dr. McMahon or Dr. Ngo for any questions. They are there to help you! You can reach them at 617-638-6428 or through the contact information provided above.

## **Booking Appointments with Specialists and Primary Care Physicians**

Please check ahead of time as clinics may move and phone numbers may change. You can always call the BMC operators at (617) 414-5000 and ask for the number of the clinic you are trying to reach.

### **Pediatrics**

<b>Specialties</b>	<b>Contact Information</b>
<b>Dentistry</b>	Yawkey Ambulatory Care Center, 5 <sup>th</sup> Floor Call: 617-414-4046
<b>Ophthalmology (Eyes)</b>	Yawkey Ambulatory Care Center, 2 <sup>nd</sup> Floor Call: 617-638-8350
<b>Orthopedic Surgery (Bones)</b>	Shapiro Center, 4 <sup>th</sup> Floor, Suite 4B Call: 617-638-5633
<b>Pediatric Specialties Group</b>	Call: 617-414-4841
<ul style="list-style-type: none"><li>• <b>Cardiology (Heart)</b></li></ul>	Yawkey Ambulatory Care Center, 5 <sup>th</sup> Floor 617-414-4841
<ul style="list-style-type: none"><li>• <b>Developmental and Behavioral</b></li></ul>	Yawkey Ambulatory Care Center, 5 <sup>th</sup> Floor 617-414-4841
<ul style="list-style-type: none"><li>• <b>Endocrinology/Diabetes</b></li></ul>	Yawkey Ambulatory Care Center, 5 <sup>th</sup> Floor 617-414-4841
<ul style="list-style-type: none"><li>• <b>Gastroenterology</b></li></ul>	Yawkey Ambulatory Care Center, 5 <sup>th</sup> Floor 617-414-4841
<ul style="list-style-type: none"><li>• <b>Hematology/Oncology (Blood)</b></li></ul>	Yawkey Ambulatory Care Center, 5 <sup>th</sup> Floor 617-414-4841
<ul style="list-style-type: none"><li>• <b>Neurology (Brain)</b></li></ul>	Shapiro Center, 7 <sup>th</sup> Floor 617-414-4841
<ul style="list-style-type: none"><li>• <b>Pediatric Surgery</b></li></ul>	Shapiro Center, 8 <sup>th</sup> Floor 617-414-4841
<ul style="list-style-type: none"><li>• <b>Pulmonology (Lungs)</b></li></ul>	Shapiro Center, 8 <sup>th</sup> Floor 617-414-4841
<b>Primary Care</b>	Yawkey Ambulatory Care Center Call: 617-414-5946
<b>Renal Medicine (Kidney)</b>	Shapiro Center, 7 <sup>th</sup> Floor, Suite 7A Call: 617-414-8680
<b>Urology</b>	Shapiro Center, 3 <sup>rd</sup> Floor, Suite 3B Call: 617-638-8485

## **Adults**

<b>Specialties</b>	<b>Contact Information</b>
<b>Cardiology (Heart)</b>	Cardiovascular Center Preston Family Building, 3 <sup>rd</sup> Floor Call: 617-638-7490
<b>Dentistry</b>	Boston University Goldman School of Dental Medicine; 100 East Newton Street Suite G-407 Call: 617-638-3430
<b>Endocrinology</b>	Nutrition & Weight Management Preston Family Building, 2 <sup>nd</sup> Floor Call: 617-638-7470
<b>Gastroenterology (Stomach)</b>	Moakley Building, 2 <sup>nd</sup> Floor Call: 617-638-6525, option #1
<b>Hematology/Oncology (Blood)</b>	Solomont Center for Hematology/Oncology Moakley Building, 3 <sup>rd</sup> Floor Call: 617-638-6428
<b>Neurology (Brain)</b>	Shapiro Center Call: 617-638-8456
<b>Ophthalmology (Eyes)</b>	Yawkey Ambulatory Care Center, 2 <sup>nd</sup> Floor Call: 617-638-8350
<b>Pulmonology (Lungs)</b>	Shapiro Center, 9 <sup>th</sup> Floor, Suite 9B Call: 617-638-7480
<b>Primary Care/General Internal Medicine</b>	Shapiro Center, 5 <sup>th</sup> and 6 <sup>th</sup> Floors Call: 617-414-5951
• <b>Family Medicine</b>	Yawkey Ambulatory Care Center, 4 <sup>th</sup> Floor Call: 617-414-2080
• <b>Integrative Medicine &amp; Health Care         Disparities</b>	Yawkey Ambulatory Care Center, 4 <sup>th</sup> Floor Call: 617-414-6795
<b>Renal Medicine</b>	Shapiro Center, 7 <sup>th</sup> Floor, Suite 7A Call: 617-414-8680
<b>Women's Health Group (Primary Care)</b>	Shapiro Center, 5 <sup>th</sup> Floor, Suite 5A Call: 617-638-7428

## **Common Differences between Pediatric and Adult Care**

You may notice that there are some differences in the pediatric and adult medicine clinics. Neither one is better nor worse, but understanding what to expect may help make the transition easier.

<i><b>Pediatrics</b></i>	<i><b>Adult</b></i>
Parent/guardian is in charge of most of your care needs	Care is self-directed (as an adult, you are in charge)
Parent/guardian usually tells the doctor about how you have been doing	You give the doctor your medical history since your last visit
Parent/guardian helps to schedule your appointments	You schedule your own appointments
Support services are offered for financial and emotional issues	You can ask for financial or emotional support services based on your needs
Transportation to your appointments is usually provided or arranged by an adult	You must provide or arrange your own transportation
Your parent/guardian has insurance or health benefits	By age 26, you must have your own insurance or health benefits

The above chart provides a very simple overview of some differences between pediatric and adult care. Everybody comes with different experiences with their own healthcare. We value you and are here to help you with the transition process. For some of you, that may mean assuming new roles and responsibilities, for others it may not. Regardless of where you are coming from, an important part of becoming an independent adult is working towards assuming responsibility of your healthcare.

## **Navigating BMC and the Health Care System**

### **Keeping track of medical appointments**

- When you make a medical appointment make sure you get a card with the date, time and location on it.
- Write your appointment down in your calendar or put it in your phone right away.
- You should get a reminder call and receive a reminder letter ahead of time. However, do not depend on this! Make sure you are keeping track of your own appointments.
- If you are not going to be able to keep your appointment, call as soon as possible to reschedule – this way your canceled appointment can be filled by other patients who need to see their provider.

### **Getting prescriptions filled/refilled**

- Do not wait until you run out of medicine to call and ask for a refill.
- If there are refills left on your prescription, call the pharmacy phone number on the bottle and you can directly refill it yourself.
- Take ownership, when you have an appointment check your medication first. At the appointment, ask for any prescription refills you need.
- \*\*Prescriptions for opioid pain medication must be given to **you** in person; always make sure you have some pain medication at home in case you need it. When you are starting to get low, call for a refill, or ask at your next visit.

### **Utilizing the Emergency Department**

- If you are having pain at home first follow your sickle cell pain plan; if you need advice see the table on page 3 and call your doctor to discuss what you should do.
- Even if you think you need to come to the ED, paging the doctor ahead of time can sometimes help speed things along.
- If you ever need to be seen at an outside ED it is particularly important to page your hematologist; otherwise we will not know you are there and cannot help them take the best possible care of you.

### **Primary Care**

- Your hematologist is a specialist in Sickle Cell Disease; however, there is a lot more to maintaining your health than just following up with your hematologist! It is extremely important to have a primary care doctor who can help with routine medical needs and coordinating care with different specialists. You should see your primary care doctor for a regular check-up once or twice a year.



## **Facts about Sickle Cell Disease**

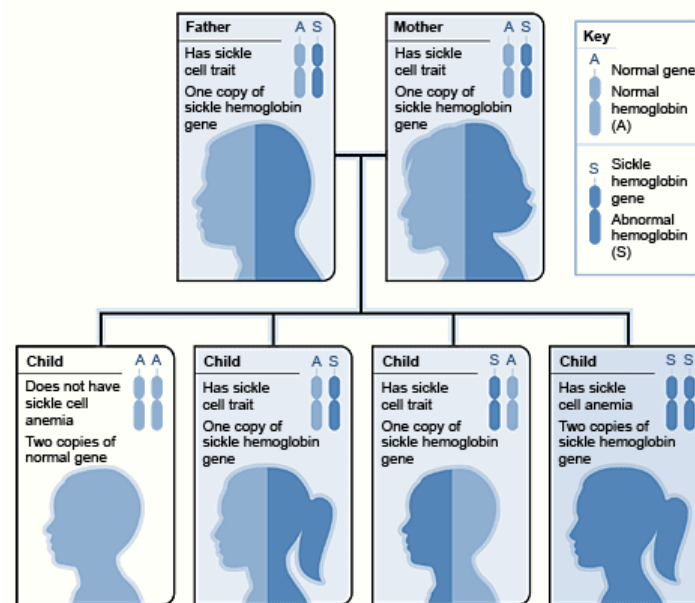
### **How did I get Sickle Cell Disease?**

You cannot “catch” Sickle Cell Disease; it is inherited. That means that to have Sickle Cell Disease you have received one gene for the disease from each of your parents. One gene means you are a carrier, two genes mean you have the disease.

Everyone has two genes for hemoglobin (the protein in the red blood cells that carries oxygen), one from each parent. “A” is normal hemoglobin, and “S” is sickle hemoglobin.

If both parents have one normal gene and one sickle gene, they have AS, also known as Sickle Cell Trait. Each of their children has a one in four chance of inheriting Sickle Cell Disease (SS). Each child has a 25% chance (1/4) of inheriting two normal genes (AA), a 50% chance (2/4) of inheriting one normal gene and one abnormal gene (AS or Sickle Cell Trait), and a 25% chance (1/4) of inheriting two abnormal sickle genes (SS). Inheriting two abnormal sickle genes gives a child “SS” or Sickle Cell Anemia.

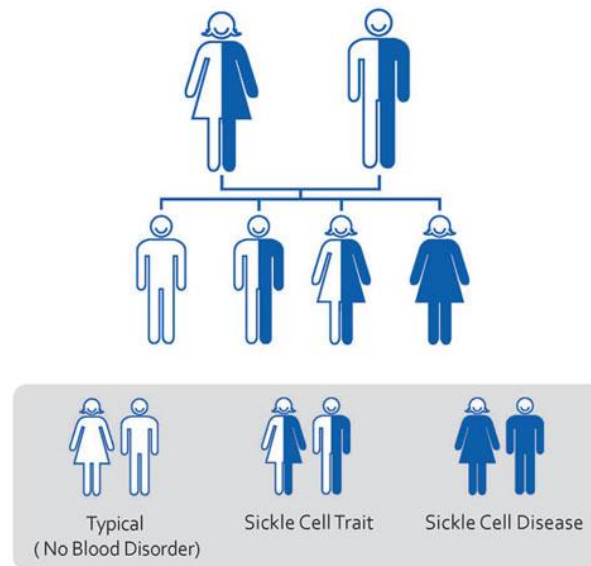
The picture below illustrates how someone can get Sickle Cell Disease (SS) from his/her parents.



From NHLBI <http://www.nhlbi.nih.gov/health/health-topics/topics/sca/causes.html>

Some people have a “C” gene which is another variation of hemoglobin. If you have “SC” then you have a different type of Sickle Cell Disease.

The image below shows how someone can get Sickle Cell “SC” Disease from his/her parents.



From CDC <http://www.cdc.gov/ncbddd/sicklecell/traits.html>

Some people inherit a combination of Sickle Cell Disease and Beta Thalassemia. Beta Thalassemia is a condition, which occurs when not enough (beta) hemoglobin is made. If one parent has “AS” (Sickle Cell Trait) and one parent has  $\beta^0$  (Beta) Thalassemia trait, there is a 25% chance for each child to have Sickle-  $\beta^0$  Thalassemia.

### Can I pass on Sickle Cell Disease to my children?

Yes! If you have “SS” and you have children with someone who has Sickle Cell Trait “AS” then each child has a 50% chance (1/2) of having Sickle Cell Disease “SS” as illustrated in the table below.

If your partner has only normal hemoglobin all your children will be carriers of the disease and no one will have the disease.

You can prevent this from being a surprise by making sure your partner knows their sickle status. Your partner’s parents may be able to tell them their sickle status. To be sure, your partner can ask their doctor for a hemoglobin electrophoresis test. If you or your partner were born after the early 1990’s in the United States, it is likely that you were screened with newborn screening tests for Sickle Cell Disease and other abnormal hemoglobin. If you were born outside the United States it is possible you were not tested as a baby.

## Sickle Cell Inheritance

If I have...	If my partner has...	Our children may have...
Sickle Cell Anemia (SS)	Sickle Cell Trait (AS)	50% Sickle Cell Trait (AS) 50% Sickle Cell Anemia (SS)
Sickle Cell Anemia (SS)	Normal hemoglobin (AA)	100% Sickle Cell Trait (AS)
Sickle Cell/Hemoglobin C (SC)	Sickle Cell Trait (AS)	25% Sickle Cell Trait (AS) 25% Hemoglobin C Trait (AC) 25% Sickle Cell Anemia (SS) 25% Sickle Cell/Hemoglobin C (SC)
Sickle Cell/Hemoglobin C (SC)	Normal Hemoglobin (AA)	50% Sickle Cell Trait (AS) 50% Hemoglobin C Trait (AC)
Sickle Cell/Beta Thalassemia	Sickle Cell Trait (AS)	25% Sickle Cell Trait (AS) 25% Sickle Cell Anemia (SS) 25% Thalassemia Trait 25% Sickle Cell/Beta Thalassemia
Sickle Cell/Beta Thalassemia	Normal Hemoglobin (AA)	50% Sickle Cell Trait (AS) 50% Thalassemia Trait

## Can I grow out of it?

No, your genes do not change. The symptoms of Sickle Cell Disease may change when you get older, but if you are born with “SS” you will always have “SS.”

## Is there a cure?

The one cure for Sickle Cell Disease is a stem cell transplant, usually from a brother or sister with the same mom and dad. Talk with your doctor to find out if this is an option for you.

## What are the complications of Sickle Cell Disease?

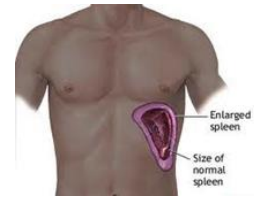
Sickle Cell Disease affects many organs/systems in the body. Complications are caused by the abnormal 'sickle' shape of the red blood cells as well as inflammation and hemolysis (breakdown of red cells). These can often be prevented or reduced if you are well-monitored by your doctor and follow the preventative recommendations in your sickle cell care plan. We recommend always keeping regular clinic appointments and following up with specialists. Some common complications other than pain include:

- **Acute Chest Syndrome:** Acute chest syndrome is caused by sickled hemoglobin trapped in the small blood vessels of the lungs. This causes shortness of breath, fever and chest pain. It can be triggered by a chest infection such as pneumonia. Acute chest syndrome can also develop before, during, or after an episode of sickle cell pain. This is why it is so important to use your incentive spirometer if you are admitted for a pain episode.
  - Acute chest syndrome is a medical emergency and requires hospitalization and treatment with antibiotics and may require a blood transfusion. If you think you are experiencing acute chest syndrome or any problems with your chest come to the ER immediately, calling ahead to let the staff know you are coming in sick.
- **Eye problems:** Sickle Cell Disease can lead to obstruction of blood vessels in the retina, part of the back of the eye. This can, over time, lead to problems with vision. If this sickle retinopathy is detected early it can be treated. For this reason, we recommend that everyone with Sickle Cell Disease have a dilated eye exam by an eye doctor every year.
- **Gallstones:** When the hemoglobin in red blood cells breaks down in the body, it releases bilirubin. In an individual with Sickle Cell Disease, the red blood cells are constantly being broken down and bilirubin forms rapidly. Excessive bilirubin in the body can form hard substances in the gallbladder called gallstones.
  - People with gallstones usually have pain at the upper right side of the abdomen, under the right shoulder, or between the shoulder blades. They may also have nausea, vomiting, fever, sweating, chills, pale colored stool, dark urine or yellowish discoloration of the eyes. If you have repeated episodes of pain from your gallbladder, the hematologist or the surgeon may recommend its surgical removal.
- **Infection:** In people with Sickle Cell Disease, the spleen stops working well in childhood, increasing the risk of frequent infection. You should receive a flu shot every year and get all available vaccines against infections. Always call your doctor or report to the hospital if you have a fever (greater than 101.3), which might be a sign of serious infection.
- **Leg Ulcers:** People with Sickle Cell Disease may have one or more sores on the leg called ulcers. This is often found in the lower third of the legs. Ulcers can sometimes persist for

years or re-occur after healing. If you have any ulcers show your doctor as the doctor does not always look at your legs and may not know that you have this.

- **Priapism:** This is a painful erection that occurs in males with Sickle Cell Disease. It is caused by a blockage of blood flow out of an erect penis. If you experience priapism treat it like you would a pain episode—drink lots of fluids, take a warm shower, use your pain medication, and attempt to urinate. If the erection lasts for more than 1 hour go to the emergency room since prolonged priapism can lead to impotence. Call ahead to let staff know that you are coming in with this problem.

- **Pulmonary Hypertension:** The blood vessels in the lungs can be damaged by the sickled cells making it difficult for the heart to pump blood through the lungs. This eventually leads to an increased blood pressure in the lungs. This is one reason we may recommend that you see a pulmonary (lung) specialist in your late teen or early twenties, so that this can be detected early.



- **Splenic Sequestration:** The spleen is an organ in the body found in the upper left part of the abdomen, under the rib cage. It helps to separate abnormal red blood cells from the normal ones, and also fights infections. In people with Sickle Cell Disease, the spleen may trap both abnormal and normal red cells. The abnormal cells may block the normal flow of blood out of the spleen. This makes the spleen become big and sometimes painful. When the spleen traps many cells and anemia follows this is known as splenic sequestration. Splenic sequestration is more common in young children, but if you have sudden pain in your left upper abdomen call your doctor right away.
- **Stroke:** The blood vessels in the brain can also be blocked by sickled cells. This may reduce the blood supply with oxygen to the brain causing a condition called stroke. Common symptoms of stroke include weakness in the arms, feet or legs, slurred speech, changes in vision, severe headache and vomiting. In patients with Sickle Cell Disease a stroke can also be caused by bleeding in the brain. Stroke is common in young children with Sickle Cell (SS and S beta zero Thalassemia) Disease and older people with these forms of the disease. When you were younger if you have SS disease or S beta zero thalassemia, your doctor will have ordered Transcranial Doppler (TCD) Ultrasound studies. If you have not had an abnormal TCD study by your teenage years it is less likely that you will have a stroke. Ask your doctors if want to know more about strokes and your risk of having one.

## **Pain**

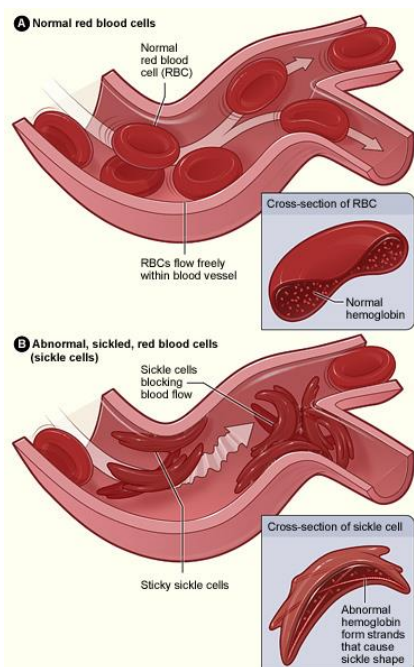
### **What causes pain?**

People with Sickle Cell Disease have red blood cells that form 'sickle' or half-moon shapes (see next page). These sickle shaped cells can stick in the blood vessels, block blood flow, and cause pain (which is called vaso-occlusive pain). When the individual with Sickle Cell Disease is well, most of his or her red cells are shaped like those of people without the disease. It is when the individual with Sickle Cell Disease is stressed or sick that the cells become sickle shaped.

Vaso-occlusive pain can be triggered by factors such as cold weather, having an infection, being dehydrated, or stress. You can help prevent some pain episodes by avoiding these kinds of triggers.

Some women with Sickle Cell Disease notice they have more sickle pain around the time of their period. If this happens to you, please discuss it with your doctor. Sometimes hormone therapy may help reduce the frequency or severity of the pain.

The two pictures below show the difference between normal red blood cells in the blood vessel and sickled red blood cells, and how the sickled red cells can block blood flow to organs which often results in painful episodes.



From NHLBI: <http://www.nhlbi.nih.gov/health/health-topics/topics/sca/>

## How can I prevent pain?

- Always dress appropriately for the weather; make sure you have warm clothes with you in case the temperature drops.
- Limit your time outside when it is very cold.
- If you go swimming, always swim in a heated pool.
- Keep yourself well hydrated (drink between 2-3 liters of water a day); Sickle Cell Disease causes your kidneys not to hold water well so you will need to drink extra fluids, especially if it is warm outside or when you are exercising.

## How do I treat my pain?

You should have an individual pain treatment plan that you have discussed with your doctor. This should include:

- Drinking extra fluids.
- Using warm packs or taking a warm shower or bath.
- Using your anti-inflammatory medicine (ibuprofen/motrin/advil/naprosyn) and a short-acting opioid medicine (such as oxycodone) when pain starts. It is OK to take a short acting opioid with an anti-inflammatory medication together, and the sooner you start treating your pain the better.
- Using deep breathing, guided imagery, meditation (Please refer to pages 19-20 for more information).



If your pain is not controlled or you have any questions, call your hematologist. Sometimes we can give you advice over the phone to treat your pain and keep you out of the emergency room.

Always make sure to have pain medication with you at home, at school, or in your bag if you might be spending time away from home. If you are traveling, call your doctor to let her know, keep your prescriptions in their original bottles, and stay hydrated.

**Refills (paper copies of scripts) for opioids (Oxycodone, Percocet, Tylenol with Codeine, Dilaudid or Long Acting Morphine) must be given to you in person. These drugs cannot be called in, sent in electronically, or faxed to the pharmacy. Therefore always make sure to contact your doctor for a refill BEFORE you run out of your medicine.**

## Should I Be Worried About Taking Too Much Medicine or Developing an Addiction to Medications?

No! If you use your pain medications appropriately as prescribed by your doctor, it will not lead to addiction. Just remember: **NEVER SHARE MEDICATIONS**. Your doctor prescribes you medication based on **your** needs so it is dosed for you!

Make sure you follow the instructions as to when and how to take pain medicines given by your provider(s) and take the required doses to control your pain. If your pain persists despite all medications given to you, please call your doctor or go to the emergency department.

**\*\*Never use your pain medications to relieve stress or anxiety. If you are experiencing stress or anxiety, contact your primary care provider, hematologist and/or social worker for assistance.\*\***

## Pain Medication Education

**Ibuprofen (Motrin and Advil),**

- pain relief
- anti-inflammatory

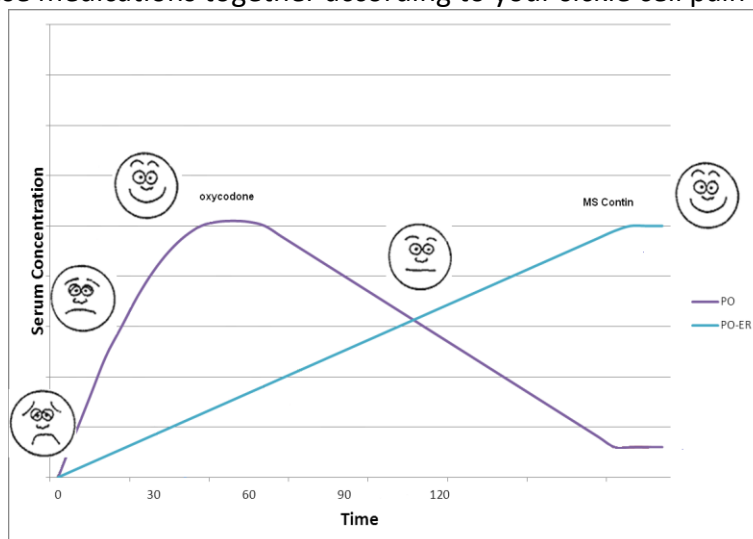
**Oxycodone:**

- fast acting/short lasting opioid pain medication (starts working in 20 minutes, lasts 4-6 hours)

**MS Contin (“Long Acting Morphine”: extended release morphine):**

- slow acting/long lasting opioid pain medication (starts working in 1 ½ hours, lasts 8-12 hours)

It is OK to take these medications together according to your sickle cell pain plan.



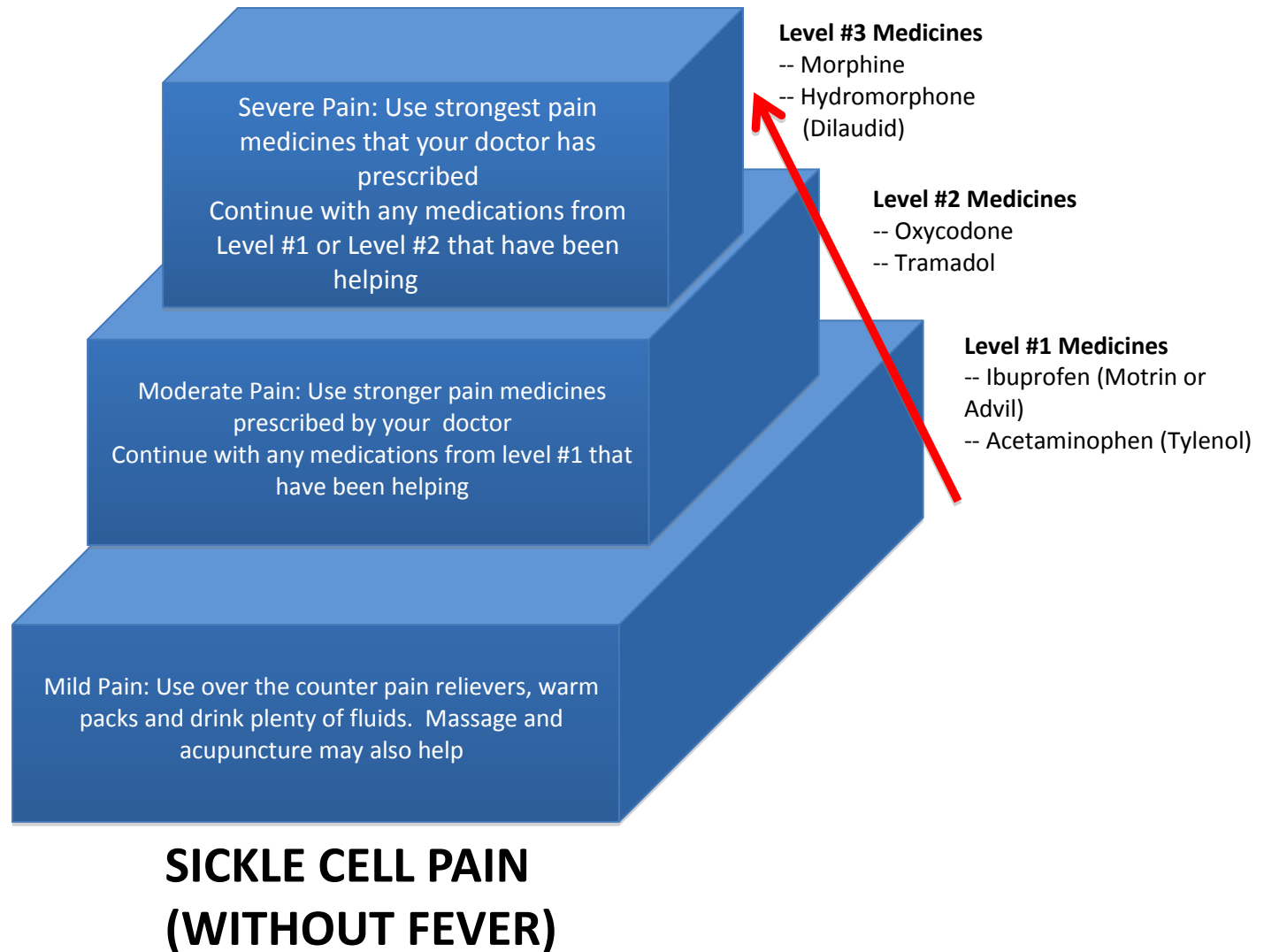
\*Serum Concentration = blood level

## Remember

1. Never run out of medicine.
2. Call your doctor for help before having to go to the ED



## Pain Pyramid



### What if my pain is interfering with my life?

There is a medication named **Hydroxyurea**. This medication has been shown to reduce the number of painful episodes for many people with Sickle Cell Disease. Studies also show that Hydroxyurea may help you live longer and lead a healthier life with the disease. If you have frequent pain and it is interfering with work, school, etc. talk to your doctor about Hydroxyurea.

## **Hydroxyurea for Individuals with Sickle Cell Disease**

### **What is Hydroxyurea?**

Hydroxyurea is a medicine that has been shown to help adults and children with Sickle Cell Disease. Studies have shown that Hydroxyurea can decrease the number of pain events, acute chest syndrome (pneumonia), blood transfusions and admissions to the hospital. Patients take it by mouth once a day. It must be prescribed by a doctor and is available at most drug stores. The U.S. Food & Drug Administration approved it in 1998 for treatment of Sickle Cell Anemia in adults, although it has been used since the 1960s for other diseases. Hydroxyurea has been used in children with Sickle Cell Disease for close to 20 years.

### **How does Hydroxyurea work?**

Red blood cells contain hemoglobin, which carries oxygen. In patients with Sickle Cell Disease, abnormal sickle hemoglobin causes the red blood cells to become long, rigid “sickle shaped” and sticky. Sickling causes blockage of blood flow to vital organs, muscles and tissues. With Hydroxyurea, red cells have more fetal hemoglobin, become larger, less sticky, and travel more easily through blood vessels. Hydroxyurea also decreases the number of white blood cells which causes less inflammation and sickling.



### **Who should take Hydroxyurea?**

People with Sickle Cell Disease may be eligible for Hydroxyurea treatment. Only those who can make regular Hematology Clinic visits for required blood counts and physical exams would be given Hydroxyurea. People with severe complications of Sickle Cell Disease (frequent pain, pneumonia, very low hemoglobin, etc.) are especially suited for Hydroxyurea. Even those with milder disease may benefit since the treatment may prevent sickle complications.

### **What are the proven benefits of Hydroxyurea?**

- Fewer pain events
- Fewer episodes of pneumonia and acute chest syndrome
- Fewer hospital admissions
- Fewer blood transfusions
- Improved appetite

- Increase in height and weight
- More energy
- Fewer missed school days
- Longer life

### **Are there side effects?**

Hydroxyurea is extremely well tolerated. It can cause a decrease in blood counts and must be carefully monitored for this side effect. Blood tests every 1-3 months are usually required.

### **Is it safe?**

Yes. There have been no severe side effects seen in small groups of children, ranging in age from 6 months to 15 years. Some pediatric patients have been treated with Hydroxyurea for more than twenty years, and they have no reported irreversible complications.

### **How do you take it?**

Hydroxyurea comes as a capsule or a liquid and is taken by mouth just once a day. Treatment will begin on a low dose daily based on weight and increases every few weeks depending on its effect.

### **What is the cost of Hydroxyurea?**

Hydroxyurea is fully covered by most private drug insurance policies and by MassHealth.

### **How do I get more information?**

Contact your Hematologist for more information about whether Hydroxyurea is right for you.

## **Alternative Methods of Treating Pain**

Aside from medication to help ease your pain there are many other pain management strategies. Sickle Cell Disease is a chronic disease, it is lifelong so finding successful ways to manage pain can help improve your overall quality of life. For more information about these pain management strategies, please contact the Program for Integrative Medicine and Health Disparities at Boston Medical Center, at **617-414-6795**.

**Acupuncture/Acupressure** 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 you are having pain. This needle blocks the meridian, to stop or decrease the pain. You can get acupuncture right here at BMC and it may even be covered by your insurance.

Acupressure uses the same pressure points and meridians as Acupuncture, but a gentle to firm finger pressure is applied instead of needle.

**Aromatherapy** is a way of using good smells to help you 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 mood and helps you relax. It may also help your brain make special chemicals like endorphins, which can help decrease pain.

**Breathing exercises** are another way to help your body relax. Teaching the body to relax helps lessen pain. You can teach yourself to breathe in and out very slowly. A fun way to practice breathing slowly is to blow bubbles.

Some Additional Breathing Exercise Examples:

- Breathe in slowly through your nose, count to 5 and then breathe out slowly through your mouth counting to 5 again
- Breathe in deeply through your nose and imagine your breathe bringing calm, comfort, and relaxation to the painful area(s) in your body and then breathe out through your mouth imagining the pain, tension, and discomfort leaving your body with your breath
- Breathe in through your nose and imagine a place that is comforting to you and then breathe out through your mouth, slowly, still picturing that comfortable setting

**Distraction** teaches you to focus your attention on something other than pain. Watching TV, reading a book, spending time with friends/family, playing board games or video games may help you relax. This can help keep you from thinking about the pain. These tools can be helpful to you during medical appointments, procedures, or blood draws, too.

**Guided imagery** teaches you to put pictures in your mind to help make the pain less intense. With guided imagery, you learn how to change the way your body senses and responds to pain.

You can imagine floating in the clouds, remember a favorite place, or imagine doing a favorite activity. Think about the things you see while you are doing this.

An example of this is to imagine that you are on a beach. Start by picturing the sand and the water. Then focus in on the water. Imagine you can hear the sound of the waves crashing into the sand, laughter of people splashing in the water. Imagine you can feel the cool comforting temperature on your toes. Then think of the warm sun shining down on you. Try to imagine the smell of the beach, other people enjoying the day, what you would be doing while you were there, etc.

**Heat** can help decrease pain. Some types of pain ease by using heat. A warm bath can be calming and can help your 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 you take in more air. It does not matter whether you listen, sing, hum, or play an instrument. Scientists are learning that music increases energy and helps change your mood. Music also may cause your brain to make special chemicals like endorphins.

**Relaxation and biofeedback** teach your 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 breathing also becomes faster and shallower. These responses can make the pain worse. Relaxation helps lessen the pain by changing these responses.

**Massage** is often used to help someone become more relaxed. You can ask friends or family members to gently massage your back, shoulders, and neck. Massage may work even better if you use guided imagery, breathing exercises, or music.

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

**Self-hypnosis** is a way for you to change your level of awareness. This means that by focusing your attention, you can move away from your pain by making yourself 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 your normal activities. Self-hypnosis gives you better control of your body. You may feel less hopeless and helpless because YOU are doing something to decrease the pain.

## **What is a Fever and What Should I do if I Develop a Fever?**

Fever is a temperature of greater than normal (98.6 °F). In order to ensure adequate care, any individual with Sickle Cell Disease who has a temperature of 101.3 °F (38.5 °C) or greater needs to seek immediate medical attention.

Fever is a normal response of the body to infection. **Remember: although taking Tylenol or Motrin may bring your temperature down, these medicines do not treat infections.** Always call your doctor or go to the emergency room if you have a fever of 101.3 °F or greater. Keep a thermometer at home so you can take your temperature. If you have a low grade fever but feel sick at the same time, this is also a reason to call your doctor.

People with Sickle Cell Disease are at higher risk of infections because their spleen does not work properly to remove bacteria from the blood. To prevent an infection, make sure you are up to date on all your vaccines, especially pneumococcal and meningococcal vaccines. The pneumococcal vaccines may protect you from developing pneumonia; an infection of the lungs, and the meningococcal vaccines may protect you from getting meningitis, an infection around the brain. If you have had a splenectomy you may also need to be on long term antibiotics.

Make sure you have a thermometer with you that you know how to use so that you can check your temperature if you think you have a fever. Ask your doctor to write a prescription for a thermometer if you do not have one.

If you have a fever, call your doctor and come to the emergency department right away. At the ED, they will take a sample of blood and test it for any bacteria. Since bacteria can take 1-2 days to grow they will give you a dose of antibiotics while waiting for results. In many cases you will be able to go home from the ED.

## **Dental Care**

Always schedule and keep appointments with your dentist in order to prevent mouth or teeth infections that may lead to complications of Sickle Cell Disease. A dental evaluation should be carried out every 6 months. You can go to <http://www.masshealth-dental.net/MemberServices/> for a complete listing of local dentists.

Cleanings and dental fillings do not require special care, but operative procedures such as extractions and root canals may require antibiotic prophylaxis in order to reduce the risk of bacterial infection. Dental procedures under anesthesia may require a transfusion ahead of time. If you need dental work done, make sure your dentist and hematologist discuss your case before anything is done.



## **Diet and Sickle Cell Disease**

### **How do I Meet My Daily Fluid Needs?**

Individuals with Sickle Cell Disease have a higher risk of developing dehydration than other people because their kidneys cannot hold water. It is important therefore to drink plenty of fluids to meet your daily fluid needs and prevent dehydration. Dehydration may cause your red blood cells to sickle more than normal and this can lead to painful episodes.

We advise you to:

- carry a water bottle with you at all times.
- start your day by drinking a glass of water and then have something to drink approximately every 2 hours.
- drink extra fluid when you have pain and with exercise.
- choose fluids such as water (spring/tap/flavored), milk, and 100% fruit juice over others (soda, coffee, tea or fruit drinks).
- drink at least 2-3 liters of water per day.

### **Eating Healthy Diet – Do I have to go on a Special Diet?**

There is no special diet for anyone with Sickle Cell Disease. However, it is important to eat a healthy, balanced diet including fruits, vegetables, whole grains, lean meat and fish. If you drink milk, choose low fat or fat free dairy products.

Studies have revealed that individuals with Sickle Cell Disease need about 20 percent more calories than others to fuel their production of red blood cells. Not getting enough calories may lead to delays in growth and maturation. It is advisable to eat less saturated fats, trans fat, cholesterol, sodium and added sugar.



Food Groups	Examples of foods and what they give our bodies.
<b>Grains</b> 	<p>Whole grain breads, rice, pastas, cereals and crackers – aim to make at least half of the grains that you eat “whole” grains</p> <ul style="list-style-type: none"> <li>• Fiber – helps to reduce blood cholesterol and keeps your bowels moving</li> <li>• Folate (in fortified grains) – helps our body to make new red blood Cells</li> <li>• B-vitamins – helps our body to use the energy from foods that we eat</li> <li>• Magnesium – important for healthy bones</li> <li>• Selenium – important for healthy immune system</li> </ul>
<b>Vegetables</b> 	<p>Spinach, carrots, broccoli, tomato, green beans, salad – aim for orange and dark green leafy vegetables</p> <ul style="list-style-type: none"> <li>• Fiber – Tip: keep the skin on veggies and fruits for extra fiber</li> <li>• Folate – Tip: choose leafy greens</li> <li>• Vitamins A – keep eyes and skin healthy, helps protect against infections</li> <li>• Vitamin C – helps heal wounds, keeps teeth and gums healthy</li> <li>• Potassium – may help maintain healthy blood pressure</li> </ul>
<b>Fruits</b> 	<p>Orange, bananas, apples, grapes, melon, berries, kiwi, peach, plums</p> <ul style="list-style-type: none"> <li>• Provide similar vitamins, minerals and fiber as vegetables</li> <li>• 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.</li> </ul>
<b>Milk</b> 	<p>Low fat milk, yogurt and cheese</p> <ul style="list-style-type: none"> <li>• Calcium and Vitamin D – for strong, healthy bones</li> <li>• Potassium – especially in milk and yogurt</li> </ul>
<b>Meats and Beans</b> 	<p>Lean chicken, pork, fish and beef, nuts, seeds, peas and beans</p> <ul style="list-style-type: none"> <li>• Protein and zinc – for energy and growth</li> <li>• Iron – helps to carry oxygen in our blood</li> <li>• Omega 3 fatty acids – in certain fish, nuts and seeds – help to reduce inflammation and decrease risk of chronic diseases, like heart disease</li> </ul>
<b>Oils</b> 	<p>Liquid vegetables oils like olive, canola, corn oil; nuts</p> <ul style="list-style-type: none"> <li>• Vitamin E – works as an antioxidant to help to prevent disease</li> <li>• Omega 3 fatty acids – in flax, canola, soybean and walnut oils, and walnut flaxseeds and pumpkin seeds</li> </ul>

### **Does Sickle Cell Disease Affect Pregnancy in Any Way?**

Most commonly, Sickle Cell Disease does not affect fertility and many young women go on to have successful pregnancies. Women who may become pregnant or men who may father a child should talk to their hematologist if they are on Hydroxyurea, since they may need to stop the medication while pregnant. Sickle Cell Disease can also worsen during pregnancy. There is an increased chance of having complications such as pregnancy induced hypertension, pre-term birth and/or low birth weight babies. Therefore women with Sickle Cell Disease should get special prenatal care and frequent checkups to ensure a healthy pregnancy. It can be beneficial for individuals with Sickle Cell Disease to speak to a genetic counselor or maternal-fetal medicine specialist BEFORE becoming pregnant. If you are thinking about becoming pregnant, contact your primary care provider, or hematologist for advice.

### **Sexual Health and Relationships**

#### **Things to Remember**

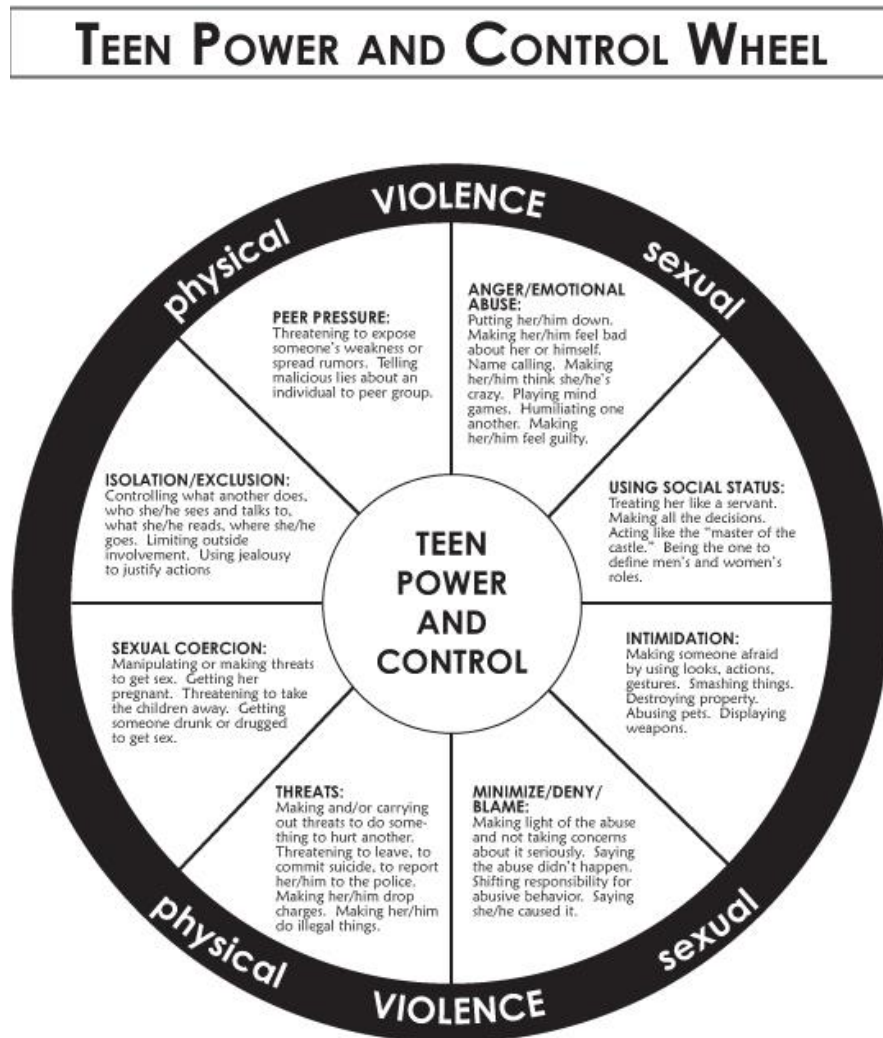
- Deciding when to become sexually active and with whom are decisions that should be YOUR choice.
  - Consent is a very important part of healthy sexuality and should be an on-going process during each part of sexual intimacy.
- Talk to your doctor about ways to prevent pregnancy and sexually transmitted infections.
  - Decide which method(s) of contraception and protection from sexually transmitted infections to use *before* becoming sexually active.
  - Keep in mind, contraception methods vary in effectiveness and cost.

#### **What Are Some Qualities of a Healthy Relationship?**

- Mutual Respect
- Trust
- Honesty
- Support
- Fairness/Equality
- Separate Identities
- Good Communication

## Abuse in Relationships

Any young person can experience unhealthy relationship behaviors or dating abuse, regardless of who they are or where they come from. Abuse can happen in many types of relationships, whether casual and short-term or exclusive and serious. This wheel shows some elements of unhealthy relationships.



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**NATIONAL CENTER**  
on Domestic and Sexual Violence  
training • consulting • advocacy  
4612 Shoal Creek Blvd. • Austin, Texas 78756  
512.407.9020 (phone and fax) • [www.ncdsv.org](http://www.ncdsv.org)







If you are being hurt in your relationship, please get help. Talk to supportive friends and family or a medical provider about the services available to you. Remember, you can always call 911 in an emergency. You can also contact a BMC Safety and Support Advocate for support. BMC Safety and Support Advocates can be reached Monday-Friday during business hours on their intake line at (617)414-5457.

### **What types of contraception and protection are there?**

The chart on the following 2 pages from [www.reproductiveaccess.org](http://www.reproductiveaccess.org) outlines multiple options for contraception and protection from sexually transmitted infections. Talk to your doctor about what method(s) make the most sense for you.

## Your Birth Control Choices

Method	How well does it work?	How to Use	Pros	Cons
<b>The Implant</b> (Nexplanon™) 	> 99%	A health care provider places it under the skin of the upper arm It must be removed by a health care provider	Long lasting (up to 3 years) No pill to take daily Often decreases cramps Can be used while breastfeeding You can become pregnant right after it is removed	Can cause irregular bleeding After 1 year, you may have no period at all Does not protect against human immunodeficiency virus (HIV) or other sexually transmitted infections (STIs)
<b>Progestin IUD</b> (Mirena®, Skyla®) 	> 99%	Must be placed in uterus by a health care provider Usually removed by a health care provider	Mirena™ may be left in place up to 7 years Skyla™ may be left in place up to 3 years No pill to take daily May improve period cramps and bleeding Can be used while breastfeeding You can become pregnant right after it is removed	May cause lighter periods, spotting, or no period at all Rarely, uterus is injured during placement Does not protect against HIV or other STIs
<b>Copper IUD</b> (ParaGard®) 	> 99%	Must be placed in uterus by a health care provider Usually removed by a health care provider	May be left in place for up to 12 years No pill to take daily Can be used while breastfeeding You can become pregnant right after it is removed	May cause more cramps and heavier periods May cause spotting between periods Rarely, uterus is injured during placement Does not protect against HIV or other STIs
<b>The Shot</b> Depo-Provera® 	97-99%	Get shot every 3 months	Each shot works for 12 weeks Private Usually decreases periods Helps prevent cancer of the uterus No pill to take daily Can be used while breastfeeding	May cause spotting, no period, weight gain, depression, hair or skin changes, change in sex drive May cause delay in getting pregnant after you stop the shots Side effects may last up to 6 months after you stop the shots Does not protect against HIV or other STIs
<b>The Pill</b> 	92-99%	Must take the pill daily	Can make periods more regular and less painful Can improve PMS symptoms Can improve acne Helps prevent cancer of the ovaries You can become pregnant right after stopping the pills	May cause nausea, weight gain, headaches, change in sex drive – some of these can be relieved by changing to a new brand May cause spotting the first 1-2 months Does not protect against HIV or other STIs
<b>Progestin-Only Pills</b> 	92-99%	Must take the pill daily	Can be used while breastfeeding You can become pregnant right after stopping the pills	Often causes spotting, which may last for many months May cause depression, hair or skin changes, change in sex drive Does not protect against HIV or other STIs
<b>The Patch</b> Ortho Evra® 	92-99%	Apply a new patch once a week for three weeks No patch in week 4	Can make periods more regular and less painful No pill to take daily You can become pregnant right after stopping patch	Can irritate skin under the patch May cause spotting the first 1-2 months Does not protect against HIV or other STIs
<b>The Ring</b> Nuvaring® 	92-99%	Insert a small ring into the vagina Change ring each month	One size fits all Private Does not require spermicide Can make periods more regular and less painful No pill to take daily You can become pregnant right after stopping the ring	Can increase vaginal discharge May cause spotting the first 1-2 months of use Does not protect against HIV or other STIs

Method	How well does it work?	How to Use	Pros	Cons
<b>Male Condom</b> 	85-98%	Use a new condom each time you have sex Use a polyurethane condom if allergic to latex	Can buy at many stores Can put on as part of sex play/foreplay Can help prevent early ejaculation Can be used for oral, vaginal, and anal sex Protects against HIV and other STIs Can be used while breastfeeding	Can decrease sensation Can cause loss of erection Can break or slip off
<b>Female / Internal Condom</b> 	79-95%	Use a new condom each time you have sex Use extra lubrication as needed	Can buy at many stores Can put in as part of sex play/foreplay Can be used for anal and vaginal sex May increase pleasure when used for vaginal sex Good for people with latex allergy Protects against HIV and other STIs Can be used while breastfeeding	Can decrease sensation May be noisy May be hard to insert May slip out of place during sex
<b>Withdrawal</b> Pull-out	73-96%	Pull penis out of vagina before ejaculation (that is, before coming)	Costs nothing Can be used while breastfeeding	Less pleasure for some Does not work if penis is not pulled out in time Does not protect against HIV or other STIs Must interrupt sex
<b>Diaphragm</b> 	84-94%	Must be used each time you have sex Must be used with spermicide A health care provider will fit you and show you how to use it	Can last several years Costs very little to use May protect against some infections, but <b>not HIV</b> Can be used while breastfeeding	Using spermicide may raise the risk of getting HIV Should not be used with vaginal bleeding or infection Raises risk of bladder infection
<b>Rhythm</b> Natural Family Planning, Fertility Awareness 	75-88%	Predict fertile days by: taking temperature daily, checking vaginal mucus for changes, and/or keeping a record of your periods It works best if you use more than one of these Avoid sex or use condoms/spermicide during fertile days	Costs little Can be used while breastfeeding Can help with avoiding or trying to become pregnant	Must use another method during fertile days Does not work well if your periods are irregular Many things to remember with this method Does not protect against HIV or other STIs
<b>Spermicide</b> Cream, gel, sponge, foam, inserts, film 	71-85%	Insert more spermicide each time you have sex	Can buy at many stores Can be put in as part of sex play/foreplay Comes in many forms: cream, gel, sponge, foam, inserts, film Can be used while breastfeeding	May raise the risk of getting HIV May irritate vagina, penis Cream, gel, and foam can be messy
<b>Emergency Contraception Pills</b> Progestin EC (Plan B® One-Step, Next Choice™ and others) and ulipristal acetate (ella®) 	0-94% Ulipristal EC works better than progestin EC if you weigh more than 155 pounds (BMI > 26) Ulipristal EC works better than progestin EC in the 3-5 days after sex	Works best the <b>sooner</b> you take it after unprotected sex You can take EC up to 5 days after unprotected sex If pack contains 2 pills, take both together You should start a birth control method right after using EC to avoid pregnancy	Can be used while breastfeeding Available at pharmacies, health centers or health care providers: call ahead to see if they have it Women and men of any age can get some brands without a prescription	May cause stomach upset or nausea Your next period may come early or late May cause spotting Does not protect against HIV or other STIs Women under age 17 need a prescription for some brands Ulipristal requires a prescription May cost a lot

## **Other Helpful Websites and Resources**

1. [www.youngwomenshealth.org](http://www.youngwomenshealth.org)
  - a. Includes an option to ask anonymous questions!
2. [www.reproductiveaccess.org](http://www.reproductiveaccess.org)
  - a. Information on reproductive health!
3. [www.sexetc.org](http://www.sexetc.org)
  - a. Written for teens by teens!
4. [www.mariataalks.com/about-maria](http://www.mariataalks.com/about-maria)
  - a. Founded by Aids Action in MA! For teens/young adults!
5. [www.loveisrespect.org](http://www.loveisrespect.org)
  - a. Find out more about healthy relationships!
6. [www.bagly.org](http://www.bagly.org)
  - a. Boston's own youth led LGBT teen program!
7. Rape Hotline for the Boston Area Rape Crisis Center
  - a. 1-800-541-8371

## **Common Issues/Questions for Young Adults with Sickle Cell Disease**

### **What about Cigarettes, Alcohol and Illicit Drugs?**

Cigarette smoking harms nearly every organ in the body. As someone living with Sickle Cell Disease, the chemicals in the tobacco smoke are harmful to your blood cells.

Tobacco can also damage the structure and function of your blood vessels, as well as the function of your heart and lungs. This damage will increase your risk of developing atherosclerosis (a disease in which a waxy substance called plaque builds up in the arteries). The plaques harden overtime and destroy the blood vessels. These plaques, in addition to blockage caused by sickled hemoglobin, may lead to frequent pain crises and organ damage.

If you are smoking, we advise that you quit. If you are ready to quit, please contact your primary care provider or a community program for assistance accessing resources for smoking cessation.

Also try to avoid second hand smoke. Ask friends and family members who smoke to quit or not to smoke in the house and car.

Alcohol will cause dehydration which can predispose you to pain crises. If you do choose to drink alcohol, please do so in moderation and never drink so much that you lose control of your own wellbeing.

Ecstasy and marijuana (cannabis) have been associated with frequent incidences of priapism in patients with Sickle Cell Disease. We advise you to avoid these drugs. If you are currently using them and wish to quit please contact your health care provider for recommendations.

## **Tattoos and Body Piercings**

Getting tattoos or body piercings may increase your risk of getting an infection if the tools are not sterilized. Make sure you are going to a reputable and licensed place with sterile equipment.

## **Can I Participate in Sports?**

Your doctors will make every effort to support you in any physical activity you would like to undertake. There are sports that may be safer and others that may be less safe for someone with Sickle Cell Disease. As a general rule, any sport that would require overexertion, causes overheating, chilling or dehydration may trigger pain crises. In addition to this, any form of activity in a high altitude could also be harmful to you. If you have an enlarged spleen, it is advisable you avoid contact sports which may predispose the spleen to rupture.

## **Can I still do the things I enjoy?**

Absolutely, just use good judgment. For instance, take frequent water breaks while you are playing sports. Do not become dehydrated being outside in the heat/humidity. Make sure you have warm clothes if you like to spend time outside in cooler months.

## **What else should I think about?**

Alcohol and caffeine can both lead to dehydration. It is advisable to drink in moderation. If you are consuming alcohol or caffeine, increase the amount of water you are drinking.



## **Coping with Sickle Cell Disease**

Living with Sickle Cell Disease can be stressful and challenging at times, so it is critical to develop healthy coping skills to help you manage both Sickle Cell Disease related stressors as well as general life stressors. There are many ways to cope with the stress of Sickle Cell Disease. Seek advice from and ask questions of your providers during visits to the hospital/clinic, talk with family, friends and others who are facing similar challenges.

### **Some Examples of Healthy Coping Skills**

- Talking to trusted friends and family
- Connecting with your church or other religious institution
- Reading
- Listening to music
- Drawing/painting
- Writing/keeping a journal
- Exercising
- Cooking

### **Tips for Supporting Yourself When You are Ill or Hospitalized:**

- Remain as active in social and school activities as you are able.
- Be actively involved in your treatment plan by talking to the team and providers.
- Ask to have the details of your care written down so you can look at it later.
- Do things that make you feel good about yourself.
- Let those around you know what you are capable of doing on your own and what things you may need some help with.
- Let your family and friends visit or call you in the hospital or home.
- Ask for help to plan for the future.
- Keep doing normal things like school and work.
- Find ways to express your feelings such as physical activity, talking, or writing. Know that all of your feelings are normal, such as guilt, fear, or sadness. However, if these occur all the time, please call your doctor.
- Stay connected with friends/family through email, social media (Facebook, Twitter, Instagram etc.)

## **Sickle Cell and Your Education/Career**

### **Thinking of Going to College?**

- Create a list of schools that you are interested in going to/finding more information on.
- Talk to your high school guidance counselor to see if there are any programs going on to help you apply to college.
- Track deadlines (when are applications due? e.g. for FAFSA – Free Application for Federal Student Aid), and keep on top of teachers/mentors who are completing letters of recommendation.
- Apply for other loans, grants, etc.
- Fill out college applications.
- Complete FAFSA applications for financial aid.
- Talk with your Social Worker at Transition Clinic.
- Ask your providers at Boston Medical Center about STRIVE and if this program might be of help to you.
  - Strive is an afterschool program that helps with intensive one on one academic tutoring, mentoring, peer support, disease management education and medical self-advocacy training programs. Teens are paired with college students who provide individualized support and guidance through weekly group sessions and hospital visits. For more information please take a look at the following web page. <http://www.nextstepnet.org>

### **Special Education**

Individuals with Sickle Cell Disease often face many challenges during school. In order to ensure a successful education experience, the state and federal government have legal, written documents that focus on your specific needs in school.

Children with disabilities or special needs between the ages 3-21 years are eligible to receive accommodations and benefits from the state. Sometimes people with Sickle Cell Disease qualify for these accommodations and benefits. Laws have been created and put in place such as the Individualized Education Program (IEP) and the 504 Plan to ensure that children are receiving the help that is necessary for their educational success.

### **Individualized Education Program (IEP)**

The Individualized Education Program (IEP) describes special educational services and accommodations. This document is put in place to help students that have a disability that affects their ability to learn and can be helped by special education accommodations or services. When a student is “placed” on an IEP, it is a document that must be reviewed and agreed upon annually.

- A list of your strengths and areas to improve.
- A vision statement of your hopes and goals.
- Measurable educational goals and a plan for achieving them.
- Specially designed teaching and/or services (such as speech, occupational, and physical therapies, assistive technology) you need to reach those goals.
- Beginning at age 14, a description of special instruction that will help you transition from school to adult life activities when ready.
- If you had an IEP in school it may be that you can take it with you to college. Talk to your high school guidance counselor and the College's Office of Disabilities to find out if this applies to you.

## **504 Plan**

A 504 plan is designed to help students whose disabilities affect their daily living and provides accommodations so they can access programs and educational offerings provided by public funding (public schools, not private). It includes:

- Extra sets of textbooks.
- Access to tutors when hospitalized.
- Classroom liaison to communicate missed or catch-up work.
- Hall passes to visit the restroom.
- Ability to wear coats when necessary.
- Elevator access.
- Modified or limited participation in gym.
- Plans to make a school wheelchair accessible.
- Use of assistive technology as needed.
- Permission to type assignments instead of writing them by hand.
- Permission to hand in assignments late due to illness or a hospital stay. Talk to your high school guidance counselor and the College's Office of Disabilities to find out if this applies to you.

## **Individualized Health Care Plan (IHCP)**

An IHCP helps to make sure you receive the health services you need during the school day. Although there is no law that says you have a right to an IHCP, you can ask for an IHCP if you need one. Contact your school nurse and your primary care provider.

The IHCP should include:

- The health services you receive at school.
- When, where, and how the health services will be provided.
- Who will provide the health services.
- Information about your transportation needs; including special needs for field trips.
- An Emergency Response plan that lists possible emergencies and what to do.
- A copy of the Emergency Information Form for individuals with special health needs.

The above plans are not mutually exclusive and a student can be on more than one. Commonly school systems will try to incorporate them together to make it easier and less cumbersome for the family and student.

## **Medication and School**

If you need to take medication while in high school it is important that it be kept with the **school nurse**. In the beginning of the year, you should fill out a form authorizing the school to give you medicine.

## **College Support Services**

### **How Does Chronic Pain Interfere with Learning?**

A student experiencing pain may find it difficult to perform physical skills, such as sitting or holding and using a pen. Concentrating during class or a test may be difficult. Medication may interfere with focusing or even active classroom participation. By working with your school's available support service coordinators, you can create a plan that works for your educational success! You can go to the Office of Disability at your college to discuss Sickle Cell Disease and the accommodations you may need. For instance, you can discuss making arrangements with your teachers to allow you to be excused from classes, and to receive extended time for written assignments or exams when appropriate. Ask your health care provider or social worker if you need help doing this.

The following is a list of contact information for some of the higher education disability offices.

<b>Assumption College</b> Disability Service 508-767-7500	<b>Emerson College</b> Disability Services 617-824-8592
<b>Ben Franklin Institute of Technology</b> Disability Services 617-588-1378	<b>Fisher College</b> Student Accessibility Services 617-670-4429
<b>Boston College</b> Disability Services Office 617-552-3470	<b>Fitchburg State University</b> Disability Services 978-655-3427
<b>Boston University</b> Student Support Services 617-353-3658	<b>Framingham State University</b> Academic Support Services 508-626-4906
<b>Bunker Hill Community College</b> Support Services 617-730-7000	<b>Newbury College</b> Disability Support Services 617-288-2234
<b>Bridgewater State University</b> Disability Resources 508-531-2194	<b>Massasoit Community College</b> Academic Resource Center 508-588-9100 ext. 1082
<b>Curry College</b> Student Disability Office 617-333-2385	<b>Lasell College</b> Edward Student Center 617-234-2451
<b>Mass Bay Community College</b> Disability Resources Framingham 508-270-4267 / 4286 Wellesley 781-239-2234 / 2626	<b>Middlesex Community College</b> Disability Support Services 978-656-3258 9 (Lowell) 781-280-3630 (Bedford)
<b>Massachusetts College of Pharmacy + Health Sciences</b> Disability Support Services 617-879-5925	<b>Regis College</b> Disability Support Services 781-768-7384

<b>Lesley College</b> Center for Academic Achievement P: 617-349-8194 F: 617-349-8558	<b>Pine Manor College</b> Brown Learning Resource Center P: 617-731-7181 F: 617-731-7638
<b>Northern Essex Community College</b> Learning Accommodations Center 978-556-3654	<b>Salem State University</b> Disabilities Services P: 978-542-6217 F: 978-542-2064
<b>Mount Ida College</b> Student Affairs 617-928-4563	<b>Northeastern University</b> Disability Resource Center P: 617-373-2675 F: 617-373-7800 (confidential)
<b>Quincy College</b> Office of Disability Services 617-984-1656	<b>Roxbury Community College</b> Students with Disabilities Center 617-427-0060 ex. 5006
<b>Simmons College</b> Disability Services 617-521-2472 617-521-3079	<b>Wheelock College</b> Ross Center for Disability Services 617-287-7430
<b>UMASS Dartmouth</b> Center for Access and Success 508-999-8711	<b>Westfield State</b> Banacos Academic Center 413-572-5676
<b>UMASS Lowell</b> Student Disability Services 978-934-4574	<b>Worcester State</b> Disability Service Office P: 508-929-8733 F: 508-929-8214

## **Finding a Job**

### **First Time Job Searching?**

- Put together a resume.
  - For examples, please look at:  
<http://jobsearch.about.com/od/sampleresume1/a/high-school-resume-examples.htm>
- Fill out applications either on site or online.
- Do you own appropriate dress attire?
  - Appropriate clothing for interviewing and job searching includes pants, skirts/dresses to the knees, blouses or shirts, and ties. Avoid revealing clothing and clothing with tears or stains.
- Prepare for the interview by practicing answering interview questions (see below for examples).
- Contact your local career services for assistance and/or support.
- Be sure to be on time for scheduled interviews! \*\*It is ALWAYS better to be early for an interview than late.

### **Second, Third, Fourth ...Twelfth Job?**

- Keep your resume up-to-date
- Write a cover letter
- Keep a positive attitude
- Make sure your wardrobe is appropriate
- Practice job interview skills with a friend or even in the mirror

### **Information on Jobs, Careers, and Training Can be Found on:**

<http://www.usa.gov/Citizen/Topics/Education-Training/Finding-Jobs.shtml>

<http://bostonjobsource.com/>

<http://www.monster.com/>

<http://www.simplyhired.com/>

<http://www.indeed.com/>

<http://www.careerbuilder.com/>

<http://www.snagajob.com/>

## Sample Interview Questions

- Tell us about yourself?
- Why do you want to work at ***\*Name of Company/Organization\****?
- What can you bring to our team?
- Would you describe yourself more as a team player or individual worker and why?
- What are your strengths and weaknesses?
  - This is a very hard question to answer but something a lot of interviewers ask. It may also be asked as what comes really easy to you and what do you need to work more on?

## Are there Job accommodations for people with Sickle Cell Disease?

Yes! It is important for you to inform your employer of your medical condition before accepting a job. The following guidelines on job accommodations have been put together by the Job Accommodation Network (JAN), and the U.S. Department of Labor's Office of Disability Employment Policy.

Because individuals with Sickle Cell Disease may have a recurrent need for medical intervention or transfusions, your employer should:

- allow time off for medical appointments.
- allow you to work from home full or part time.
- permit a family member or friend to call out for you when in "crisis".
- provide additional unpaid leave if you exhaust accrued time off.
- allow telephone calls during work hours to doctors and others for support.
- provide information on counseling and employee assistance programs.

Secondly, to avoid fatigue or weakness while at work, your employer can allow you:

- to schedule periodic rest breaks away from the workstation to reduce physical exertion and workplace stress.
- design a workstation that best suits your body (Ergonomics).

Thirdly, to prevent respiratory difficulties / reduced immunity, your employer can:

- provide adjustable ventilation and air cleaner.
- keep work environment free from dirt, dust, smoke, odors, and fumes.
- provide anti-bacterial wipes to clean workstations.
- implement an illness policy, requiring employees to stay home if contagious to avoid exposing co-workers to colds, flu or other air-borne infections.
- your employer can modify work-site temperature or provide you an office with separate temperature control

**\*\*For further information on job accommodation, please visit [www.askjan.org](http://www.askjan.org).**



## **Health Insurance**

As a young person with a chronic illness, it is very important that you have health care coverage for your doctor's visits, medications, and hospitalizations.

As a Massachusetts resident, it is the law that you must have insurance (this is called an **individual mandate**). There are several kinds of health insurances to choose from and the process for getting and staying on insurance can get complicated. Here is some basic information to guide you.

### **Public Programs**

Public programs are health insurance programs paid for in part by the state and federal governments.

**MassHealth** is insurance for Massachusetts residents. The level of MassHealth coverage that you are eligible for is based on income and disability. MassHealth services may be limited for people who are NOT disabled, and depending on immigration status. For more information, go to: [www.mass.gov/eohhs/gov/departments/masshealth](http://www.mass.gov/eohhs/gov/departments/masshealth)

**Commonwealth Care** is an individual insurance plan offered by the state. Individuals who cannot get MassHealth or coverage through their school, work, or parents can purchase a plan through the Massachusetts Connector Board. The state will sometimes subsidize (help pay for) the cost of this insurance depending on your income. For more information, go to: [www.mahealthconnector.org](http://www.mahealthconnector.org)

**Medicare** is a federal health insurance program for people age 65 and older OR who have a permanent disability and have been on SSI/SSDI for at least two years. For more information, go to: [www.medicare.gov](http://www.medicare.gov)

### **Private Insurance Programs**

These are health insurance policies paid for by individuals and/or employers:

**Through your legal guardians:** If your legal guardian(s) have a health insurance plan through their employer, their child can stay on the plan for up to two years after you lose **dependent** status, up to the age of 26 years.

**Through Work:** If your employer offers a plan, you usually can sign up when you are hired (you may have to wait for 30 days for coverage to kick in). If you do not elect a plan at the time of hire, you might have to wait until an open **enrollment period** to get coverage.

**Through School:** Many colleges require students to have a health insurance plan. This can be your family plan, MassHealth, Commonwealth Care, or a plan offered through the school.

## Dental Coverage

As with regular health insurance, there are different dental insurance programs that you may be eligible for.

**MassHealth Dental Coverage:** If you are on MassHealth, they will cover emergency and preventative (check-ups) treatment for adults over the age of 21. Adults over 21 do NOT have coverage for “restorative” services, like fillings, root canals, crowns, dentures, etc.). Emergency, preventative, and restorative treatment is available if you are under 21 and on MassHealth.

**Other Dental Health Care Plans:** You may be offered dental insurance through your school, work, or parent’s insurance plan. Dental insurance is not mandatory in Massachusetts.

There are several clinics offering reduced-cost dental care. Find more info at:  
<http://www.massdental.org/content.aspx?id=792>.

## Your Responsibilities

It is important to have continuous health care coverage so that you can access your doctors, use emergency services, and keep your prescriptions filled. As mentioned earlier, in Massachusetts if you do not have health insurance you can be fined when you do your tax returns. Here are some things to remember when it comes to maintaining your insurance:

- Keep your insurance company updated if your address or phone number changes.
- **Read and answer any mail sent to you by your health insurance company.** MassHealth sends a yearly “**eligibility review**” form that must be completed and returned, otherwise your MassHealth coverage will end.
- If you have Commonwealth Care or a private insurance plan, you must pay your **premiums** and **deductibles** in order not to lose coverage.
- Your insurance company will send you a statement (by mail or email) every year stating that you have “**minimum creditable coverage**”. A copy of this statement needs to be sent in with your tax returns so you can show the state that you have complied with the mandatory health insurance law. It is VERY important that you open and read any form you get from your insurance company. If you do not understand something bring it with you to your next visit.

## For More Information, Please Contact:

Patient Financial Services at 617-414-5155

Menino Building 2<sup>nd</sup> Floor – Monday-Friday 8-6:30 & Saturday 9-3

Shapiro Building 3<sup>rd</sup> Floor – Monday-Friday 8-5

## Important Health Insurance Terms

**Copay:** A predetermined (flat) fee that an individual pays for health care services, like medications, in addition to what the insurance covers.

**Deductible:** The amount an individual must pay for health care expenses before insurance (or a self-insured company) covers the costs.

**Dependent:** A person or persons relying on the health insurance policy holder for support. This may include the spouse and/or unmarried children (whether natural, adopted, or step) of the health insurance policy holder.

**Eligibility Review:** MassHealth's yearly process of reviewing its members' eligibility for MassHealth insurance.

**Enrollment Period:** The time during which you are allowed to enroll in a group health insurance plan. As a rule, there are specific times when others may join the group or change their existing coverage. Those times vary depending on the insurance.

**Individual Mandate:** Massachusetts residents age 18 and older must have health insurance.

**Minimum Creditable Coverage:** The essential health insurance benefits you need to avoid tax penalties in Massachusetts.

**Premiums:** The money paid by an insurance person or business for a health insurance policy.

**Subsidy:** Help with the cost of health insurance premiums, most often offered by the state or federal government.

## **Income Supports for Persons with Disabilities**

### **Supplemental Security Income Benefits (SSI)**

SSI provides a monthly benefit to help cover cost of living to disabled, blind or those 65 and over receiving a limited income. SSI is not Social Security, but is administered via the Social Security Administration. To find out eligibility requirements and apply, visit [www.ssa.gov/ssi](http://www.ssa.gov/ssi).



### **Social Security Disability Insurance (SSDI)**

SSDI provides a monthly stipend to help cover costs if you are disabled and unable to work. SSDI is a part of Social Security and requires that applicants have contributed to social security while employed. SSDI is given for as long as the individual is disabled and unable to work due to a medical condition. Generally, Social Security determines that someone is disabled if they cannot work for one year or longer.

Visit [www.ssa.org/disability/](http://www.ssa.org/disability/).

Other sites include:

<http://www.ssa.gov/boston/>

<http://www.ssa.gov/boston/MA.htm>

<http://socialsecurityhop.com/offices/social-security-office-boston-ma-02119-massachusetts>

[http://www.ultimatedisabilityguide.com/ma\\_ssdi\\_ssi.html](http://www.ultimatedisabilityguide.com/ma_ssdi_ssi.html)

### **Who can Help Me Make Important Decisions about my Health, Financial, and Personal Affairs?**

- **Guardian**– If due to a medical condition, such as a stroke, an adult is not *able* to make *effective* decisions about their own *care, daily needs, and safety*, a guardian can be appointed by the Massachusetts' Court to help make those decisions on behalf of the adult in question, called the Incapacitated Person. The Guardian can also be a person previously selected by the Incapacitated Person (like a parent or family member

designated as a Health Care Proxy), or an organization designated by the Court. As a Guardian, that person or organization makes key decisions about the Incapacitated Person's well-being, care, and daily needs while respecting their autonomy and personal rights. A Guardian can be temporary or have limited authority depending on a person's needs. For more information visit [www.massguardianshipassociation.org](http://www.massguardianshipassociation.org).

- **Representative Payee**- This is a service through the Social Security Program that provides financial management for Social Security and SSI payments. This program is for beneficiaries who are incapable of managing their Social Security or SSI payments. If a person cannot be appointed, the Social Security Agency can designate an individual of their choosing. This is different from a Guardian, Conservator and Health Care Proxy. For more information, visit [www.socialsecurity.gov/payee/](http://www.socialsecurity.gov/payee/)
- **Health Care Proxy** – This is a legal document signed by the patient. In this document, the patient designates an individual of his/her choice as an agent to make health care decisions for him/herself. The only time an agent is able to make decisions is if the patient is unable to do so for him/herself. A patient may also choose an alternate agent. An alternate agent would step in if the agent is unable to fulfill his/her duties. The document is completed *prior* to any emergency, and can only be “enacted” (or activated) by a doctor *if* the patient is unable to make healthcare decisions. Visit [www.massmed.org](http://www.massmed.org) and click on “Patient” in the toolbar at the top of the screen to learn more and see a copy of the Massachusetts form.
- **Conservator of an Adult** – This is NOT a Guardian. A Conservator is a person appointed (by patient or Massachusetts Probate and Family Court) to provide *protection* in managing *money, property or business* for a patient (called the Protected Person) who is unable to do so due to a disability. Visit [www.massguardianshipassociation.org](http://www.massguardianshipassociation.org) for information.

## **Independent Living**

### **Housing**

Before getting your own apartment, it is important to understand your rights as a tenant and the rights of the landlord.

According to the law, a tenant has the right to:

- Use the property they are renting according to the terms of lease.
- Privacy. Your landlord may only enter your apartment to make repairs, deliver a message, inspect or show the apartment to anyone who intends to move in.
- File complaints against your landlord if the conditions of the apartment become a threat to your health or safety.
  - For example, no heat, leaking pipes, roof, etc. mold, insect infestation
- Know the contact information of your landlord.

On the other hand, you should realize that your landlord also has the right to:

- Have the property maintained by you according to the terms of the lease.
- Rent the apartment to anyone of his/her choice, but must not discriminate according to race, color, religion, sex, nationality, or disability.

## **What is a Lease?**

A lease is an agreement or contract between a landlord and a tenant. It is a legal document that protects the rights of both you and the landlord. Before signing a lease, always read carefully to make sure you are willing to abide by everything written in it. Take note of the length of time (months/years) the lease covers, how much the security deposit is, who pays the utility bills, the day rent is due, and other Dos and Don'ts while living in the apartment.

Some landlords require a security deposit before moving in. This, in most cases, amounts to a month's rent and is often used to cover any damage you may cause while living in the apartment. You must also keep the apartment clean and in good order.

## **What are my Responsibilities as a Tenant?**

Once you sign a lease, it forms a legal agreement between you and the landlord. By signing the lease both you and the landlord are responsible for keeping the terms and conditions on the lease.

You should pay your rent on time. You should also obey laws related to health and safety such as garbage disposal and fire safety.

## **Where is the Best Place to Live?**

Identify the type of home and neighborhood that best suits your needs. Also consider looking for an apartment that is close to family, friends, school, work, church, laundry facilities and other community resources.

There are many resources for finding housing in the Boston area, some of which include:

<http://www.cityofboston.gov/rentalhousing/>

<http://www.bostonhousing.org/>

[http://portal.hud.gov/hudportal/HUD?src=/program\\_offices/public\\_indian\\_housing/programs/hcv](http://portal.hud.gov/hudportal/HUD?src=/program_offices/public_indian_housing/programs/hcv)

<http://www.mass.gov/hed/economic/eohed/dhcd/>

[http://www.eap.partners.org/WorkLife/Housing/Emergency\\_and\\_Low\\_to\\_Moderate\\_Income\\_Assistance.asp](http://www.eap.partners.org/WorkLife/Housing/Emergency_and_Low_to_Moderate_Income_Assistance.asp)

[http://www.eap.partners.org/WorkLife/Housing/Emergency\\_and\\_Low\\_to\\_Moderate\\_Income\\_Assistance.asp](http://www.eap.partners.org/WorkLife/Housing/Emergency_and_Low_to_Moderate_Income_Assistance.asp)

<http://www.prohope.org/programs.htm>

<http://www.mbhp.org/>

[http://portal.hud.gov/hudportal/HUD?src=/topics/rental\\_assistance](http://portal.hud.gov/hudportal/HUD?src=/topics/rental_assistance)

<https://www.masshousing.com/portal/server.pt?>

<http://www.homestartinc.org/>

<http://www.liftcommunities.org/boston/our-work/clients>

## **Boston Center for Independent Living (BCIL)**

### **Promoting Independence for People with Disabilities**

BCIL is a 501(c)(3) non-profit organization that has provided services to people with disabilities since the organization's founding in 1974, when it became the second independent living center in the country. BCIL aims to empower people with disabilities with the practical skills and self-confidence to take control over their lives and become active members of the communities in which they live.

BCIL can help you:

- Learn options you have for personal care and in-home support as you plan to leave a nursing home or hospital
- Find affordable and accessible housing
- Learn how you can acquire assistive technology and communication equipment
- Plan your education, particularly as you near high school graduation
- Find out about accessible transportation services
- Obtain and maximize benefits
- Set career goals in a current or future job, or finding employment
- Address communication needs due to a language or communication barrier
- Understand your civil rights under the ADA or Fair Housing law
- Appeal a decision related to housing, education, medical service or employment
- Increase your access to necessary healthcare

**BCIL**

**60 Temple Place**

**Boston, MA 02111**

**Phone: 617.338.6665 Fax: 617.338.6661**

**[www.bostonicil.org](http://www.bostonicil.org)**

\*Check with your local towns about independent living programs in your area.

## **Managing Money**

Once you have a steady income, the next thing to do is to learn how to spend it wisely. Managing money is one of the most important skills to have as a young adult living independently.

Always keep track of your money, plan for purchases ahead of time, and ensure you have the funds for the things you need (rent, water, heat, electricity, gas, food, cell phone bills, medications, personal care items, and emergency money). Be careful with credit cards; you should only spend with your credit card what you are able to pay off each month! Develop good savings habits!!

In addition, set up a budget for yourself (daily, weekly, or monthly) and know the difference between your “wants” and “needs” when it comes to purchases.

## How do I use Bank Checks/ATM Cards?

First you need to open an account with a bank of your choice. A check is often used for a checking account. It cannot be used for a savings account.

A savings account is used to store money and earn interest, while a checking account provides you with an alternative to cash through the use of checks or debit cards. You can write a check or use your debit card to pay your bills or settle other expenses.

MIKE BECKMAN		1178
101 JONES STREET		
ANYWHERE, MA 00031		Date: Jan. 6 <sup>th</sup> 2000
Pay to the		
Order of	Jane Doe	\$ 100.00
Amount:	One Hundred dollars and zero cents -----	
Community Bank PLC		
For	Room and Boards	Mike Beckman
: 1010000019 !!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!! 1178		

## How do I Write a Check?

The figure above is an example of a filled bank check. Always take care to fill out a check properly.

- Write a check with pen not pencil.
- Do not pre or post date a check. Write the current date on the check.
- Write the amount you want to pay in numbers close to the dollar sign in order to avoid someone inserting a number before the amount you have written.
- Write the amount in words starting from the far left and draw a line to fill unused space.
- Sign your check with the same signature you registered with in the bank.
- **NEVER** sign a blank check at any point.



## **Automated Teller Machines (ATMs)**

These are machines often times located outside of your bank that you can withdraw money as well as deposit it too. They are convenient, and easy-to-use. Once you have an ATM card issued to you by your bank, it can be used to withdraw and deposit money as soon as it is activated.

Note that with an ATM card, there is a greater temptation to spend money on things you never planned for. Always use your budget to guide your spending.

The use of an ATM card requires you to have a password before making a transaction at the machine. Choose a secret password, do not write it on your card or anywhere people could see it, and do not give your password to others. Always remember to remove your card from the machine at the end of every transaction. Call your bank immediately if you lose your card.

## **Home Management**

- Clean your living areas.
- Keep dishes clean.
- Attend to trash/recycling.
- Be aware of when your monthly bills are due.
- Going to a Laundromat? You'll need quarters and your own detergent!

## **Time Management**

- Plan a daily/weekly schedule.
- Make a "To-Do-List".
- Try to go to bed at the same time each night and try to wake up at the same time every morning.
- Complete any necessary homework and/or work tasks.
- Set aside time for self-care (examples: going to the gym, relaxing, reading, listening to music, creating artwork, writing, practicing deep breathing exercises, spending time with loved ones etc.)

## **Health & Safety**

- Take medications as needed and at the correct times/doses/intervals.
- If you have a number of medicines to take daily, consider asking if your pharmacy can prepare your medicines in a bubble pack.
- Schedule and go for your doctor's appointments and go for your appointments.
- Schedule follow-up appointments.

- Call to cancel appointments (if necessary) at least 24 hours in advance.
- Have a list of contact numbers in case of an emergency.
- Take care of yourself.
- Know when to go to the hospital in a crisis.

## Transportation

### Have a car?

- Always have your license on you when you're driving.
- Make sure there is gas in the tank.
- Make sure the car registration is up to date.
- Change your oil every 3000-5000 miles.
- Make sure you have car insurance.
- AAA or other roadside assistant services can be helpful.
- **NEVER** drive under the influence of alcohol or drugs; \*\*\*this includes when you have been taking your prescribed opioid medication.

### Take public transportation?

- Learn about the MBTA train and bus schedules.
- Plan your route from starting to end destination.
- Be aware of bus and train stops.
- Get a Charlie card (weekly pass, monthly LINK pass, semester pass, or whatever fits your need).
- Be aware of your surroundings.
- Keep your belongings on you at all times.

### Need a taxi?

- Metrocab Boston: 617-536-5000
- Wonderful Boston: 617-782-5500
- Uber Car: [www.ubercar](http://www.ubercar)



Get a CharlieCard and Save!  
Then upgrade your CharlieCard with MyCharlie

CharlieCard	<b>\$2.10</b> Free transfer to local bus Discounted transfer to Express Bus One Transfer valid within two hours of paying our fare.
CharlieTicket/ Cash-on-board	<b>\$2.65</b>
Monthly LinkPass	<b>\$75/month</b> Valid on Subway plus Local Bus.
Day/Week LinkPass	<b>\$12.00</b> for 1 day <b>\$19.00</b> for 7 days Valid on Subway, Local Bus, <u>Commuter Rail Zone 1A</u> , and Inner-Harbor Ferry.
<u>Seniors and Persons with Disabilities</u> (Blind persons ride for free)	<b>\$1.05/ride</b> <b>\$29/month</b> Valid on Local Bus and Subway. Requires a <u>Senior/T.A.P ID</u> or Blind Access Card.
<u>Students</u> (Junior High and High School)	<b>\$1.05/ride</b> <b>\$26/month</b> Valid on Bus, Subway, Express Bus, and <u>Commuter Rail Zones 1, 1A and 2</u> . <u>Requires Student ID Badge</u> .
<u>Children 11 and under</u>	<b>Free</b> Children 11 (eleven) years of age and under ride for free when accompanied by an adult, with a limit of two children for each adult.

\*This information is subject to change.

## **Sickle Cell Resource List**

### **American Red Cross**

Website: [www.newenglandblood.org](http://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

### **Greater Boston Sickle Cell Disease Association**

Telephone: (617) 427-4100

1542 Tremont Street, Roxbury, MA 02120

<http://www.gbscda.org>

### **Massachusetts Department of Public Health - Genetics Program**

Telephone: (617) 534-5121

### **Massachusetts Rehabilitation Commission**

Website: <http://www.mass.gov/eohhs/gov/departments/mrc/>

The mission of MRC is to promote equality, empowerment and independence of individuals with disabilities.

### **National Health Care Transition Center**

<http://www.gottransition.org>

### **National Institute of Health – Sickle Cell Anemia**

Website: <http://health.nih.gov/topic/SickleCellAnemia>

### **New England Pediatric Sickle Cell Consortium**

Website: [www.nepscc.org](http://www.nepscc.org)

### **Sickle Cell Disease Association of America**

Website: [www.SickleCelldisease.org](http://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](http://www.SCInfo.org)

The mission of this site is to provide Sickle patient and professional education, news, research updates, and worldwide Sickle Cell resources.

## **Education**

### **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](http://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

**Massachusetts Department of Education (DOE)**

(781) 338-3000

Bureau of Special Education Appeals

(781) 338-6400

Program Quality Assurance

(781) 338-3700

350 Main Street

Malden, MA 02148

[www.doe.mass.edu/sped](http://www.doe.mass.edu/sped)

**Sickle Cell Disease: Information for School Personnel**

Website: [www.state.nj.us/health/fhs/SickleCell](http://www.state.nj.us/health/fhs/SickleCell)

Located in Ashford, Connecticut, this camp offers free sessions for children age 7 to 15. Special sessions are available for specific illnesses

**Legal Aid****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](http://www.ppal.net)

**Patient Advocate Foundation**

Website: [www.patientadvocate.org](http://www.patientadvocate.org)

Telephone: 1-800-532-5274

Provides education and legal counseling on managed care, insurance, and financial issues for Sickle Cell patients

**Volunteer Lawyers Project**

(617) 423-0648

(VLP of the Boston Bar Association)

29 Temple Place, 3rd Floor, Boston, MA 02111

## **Government Agencies**

### **Health Care for All**

Health Care for all is a Massachusetts organization dedicated to making adequate and affordable health care accessible to everyone, regardless of income, social or economic status. Their website has detailed information on health insurance programs: [www.hcfama.org](http://www.hcfama.org). They have a free helpline service and can be reached at 1-800-272-4232.

### **Massresources.org**

This is a free online resource for Massachusetts residents in need of housing, food, health care, and other basic services. [www.massresources.org](http://www.massresources.org)

### **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

### **Massachusetts Rehabilitation Commission**

1-617-204-3603

[www.mass.gov/eohhs/gov/departments/mrc/](http://www.mass.gov/eohhs/gov/departments/mrc/)

### **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)

## **My Sickle Cell Disease**

The type of Sickle Cell Disease I have is:	
<input type="checkbox"/> HbSS	<input type="checkbox"/> HbSC
<input type="checkbox"/> HbS Beta Plus Thalassemia	<input type="checkbox"/> HbS Beta Zero Thalassemia
<input type="checkbox"/> Other	

Baseline Values	Levels
Hemoglobin	
White Blood Cell Count	
Oxygen Saturation	

History		
Acute Chest Syndrome	YES <input type="checkbox"/>	NO <input type="checkbox"/>
Gallbladder Disease	YES <input type="checkbox"/>	NO <input type="checkbox"/>
Splenic Sequestration	YES <input type="checkbox"/>	NO <input type="checkbox"/>
Cholecystectomy	YES <input type="checkbox"/>	NO <input type="checkbox"/>
Splenectomy	YES <input type="checkbox"/>	NO <input type="checkbox"/>

Specialty	Doctors Name	Phone Number
Primary Care		
Hematologist		
Cardiologist		
Neurologist		
Pulmonologist		
Ophthalmologist		

Notes/Questions: \_\_\_\_\_

\_\_\_\_\_

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"Life is one big transition."  
Willie Stargell